People living with dementia will experience a range of challenges. Many of these will not be affected by the person’s sexual orientation or gender identity. However, there are certain challenges that lesbian, gay, bisexual and trans people with dementia are likely to face.

Some of these challenges will be similar whether the person is lesbian, gay, bisexual or trans. Others will be different. When supporting an LGBT person – as with all people with dementia – it is important to treat them as an individual. Do not assume that what is true for a lesbian woman is true for a bisexual man, or indeed what is true for one trans person is true for another, for example.

This factsheet is for anyone caring for or supporting a lesbian, gay, bisexual or trans (LGBT) person with dementia. The information is intended to help you whether or not you are also LGB or T. The person with dementia may find it helpful to look at booklet 1511, LGBT: Living with dementia.
Contents

- Definitions
- What is dementia?
- Understanding and supporting an LGBT person with dementia
- Changes in society for LGBT people
- Relationships
- Memory problems
- Expressing identity
- Services and care settings
- Planning ahead
- Looking after yourself as a carer
- Other useful organisations.
Supporting a lesbian, gay, bisexual or trans person with dementia

Definitions
This factsheet uses the terms LGB and T to mean the following:

- **Lesbian** – a woman who has an emotional, romantic or sexual orientation towards women.
- **Gay** – a man who has an emotional, romantic or sexual orientation towards men.
- **Bisexual** – a person who has an emotional, romantic or sexual orientation towards men and women.
- **Trans** – a person who doesn’t identify with their assigned gender at birth, or who see themselves as between, beyond or outside of the two standard categories of male and female.

The factsheet will also use the following terms:

- **Heterosexual** – a person who has an emotional, romantic or sexual orientation towards people of the opposite sex.
- **Cisgender** – a person whose gender identity is the same as the sex they were assigned at birth.

A person’s sexual orientation (sexual, romantic or emotional attraction to others) is different to their gender identity (how they see themselves – male, female, both or neither). Everyone will have both a sexual orientation and a gender identity. However, trans people sometimes find that their sexual orientation is overlooked by the people supporting them. It is an important part of who they are and they should be supported to express it.

What is dementia?
The word dementia describes a set of symptoms that may include memory loss and difficulties with thinking, problem-solving or language. These changes are often small to start with, but for someone with dementia they have become severe enough to affect daily life. A person with dementia may also experience changes in their mood or behaviour.
For more information see factsheet 400, What is dementia?

It is important to know that support is available for the person with dementia and for those caring for them. There are also laws protecting the rights of LGBT people.

Understanding and supporting an LGBT person with dementia

Living with dementia as an LGBT person can bring unique challenges, both for the person and those supporting them. Every person will experience dementia as an individual with their own experiences and life history, relationships, environment and support.

If an LGBT person with dementia has had or still has difficult experiences in the past these could negatively impact their experiences of dementia. For example, if they have encountered prejudice or discrimination from professionals or services they may not want to access services, or they may feel uncomfortable being open about their sexual orientation or gender identity around professionals. It is important to be sensitive to the person’s needs, history and experiences in order to support them to live well.

While the person’s identity as an LGBT person may be an important part of who they are, it is not the whole of their identity. They will have experiences, interests and hobbies and the person should be supported to continue doing the things that they enjoy and that make them who they are.

Feeling safe is important for people with dementia and is likely to be especially important if a person is LGB or T. Some LGBT people may never have felt safe to express their identity, because of fear of how others will treat them. They may worry about seeing professionals, such as GPs, nurses or social workers, because of this. Intimate relationships, friends and the LGBT community can help the person to feel safe and be themselves, and to help their environment feel like a ‘safe space’.
**Tips for supporting an LGBT person with dementia**

- Treat the person as an individual and respect their wishes.
- Talk to the person about letting those who are important to them know that they have dementia. This will help them to understand what is happening and to support both the person and you.
- Talk to the person about how they want to express themselves to others – for example, they may identify as a bisexual man, or a trans woman – and make sure they feel supported to make the decision.
- Support the person to be open about their gender identity or sexual orientation with whoever they choose to be. If there is anyone they don’t want to tell, respect this too.
- Talk to the person about their wishes as early as possible – around treatment and care, other needs and who they want to make decisions. Make sure these wishes are recorded, to help ensure they are met later on when the person is no longer able to make decisions. For more information see ‘Planning ahead’ below.

