



www.carerhelp.com.au

Being an LGBTIQ+ carer for a partner, relative or friend at the end of life



Most information on the CarerHelp website is useful and relevant for carers who are LGBTIQ+. This factsheet highlights some additional considerations for carers who are part of LGBTIQ+ communities and/or are caring for someone who is part of LGBTIQ+ communities.



LGBTIQ+ People and Communities

LGBTIQ+ refers to a diverse group of people who are lesbian, gay, bisexual, transgender, intersex, queer or who have a diverse gender, sexuality or body. LGBTIQ+ communities are made up of many different people, all with unique experiences, histories and stories. This diversity means it's important to always give people the space to tell you who they are and what this means to them.

Navigating the health system

Many people who are LGBTIQ+ have had prior experiences of being discriminated against when accessing health care services. Ignorance surrounding LGBTIQ+ status can be a result of inexperienced health professionals or a lack of training in working with LGBTIQ+ communities.





This often affects different LGBTIQ+ communities in different ways.

Bisexual people can face a high degree of invisibility when healthcare providers make assumptions about their sexuality.

Many intersex people have trauma from invasive, non-consensual medical procedures in the past that make hospitals feel unsafe.

Transgender people can find navigating the healthcare system challenging as assumptions are made about their gender and bodies.

Health care practitioners can make a range of assumptions around the role a carer plays in a person's life. It is common for practitioners to make assumptions that a person's carer is a friend or relative instead of acknowledging them as a partner.



This can result in patients and carers feeling that they are invisible and their individual needs are not being met.

We all have the right to quality healthcare that caters for individual need and choice.

Carers are an important part of our healthcare system and have the right to feel supported and respected. If a health professional has treated you or the person you are caring for in a discriminatory or disrespectful way, or is not meeting your needs, you have the right to:

- Speak up and ask for what you need.
- Advocate for what the person you are caring for needs.
- Ask to speak to a different health professional.
- Give feedback on unacceptable behaviour.
- Be clear that you are the primary carer and have the person's permission to be involved in health-related decisions.

It is a personal choice to disclose any details of your relationship, sexual orientation or identity to health professionals.

Regardless of what you want to communicate, you should feel safe to be able to make this decision for yourself and be supported by the health care practitioners you engage with.

Family relationships and the concept of 'chosen family'

People who are LGBTIQ+ can experience negative responses from their family of origin around their sexuality, gender identity and bodily diversity. This can often result in a breakdown in family relationships.

As a response to this, LGBTIQ+ people often recognise the concept of 'chosen family' – that is, the person or people that someone sees as significant to them. It may or may not include biological family.

Sometimes estranged biological family members can suddenly reappear in people's lives at the end of life. This can cause stress and conflict for the carer as well as the person who is being cared for. Questions and conflict can arise over who gets to make health-related decisions, who is privy to health-related information, who is the primary carer, who plans the funeral and what happens to the person's estate after death. Sometimes there are issues around who knows about the person's sexuality, gender, bodily diversity or about a person's relationship. It is important that privacy and confidentiality is upheld by all health care professionals.

Where possible, conversations about end of life wishes should be initiated early and documented clearly.

Formal documentation may include:

- A last will and testament.
- Power of Attorney or Medical Power of Attorney.
- Advanced care plans.
- Pre-planned funeral with clear input and directions from the person who is at the end of life.
- Financial planning and preparation to ensure joint bank accounts or assets are in the correct names.





Celebrating the person you are caring for in your own way

It is important that you feel like you can celebrate the person's life in the way that is most meaningful to you and the person you are caring for.

This may include:

- Bringing in special items from home into the hospital room or hospice room.
- Having your own rituals.
- Inviting people to the hospital or hospice to visit your loved one.
- Playing music that the person enjoys most.
- It is important that you feel safe to bring your own humour, culture, community, and language with you into the hospital or hospice.

For more information and support

Carer Gateway has a list of organisations that provide support for LGBTIQ+ carers.

