



Southern Caregiver Resource Center

Caring for those who care for others

Fact Sheet: **LGBT Caregiving:** **Frequently Asked Questions**

Introduction

Over the past two decades as the population of seniors—65+ years—has grown, government (local, state, federal) agencies, nonprofit community organizations, for profit businesses, and the media have focused increasing attention on the needs of seniors and those who provide them with support, assistance, or care. It is estimated that by 2050 the population of people over 65 will be 20.9% of the population. These are startling numbers affecting everyone in the United States.

Much less attention is given to the needs of older Lesbian, Gay, Bisexual and Transgender (LGBT) adults and in particular, to those of their caregivers, whether spouses, partners, friends, or other family members. If the LGBT population is indeed around 10%, as many studies have claimed, the growth in LGBT seniors will also be exponential.

Many of the issues you or your loved one may confront—such as where to turn for help, what kinds of programs can support caregivers, how to access services—do overlap with those faced by heterosexuals. LGBT caregivers and care receivers can also face some specific concerns and particular challenges. For more information about legal documents you must have in place as soon as possible (see *Legal Issues for LGBT Caregivers* fact sheet).

The support that a caregiver receives from friends and family is often critical in relieving some of the stress of providing assistance to someone who has a chronic illness. Hopefully, you have the support of accepting family and friends to help you. However, it is often true that LGBT caregivers may find that they have less support than they would like from their own—or the care receiver’s—biological family members. This fact sheet addresses a number of important concerns and frequently asked questions (FAQs) that LGBT caregivers have. It should help you navigate through changing caregiving options for seniors and locate assistance in your area.

Caregiver Questions

Q: My partner was diagnosed with Alzheimer’s about three years ago. We’ve been going it alone, but now we need some additional help. How can I tell if a service or organization is open to working with LGBT families?

Kudos to you for managing to “go it alone” for three years. But, as you have learned, going it alone can get you only so far. For anyone facing an Alzheimer’s diagnosis, it is much better to enlist some help as soon as a situation presents itself. It is also important to act immediately on a diagnosis of dementia. Now that you are ready for help, there are many agencies, public and private,

that are available to you. In cities with sizeable gay and lesbian communities, some public and private agencies will have experience with caregiving issues and LGBT families particularly in the three decades since the start of the AIDS epidemic. In less densely populated areas, where programs may have less opportunity to work with LGBT individuals and families, determining whether an agency will be supportive may be more difficult.

Many agencies have official policies stating that they do not discriminate on the basis of gender, race, religion, or sexual orientation. Sometimes this information is stated in their brochure, on the internet or in other promotional materials. Look for a rainbow logo for a visible cue. Others may acknowledge LGBT sensitivity and acceptance through the use of such terms as “domestic partner,” “life-partner,” or “significant other” - in addition to “spouse.” Agencies may also state they define a family in the broadest sense including other non-married partnerships, friends and neighbors, or any persons that choose to live together to provide mutual help and support. Either as a caregiver or care receiver, one’s decision to disclose being lesbian, gay, bisexual or transgender when seeking assistance will depend on the particular set of circumstances in your life, such as geographic location, family dynamics and relationships, medical necessities, the agencies in question, and other factors.

Before you even check out agencies, you might want to explore closer to home. One of the best approaches to finding help is to check with friends and acquaintances who have been in similar circumstances. Ask them for referrals to agencies and organizations that have

been most accepting of their needs and concerns. Even if an agency has an official nondiscrimination policy, those who’ve been through this before may know which staff or departments within an organization are likely to be the most open and responsive. The office of the doctor who made the diagnosis might have some literature on tables; if you are comfortable with the doctor, asking outright about resources is in order.

Local and national LGBT organizations can be another vital resource in locating community agencies that are sensitive and supportive. Many areas have a gay switchboard or hotline that provides information anonymously over the phone. Larger cities frequently have LGBT-specific medical clinics or other centers devoted to gay and lesbian health issues. In recent years, older gays and lesbians have formed their own organizations offering recreational activities and other opportunities to socialize as well as support groups.