There are fewer services specifically for LGBT people available. It can help to plan ahead and think about what the person might need in the future and how to go about putting these things in place. The following suggestions might help:

- Think about services and look into what support is available for both the person and you. You may want to speak to services to find out what support they offer LGBT people. It may also be helpful to ask local LGBT services if they provide any support for people with dementia.
- You and the person with dementia may want to look up care homes or supported living options as early as possible, so that you are prepared if it is needed in the future. This can help make sure the person will move to a place where their gender identity or sexual orientation is respected and they are supported and treated equally.
- You may want to help the person with dementia to record what is important to them, such as their life history, likes and dislikes. This can help care professionals to have a better understanding of the person, and enable them to provide better, more person-centred care. This can be very helpful in a new environment.
Alzheimer’s Society produces a tool called This is me, which can be used to record these details. To order a free copy go to alzheimers.org.uk/thisisme or call 0300 303 5933. This can be particularly useful if the person has communication difficulties.

Remember that legally, everyone has the right not to be discriminated against because of their gender identity or sexual orientation.

For more information see factsheet 524, Understanding and supporting a person with dementia.

Changes in society for LGBT people

Many people with dementia are over 65. However, it is possible for people under 65 to develop dementia. Older LGBT people in the UK have experienced significant changes in the law, and in society’s attitudes towards LGBT people. LGBT people of any age will be aware of this history and it can have an impact on all LGBT people. For example:

- Until 1967, sex between men was against the law in England and Wales (and until 1982 in Northern Ireland).
- Until 1973, homosexuality was listed as a mental illness in the manual used by mental health professionals in the UK.
- In 1980, ‘gender identity disorder’ was added to the list of disorders in the manual used by mental health professionals in the UK.
- In the 1980s, the AIDS epidemic developed, which affected large numbers of gay men in the UK. It also affected people’s attitudes towards gay men.

In recent years, there have been a number of positive changes in the law for LGBT people:

- In 2004, the Gender Recognition Act was introduced, allowing transgender people the opportunity to have their chosen gender legally recognised via a gender recognition certificate. For more information see ‘Gender recognition certificate’ below.
In 2004, the Civil Partnerships Act was also introduced, allowing same-sex couples to have their relationships legally recognised.

In 2013, the Marriage (Same Sex Couples) Act was introduced in England and Wales, enabling same-sex couples to get married.

Although these more recent changes have been much more positive, it is important to remember that the person is likely to have lived through many of the negative experiences listed above too. They may have affected the person’s identity or understanding of the world. They may also have an impact on how they cope day to day.

LGBT people may be less likely to access the care and support they need, and may feel they are likely to experience discrimination. This can put the person and those supporting them under a lot of strain. It is important to be aware of the experiences that they may have had as an LGBT person in the past and how they may affect them today.

Most types of dementia cause people to experience memory problems. LGBT people may be affected by these in different ways. For example, if an LGBT person has told some people about their sexual orientation or gender identity but not others, the person may forget who they’ve shared this with. They may think they have told some people when they haven’t, for example.

Relationships

It is important not to make assumptions about a person’s relationships. These may be influenced by a number of factors. For example:

- Some LGBT people do not see their biological family regularly (this could be for a number of different reasons).
- Some LGBT people are part of a family made up of people they’re not biologically related to – sometimes known as a ‘family of choice’. You might be included in this.
- Some LGBT people do not have children or grandchildren, and their main relationships will be with other adults.
Older LGBT people are more likely to be single and live alone. This can have an impact on the support that they have and need.

Some people may not understand the relationships that LGBT people have, or may not consider them as important as heterosexual relationships (between cisgender male and female people). This can be a difficult and frustrating experience.

If the person and those supporting them aren’t in touch with their biological family, they may have less support as their dementia progresses than others would. They may instead find themselves being supported by paid care professionals who don’t understand them or respect their relationships. This can create problems and may lead to unmet needs for the person. Advance care planning (see section below) can help LGBT people with dementia decide who they want to be involved in their care and to make decisions for them (when they are no longer able to).

