

Supporting lesbian, gay and bisexual people with dementia

Lesbian, gay and bisexual (LGB) people with dementia, and their carers, partners, friends and relatives, face many challenges – not only the challenges that people who are not in same sex relationships experience, but possibly many more. This factsheet will help health and social care professionals to understand some of the issues that LGB people may face and how to offer appropriate support.

Issues faced by older lesbian, gay and bisexual people

Older LGB people are more likely to be single and more likely to live on their own than heterosexual people. They are also much less likely to have children or regularly see family members. If people do not have a partner or family to support them as they get older, they are more likely to need to use social care services for help.

However, some LGB people do not feel that support services will be able or willing to meet or understand their specific needs. Many feel that they would be uncomfortable with care home staff or paid carers knowing their sexual orientation. This is often for fear of hostility and prejudice as they may have experienced discrimination in the past.

Older LGB people may feel out of place in traditional support groups. In these settings, people will tend to talk freely about their husband, wife or children. However, many gay people fear that others will react with shock, awkwardness or even rudeness if they talk openly about their partner or family. They may therefore feel more comfortable in a group made up of other gay people but there may be few or no services of this kind available.

For these reasons, some gay people avoid seeking social care services when they need them.

In some situations, a person's sexuality may be more evident because of reduced inhibition sometimes caused by dementia. This makes it even more important for them to be in a non-judgmental environment. It is as important to ensure that care workers supporting the person are not homophobic (displaying fear or contempt for gay people) as it would be to ensure that they are not racist or sexist.

Dementia can cause some people to lose their inhibitions. For some people, this may mean that they make inappropriate sexual advances. This can happen whether the person is gay or straight. Advice on dealing with challenging sexual behaviour and changes in inhibitions can be found in factsheet 514, Sex and dementia.

What can health and social care professionals do to make a difference?

Some professionals assume that their services are open to lesbian, gay and bisexual people but this is not always the case. However, there are many steps you can take that will help to make a service welcoming and inclusive for all.

- Review the publicity material and policy documents produced by your group or organisation. You might want to show policies relating to confidentiality or zero-tolerance to homophobic language, for example. Make sure that the language used is inclusive of people who are not in heterosexual partnerships and acknowledges that not

all carers are heterosexual and/or blood relatives of the person with dementia. If pictures or photographs are used, think about including some images of people in same-sex relationships.

- Don't assume that just because someone has never married they have never had an intimate partnership. Of course, this doesn't automatically mean that they are lesbian or gay either but be aware that a person may have had important romantic and sexual relationships that go unnoticed when they get older simply because they have not been legitimised by a marriage.
- If someone is living with someone of the same sex and you think it may be a gay relationship, try to offer positive messages in subtle ways. For example: 'You obviously mean a lot to each other'; 'Have you lived together a long time?' These kinds of questions do not compel someone to 'come out' if they don't want to, but they do give an opening, indicating that you are happy to talk about the relationship.
- If the person with dementia or their carer feels able to come out to you, your first and immediate reaction will be very significant. If you feel embarrassed or surprised you might change the subject or avoid direct acknowledgement of what the person has shared with you. This might stop the person feeling comfortable with you and opening up further. Find ways to acknowledge the person's sexual orientation and give reassurance that you are not prejudiced – for example, 'Thank you for telling me. It must be hard having different professionals coming in to your house, not knowing what their attitudes are,' or, 'Let me know if there are any particular things we need to consider about services for you, which might make you feel more comfortable.'
- Not all LGB people feel comfortable with the relatively modern words 'lesbian', 'gay' or 'bisexual'. They may refer to their friend or companion rather than to a boyfriend/girlfriend or partner. Take your cue from the person as to the kind of language you should use.
- If the person with dementia is lesbian or gay, they may have difficulties with the kind of support offered. The people they talk about, the memories that are important, their interests and humour will have been affected by their experience as a lesbian or

gay person, but they may feel unable to express this. It might be particularly important for the person to have contact with other gay people to support their identity and confidence at a time of loss and change.

If you are lesbian or gay yourself, you will need to consider whether it is appropriate to 'come out' to your client or their carer. Professional boundaries have traditionally dictated that offering personal information is not good practice. However, in some situations, and where you are confident and open about your own sexuality in the workplace, it might be entirely appropriate to reassure your client that, as a gay person, you might be able to offer empathy and support at a difficult time.

