



Del Mar Caregiver Resource Center
A program of Health Projects Center

Fact Sheet

LGBT Caregiving: Frequently Asked Questions

Government agencies, nonprofit organizations and the media have focused increasing attention on the needs of seniors and those who provide them with support, assistance or care. Less attention has been focused on the needs of Lesbian, Gay, Bisexual and Transgender (LGBT) older adults and in particular, their caregivers, whether partners, friends or other family members. 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—overlap with those faced by heterosexuals. LGBT caregivers and care receivers can also face some specific concerns and particular challenges.

Increased acceptance in the past two decades has prompted a greater awareness nationwide among social service providers about the LGBT community, especially in major urban centers. Depending on where you live and what kind of support or prejudice you've experienced in the past, you may feel reluctant discussing issues related to sexual orientation when dealing with government and private agencies. Whether the person for whom you care is a parent, partner or friend, you will find it easiest to get answers or act as an advocate with public agencies, community nonprofits and hospitals if your loved one has

legally designated you to act on her/his behalf.

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. LGBT caregivers may find that they have less support than they would like from their own—or the care receiver's—biological family members. If this is true in your situation, developing a support system comprised of trusted friends and sensitive community services and programs will be especially important. This Fact Sheet addresses a number of important concerns LGBT caregivers have and should help you find answers and locate assistance in your area.

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?

In cities with sizeable gay and lesbian communities, some public and private agencies will have experience with caregiving issues and LGBT fam-

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ilies, particularly in the two decades since the start of the AIDS epidemic. In less densely populated areas, where programs may have less opportunity to encounter and 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 or promotional materials.

Others may acknowledge LGBT sensitivity and acceptance through the use of such terms as “domestic partner,” “life-partner,” or “significant other”—rather than simply “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, deciding whether to “come-out” when seeking assistance will depend on your particular set of circumstances, such as geographic location, family dynamics and relationships, medical necessities, the agencies in question and other factors.

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 have useful recommendations for which staff or departments within an organization are likely to be the most open and responsive.

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.

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 orientation. 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 contract with community agencies to provide caregiver support. The legislative 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 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 agencies that provide these caregiver programs may vary from county to county. 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 search on the web at www.eldercare.gov.

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 is comfortable with. You will find dealing with Social Security and Medicaid (Medi-Cal in California) much easier if

the care receiver has completed certain standard legal documents in which they designate you, or a partner or friend, to act on their behalf if they are incapacitated. Otherwise, it may be difficult for you to obtain information from these agencies.

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

Unfortunately, the 1993 legislation, which requires most companies to allow employees at least twelve weeks of unpaid leave to care for ailing family members, does not cover same-sex—or, for that matter, unmarried heterosexual—domestic partners. However, many private employers, including some in the Fortune 500, offer domestic partners the same medical leave and bereavement policies as they do to married employees. The same is true for public employees in cities and states that provide equal benefits to domestic partners, as well as some federal agencies.

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

Nursing homes and residential care facilities in general continue to struggle with the sex and sexuality of their residents, including those with residents who are heterosexual. Additionally, there is no law prohibiting discrimination against people based on sexual orientation in housing or public accommodation in 41 states. Homophobia 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. Each nursing home must list and give all new residents a copy of these rights. For a copy of the Resident Rights go to www.medicare.gov/nursing/residentrights.asp.

If problems occur, the first step in resolving the issue 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 har-

assed or mistreated by other residents? 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 worker, talk to the appropriate supervisor or administrator, explain the problem, and ask if another staff person can be assigned to assist your loved one. 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 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/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.

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

Because LGBT relationships are not generally recognized by law, biological family members can sometimes step in, take over decision-making authority, and exclude partners and close friends from being involved in the process. Certain steps should be taken to legally acknowledge your chosen family and in writing state your wishes concerning care in the event that you are unable to make decisions on your behalf in the future. For further information on *Durable Powers of Attorney* and other documents, see the Family Caregiver Alliance Fact Sheet on *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 person 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. Your siblings may not understand or appreciate your situation and assume that you have no outside family responsibilities. 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 choices in life leave 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. 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. Some local agencies work with caregivers as well as private social workers, and can assist by helping to facilitate a family meeting. It is helpful for all parties invited to a family meeting—especially the primary caregiver—to think about what should be discussed. Caregivers who are 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 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 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, no cut-and-dried formula to follow. How you proceed may well depend upon whether state and local laws where you live protect LGBT individuals from discrimination. You may decide it is best to be open with service agencies from the start, especially if you have learned from acquaintances or local LGBT resources which organizations are likely to maintain an open attitude. Or you may adopt a step-by-step approach, confiding in individual care providers whom you have come to trust or raising concerns only when you feel your needs are not being fully met.

The importance of having the proper documents in place before a loved one becomes ill and can no longer make decisions cannot be stressed enough. This will allow you the greatest flexibility in developing a network of available services and grant you, your partner, or a close friend the legal right to act in each other's behalf without having to offer anyone—biological family members, service organizations, government agencies—in-depth explanations about your relationship. As the person with legal authority, you do not need to define your relationship. If you prefer, 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 will not provide medical information to individuals who are not next of kin or not legally designated as being responsible.

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

One of the strengths of LGBT life is that, especially in urban centers, many people have developed a strong support network. While some gays and lesbians may feel estranged from biological relatives, their “families-of-choice”—a common term for these support networks—are frequently willing to fulfill vital caregiving functions. Many LGBT organizations, particularly those that address the

needs of the elderly, are establishing visiting companion programs specifically for isolated LGBT older adults.

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 development stages and are primarily designed for affluent individuals. Hopefully, as the community continues to advocate on behalf of LGBT seniors, a greater variety of housing options will ultimately be available.