For referrals to LGBT-sensitive homecare providers or social work services, you can also try contacting community agencies which provide AIDS support and services. Finally, the Gay and Lesbian Medical Association, which is based in San Francisco, can provide referrals to LGBT-sensitive medical professionals in many areas of the country. See the list of LGBT-Friendly Resources at the end of this fact sheet.

Q: What response can I expect from state and federal programs that assist caregivers?

There are various state and federal programs designed to support caregivers, and they differ in their approach to issues related to sexual identity and gender identity. As part of

the reauthorization of the Older Americans Act, the federal government created the National Family Caregiver Support Program (NFCSP). This program distributes money to states, which in turn fund local Area Agencies on Aging to either provide services themselves or to contract with community agencies to provide caregiver support. The legislative language authorizing the program is broad and inclusive and defines 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 which are funded in your area by the NFCSP may include information, education, counseling, legal advice, and access to a respite or break from caregiving.

The LGBT sensitivity of the government agencies that provide these caregiver programs may vary from county to county and state to state. To find out more about the NFCSP services in your area, contact the Office on Aging or Area Agency on Aging in which the care receiver lives. To find your local Area Agency on Aging, call Eldercare Locator, toll free nationwide at (800) 677-1116 or visit FCA’s Family Care Navigator at <https://caregiver.org/family-care-navigator>.

Through each state’s Medicaid program (Medi-Cal in California), a number of services may be funded which support those who need care (such as adult day healthcare or in-home assistance). Some states have in-home support services programs that are “consumer directed”—the client hires and supervises a worker that he or she selects. You will find dealing with Social Security and Medicaid much easier if the care receiver has completed certain

standard legal documents in which they designate you, your spouse, a partner, or a friend to act as agents on their behalf if they are incapacitated. Otherwise, it may be difficult for you to obtain information from these agencies (see fact sheet, *Legal Issues for LGBT Caregivers*).

Q: If one of us becomes ill and needs care from the other, does the Family and Medical Leave Act (FMLA) provide us with any job protection?

FMLA requires most companies (with 50 or more employees) to allow eligible employees at least twelve weeks of unpaid leave to care for ailing family members. In order to provide FMLA rights to all legally married same-sex couples consistent with the Windsor decision and President Obama’s directive, the United States Department of Labor issued a Final Rule on February 25, 2015, revising the regulatory definition of spouse under the FMLA. The Final Rule amends the regulatory definition of spouse under the FMLA so that eligible employees in legal same-sex marriages will be able to take FMLA leave to care for their spouse or family member regardless of where they live. This will ensure that the FMLA will give spouses in same-sex marriages the same ability as all spouses to fully exercise their FMLA rights. The Final Rule was effective on March 27, 2015. Also, be sure to research if your state offers paid family leave (PFL).

For timely updates on the progress in employment situations, go to Lambda Legal (www.lambdalegal.org) or the National Center for Lesbian Rights (www.NCLRights.org) websites, both listed in Resources at the end of this fact sheet.

Q: If my loved one is being mistreated in a nursing home because of his or her sexual or gender identity, what can I do about it?

Homophobia and transgender phobia can be expressed in a number of ways in a care facility ranging from comments made directly to your loved one by other patients or staff to problems with the care that is or should be provided. Under the law, every nursing home resident has certain rights and protections and must be given a copy of these rights. For information about nursing home resident rights, see *Nursing Home Resident's Rights* (<http://ltcombudsman.org/uploads/files/support/Module-2.pdf>) a document excerpted from *A Family Council Manual* prepared by the Minnesota Alliance of Health Care Consumers.

Not surprisingly, nursing homes (also known as a skilled nursing facility or SNF) and residential care facilities, in general, continue to struggle with the sex and sexuality of their residents, heterosexual or homosexual. Contrary to popular belief, many seniors maintain active sex lives and desire, that does not go away with aging. This may particularly an issue for a care receiver who has dementia and may be further complicated by the relationship between dementia, and other cognitive conditions and brain disorders, and lack of inhibition and self-regulation. Additionally, there are still no laws prohibiting discrimination against people based on sexual orientation in housing or public accommodations in 28 states. This number will no doubt change going forward.

