

LGBT Caregiver Fact Sheet for Providers

As a health care provider, it is important to remember that caregivers are an essential part of a patient's support team. However, people caring for loved ones, in particular those with long-term illnesses, can develop caregiver's fatigue, where they simply feel unable to continue giving. It is common for a caregiver to feel tired, apathetic, angry or depressed, impatient, withdrawn, lonely, and anxious. To help caregivers care for their loved ones, here are some tips.

Lesbian & Gay Caregivers

(Modified from the American Cancer Society's Tips for LGBT Caregivers)

LGBT families face different challenges in caregiving than their heterosexual peers. Even though Americans increasingly support basic civil rights for LGBT people, lesbians and gay men and their families still experience stigma and discrimination in law (e.g. the Defence of Marriage Act, adoption restrictions) and in every day interactions. These experiences may increase stress in general, as well as anxiety in dealing with medical professionals, hospitals, etc. Also, biological families may place a disproportionate burden of caregiving for a parent on LGBT children, as they may be seen as "single" even if they live with partners and young children. Many LGBT adults have extensive experience caregiving for 'families of choice' - friends, neighbors, and other loved ones who lack the traditional support from family. After several friends have experienced advanced HIV/AIDS, cancer, and/or death, the remaining members of the social network may begin to feel burnt out. Studies have shown that "caregivers in lesbian or gay relationships, compared with those in opposite sex relationships, were providing significantly more hours of care and higher levels of assistance and were experiencing increased levels of role strain and likelihood of job termination as a result of their family care responsibilities" (Fredriksen 1999). Along with too much caregiving responsibility, an LGBT person may feel unwelcome in mainstream support groups, and feelings of isolation may develop as a result of limited access to safe environments. Fredriksen's study also showed that the majority of LGB people (82 percent) with adult caregiving responsibilities "had experienced harassment because of their sexual orientation" (1999). Existing normally in society is already a source of anxiety for many LGBT people, and fear of discrimination with the added burden of the worries and stress that come with caregiving may be difficult to cope with.

Here are some suggestions on caregiving that may be especially important for LGBT families:

1. *Call on family, friends, and community - including Mautner Project - for help with the avalanche of responsibilities that may come with caregiving.* Caregiving for a seriously ill person can be a burn-out job if done alone, and same-sex couples may not have as much support as they could use from biological family members. In fact, according to Reverend Ken South, in the report *Outing Age*, "studies show that 80 percent of all care for frail elderly people is done by family, but 80 percent of gay people don't have family: they don't have children and may be estranged from their families of origin.

So while gay siblings may be expected by other family members to take care of elderly parents because they don't have children, it is unclear who will take care of the gay siblings when they are elderly or dying" (*End-of-Life Issues and the Gay Community* 2005). If this is the case with your patient, it may be necessary for a patient or caregiver to draw on friends and 'family of choice' instead. Tell the caregiver not to worry about inconveniencing them - if she needs help, she needs to ask for it! Remind the caregiver that if she wears herself out, then she won't be able to provide the necessary care to her loved one.

2. When people offer to help, *the caregiver should be ready with specific requests*. Delegating tasks is key. Someone will need to help plan treatment schedules, transportation, & childcare; another person may provide emotional support and relay information to the family. Also, have the caregiver think of asking for concrete tasks such as help with meals or errands. Delegating specific tasks helps caregivers stay organized, and is more likely to get much-needed help.
3. If the caregiver is the patient's partner, she should *have clear legal authority to act on behalf of the person who is ill*. Same-sex relationships are not recognized in most US courts. So, unfortunately, biological family members sometimes take control over medical & financial decisions for an LGBT person, possibly preventing that person's partner from being involved. While this tends to be an extreme situation, a family conference with proper documentation drawn up by an attorney can prevent misunderstandings and arguments about care. An LGBT partner should have durable power of attorney for health care and some type of advance directive such as a living will or a do-not-resuscitate order. Along with questions of legal authority, LGBT caregivers face other legal concerns: "Many privileges taken for granted by heterosexuals are often difficult to obtain or flatly denied to LGBT caregivers. They are usually excluded from their partners' health insurance and are frequently discriminated against, no matter the length of their partnership, in terms of survival benefits, inheritance rights and community property rights" (Coon 2003). This additional stress makes caregiving even more difficult and worrisome for LGBT people. As a health care provider, you may be able to facilitate a family meeting or provide the caregiver with helpful resources to overcome these barriers. See the Family Caregiver Alliance's article on [Legal Issues for LGBT Caregivers](#) for more information on the issues and what you can do to ease the stress of LGBT caregivers.