Many LGBT people may be more reliant on friends and other members of the LGBT community as they get older. Friends are an important source of support and continuity for LGBT people, and often make up the person’s ‘family of choice’. However, friends may be of a similar age to the person and may have their own health and care needs to manage. This can lead to the person becoming isolated and not having as much support as they might need. If the person develops dementia they may find it harder to stay in touch with people. It’s important that people are supported to continue these relationships and avoid becoming isolated.

While the person’s identity as an LGBT person may be an important part of who they are, it is not the whole of their identity. They will have experiences, interests and hobbies and the person should be supported to continue doing the things that they enjoy and that make them who they are.
Memory problems

Most types of dementia cause people to experience memory problems. LGBT people may be affected by these in different ways. For example, if an LGBT person has told some people about their sexual orientation or gender identity but not others, the person may forget who they’ve shared this with. They may think they have told some people when they haven’t, for example.

For some older LGBT people, they may have gone through the process of sharing their sexual orientation or gender identity – ‘coming out’ – more recently. They may forget that they have come out, which might be distressing for the person, and for those supporting them.

They may also be unable to remember whether other people know about their partner or friends’ sexual orientation or gender identity, and may therefore reveal it without meaning to (known as ‘outing’). This can be distressing for those supporting the person and can put them in an uncomfortable situation. Some people may avoid going to events with groups of people to stop this from happening.

Trans people who have changed gender (or are in the process of doing so) may not remember that they have been through this process, and so may think they haven’t. A trans person might forget that they have – or have not – started the process of changing gender (gender reassignment). If they have a partner or friend who is changing gender, they may also forget this.

A trans person may also be taking hormones or undergoing long-term hormone therapy. If the person forgets to take the hormones or suddenly stops, they may develop health problems (for example, an increase in their risk of developing osteoporosis). It’s important for those supporting the person to be aware of the treatment the person is having and to support them to take the right medications.

As dementia progresses, the person is more likely to remember older memories than more recent ones. The person may behave as though they are living in an earlier time in their life. This may include positive experiences that helped shape their identity, such as protest marches and
campaigning for equal rights. Some LGBT people may believe that they are living in a time when they had to hide who they were for fear of negative consequences, or when they experienced negative attitudes or distressing life events such as arguments with their biological family members.

This can be very difficult for the person and can have a big impact on how they feel. It is important for those supporting the person to be aware of their life history (if the person is comfortable with this), so they can support them appropriately and help them to manage their emotions and memories, including any that are negative. This is especially important if any professionals support the person with life story or reminiscence work, as this involves encouraging the person with dementia to think and talk about their past. For more information about these and other treatments see factsheet 526, **Coping with memory loss**.

**Tips for supporting an LGBT person with memory problems**

- For life story and reminiscence work, find out about the person’s past experiences and positive memories, especially those other people may not know about.

- Use past experiences and events to engage the person in conversation and as a means of finding out more about their personal experience of being LGB or T. For example, news stories, pin badges, photos, videos or memorabilia from marches can all help stimulate conversation.

- Some people may have had negative experiences and going through their life history could cause them to relive these. If the person becomes upset or distressed, support them to manage these feelings.

- Make sure that those supporting the person are aware of any life events that may cause them distress or upset.

**Expressing identity**

It is important that the person is supported to express their gender identity or sexual orientation. For example, if the person is trans, it is important that they are able to choose clothes and present themselves in ways that help them to express their gender.
Many LGBT people – especially trans people – will have experienced negative attitudes. They may have encountered prejudice (people making judgements about them because of their sexual orientation or gender identity) or discrimination (being treated differently to other people because of their sexual orientation or gender identity). They may have found that some people are uncomfortable with their sexual orientation or gender identity. LGBT people with dementia may worry about experiencing these attitudes from friends, family and health and social care professionals.

Some people with dementia also experience negative attitudes from people who do not understand the condition, or who find it difficult to accept that the person has dementia. If a person experiences prejudice or feels isolated because of both their dementia and their sexual orientation or gender identity, they may be feeling very vulnerable. It is important to try and help the person to feel safe. They should feel that their sexual orientation or gender identity and their dementia are acknowledged, and that they are not being judged, ignored or discriminated against.

If a lesbian, gay, bisexual or trans person is in a relationship, it is important that this is acknowledged. Sometimes LGBT people find that others, such as care professionals, make assumptions about their relationships. For example, if a gay man is visited by his partner, care professionals might assume the person is his brother or friend. This may not be discrimination but it can still make a person feel distressed and that their identity isn’t being acknowledged.

