

Special Concerns of LGBT Caregivers

Introduction

As Americans live longer, greater attention is being paid to the concerns facing aging adults and caregivers. While many issues are the same for all older adults and those who care for them, some unique considerations arise for lesbian, gay, bisexual, and transgender (LGBT) people dealing with aging.

How Chosen Families Affect Caregiving

As you may already know, many LGBT people form strong “families of choice” in addition to their families of origin as a way of coping with possible or actual rejection by parents, siblings, and other relatives for being open about their sexual orientation or gender identity. Even as attitudes have changed and LGBT people have become more visible and accepted, families of choice still provide invaluable networks of emotional and social support. Nearly two-thirds of LGBT older adults say they consider their friends to be chosen family.

Being a member of both a chosen family and a family of origin creates situations where an LGBT person may become a primary caregiver for a spouse, domestic partner, or legal spouse, a close friend who is also LGBT, or an aging parent or other relative—sometimes simultaneously. In the community at large, it is most common for informal caregivers such as spouses and adult children to provide the majority of care to older adults in the United States. In the LGBT community—with older adults twice as likely to be single and living alone, and three to four times less likely to have children—a family of choice is depended upon to provide support and care.

In January 2011, federal regulations took effect allowing patients at most hospitals in the country to decide who has visitation rights and who can make medical decisions on their behalf, regardless of sexual orientation, gender identity, or family makeup. President Obama issued a presidential memorandum on hospital visitation that called for “appropriate rulemaking ... to ensure that hospitals that participate in Medicare or Medicaid respect the rights of patients to designate visitors.” The memorandum recommended that the U.S. Department of Health and Human

Services provide detailed guidelines for hospital visitation that prohibit discrimination based on “race, color, national origin, religion, sex, sexual orientation, gender identity, or disability.” These protections are further reinforced in the Affordable Care Act. But as you will see in the news, instances occur where some hospital personnel remain confused or continue to deny health care proxies to same-sex couples. For more information on health care visitation rights and decision making, see resources available from the [Human Rights Campaign](#).

It is also important for LGBT seniors and their caregivers to complete basic legal documents establishing the right to make care decisions and to document treatment preferences for hospital and healthcare providers. (See the FCA fact sheet [Legal Issues for LGBT Caregivers](#).)

Dealing with Your Employer

Another concern that some LGBT caregivers face is scheduling time off with their employer to care for an aging loved one. Time off can range from occasional doctor visits to extended unpaid leave to be with someone who is more seriously ill. This concern may be further complicated by the degree to which you are “out” at work, and whether your employer has a nondiscrimination policy that affirms LGBT people and offers domestic-partner benefits.

Ask your human resources department for written copies of your company’s policies and benefits. Discuss any concerns with your manager or boss. If you are not “out” to your employer or do not feel comfortable discussing personal issues with your manager or HR department, seek referrals for legal advice from local or nearby LGBT organizations, the National Center for Lesbian Rights (available to all LGBT people), or Lambda Legal.

The federal Family and Medical Leave Act—which requires most companies to offer employees at least 12 weeks unpaid leave to care for ailing family members—does not provide job protection to LGBT (or unmarried heterosexual) domestic partners. However, many private employers, including more than half of Fortune 500 companies, now offer domestic partners the same medical leave and bereavement policies as married employees. Public employees also enjoy these benefits in cities and states where domestic partner benefits are offered, as do employees of some federal agencies.

In California, workers who contribute to the State Disability Insurance (SDI) fund are entitled Paid Family Leave, up to six weeks of partial pay each year while taking time off from work to: bond with a newborn baby, adopted or foster child; and care for a seriously ill parent, child, spouse or registered domestic partner. Workers may receive up to 55% of their weekly wages up to a maximum weekly benefit amount (determined by weekly wages in the base period).

Some states may provide registered domestic partners and same-sex spouses with the right to receive unemployment benefits when they leave a job position to join their partner at a new location where commuting is impractical and a job transfer is not available. Although it will vary by state, in California, this benefit is not charged to the employer's account.