If problems occur with a loved one in a nursing or residential facility, the first

step would be to determine whether the mistreatment is isolated or systemic. Is a particular health professional, aide, or other worker the source of the problem? Or, is the person being harassed or mistreated by other residents? If the harassment is by another resident, possibly a roommate, request that your loved one be moved to another room or another part of the facility. If the problem stems from an individual worker, talk to the appropriate supervisor or administrator. Explain the problem and request another staff person to be assigned to assist your loved one. These requests should be friendly and followed up by descriptive letters to the persons with whom you speak. You will want to keep a record of your requests and the responses you receive. However, 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. Each facility must have the contact information for reaching the Ombudsman posted in highly visible places. If you do not see this posted, contact the Office on Aging/Area Agency on Aging in the county in which the facility is located to get information about your local Ombudsman Program. Ombudsmen are usually very busy in their county, and you may have to exercise diligence to set an appointment. Once informed about the problem, the Ombudsman will visit to verify claims of mistreatment or abuse in licensed care facilities and to help to mediate a resolution. Each facility's Local Ombudsman Program should also be responsive to caregivers who want to

discuss their concerns about care in a licensed facility and should assist caregivers in determining if a formal complaint should be filed. Formal complaints are made in writing. 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, residential care facilities, or board and care homes. If the problem rises to the level of elder abuse, be forewarned that lodging a formal complaint against a nursing home or other senior residential facility can become a long and difficult undertaking often requiring attorneys and court time. Attorneys who handle elder abuse matters in nursing homes are highly specialized. Visit the National Center on Elder Abuse website (www.ncea.acl.gov) for more information about concerns in assisted care and nursing facilities or at home.

Q: Are there proactive steps we should take to ensure that our wishes will be followed if either of us becomes incapacitated?

If you are in a non-married LGBT recognized by law (an exception is made for registered domestic partners and civil marriages in some states). Under these circumstances, biological family members sometimes step in, take over decision-making authority, and exclude partners and close friends from being involved in the care of your friend or loved one. Certain steps should be taken to legally acknowledge your chosen family to take charge of your care. At the very least, you must state your wishes in writing, authorizing particular persons to act for you in the event that you are unable to make decisions on your behalf. That document is called an Advance Health Care Directive in California or a Durable

Power of Attorney for Healthcare. For further information on the documents you must execute including powers of attorney for health care and for finances as well as other necessary legal documents (see fact sheet, *Legal Issues for LGBT Caregivers*).

Q: My siblings expect me to provide more and more of the care for our ailing parents. How can I address this issue without alienating them?

Even in families where everyone is heterosexual, one sibling often ends up assuming the largest share of the caregiving load. The role of primary caregiver frequently falls to the adult child who lives closest to the parents or to the one who does not have young children. If you are not married, or not out to your family and do not have children, your siblings may assume, incorrectly, that you have no other family responsibilities. Based on what they see, they may be expecting you to fulfill the primary caregiving function even if the matter has never been discussed.

How you address this depends upon several factors. If your siblings are not aware of your sexual orientation, they may not realize that your own life leaves you with many obligations and as little free time as they have. Even if they know you are gay or lesbian, they may not know other important aspects of your life. Unbeknownst to them, you may be currently caring for a close friend or partner or co-parenting a child. These kind of assumptions and expectations about caregiving responsibilities often create tensions in families, both gay and straight.

One way to deal with the situation is to call a family meeting of siblings. There are local agencies that work with caregivers as well as private social

workers to assist facilitating a family meeting. This meeting would ideally take place early on when the situation arises rather than later when tensions have been simmering. It is helpful for all parties invited to a family meeting—especially the primary caregiver—to think about what should be discussed. Caregivers who will be providing most of the care should explain what part of the burden they feel able to shoulder and what help they need. It is important to set limits at the outset and to not agree to more than you can handle just to preserve family harmony. If your siblings are not aware of your other responsibilities and demands, you may decide it is time to “come out” and spell everything out for them.

Q: Now that my partner’s health has deteriorated, we’re concerned that if we come out to a community agency, we’ll face further discrimination.

