

The background features a collage of autumn leaves in shades of yellow, green, and blue. A horizontal rainbow-colored bar is positioned behind the word 'LGBT'.

Palliative & End-of-Life Care for **LGBT** People

A guide for lesbian, gay,
bisexual and/or trans people
facing advanced illness

Why does sexual orientation and gender history matter when facing life-limiting illness?

“I certainly expect that my partner is treated equally with me, that we are part of a couple. I want that recognition that she’s my next of kin and that she is the person that nursing staff talk to if I can’t talk for myself or even if I can talk for myself and can’t get it out very well.”

Marie, 59 year-old lesbian woman living with lung disease

About this leaflet

When facing a life-limiting illness, it is important that the care and support you receive is shaped around who you are and your individual needs.

If you or your partner, friend or relative identify as LGBT (lesbian, gay, bisexual and/or trans) and are living with a life-limiting illness, this booklet can help you think about:

- ▶ Why your sexual orientation or gender identity may be important in relation to your care needs, and preferences
- ▶ The care you are entitled to receive
- ▶ What you should do if you think you have been discriminated against, because of your sexuality or gender identity
- ▶ Where you can go for more help and information

When facing a life-limiting illness, it is important that the health and social care professionals caring for you are able to offer you the help and support that you need. This involves getting to know you, understanding what matters most to you, and who is important to you. This can help to make sure that the care delivered is shaped around your individual needs, as well as the needs of your partner, biological and chosen family.

Some people feel more comfortable than others about sharing information related to their LGBT identity. However, when facing life-limiting illness, those close to you may also need support. Sharing information about who is close to you, can not only help to make sure their needs are considered, but will also help health and social care professionals to know who you would like involved in discussions and decisions about your care.

Sharing your gender identity may be important in relation to treatment preferences, and your priorities, as described by Bridget, a 68 year old trans woman living with lung disease.

“Taking oestrogen increases the risk of blood clots. So now I’ve got these blood clots, I had a conversation with a consultant. The logical thing to do is to stop taking them to reduce the risk to a minimum for the future. So then we had to talk about how important it was psychologically, and I said that I think it is very important. I mean if someone said, “Your heart will stop in 10 minutes if you don’t stop taking them”, I’d stop, but I had to work with the gender clinic people and they said there is an elevation of the risk but it’s acceptable. It’s easy for somebody else to say it’s acceptable, I know, but, so we carried on.”

Bridget, aged 68, trans woman living with lung disease

What care might you need when facing a life-limiting illness?

When living with a life-limiting illness you may be offered palliative care. The goal of palliative care is to help everyone affected by your illness to live as well as possible, by helping with physical symptoms, such as pain, but also psychological, social or spiritual needs, whatever your beliefs. Often palliative care is delivered alongside other treatments for your illness (such as chemotherapy). Palliative care is for people who are living with an illness which cannot be cured, or a complex illness with symptoms which need to be controlled. It can be delivered by your GP and community healthcare teams, or by specialists in your own home, hospitals or hospices.

Palliative care is designed to support you and those close to you. As an LGBT person, this may include your partner, biological or chosen family.

For more information about care when facing a life-limiting illness: [What Are Palliative Care and End of Life Care?](#)

“ I didn't find it that easy to ask for emotional support for me, because it always seemed so very secondary compared to the firefighting that they were doing elsewhere. I almost felt guilty for asking them a question. Because you know they were just running around. But I didn't feel that with the palliative care nurse. I felt like that team gave me all the time in the world without ever seeming that they were busy. That's an incredible gift. If there were some kind of essence that you could bottle and give to the people that are training, it would be something like that. Such a gift to be able to be with someone in a quiet space and feel heard and to feel supported...”

**Rebecca, aged 38,
bereaved partner of bisexual woman who died of breast cancer**

What care should you expect?

“ Expect to be treated equitably...expect to be treated as a couple... There's something about having the confidence for it not to be an issue, because you don't want to have to deal with that as an extra worry, as an extra concern, as something that inhibits anybody asking questions, or getting the right kind of answers.”

**Pauline, aged 63,
bereaved partner of bisexual woman who died of ovarian cancer**

Every person seeking health care is entitled to be treated with respect, and sensitivity without discrimination. Sexual orientation and gender reassignment are protected characteristics under the Equality Act (2010). This legislation legally protects people from discrimination in the workplace and in wider society. However, despite this, some people still fear discrimination from health and social care providers, due to past negative experiences.

Regardless of where you are receiving care, in a hospital, hospice, or in the community, you have the right to be treated fairly, without discrimination.

For more information about your health rights as an LGBT person:

[Equality and Diversity in the NHS](#)

[Equality Act 2010](#)

[Complaining About Discrimination in Health and Social Care Services](#)

[The Route to Success in End of Life Care: achieving quality for lesbian, gay, bisexual and transgender people](#)

What can you do if you feel you've been treated differently because of your sexual orientation or gender identity?