Finding Supportive Healthcare and Service Providers

As a caregiver, the time may come when you need additional support to provide proper care for your loved one. Paid care is available at nearly every stage along the continuum of care, from in-home service to residential assisted-living to skilled nursing facilities. Entrusting the care of a loved one to a stranger can be a difficult decision—one that can be compounded by fear of inadequate treatment or discrimination for being LGBT. Too often, LGBT older adults can allow this fear to postpone seeking assistance or support—which further increases isolation and decreases mental and physical health.

For these reasons, it is important to do some preliminary research on in-home care and support and other community resources that are available before discussing it with the person for whom you are providing care. Having answers at the ready will help ease concerns that your partner, spouse, or friend may raise, and will better allow you to move forward with a plan for additional care.

The best source for information about service providers is firsthand knowledge from other LGBT people you know. Ask friends and work colleagues with similar circumstances for referrals to LGBT-affirming healthcare and service providers with whom they have worked, and discuss what they liked and didn't like about their care. Make notes about specific departments and people they considered to be strong allies.

Similarly, local or nearby LGBT community centers, LGBT health organizations, and LGBT senior advocacy groups can provide excellent referrals and support. You may also consider reaching out to HIV/AIDS service organizations for a list of LGBT-affirming home healthcare providers. Another option is to contact the Gay and Lesbian Medical Association, which offers referrals to LGBT-sensitive medical professionals in many parts of the country. Lastly, you may want to see which, if any, senior service providers advertise in local LGBT publications or websites in your area. This can be a good first sign that an agency or organization has experience with and ties to the community.

Once you have a list of providers, review their websites and literature. Are LGBT couples represented in images? Do they use inclusive words such as domestic partner, significant other and life partner as well as spouse? Do they describe a broad definition of family? Is there a stated nondiscrimination policy that specifically affirms the rights of LGBT people? Call agencies and ask about their policies directly. Ask them how many LGBT clients they work with currently and what steps they have taken to create a welcoming environment for LGBT seniors.

For most people, the price of care will factor heavily into decisions about bringing on additional support. Through each state's Medicaid program (MediCal in California), a number of services, such as adult day healthcare and in-home assistance, may be funded to support those needing care. Some states have "consumer-directed" in-home support-service programs, which allow aging adults with disabilities to hire and supervise a paid support worker with whom they feel comfortable. In many states with consumer direction, spouses are restricted from being hired to provide paid care. In this case, for LGBT caregivers, non-married same-sex couples can hire their partner to provide care.

You will find it much easier to work with and obtain information from Social Security, Medicaid/Medi-Cal, and other service providers if the person for whom you are caring has completed certain standard legal documents that designate you to act on his or her behalf. Even if you and your loved one currently have an understanding with certain physicians or care staff, it is still important to take these legal steps. In an emergency, you may have to deal with doctors and other professionals outside your regular care network who will not provide medical information to individuals who are not next of kin or who are not legally designated to make decisions on behalf of the patient. (See the FCA fact sheet [Legal Issues for LGBT Caregivers](#).)

Depending on where you live, your expectations for finding LGBT-affirming care and support may vary widely. In cities with visibly large LGBT communities, you may find that older LGBT people have formed their own social and support organizations, and that there are dedicated LGBT medical clinics, assisted-living facilities, and retirement communities. In many other cities and towns, senior care providers may not know that they have worked with LGBT aging adults or why a person's sexual orientation is even relevant. (Unfortunately, unless providers receive training on reaching and serving LGBT caregivers and their families, their needs may remain largely invisible.) Continue seeking referrals from friends, colleagues, and local and national LGBT organizations until you feel good about working with a provider.

Experiencing Mistreatment or Discrimination

A recent survey of LGBT baby boomers found that a growing number of LGBT aging adults expect to be treated with respect and dignity at the end of their life. In spite of this, one in five of the LGBT adults surveyed cited fear of double discrimination (for being older and LGBT), as a significant concern about aging. These fears are particularly important to seniors moving into nursing homes or residential care facilities. Unfortunately, 41 states do not currently have any housing or public accommodations laws prohibiting discrimination against people based on their sexual orientation.

