

Caring for LGBT people at the end of life

Please be aware - this information is for healthcare professionals.

Everyone living with a terminal illness should have access to high-quality palliative care, and to be treated with dignity and respect. People who identify as LGBT may have specific experiences, needs and preferences that health and social care professionals can be aware of so that they can provide the best end of life care.

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What do we mean by LGBT people?

LGBT is a term that covers a large and diverse group of individuals who have unique experiences, needs and preferences.

Being familiar with the terms people use to identify themselves is important to be able to understand their experiences.

LGBT terms and their meanings

LGBT

LGBT is the abbreviation for lesbian, gay, bi and trans. These terms can be described in the following ways:

- Lesbian – refers to a woman whose sexual and/or emotional attraction is towards women.
- Gay – a man whose sexual and/or emotional attraction is towards men, or a woman whose sexual and/or emotional attraction is towards women. Some women prefer the term lesbian.
- Bi – refers to people whose sexual and/or emotional attraction is towards more than one gender. Bi people may describe themselves using a variety of terms including bisexual, pan sexual, bi-curious, queer and other terms.
- Trans – an umbrella term to describe people whose gender is not the same as, or doesn't sit comfortably with, the sex they were assigned at birth.

More terms and their meanings

What issues affect LGBT people at end of life?

Being diagnosed with a terminal illness and approaching end of life can be extremely difficult for all patients. LGBT people have all the palliative care needs that other people have including symptom management such as [pain](#), [spiritual needs](#) and [emotional needs](#). But they may face additional challenges and barriers to getting the care they need. A recent [report](#) by Marie Curie looked at the experiences of LGBT people at the end of life and describes some key issues.

To treat a person unfairly or less favourably because they are LGB and/or T is discrimination, and it is against the law in the UK. However, many LGBT people have experience of being discriminated against or targeted with abuse. Older gay men may have been alive when it was illegal to be a gay man in the UK and may have experienced hostile treatment from the state.

The Marie Curie report found that some LGBT people had experienced discrimination in palliative care settings with staff not being accepting of them. Some LGBT people said that they don't access palliative care services because they think they will be discriminated against.

Some LGBT people anticipate discrimination in other healthcare services too and might not attend screening or have regular contact with a GP. If this happens, people are more likely to be diagnosed at a later stage and have more complex health needs.

Health and social care staff often make assumptions about people's sexuality or gender identity. For example, they might assume that a man will have a wife or that a female partner of a lesbian patient is her sister or friend. This can make LGBT people and their partners feel excluded. Carers and partners of LGBT people are less likely to be offered support while they are carers, and also with bereavement.

How can I support LGBT people at end of life?

Sexual orientation and gender identity can be significant parts of who someone is. Supporting someone with a terminal illness includes allowing them to feel comfortable to express these parts of themselves.

There are lots of things you can do to make LGBT people feel more accepted and supported at the end of their lives. Many of these apply to people at earlier stages of their illness too.

- Avoid making assumptions about someone's sexual orientation or gender identity.
- Use inclusive language – ask if someone has a partner, rather than a husband or wife, boyfriend or girlfriend.
- Instead of asking someone who their family is, or who their next of kin is, ask them who's important to them and who they would like to be involved in their care. This may include partners, family members, and friends.
- Involve partners and others important to the person in their care as much as the person would like them to be.
- Ask someone what pronouns they use. This could be he/him, she/her, they/them or others. You can tell them what pronouns you prefer as well.
- If a trans person uses a name that is different from the name on their records, make sure you use the name that they prefer.
- Be aware that someone may have had difficult experiences in the past including homophobic, biphobic or transphobic abuse. Be sensitive and tactful.
- If someone tells you their sexual orientation or gender identity, they may not want you to tell others. Ask them for their consent before sharing information with colleagues or writing it in their care plan.
- Be familiar with terms that people may use to identify their sexual orientation and gender identity. If you're unsure what they mean, sensitively ask them to explain. Common terms that people to describe themselves use can change over time, so keep up to date.
- Attend any training offered by your organisation.

You may find it useful to share this [leaflet about palliative and end of life care for LGBT people](#) with patients and those important to them.

There are things that the team or organisation you work for can do too:

- Have policies and procedures in place to protect LGBT people from discrimination.
- Create a welcoming environment for LGBT people. This includes patients, carers and staff.
- Include LGBT people in any printed or online information about your service. For example, include pictures of LGBT people in leaflets and posters.
- Staff can show that they are committed to LGBT inclusion, for example by wearing rainbow lanyards or badges.
- Set up partnerships with LGBT groups to learn about their needs and increase awareness of your service.
- Provide training for staff.

Useful resources

[Marie Curie nurse Tracey's blog – Supporting LGBT people at the end of life](#)

[Marie Curie report – Hiding who I am: The reality of end of life care for LGBT people](#)

[Leaflet for patients – Palliative and end of life care for LGBT people](#)

[Stonewall – information on issues affecting LGBT people and a useful glossary of terms](#)

Key points

- Everyone should have access to high quality palliative and end of life care if they need it, regardless of their personal circumstances.
- LGBT people can feel excluded from palliative and end of life care services.
- Feeling excluded from palliative and end of life care services can mean that someone doesn't get the care they need.
- There are lots of things you and your organisation can do to include LGBT people and support them at end of life.
- Don't make assumptions about someone's sexual orientation or gender identity.
- Include partners and those important to the person in their care, as much as the person wants.
- Be responsible for making sure that your own actions, words and behaviours are not homophobic or transphobic.

Let us know what you think

Email your feedback to knowledgezone@mariecurie.org.uk


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Disclaimer

This information is not intended to replace any training, national or local guidelines, or advice from other health or social care professionals.

The Palliative Care Knowledge Zone is not intended for use by people living with a terminal illness or their family and friends, who should access our [information for the public](#).

Published date: 1 February 2019 Review date: 1 February 2021

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