Remember that care home staff cannot legally discriminate against the person because of their gender identity or sexual orientation.

Telling others about sexual orientation or gender identity
Choosing to tell others about (‘disclose’) sexual orientation or gender identity can be a difficult decision for an LGBT person. However, the person may have regularly made decisions about who to share their sexual orientation or gender identity with in the past, so they may be used to doing this.
It is for the person to decide if they want to disclose this information. If they choose to disclose, it is important that the person is able to choose who they want to share these parts of their identity with. If the person is worried about negative attitudes and chooses not to share their identity with someone, this wish should be respected.

When the person develops dementia, it can be even more challenging to make this decision. There may be several people involved in their support and care and they may have to decide whether to disclose their sexual orientation or gender identity to all of them.

If the person is unable to decide whether to disclose their sexual orientation or gender identity, they should be supported to make a decision as far as possible. If they do not have the capacity to decide, there may be circumstances where their carer may have to make this decision. It is important that any such decision is made in the person’s best interests, and not to satisfy anyone else.

Some people will want professionals to know about them being L, G, B or T, so that services can provide them with appropriate support. However, other people won’t want to disclose their sexual orientation or gender identity and this should be respected.

If a trans person hasn’t had gender reassignment surgery and professionals are providing personal care, they may become aware of the person’s gender identity even if they haven’t chosen to disclose it. However, it is important for the person to be respected and there are ways to manage this. It can help to talk to the person about how they would like to address the situation and consider building relationships with care professionals early so that the person feels safe and comfortable with them. They should be able to support the person appropriately and with dignity and respect.

If someone chooses to tell a professional about their previous gender, or the professional was to find out, it can be reassuring to know that they cannot then disclose this information to others, without the person’s consent. This means that the professional must treat this information as confidential and not tell others unless the person wants them to.
Losing sexual inhibition
People with dementia can sometimes lose their sexual inhibitions. In addition, as dementia changes the brain over time, people occasionally become much more or much less interested in sex.

These changes can affect anyone with dementia. However, for an LGBT person who has not shared their sexual orientation or gender identity, the ways they behave may reveal these to other people. For instance, a bisexual woman with dementia may express emotional, romantic or sexual attraction to another woman in front of people who don’t know she is bisexual. It may help to talk to each other about what to do in this situation so that you are both prepared. For example, ask the person if they would want to disclose their sexual orientation if this happened.

Services and care settings
As the person’s dementia progresses, they will need more support from different care professionals. In the later stages of dementia, they may need to move into supported living or a care home.

It is important to know that, in any care setting, the person has a right to the same treatment as people who are not LGB or T. The Equality Act 2010 made it illegal for staff and organisations providing services in England and Wales to discriminate against someone because of their sexual orientation or gender identity. This means that it is against the law for health and social care staff or local authorities to treat the person less favourably because they are LGB or T. In Northern Ireland, there are similar laws – the Equality Act (Sexual Orientation) Regulations (Northern Ireland) 2006 and the Sex Discrimination (NI) Order 1976.

Some LGBT people may be worried about meeting different care staff or going into care settings. They may worry that they will experience prejudice or discrimination. In some settings, care professionals may not have enough knowledge or awareness to support the needs of LGBT people with dementia. They may not realise that LGBT people access their services or understand that the person’s sexual or gender identity can have a big impact on their needs. For example, reminiscence activities may focus on people’s family and children, not realising that LGBT people may not be in touch with families or have children.
It is important to find a setting where the person feels that they are understood and their wishes are respected. Care professionals may not know how to support LGBT people appropriately, or they may feel that it is not an issue because they treat everyone the same. However, many LGBT people want to be treated as unique individuals and have their history and identity respected and their needs met.

**Moving into a care home**

Many people with dementia remain living at home independently when they have the right level of support in place. However, the time may come when the person needs to move into a care home. They may be worried about staff not supporting them or meeting their needs. They might feel like their home is a ‘safe space’ where they are free to express their identity, and may be worried about leaving it.

The person with dementia, with your support, may find it helpful to talk to care home staff about their sexual orientation or gender identity as early as possible. This can help them find out whether staff have any negative attitudes towards LGBT people.

If the person is trans but does not wish to share this with everyone in the care home, they may wish you to tell one (or a few) of the care home staff. It is against the law for the member of the care home staff to share the person’s identity without the person’s consent.