“As long as the people I want to associate with are permitted entry, and are accepted for who they are ... and aren't given any snide remarks or looks... then I'm happy with that. I think. I've got to that stage now where ... If I see anything that I don't like I will tell them. It's totally unacceptable in this day and age.”

John, aged 52, gay man living with lung disease

Despite the legislation protecting individuals, sometimes discrimination does occur. Each health or social care provider will have their own complaints procedures. Often a good first point of contact is the Patient Advice and Liaison Service (PALS), or the service manager, who will be able to advise you, should you wish to take the matter further.

For more information about taking action against discrimination:

[Complaining About Discrimination in Health and Social Care Services](#)



What legal and financial issues could occur, and where can you get information?

Many people face legal or financial concerns when their health is deteriorating, which can be a source of stress and worry. For people in a same sex relationship, but not in a civil partnership or marriage, there can be added complexities or concerns. In particular, financial concerns often relate to benefits, pensions and inheritance. However, LGBT people also express concerns about those who are important to them being excluded or denied information at critical times. Thinking in advance about your preferences and priorities for care (sometimes called Advance Care Planning), including naming someone as your Next Of Kin (the person you want kept informed about your care, and any decisions that need to be made), can help to alleviate these concerns. There are no rules about who can or cannot be your Next Of Kin. You can choose anyone within your personal network, such as a partner, friend, biological or chosen family.

“My partner had a teacher's pension which was quite reasonable, but that stopped. I wasn't old enough to have my own pension. So no pension no income. We really had left a socking great hole there and not even thought about it as a possibility. So I was thinking how am I gonna go back out to work at this point.”

**Nicola, aged 68,
bereaved partner of lesbian woman who died of ovarian cancer**



For more information about legal and financial issues for same-sex couples:

[Legal Differences of Living Together and Civil Partnership](#)

[Benefits](#)

[Making Sure You Get the Right Entitlements](#)

[Marie Curie: guidance on planning your care in advance](#)

[The Route to Success in End of Life Care: achieving quality for lesbian, gay, bisexual and transgender people](#)

[Your Treatment and Care: planning ahead for the LGBT community](#)

[Gay Friendly Lawyers UK](#)

“There was a complete lack of recognition. The consultant even on the tenth or twentieth time of being told I was his partner still referred to me as his brother.”

**James, aged 35,
partner of gay man living with motor neurone disease**



What help and support is available to help you to live as well as possible when facing advanced illness?

For some individuals, talking to other LGBT people who have been through a similar situation can be very helpful, in terms of sharing experiences and advice.

Your GP, health or social care team may be able to advise you regarding local sources of support for LGBT people living with life-limiting illness. However, if you would like to seek out other groups and resources, the following list may be a good starting point.

More sources of support:

[The Emerging Picture: LGBT people living with cancer](#)

[LGBT in Later Life](#)

“They had a group of people, half a dozen people, who provided a helpline, and that was absolutely invaluable for me. I got this guy called John... and we just used to talk. He was massively helpful... There is something very helpful about having support from somebody else who’s gay. Because you immediately feel like you’re coming from the same sort of assumptions of background and culture... he was good, because he wasn’t a counsellor, and he wasn’t a friend, but he was somebody who was in the know, and was caring, and could find me advice and tips. So that was very helpful. I do think that there’s something about the gay and lesbian community that’s important.”

**Trisha, aged 61,
bereaved partner of lesbian woman who died of dementia**

What support is there for partners, friends, biological and chosen family?

“I do think talking to a gay woman who’d been through it, both at diagnosis and after the death, might have been really helpful. The prognosis was shattering frankly. There is a slightly different dynamic between two women who had never even considered having a family as it really ‘wasn’t done’. You’re perhaps bound up in each other rather more to the exclusion of others.”

**Nicola, aged 68,
bereaved partner of lesbian woman who died of ovarian cancer**

The goal of palliative care is to support everyone affected by advanced illness, including partners, friends and family. Caring for someone who is living with a life-limiting illness can be very isolating. It is more difficult to maintain friendships and socialise, and it may be hard to get the support you need, practically and emotionally. Isolation is particularly common among older LGBT people.

The health or social care team caring for your partner, friend or relative will be able to advise you on local groups and services. There are also a number of other agencies, some of which are LGBT-specific, who will be able to direct you to sources of support in your local area.

More sources of support:

[LGBT Carers](#)

[Local Support](#)

[LGBT in Later Life](#)

[LGBT Consortium](#)

[LGBT Switchboard](#)

[Cruse Bereavement Support](#)

[Carers UK](#)





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Curie**

Care and support
through terminal illness



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