This is clearly one of the most delicate - and important - questions you can face. Unfortunately, there is no easy answer and no cut-and-dried formula to follow. How you proceed may depend upon many factors including where you live, your legal status vis-à-vis your partner (married, registered domestic partners, none of these); and whether state and local laws where you live protect LGBT individuals from discrimination. At this point in time, you want the quickest and best information and services available. You may decide it is best to be open with service agencies, especially if you have learned from acquaintances or local LGBT resources which organizations are likely to maintain an open attitude. Much investigation about agencies in your area is available online. You may review the list of LGBT-friendly resources in the Resource section of this fact sheet. Or, you may

adopt a step-by-step approach, confiding in individual care providers whom you have come to trust through working with them.

The importance of having the proper legal documents in place - before a loved one becomes ill and can no longer make decisions - cannot be stressed enough. (See fact sheet, *Legal Issues for LGBT Caregivers*.) The proper legal documents will allow you the greatest flexibility in developing a network of available services and grant you, your spouse, partner, or a close friend the legal right to act in each other’s behalf, in any state, without having to offer anyone—biological family members, service organizations, government agencies—in-depth explanations about your relationship. The persons you name in these legal documents to act as your agent will have legal authority to act for you and in your place, without your having to define your relationship. If you have great concerns about not disclosing the nature of your relationship, you can simply say you are a good friend who has the legal authority to make decisions on her/his behalf.

Even if you currently have an understanding physician and/or care staff, it is still important to take these legal steps. In an emergency, you may have to deal with doctors and other staff who do not know you and who will not provide medical information to individuals who are not next of kin or who are not legally authorized to share information with you.

Q: How is the LGBT community working together to address the care needs of its elders?

One of the strengths of LGBT life, especially in urban centers, there are

numerous agencies both public and private that serve the LGBT population. These agencies have been available for LGBT people to develop a strong support network before there is need of care. While some gays and lesbians may feel estranged from their biological relatives, many if not most have created “families-of-choice”—a common term for these support networks—with people who are frequently willing to fulfill vital caregiving functions. In the last decade or so, many LGBT organizations, particularly those that address the needs of the elderly, have established visiting companion programs specifically for isolated LGBT older adults. Some states strongly encourage, some even require medical personnel to include LGBT cultural competency training as part of their required continuing medical and health education training.

In a number of areas across the country, LGBT community members have launched efforts to create senior housing and retirement communities specifically designed with their needs in mind. Many of these projects are still in developmental stages; many are primarily designed for affluent individuals. However, there are those others that are tailored to provide at least some affordable housing. Hopefully, as the community continues to advocate on behalf of LGBT seniors, a greater variety of housing options will become available.

Resources

Southern Caregiver Resource Center
3675 Ruffin Road, Suite 230
San Diego CA 92123
(858) 268-4432 | (800) 827-1008 (in CA)
E-mail: scrc@caregivercenter.org
Website: www.caregivercenter.org

The Southern Caregiver Resource Center offers services to family caregivers of adults with chronic and disabling health conditions and is for residents of San Diego and Imperial counties. Services include information and referral, counseling, family consultation and case management, legal and financial consultation, respite care, education and training, and support groups.

Family Caregiver Alliance
National Alliance on Caregiving
(415) 434-3388 | (800) 445-8106
Website: www.caregiver.org
E-mail: info@caregiver.org

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.

FCA is committed to nondiscrimination on the basis of sexual and gender identity. FCA welcomes members of LGBT communities to contact us for information and caregiver support services.

Eldercare Locator
www.eldercarelocator.gov

National Center for Lesbian Rights (NCLR)
www.nclrights.org

Resource for updates on legal issues affecting LGTB people

Lambda Legal
www.lambdalegal.org

Gay and Lesbian Medical Association
www.glma.org

**National Resource Center on LGBT
Aging**

www.lgbtagingcenter.org

**Senior Action in a Gay Environment
(SAGE)**

www.sageusa.org

Old Lesbians Organizing for Change

www.oloc.org

A national organization that seeks to empower lesbians 60+ to fight ageism.

The Center

www.thecentersd.org

The fact sheet was prepared by Family Caregiver Alliance and reviewed and update by Helene V. Wenzel, an attorney at law in private practice specializing in estate planning, wills, trusts, probate and conservatorships. She is a member of Bay Area Lawyers for Individual Freedom (BALIF), the National Center for Lesbian Rights (NCLR) and the National Academy of Elder Law Attorneys (NAELA). © 2015 Family Caregiver Alliance. All rights reserved.

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