

Section 3

LGBT Information and Resources



LGBT Alzheimer's Information & Services

Many lesbian, gay, bisexual and transgender (LGBT) people have experienced difficult and alienating relationships with family, friends, employers and service providers. Some have felt the need to move away from their families of origin, to stay in the closet or to distance themselves from discriminating and prejudiced situations. Yet, LGBT people are more likely to become caregiver for a partner, friend or biological family member. While caregiving can be rewarding, it can also be isolating. This topic sheet will help you navigate community resources and options for support.

Resources for LGBT Caregivers

As a caregiver of someone with Alzheimer's disease, you will face challenges during your journey. These challenges may be common among caregivers of they may be singular to you and your situation. As an LGBT caregiver, you may also have additional considerations or concerns.

Learn More About Alzheimer's Disease

Signs of Alzheimer's disease may appear gradually. It can be easy to explain away changing or unusual behavior as signs of aging when a loved one seems physically healthy. However, it's imperative to consult a doctor or health professional when you see changes in memory, mood or behavior. To learn more about the signs of Alzheimer's disease, visit alz.org/10signs.

Access Quality Health Care

LGBT individuals may access routine health care less often than other individuals for fear of inadequate treatment or discrimination. It is important to seek supportive health care that will make you and the individual with Alzheimer's feel comfortable. You may want to seek a medical provider that is sensitive to the LGBT community. Check for referrals to providers from the Gay and Lesbian Medical Association or an LGBT community center in your area.

Connect to Community Resources

The Alzheimer's Association provides information and resources, as well as a number of programs and services to caregivers. You can find out more information on these through our website, alz.org/dsw, or by calling us at **800.272.3900**.

Seek Help

Caring for an individual with Alzheimer's can be isolating and lonely. Don't be afraid to seek help from family, friends, and neighbors – and tell them exactly what to do to help.

Visit the Alzheimer's Association Caregiver Center at alz.org/care and tap into the tools available through the Care Team Calendar. This interactive scheduling tool allows friends, family members and neighbors to sign up for caregiving responsibilities – so you get the help you need, when you need it.

Share your experiences with other caregivers facing similar challenges at ALZConnected (www.alzconnected.org), an online community where people with Alzheimer's and their caregivers can ask questions, connect with others and find support.

For additional support, call the Alzheimer's Association 24-hours a day at **800.272.3900** and speak with a care consultant who can offer information and support.

Take Good Care of Yourself

Stress can cause physical problems (blurred vision, stomach irritation, high blood pressure) and changes in behavior (irritability, lack of concentration, changes in appetite). Note your symptoms and use relaxation techniques such as yoga or meditation to alleviate them. Watch your diet, exercise and get plenty of rest. Staying healthy will help you be a better caregiver.

To get a tailored list of resources to help, take the Alzheimer's Association Caregiver Stress Check at alz.org/stresscheck.

Plan for the Future

It is important for the individual with Alzheimer's to have legal and financial documents in place to establish his or her wishes for care as the disease progresses. Medical and financial powers of attorney and hospital visitation authorizations are best filed in advance while the person is still able to make decisions. In addition, as a caregiver, you should complete legal documents to ensure the individual with Alzheimer's will be cared for should something happen to you. For more information, contact the Desert Southwest Chapter at **800.272.3900**.

Balance Dual Caregiving Roles

It is common for LGBT caregivers to care for their partner and for another friend or family member. It can be difficult to attend to your own physical, emotional and social well-being while providing care to multiple individuals. The Alzheimer's Association can assist you with information and referrals to community resources that can provide support and care for you and your loved ones.

Making Decisions About Long-Term and End-of-Life Care

Long-term care encompasses many types of care situations, ranging from independent living to a variety of assisted living options. The decision to move a loved one into an assisted living facility can be emotional and difficult for anyone to consider. The Alzheimer's Association can help with information on facilities and options for care.

When facing a fatal disease such as Alzheimer's, it is essential for LGBT individuals to have advance directives in place. With advance planning, you can ensure that the individual with Alzheimer's will have optimum care and that you will have the level of access and authority desired by you both.

Consider seeking hospice care to ensure the comfort of the individual with Alzheimer's and to gain emotional support. Contact the Desert Southwest Chapter for information on counseling and hospice agencies in the area.

Disclosing Your Sexuality

You may worry that service providers will respond negatively to your LGBT identity. Perhaps you don't feel it necessary to disclose your sexual orientation or identity. Remember to trust yourself and make sure you are comfortable with what you share. To help with any challenges you face during your caregiving journey, the Alzheimer's Association is available 24/7 through our Helpline at **800.272.3900** to provide you with assistance, information and resources.