Readings

Outing Age: Public Policy Issues Affecting Gay, Lesbian, Bisexual and Transgender Elders, Sean Cahill, Ken South & Jane Spade.

This comprehensive report from the National Gay and Lesbian Task Force addresses the specific problems facing LGBT seniors in housing, health care, financial benefits, the law and other areas. It can be downloaded from NGLTF's website (www.nglhf.org) or ordered from:

The Policy Institute of NGLTF
121 West 27th Street/Suite 501
New York, NY 10001
(212) 604-9830

When You're Gay and Gray: Planning Ahead and Fighting Discrimination

Provides an overview of the advanced directive documents and explains the importance of their completion to LGBT individuals. Contact the Lambda office that serves your area.

Lambda Legal Defense National Headquarters
120 Wall Street, Suite 1500
New York, NY 10005
(212) 809-8585
www.lambdalegal.org

Lambda Western Regional Office
6030 Wilshire Blvd., Suite 200
Los Angeles, CA 90036
(323) 937-2728

Lambda Midwest Regional Office
11 East Adams, Suite 1008
Chicago, IL 60603
(312) 663-4413

Lambda Southern Regional Office
1447 Peachtree St. NE, Suite 1004
Atlanta, GA 30309
(404) 897-1880

Lambda South Central Regional Office
3500 Oak Lawn Avenue, Suite 500
Dallas, TX 75219
(214) 219-8585

A Legal Guide for Lesbian and Gay Couples, Denis Clifford, Frederick Hertz & Hayden Curry, 2002, 11th edition, Nolo Press, 950 Parker St., Berkeley, CA 94710, (800) 728-3555. www.nolopress.com

Resources

MONTEREY COUNTY

Health Projects Center's

Del Mar Caregiver Resource Center

(831) 424-4359

Web site: <http://www.delmarcaregiver.org>

SANTA CRUZ COUNTY

Health Projects Center's

Del Mar Caregiver Resource Center

(831) 459-6639

Web site: <http://www.delmarcaregiver.org>

SAN BENITO COUNTY

Health Projects Center's

Del Mar Caregiver Resource Center

(831) 459-6639

Web site: <http://www.delmarcaregiver.org>

Del Mar Caregiver Resource Center supports and assists caregivers of brain-impaired adults through education, research, services and advocacy.

For residents of Central California, Monterey, Santa Cruz and San Benito Counties, Del Mar CRC provides direct family support services for caregivers of those with Alzheimer's disease, stroke, head injury, Parkinson's and other debilitating brain disorders that strike adults.

Family Caregiver Alliance

180 Montgomery Street, Suite 1100

San Francisco, CA 94041

(415) 434-3388

(800) 445-8106

Web Site: www.caregiver.org

E-mail: info@caregiver.org

LGBT Caring Community Online Support Group:

www.caregiver.org/lgbt-sptgroup.html

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 family support services for caregivers of those with Alzheimer's disease, stroke, head injury, Parkinson's and other debilitating disorders that strike adults.

FCA is committed to nondiscrimination on the basis of sexual orientation. We actively encourage members of the LGBT community to contact us for information and support services.

Eldercare Locator

(800) 677-1116
www.eldercare.gov

The Eldercare Locator helps older adults and their caregivers find local services that support older adults including contact information for local Area Agencies on Aging.

Gay and Lesbian Medical Association

www.glma.org/home.html

This association of LGBT supportive physicians and other medical professionals lets you search for healthcare provider members in your area.

Lesbian and Gay Aging Issues Network (LGAIN), a constituent group of the American Society on Aging

833 Market Street, Suite 511

San Francisco, CA 94103

(415) 974-9600

www.asaging.org/lgain.html

The Lesbian and Gay Aging Issues Network is a national resource for information relating to LGBT seniors. Their Web Guide connects you to resources on the Internet.

National Center for Lesbian Rights (NCLR)

870 Market St. Suite 570

San Francisco, CA 94102

(415) 392-6257

www.nclrights.org

The only national legal organization with a primary focus on lesbians and their families. NCLR also advocates on behalf of other groups in the LGBT community. Main program areas are family law, youth rights, elder law, immigration and asylum and transgender rights.

Old Lesbians Organizing for Change

P.O. Box 980422

Houston, TX 77098

Pride Senior Network

356 West 18th Street

New York, NY 10011

(212) 271-7288

www.pridesenior.org

www.oloc.org

Old Lesbians Organizing for Change is a national organization that seeks to empower lesbians 60 and over and fight ageism within both the LGBT and broader communities.

Maintains a service provider directory (primarily New York and vicinity), an LGBT newspaper, and provides a health resources newspaper. Has undertaken an LGBT Caregiver Research Initiative.

Senior Action in a Gay Environment (SAGE)

305 Seventh Avenue, 16th Fl.

New York, NY 10001

(212) 741-2247

www.sageusa.org

The nation's oldest and largest organization devoted to the concerns of LGBT elders. Provides programs and services in the New York area. Founder of nationwide network of local programs for LGBT seniors called SAGENET.

Other Online Information for LGBT Caregivers and Older Adults**Gay Yellow Pages**

www.gayyellowpages.com

Go to Organizations/Resources: Age-Group and Senior Focus. Provides a national directory of programs and groups for LGBT older adults.

Senior Pages

www.seniorpages.com

Click on Gay Seniors for a listing of national organizations that support LGBT older adults.

Reviewed by Lora Connolly, member of the Leadership Council for American Society on Aging's Lesbian Gay and Aging Issues Network (LGAIN). Prepared by Family Caregiver Alliance (FCA), funded by the San Francisco Office on the Aging through the National Family Caregiver Support Program.

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