Additional tips:

- Offer a caregiver information about stress relief exercises such as meditation, music, exercise, or yoga.
- Remind caregivers that it's ok to feel negative emotions in difficult situations. Caregiving for extended amounts of time is hard work!
- Encourage caregivers to ask for help and to take breaks in order to recover and relax. Provide them with information on professional services and support groups.

In order to help LGBT families caregive more effectively, it is important for your practice to be accessible and familiar with LGBT caregiving resources. To be accessible to LGBT people, create a safe, friendly environment by displaying visual cues, such as a rainbow or HRC equal symbol, and revise client forms using inclusive language such as "partner" or "spouse" instead of "married." Being aware and sensitive of LGBT issues - and making sure your staff is as well - will go a long way in helping LGBT families feel comfortable.

Resources:

Information on how to become more inclusive can be found here:

- Sherbourne Health Center - [Making Breast Cancer Support Groups Work for Lesbian and Bisexual Women](#)
- [Fenway Health](#) - An organization dedicated to bringing quality healthcare to the LGBT community
- [GLMA](#) - The Gay and Lesbian Medical Association offers information on various LGBT issues, as well as a database of friendly providers
- [American Society on Aging](#) - LGBT Aging Issues Network (LAIN) offers several studies and resources on aging LGBT people and their caregivers.
- [Mautner Project](#) - We can provide you with information on how to become LGBT-friendly, as well as information on specific health issues within the LGBT community.

Here are some organizations a caregiver can contact for *education and information*:

- [National Cancer Institute \(NCI\)](#) - 1-800-4CANCER - website provides comprehensive information on cancer prevention, diagnosis, treatment, statistics, research, clinical trials, and news.
- [American Cancer Society](#) - 1-800-ACS-2345 - offers section through website entitled, "Preparing for Treatment". Here you will find different types of treatment information and their risks and benefits, possible treatment side effects, and tips for managing them.
- [CancerCare](#) - 1-800-813-HOPE - offers many publications addressing practical, emotional, and medical concerns. Additionally, they offer *Telephone Education Workshops* which are free educational programs to help you and your loved ones understand your diagnosis, treatment options, quality-of-life concerns, and other important topics.
- [Susan G. Komen for the Cure](#) - 1-877 GO KOMEN - offers a wide variety of services regarding breast cancer, including information, events, support groups, and ways to help advocate for a cure.

Here are resources to help a caregiver can connect with *emotional support*:

- [Mautner Project](#) - We offer online LBT support groups for survivors, caregivers, and bereavement. We can also refer you to an LBT-friendly support group near you!
- [American Cancer Society](#) - offers support through cancer-specific programs and maintains a database of local support groups nationwide.

- [CancerCare](#) - provides free, professional support services to anyone affected by cancer: people with cancer, caregivers, children, loved ones, and the bereaved. Also offers support groups in-person (NYC area), by telephone, or online.
- [Cancer Hope Network](#) - connects patients with trained volunteers who have themselves undergone a similar cancer experience.
- [Family Caregiver Alliance](#) - FCA offers an LGBT Caregiver Discussion Group online as a place to share experiences, discuss ideas, and find support.
- [Wellness Community](#) - provides in-person and online support groups for patients.

Cancer-specific organizations usually offer support group information. Many of these organizations also offer "buddy" or matching programs, which bring people together for mutual support.

References:

- "Caring Advice for Caregivers: How Can You Help Yourself?" (2008). Cancer Care, Inc. <http://www.cancercare.org/>.
- Coon, David W. (2003). Lesbian, Gay, Bisexual and Transgender (LGBT) Issues and Family Caregiving. Family Caregiver Alliance.
- Fredriksen, Karen I. (1999). Family Caregiving Responsibilities Among Lesbians and Gay Men. *Social Work*, 44(2), 142-155. <http://www.yu.edu/wurzweiler/articles/Frederiksen.htm>.
- Reviewed by Gans, Steven, MD. About.com Health's Disease & Condition Content (ArticlesBase ID #515854).
- (2005). End-of-Life Issues and the Gay Community. *State Initiatives in End-of-Life Care*, 24, 8.
 - Cahill, Sean, South, Ken, & Spade, Jane. (2000) Outing Age: Public Policy Issues Affecting Gay, Lesbian, Bisexual and Transgender Elders. The Policy Institute of the National Gay and Lesbian Task Force Foundation.
- Tips for LGBT Caregivers. American Cancer Society. http://www.cancer.org/docroot/home/cgv/cgv_0.asp.