Homophobia can be expressed in different ways in a care facility, ranging from comments made to your spouse, partner, or friend by other patients or staff, to problems with the care that is or should be provided. Under the law, all residents have rights and protections. The facility must publicly list and provide a copy of these rights to all new residents. (Read more about them at: www.medicare.gov/what-medicare-covers/what-part-a-covers/skilled-nursing-facility-rights.)

If problems occur, the first step in resolving the issue is to determine whether the mistreatment is the behavior of an individual or part of a larger pattern of behavior within the facility. If the harassment is by another resident, possibly a roommate, ask if your loved one can be moved to another room or part of the facility. If the problem stems from an individual health worker or aide, talk to the appropriate supervisor or administrator and ask if another staff person can be assigned to assist your partner, spouse, or friend. If problems persist or if you determine that the homophobia is widespread and can't be resolved by talking with the facility staff,

you should contact your local Ombudsman Program.

Under federal law, each jurisdiction must maintain an Ombudsman Program that will rapidly verify claims of mistreatment or abuse in licensed care facilities and help to mediate problem resolution. Local Ombudsman Programs also should be responsive to caregivers who want to discuss their concerns about care in a licensed facility and assist in determining if a complaint should be filed. Contact the Office on Aging or the Area Agency on Aging in the county in which the facility is located to get information about your local Ombudsman Program. You can also report a problem directly to the state department (often the State Department of Health) that licenses and/or certifies skilled nursing facilities (sometimes known as nursing homes), residential care facilities, or board and care homes.

Maintaining a Sense of Community

Some older LGBT adults report feeling disconnected from or invisible to the larger LGBT community as they age. In our youth-focused culture, institutionalized ageism produces these feelings among heterosexual older adults as well. As an LGBT caregiver, it can be important to help the person for whom you care stay connected to members of your chosen family and to other LGBT older people.

As LGBT people age and depend on others for care, they may become more guarded about who they are. While this choice is understandable, one consequence can be greater feelings of isolation. Also, since LGBT seniors are more likely to be single and to live alone, extra efforts may be needed to build and maintain social support networks. Ask local LGBT organizations about regular social events for LGBT seniors in your area, or about the availability of an LGBT-friendly visitor program. Seek out multigenerational community activities such as bingo nights, film festivals, and neighborhood fairs, as ways to stay connected to the community at large. Patronize local cafes and bookstores where LGBT people congregate. Invite friends or family members to join you and your loved one.

Depending on where you live or your loved one's mobility, you may not have access to a variety of places where LGBT people gather. Try to take advantage of virtual communities. Almost every hobby has a subset of LGBT enthusiasts online with whom you can connect and chat about shared interests. A great place to start is the Family Caregiver Alliance's [LGBT Community Support: Caregiving for our Families and Friends](#) online support group.

Being an LGBT Caregiver for an Aging Parent or Relative

Most issues that you will face as an LGBT caregiver for an aging parent or relative are the same as those faced by all caregivers. In a family of origin, it is typical for one child to assume the role of primary caregiver for an aging parent or parents. That responsibility often falls to the person who lives closest to the parents or who does not have young children. For LGBT people, the assumption that they do not have family responsibilities of their own if they do not have children can be particularly hurtful.

Even if you are “out” to siblings and relatives, they may not understand or appreciate that being part of a chosen family means you have serious obligations and commitments. Depending on family dynamics and communication styles, your role as a primary caregiver may be assumed without discussion.

If you need help setting clear boundaries with your siblings and relatives, one option is to ask a local caregiver-support agency or social worker for assistance in facilitating a family meeting. All members of the family—especially the primary caregiver—should think about what needs to be discussed. The person providing most of the care should explain what part of the responsibility he or she feels able to shoulder and what help is needed. It is appropriate and important to set limits and not to agree to more than you can handle just to preserve family harmony. (See FCA’s fact sheet [Holding a Family Meeting.](#))

Maintaining Your Own Well-being as an LGBT Caregiver

Providing care for a loved one can span weeks, months, or in many cases, years. Learning to ask for support and taking care of your own emotional, physical and spiritual health are important considerations for every caregiver. LGBT caregivers may also need to consider some additional factors when strategizing ways to find support and assistance.