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ELDER CARE

A Resource for Interprofessional Providers

LGBT Older Adults in Long-Term Care Facilities

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Following decades of experience with discrimination and social stigma, the community of Lesbian, Gay, Bisexual, and Transgender (LGBT) older adults and their loved ones experience a multitude of unique concerns when contemplating placement in long-term care facilities. Administrators, staff, and clinicians in long-term care facilities may not be adequately trained to address LGBT fears and concerns. Facilities may provide care that compromises the health status of LGBT older adults, increases their sense of vulnerability, and lowers satisfaction with peer and staff interactions. Thus, it is important to improve the quality of long-term care for LGBT older adults. Recommendations for improvement are discussed in this issue of Elder Care.

Assessing Readiness to Care for LGBT Older Adults

Although many long-term care facilities may genuinely want to admit LGBT older adults, substantial transformations need to be in place before those adults, their loved ones, and the clinicians wanting to refer them, can be assured that there will be “no problems.” These transformations should be visible to prospective LGBT residents (e.g., explicit and positive LGBT pictures and language on websites, brochures, and forms), and evident in staff training and development. It is recommended that facilities assess their readiness to care for LGBT residents (Table on next page), hire external consultants and resources as needed, and highlight key aspects of LGBT culture and history, outlined below, through ongoing training for all employees.

Understanding LGBT Culture and History

Coming Out The first key aspect of LGBT culture and history is the variation and nuances in “Coming Out.” For LGBT older than the Baby Boomer cohort, safety and survival were closely linked with clandestine social gatherings prior to the 1970s Gay Liberation Movement. Invisibility and silence were adaptive responses to laws,

attacks, and pervasive discrimination enacted against LGBT communities.

Long-term care facilities must offer safe and welcoming environments. Pressures to come out or concerns of being “outed” may increase a sense of vulnerability to maltreatment. LGBT may isolate or defer medical care if environments seem dangerous. Facilities are advised to view coming out as a process vs. an event, with disclosures likely expressed over time through stories and pictures rather than overt use of LGBT language.

Families of Choice Prejudice and negative attitudes do not occur only outside homes. Rather, countless LGBT adults suffer temporary or permanent estrangement from their families of origin. The LGBT community has created important friendship networks offering a strong sense of belonging and mutual support over the lifespan; these networks are termed “families of choice.” It is highly recommended that long-term care facilities structure family events and care planning meetings to include LGBT families of choice.

Partners Furthermore, partners of LGBT residents may feel unwelcome or invisible at long-term care facilities. For example, LGBT couples may not be allowed to cohabitate at some facilities and care giving groups may not be attentive to LGBT partners. Facilities that eliminate such rules may simultaneously eliminate some of the marginalization experienced by LGBT partners.

One Size Does Not Fit All The LGBT community is a diverse group. For example, there are differences in the life experiences and expectations among the younger-old and oldest-old LGBT. There are also important considerations for LGBT with additional minority identities involving race, ethnicity, socio-economic status, gender, and acculturation. Religious/spiritual beliefs particularly merit attention in LGBT long term care. Administrators, staff, and clinicians add further to the mix of cultural differences. To facilitate optimal care, facilities should

TIPS FOR LONG-TERM CARE FACILITIES PROVIDING CARE FOR LGBT OLDER ADULTS

- Assess overall readiness to care for LGBT in welcoming and safe environments that recognize LGBT history, culture, challenges, and strengths.
- Understand variations and nuances in the “coming out” processes for LGBT older adults.
- Honor LGBT partners and families of choice.
- Respect the diversity within the LGBT community.
- Know protections and legal rights for LGBT residents in long-term care facilities.

Health and Long-Term Care Resources on LGBT Aging

Human Rights Campaign: www.hrc.org
Includes Healthcare Equality Index

Project Visibility: www.bouldercounty.org/family/seniors/pages/projvis.aspx

General Resources on LGBT Aging

Diverse Elders Coalition
www.diverseelders.org

Intersex Society of North America
www.isna.org

Lambda Legal
www.lambdalegal.org/search/node/aging

National Center for Lesbian Rights
www.nclrights.org

National Center for Transgender Equality
www.transequality.org

National Resource Center on LGBT Aging
www.lgbtagingcenter.org

National Gay & Lesbian Task Force
www.ngltf.org/our_work/public_policy/lgbt_initiative

Services and Advocacy for LGBT Elders (SAGE)
www.sageusa.org

Southern Arizona Gender Alliance (SAGA)
www.sagatucson.org/wp

Williams Institute
www.williamsinstitute.law.ucla.edu/category/research/international

World Professional Organization for Transgender Health (WPATH)
www.wpath.org

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