Remember that care home staff cannot legally discriminate against the person because of their gender identity or sexual orientation.

It is important to find a care home where the person can feel safe and accepted. For advice on housing options for LGBT people, it may be useful to contact Stonewall Housing (see ‘Other useful organisations’).

**Complaining about prejudice or discrimination**

If you or the person with dementia feel they have been treated unfairly because of their sexual orientation or gender identity, ask for the complaints procedure from the organisation that has provided the care.
If, after following this procedure, you feel that your complaint has not been properly addressed, you can take the complaint further. The next steps should be explained in the organisation’s own complaints procedure. If they are not, depending on where you are and the nature of your complaint, you can contact the relevant Ombudsman in England, Wales or Northern Ireland (see ‘Other useful organisations’).

If you are in England you can contact your local Patient Advice and Liaison Service (PALS) for help with making complaints and other support. The Community Health Council in Wales, and the Patient and Client Council in Northern Ireland, perform similar roles.

You can also get advice and support from the Equality and Human Rights Commission in England and Wales or the Equality Commission for Northern Ireland.

In some cases you might need to talk to a solicitor to get advice regarding discrimination experienced by the person with dementia or yourself.

**Planning ahead**

There are a number of legal ways to protect the interests and wishes of the person with dementia. It is important to make plans as early as possible, to prepare for a time when the person will need much more support and may not be able to make decisions for themself.

**Appointing a person to make decisions**

The person may want to appoint you, or another person who is important to them, to make decisions on their behalf when they are no longer able to make them. They can create a Lasting power of attorney (LPA) in England & Wales, or an Enduring power of attorney (EPA) in Northern Ireland.

There are two types of LPA – one for decisions about health and welfare (covering issues such as day-to-day care and treatment) and one for decisions about property and financial affairs (covering issues such as bills, bank accounts and selling property). However, the EPA in Northern Ireland currently only covers property and financial affairs.
For more information see factsheet 472, Lasting power of attorney, or in Northern Ireland see factsheet NI472, Enduring power of attorney and controllership.

**Decisions about treatment**
To record the person's wishes about treatments they do not wish to receive, they can create an advance decision to refuse treatment in England and Wales, or advance directive in Northern Ireland.

Health professionals in England and Wales must follow the person’s wishes if they are unable to make a decision for themself at the time. They should also follow these wishes in Northern Ireland. To make sure they follow these, it’s important that the advance decision or directive is recorded in writing and includes certain information. For more information and a template advance decision form see factsheet 463, Advance decisions and advance statements, or if you are in Northern Ireland see factsheet NI467, Financial and legal tips.

---

**Recording other wishes**
The person may have other important wishes. For instance, a trans person may have wishes about:

- the clothes they like to wear
- the pronoun they would like people to use when referring to them
- any prosthetics (such as an artificial penis).

It is a good idea to record the person’s wishes. An advance statement in England and Wales, or living will in Northern Ireland, is a document that lists a person’s general wishes and preferences for the future. This could include things like the clothes they like to wear, or the things they enjoy doing.
Advance statements and living wills are not legally binding but, if future decisions are made on a person’s behalf, any advance statement should be taken into account. If a decision is made that goes against an advance statement, there has to be a very good reason for this.

For more information and a template advance statement to use as a starting point see booklet 1510, Planning ahead (in England and Wales). If you are in Northern Ireland see factsheet NI467, Financial and legal tips.

Gender recognition certificate
A trans person can apply to the government’s Gender Recognition Panel for a gender recognition certificate, if they meet certain criteria. This gives the person the right to be treated legally as someone of their own gender.

For more information search ‘gender recognition certificate’ on the GOV.UK website.

Looking after yourself as a carer
Caring for a person with dementia can be rewarding but also very challenging. Supporting an LGB or T person with dementia may present unique challenges, such as:

- increased stress
- issues with accessing appropriate services and a lack of support
- conflict with others (especially biological family)
- negative attitudes from others
- lack of recognition of your relationship to the person and concern about disclosing this relationship to others
- experiencing, or being worried about experiencing, discrimination.