If you are heterosexual and have had little contact with lesbian or gay people, consider the extent to which you need to equip yourself with more information. You may need to carry out further informal research into specialist sources of support for a lesbian or gay person with dementia or their carer. You could contact a local lesbian or gay organisation to find out more about what is available.

Most important of all, avoid the excuse that sexuality is a private matter and 'nobody's business'. Be aware that, in your professional career, you will almost certainly have contact with several LGB service users looking to you for support and understanding.

Legal and financial issues

Consider legal and financial issues carefully. Same-sex civil partners have the same rights as heterosexual married couples. Lesbian, gay and bisexual people are additionally protected from discrimination under equality legislation. However, some lesbian, gay and bisexual people may be concerned that their same-sex partner will not be acknowledged by staff. It is important therefore to encourage open questions and discussion about who to nominate to arrange appropriate care.

- For anyone with dementia, whatever their sexual orientation and whether in a relationship or not, it is important to plan ahead. There are a number of ways that someone can plan their care for the future; collectively these are often referred to as ‘advance care planning’. The purpose is to let someone make choices and decisions about future care, in case there is a time when they cannot make decisions for themselves.
- Planning ahead can include making an advance statement or advance decision about future care. For example, someone may decide now that they wish to refuse certain treatment, or about other care choices. For more information see **factsheet 463, Advance decisions and advance statements** or in Northern Ireland **factsheet NI467 Financial and legal tips**.

The term ‘next of kin’ has a limited meaning, related to the disposal of property to blood relations in situations where someone dies without making a Will. The Mental Health Act 2007 gives equal recognition to same sex partners, who are in a registered civil partnership, or have lived together as civil partners for at least six months. Alert the carer to the importance of both partners having made a proper Will to ensure that inheritance of property and other assets are clearly indicated. This will be especially important if members of the family of the person with dementia are hostile to the couple and could possibly contest the Will.

Equality legislation

In England and Wales, under the Equality Act 2010, it is unlawful to treat people unfairly because of their sexual orientation. In Northern Ireland, discrimination on the grounds of sexual orientation is covered by The Equality Act (Sexual Orientation) Regulations (Northern Ireland) 2006. This means that service providers have a duty to ensure that their services and their staff do not discriminate against people on the grounds of their sexual orientation.

For more information on the Equality Act 2010 and its implications in England and Wales, please contact the Equality and Human Rights

Commission. Further information on the Northern Ireland legislation and its implications can be obtained from the Equality Commission for Northern Ireland. (See ‘Useful organisations’.)

Further reading

Ward, R., Pugh, S., and Price, E. (2010). Don’t look back? Improving health and social care service delivery for older LGB users. Equality and human rights commission, Manchester.

For details of Alzheimer’s Society services in your area, visit **alzheimers.org.uk/localinfo**

For information about a wide range of dementia-related topics, visit **alzheimers.org.uk/factsheets**

Useful organisations

Equality and Human Rights Commission

Arndale House
The Arndale Centre
Manchester M4 3AQ
T 0845 604 6610 (helpline)
E info@equalityhumanrights.com
W www.equalityhumanrights.com

Promotes and monitors human rights and equality. The helpline gives advice, information and guidance on equality, discrimination and human rights issues.

Equality Commission for Northern Ireland

Equality House

7–9 Shaftesbury Square

Belfast BT2 7DP

T 028 90 890 890 (enquiry line)

028 90 500 589 (textphone)

E information@equalityni.org

W www.equalityni.org

Promotes and monitors human rights in Northern Ireland. Provides information for individuals, employees and service providers.

Stonewall

Tower Building

York Road

London SE1 7NX

T 0800 050 2020 (Info Line)

020 7633 0759 (Minicom)

E info@stonewall.org.uk

W www.stonewall.org.uk

Stonewall works to achieve equality and justice for lesbians, gay men and bisexual people.

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This factsheet has also been reviewed by people affected by dementia. A list of sources is available on request.



Alzheimer's Society National Dementia Helpline

England, Wales and Northern Ireland:
0300 222 11 22

9am–5pm Monday–Friday
10am–4pm Saturday–Sunday

alzheimers.org.uk

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