

LGBTQ OLDER ADULTS AND DEMENTIA

WHAT YOU NEED TO KNOW

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Hundreds of thousands of LGBTQ Americans are living with Alzheimer's or another dementia. While each person's experience is unique, the challenges of this diagnosis for LGBTQ older adults may be compounded by other issues — such as barriers to accessing care and support.

Dementia is life-changing, but you can empower yourself by learning about available resources and planning ahead. The Alzheimer's Association® offers reliable information and support to those affected by Alzheimer's and all other dementia. We're committed to serving LGBTQ individuals and are here wherever, whenever you need us — online, on the phone and in communities across the country.

ACCESSING QUALITY HEALTH CARE

Fear of discrimination and a history of negative interactions with health care providers may be an obstacle to seeking care. For example, one survey found that 40% of LGBTQ older adult respondents say their providers don't know their sexual orientation. If you're anxious about seeing a doctor, a little research and preparation can help you feel more comfortable.

Find an LGBTQ-affirming provider

While disclosing sexual orientation and/or gender identity is a personal decision, it's important to seek supportive health care providers who make you feel at ease. To locate LGBTQ-affirming medical professionals in your area:

- Check for doctors referred by the GLMA: Health Professionals Advancing LGBTQ Equality (GLMA.org) or an LGBTQ community center near you (lgbtcenters.org).
- Find providers near you who have successfully completed cultural competency training by visiting sageusa.care. SAGE, America's oldest and largest nonprofit organization dedicated to improving the lives of LGBTQ older adults, offers certification to providers.
- Explore the Healthcare Equality Index (hrc.org/resources/healthcare-equality-index), a resource developed by the Human Rights Campaign (HRC) Foundation to help people find equitable and inclusive health care.

- Locate LGBTQ-inclusive care communities through the Long-Term Care Equality Index (thelei.org), a joint project of the HRC Foundation and SAGE.
- Review the provider's website, brochures and related materials to see if LGBTQ inclusion is mentioned or if there are LGBTQ-affirming photos or symbols, such as the SAGECare credential or rainbow flag.

When meeting a provider for the first time, consider it an “interview” to make sure it's a good fit. Some possible questions include:

- Do you work with LGBTQ people?
- Do you have a nondiscrimination policy that includes sexual orientation and gender identity? How is this policy enforced?
- Do you have LGBTQ staff?

Prepare for appointments

Consider what you'll need to bring in advance (e.g., a list of medications) and what you hope to accomplish during your visit. Writing down your questions and concerns can help ensure you get the most out of your appointment. Some possible questions include:

- How familiar are you with Alzheimer's disease?
- What care planning services do you provide?
- How frequently will follow-up appointments be scheduled?
- Can I contact you with questions and concerns that arise?
- If hospitalization is necessary, will you be able to provide care in this setting?
- How will you work with my care team over the course of the disease?
- Can you recommend any support services or other resources to help me live a fulfilling life for as long as possible?
- What treatment options are available to me?

Visit alz.org/talktoyourdoctor for guidance on communicating with doctors or health care professionals.

Bring a support person

If possible, bring someone you trust — like a spouse, friend or member of your chosen family — with you to the doctor's appointment. In addition to providing support and easing anxiety, they can help advocate for your health and make sure your questions are addressed. Consider asking the person to take notes for you.

FINDING SUPPORT

Social isolation is common among people living with Alzheimer's, and LGBTQ individuals with the disease face additional challenges in accessing support. For some, a family of origin is not present in their lives and cannot be relied on during difficult times. Forty percent of LGBTQ older adults report that their social networks have become smaller over time, and 34% live alone. If this is true of your situation, use these tips to find other sources of support:

Find and work with an LGBTQ center in your area (lgbtcenters.org).

- Call the free **Alzheimer's Association 24/7 Helpline (800.272.3900)** to speak confidentially with specialists and master's-level care consultants.
- Join the Association's online community, **ALZConnected®** (alzconnected.org), to share questions, experiences and practical tips via message boards, including a dedicated space for LGBTQ individuals facing dementia.
- » Visit the **Alzheimer's Association & AARP Community Resource Finder** (alz.org/CRF) to access a database of dementia and aging-related resources in your area.

CAREGIVERS NEED SUPPORT, TOO

Many LGBTQ people are caregivers for someone living with Alzheimer's or another dementia. Whether you provide daily support, participate in decision-making, or simply care about a person living with dementia — the Alzheimer's Association can help. Visit alz.org/care to access a wide variety of online caregiver resources.

PLANNING FOR THE FUTURE

Putting legal, financial and medical plans in place after receiving a diagnosis of dementia is essential. It may be difficult to look ahead, but it's critical to do so while you can fully participate in the decision-making process. This preparation also helps to ensure that someone can act on your behalf if assistance is needed.

Start by organizing and reviewing your assets (such as your home), other personal property and accounts, and your existing legal documents. Taking stock of your finances and sources of income can help guide your decisions about future care and how you'll cover costs.

It's important to create advance directives — legal documents that specify preferences, including end-of-life care — to ensure that your wishes are followed. In the absence of advance directives, these decisions will be the responsibility of the

person's spouse or — if the person is not married — a relative, usually a parent or sibling.

At a minimum, check to make sure you have the following documents in place and up-to-date:

- Durable powers of attorney for both finances and health care, which allow you to name another person to make financial and health-related decisions when you are no longer able.
- A living will, which expresses your wishes for medical treatment near the end of life.

Many legal forms can be completed without professional help. However, if you have questions, it is a good idea to seek advice. Laws determining who can make care and medical decisions vary from state to state, so it is important to know your local laws when putting your plans in place.

To find LGBTQ-friendly legal resources, visit lgbtqbar.org/about/gethelp

ADDITIONAL RESOURCES:

- National Resource Center on LGBT Aging (lgbtagingcenter.org)
- Human Rights Campaign (hrc.org)
- SAGE (sageusa.org)
- SAGECare (sageusa.care)
- SAGE National LGBT Elder Hotline: 877.360.LGBT (5428)
- Lambda Legal (lambdalegal.org)
- Eldercare Locator (eldercare.acl.gov; 800.677.1116)

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