To live openly and honestly, many LGBT people have had to make the difficult decision to live without contact or support from their family of origin. Many LGBT adults have also chosen not to have children of their own. In these cases, extended family may not be a source of assistance and support. If this is true for you, it is especially important to reach out to chosen family members for help, as well as turning to community, medical, and assisted-living support services when necessary.

There are various state and federal programs designed to support caregivers. The National Family Caregiver Support Program (NFCSP) distributes money to states, which in turn fund local Area Agencies on Aging to provide services directly or to contract with community agencies to offer support. The language authorizing the program is broad and inclusive, defining a family caregiver as “an adult family member, or another individual, who is an informal provider of in-home and community care to an older individual.” The types of services funded by the NFCSP include counseling, legal advice, and access to a respite or break from caregiving.

Familiarity with LGBT-specific issues will vary widely in these agencies. If you meet resistance from one person, ask to speak to someone who has training or experience working with LGBT seniors and caregivers. To learn more about NFCSP services, contact the Office on Aging or the Area Agency on Aging that serves the region in which the person you care for resides.

Resources

Family Caregiver Alliance

National Center on Caregiving

(415) 434-3388 | (800) 445-8106

Website: www.caregiver.org

FCA CareNav: fca.cacrc.org/login

Services by State: www.caregiver.org/connecting-caregivers/services-by-state

Family Caregiver Alliance (FCA) seeks to improve the quality of life for caregivers through education, services, research, and advocacy. Through its National Center on Caregiving, FCA offers information on current social, public policy, and caregiving issues and provides assistance in the development of public and private programs for caregivers. For residents of the greater San Francisco Bay Area, FCA provides direct support services for caregivers of those with Alzheimer’s disease, stroke, head injury, Parkinson’s, and other debilitating disorders that affect adults.

FCA Fact and Tip Sheets

A listing of all facts and tips is available online at www.caregiver.org/fact-sheets.

[Legal Issues for LGBT Caregivers](#)

[LGBT Caregiving: Frequently Asked Questions](#)

[Hiring In-Home Help](#)

[Hospital Discharge Planning: A Guide for Families and Caregivers](#)

[HIV-associated Neurocognitive Disorder \(HAND\)](#)

[Taking Care of YOU: Self-Care for Family Caregivers](#)

Additional Organizations and Links

◆ *General resources for the LGBT community*

AIDS Health Project

www.ucsf-ahp.org

Gay and Lesbian Medical Association

www.glma.org

LGBT National Hotline

(888) 843-4564

www.glbtnationalhelpcenter.org

Lambda Legal

www.lambdalegal.org

National Center for Lesbian Rights

www.nclrights.org

◆ *For seniors*

Lavender Seniors of the East Bay

www.lavenderseniors.org

National Resource Center on LGBT Aging

c/o Services & Advocacy for GLBT (SAGE)

www.lgbtagingcenter.org

Openhouse

www.openhouse-sf.org

References

Still Out, Still Aging: The MetLife Study of LGBT Baby Boomers, 2010 MetLife Mature Market Institute

www.metlife.com

Human Rights Campaign: Hospital Visitation Rights

www.hrc.org

Paid Family Leave California

www.paidfamilyleave.org

For additional support to LGBT caregivers

LGBT Community Support: Caregiving for our Families and Friends online support group offered by FCA and facilitated by Openhouse

www.caregiver.org/support-groups

FCA's Family Care Navigator, for locating caregiving services and support throughout the United States

www.caregiver.org/family-care-navigator

This fact sheet was prepared by Family Caregiver Alliance, and reviewed by Patricia Osage, Executive Director, Life ElderCare/Lavender Seniors of the East Bay in 2015, and by Openhouse in 2011. © 2011, 2015 Family Caregiver Alliance. All rights reserved.

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