

Cancer Survivorship in the LGBTQ Community

A cancer diagnosis can affect all aspects of a person's life. You and your loved ones should consider being open about your sexual orientation and gender identity with your cancer care team and should keep in mind the unique challenges that LGBT individuals can face.

There are approximately one million LGBT cancer survivors in the U.S. today, which includes those currently fighting cancer and those who have been cured. LGBT folks can face discrimination and stigma in the healthcare system, which can hinder quality care and survivorship, and often leads LGBT people to avoid getting care altogether. LGBT people are less likely to use preventive health services (such as mammography), which may result in cancer diagnoses happening later for LGBT people, risking worse outcomes in survivorship. Lower financial stability and insurance access among LGBT people also decreases access to care.

COMING OUT AS LGBT TO THE CARE TEAM CAN FACILITATE AN OPEN DIALOGUE

To address the issues above, your healthcare provider should create a safe and welcoming environment that enables you to have an open and honest conversation to share your sexual orientation and gender identity.

- Find a provider with whom you are comfortable, express your needs to the care team and provider, request that inclusive language is used, and learn about your rights with the following resources:
 - The LGBT Healthcare Bill of Rights (find a provider, learn about quality care, and know your rights): healthcarebillofrights.org
 - Q Card Project (learn how to communicate with your provider): qcardproject.com
 - National Center for Transgender Equality's healthcare rights page (know your rights): transequality.org/know-your-rights/healthcare
- Being out to health care providers can enable your social network, loved ones, and caregivers to be involved in treatment decision-making, assist with side effect management, and advocate for you when you are unable to do so yourself.
- Cancer treatment can have numerous side effects on sexual health and functioning, which you should be able to discuss with your provider.
- Treatment can affect fertility, so if maintaining fertility is important to you, you should discuss it with providers before starting treatment.

PREPARING TO HAVE THE SUPPORT YOU'LL NEED

Having support is a source of resilience for cancer survivors, including those who are LGBT. Limited research on LGBT survivors suggest that their support may come from more diverse sources than other survivors, who typically rely on spouses and children. This may mean that LGBT people need help maintaining complex support networks in the face of adversity.

- Support groups that understand the unique needs of LGBT patients can make it possible for LGBT survivors to truly thrive. An LGBT community center near you may provide support groups; find your closest center at lgbtcenters.org/LGBTCenters.
- If you cannot find an LGBT-specific or -inclusive cancer support group in your area, you may be able to join an online LGBT group at cancer-network.org/programs/support-groups-for-survivor
- Cancer treatment can have numerous side effects on sexual health and functioning, which you should be able to discuss with your provider.
- Being prepared for physical, mental and social changes during cancer treatment and beyond requires planning. Learn about healthcare planning documents at lambdalegal.org/takethepower and tinyurl.com/tgncplanning, and about creating a cancer care plan at cancer.gov/about-cancer/coping/survivorship/follow-up-care.

MAINTAINING PERSONAL RELATIONSHIPS

Following treatment, cancer survivors' needs may change and relationships may shift.

- Learn how to manage relationships and communicate your needs with Taking Time from the National Cancer Institute, available at cancer.gov/publications/patient-education/taking-time.
- During and after treatment, patients' loved ones and families can experience physical and emotional strains as well as difficulties managing both caregiving and other responsibilities, such as employment.
- Join the LGBT caregiver community and find resources for caregivers at caregiver.org/lgbt-caring-community-online-support-group and cancer-network.org/cancer-information/lgbt-caregivers
- Connecting with local LGBT organizations may provide useful social opportunities and services. Find an LGBT center at lgbtcenters.org/Centers/find-a-center.aspx.

TAKING CARE OF YOUR MENTAL HEALTH

Almost all cancer survivors experience some form of distress. LGBT cancer survivors are less likely to report they are happy with their health or feel positively about the future. They also may be more likely to experience depression or anxiety after cancer treatment. Support groups (discussed above) have been found to help mental health for LGBT survivors, as has counseling, support from families, and support from partners.

- Finding a provider who is LGBT friendly, open and inclusive can not only help to uncover sources of distress but can itself be a means of reducing anxiety for patients. For example, a provider acknowledging a patient's same-sex partner and having a discussion about the patient's sexuality can improve both survivor and caregiver well-being.
- Tips on how to speak with a mental health provider, as well as other resources, are available at nami.org/find-support/lgbtq.
- Find LGBT competent mental health providers on the resource page at glma.org.
- The American Cancer Society also recommends physical activity, stress management, conversation, and participating in activities that one enjoys to improve mental health. Read more strategies at cancer.org/treatment/treatments-and-side-effects/emotional-side-effects/anxiety-fear-depression.html.

RETURNING TO WORK AFTER TREATMENT

- Patients may be eligible for unpaid leave under the Family Medical Leave Act, which now includes same-sex spouses. Your state or employer may offer additional protections. Learn more at dol.gov/whd/regs/compliance/whdfs28.htm.
- Feeling productive may be an essential part of returning to a normal routine. Find resources at cancer.net/blog/2016-08/returning-work-after-cancer and tinyurl.com/acsrturntowork.

References for this document can be found at: <http://hlthlnk.lgbt/fact-sheets>