It is important to take care of your own needs too, as this will help you to continue to care for the person and mean that you are better able to manage. If you are also LGB or T, it is important to remember that you have the same rights as the person with dementia not to be discriminated against.
For more information see factsheet 523, **Carers: looking after yourself.**

Although an LGB or T person with dementia will experience challenges, support from you and others can help them to express their identity and enable them to live well.

**Other useful organisations**

**Community Health Councils in Wales**
www.wales.nhs.uk/ourservices/directory/communityhealthcouncils

Independent bodies who listen to what individuals and the community have to say about the health services provided for them. To find your local one, use the NHS Direct Wales page above.

**EASS (Equality Advisory and Support Service)**
0808 800 0082 (helpline, 9am–7pm Monday to Friday, 10am–2pm Saturday)
www.equalityadvisoryservice.com

Provides support and advice about your rights in England and Wales.

**Equality Commission for Northern Ireland**
028 90 500 600
information@equalityni.org
www.equalityni.org

Provides information and advice about your rights in Northern Ireland.

**GIRES (Gender Identity Research and Education Society)**
01372 801554
info@gires.org.uk
www.gires.org.uk
www.gires.org.uk/the-wiki

Aims to improve the lives of trans and gender non-conforming people, including those who are non-binary and non-gender. Also hosts Tranzwiki, a comprehensive directory of the groups campaigning for, supporting or assisting trans and gender non-conforming individuals.
GOV.UK
www.gov.uk
www.gov.uk/apply-gender-recognition-certificate

The website of the UK government. Includes information on legal issues and rights, such as gender recognition certificates and power of attorney.

LGBT Consortium
020 7064 6500
admin@lgbtconsortium.org.uk
www.lgbtconsortium.org.uk
www.lgbtconsortium.org.uk/directory

Organisation focusing on the development and support of LGBT groups, organisations and projects. Has a directory where you can search for LGBT services by location.

Local Government Ombudsman
0300 061 0614 (8.30am–5pm Monday–Friday)
www.lgo.org.uk

The final stage for complaints about councils and some other organisations providing local public services. Also includes adult social care providers (such as care homes and home care providers).

National LGB&T Partnership
0207 064 6506
nationallgbtpartnership@gmail.com
www.nationallgbtpartnership.com

Group of organisations that aims to reduce health inequalities and improve access to health and social care for LGBT people. Website includes resources and links to local organisations.
Northern Ireland Public Services Ombudsman
0800 34 34 24 (9am–5pm Monday–Friday)
nipso@nipso.org.uk
nipso.org.uk

Investigates complaints where local resolution has not been possible.

Opening Doors London
0207 239 0400
info@openingdoorslondon.org.uk
www.openingdoorslondon.org.uk

Charity providing information and support services with and for older LGBT people in London.

Parliamentary and Health Service Ombudsman (England)
0345 015 4033 (8.30am–5.30pm Monday–Friday)
www.ombudsman.org.uk

Investigates complaints about the NHS in England where local resolution has not been possible.

Public Services Ombudsman for Wales
0300 790 0203
ask@ombudsman-wales.org
www.ombudsman-wales.org.uk

Independent body whose role is to investigate and consider complaints where they have not been resolved locally.

Patient Advice and Liaison Service
www.nhs.uk

Offers confidential advice, support and information on health-related matters in England and Wales. They provide a point of contact for patients, their families and their carers at your local hospital. For details of your local PALS, see the NHS choices website.
Supporting a lesbian, gay, bisexual or trans person with dementia

Patient and Client Council (Northern Ireland)
0800 917 0222
info.pcc@hscni.net
www.patientclientcouncil.hscni.net

An independent voice on health and social care issues. Can help people with complaints, and provide advice and information.

Stonewall
020 7593 1850
0800 050 2020 (information service)
info@stonewall.org.uk
www.stonewall.org.uk

Campaigns for the equality of LGBT people across Britain. Website includes information and advice.

Stonewall Housing
020 7359 5767 (advice line, 11am–1pm and 2pm–5pm Monday–Friday)
info@stonewallhousing.org
www.stonewallhousing.org

The specialist lesbian, gay, bisexual and transgender (LGBT) housing advice and support provider in England.

Switchboard
0300 330 0630 (10am–10pm)
chris@switchboard.lgbt
www.switchboard.lgbt

Provides an information, support and referral service for lesbians, gay men and bisexual and trans people, and anyone considering issues around their sexuality and/or gender identity.