# RECOMMENDATIONS FOR SUPPORTING LGBT PEOPLE LIVING WITH DEMENTIA

ccording to a report released at the Alzheimer's Association International Conference<sup>®</sup> 2018 (AAIC<sup>®</sup>), 7.4% of the lesbian, gay and bisexual older adult population is living with dementia. This number is only expected to increase as a larger portion of the nation's population grows older, increasing their risk for developing Alzheimer's and other dementias.

LGBT adults living with dementia may face a particularly challenging set of circumstances in terms of accessing support. They are more likely to age without a spouse or partner, more likely to live alone and less likely to have children to support them, according to Issues Brief: LGBT and Dementia, a co-publication of the Alzheimer's Association<sup>®</sup> and SAGE. In addition, they are more likely to encounter barriers to quality care and support, including discrimination and a lack of cultural competency among providers.

By working together, we can ensure that LGBT adults living with dementia can receive the respectful and expert support they deserve. The following are suggested recommendations for working with LGBT people living with Alzheimer's or other dementias, as well as supporting LGBT-identified caregivers for people living with dementia.

### **1. EXPAND YOUR DEFINITION OF FAMILY.**

Often when people say the word "family" they mean the nuclear family — or biological and legal relatives. Many LGBT people either do not have a relationship with their family of origin or they may have strained relationships. Many do not have children or a partner. LGBT people may have a chosen family, or family of choice, who provide them with care and support. When discussing family members or other supports, consider using terms like "network of support" or "chosen family" so it is clear that family does not necessarily mean family of origin.

### 2. USE LGBT-AFFIRMING LANGUAGE.

Don't be shy to use the term LGBT or the words lesbian, gay, bisexual and transgender. Publicize your commitment to welcoming people of diverse sexual orientations and gender identities. Note, the word transgender is an adjective, not a noun. Please say "transgender man/woman/person" and not "transgenders" or "transgendered."

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### 3. ENGAGE IN LGBT-SPECIFIC OUTREACH.

Consider participating in your local LGBT Pride Parade or Fair. Pride events are usually held in the month of June to recognize LGBT Pride Month, but may vary regionally.

### 4. INCORPORATE LGBT PEOPLE INTO YOUR MARKETING MATERIALS.

Adding images of LGBT people and families to your website, promotional materials and brochures sends the message that LGBT people are already accessing your services, and that your organization cares enough to recognize these people and families.

#### 5. EDUCATE YOUR STAFF ON LGBT CULTURAL COMPETENCY.

Professional development is essential to person-directed care, and it is important to equip your staff with the information they need to provide culturally competent care to LGBT older adults and caregivers. Training content often includes key terminology, the history of the LGBT experience, and case studies or recommendations to help reinforce the content. SAGE, a national advocacy and services organization working for LGBT adults, offers cultural competency training and credentials through their SAGECare program. Learn more at **sageusa.care**.

### 6. FIND OR CREATE SUPPORT GROUPS SPECIFICALLY FOR LGBT CAREGIVERS AND PEOPLE LIVING WITH DEMENTIA.

There is value to having support groups for people who identify as LGBT or who are caring for an LGBT person. If these are not available in your community, consider starting LGBT-friendly support groups, perhaps in areas with a higher concentration of LGBT people, or in partnership with an LGBT community center. At the same time, it is also important to ensure that LGBT people feel welcome at all of your support groups. The Alzheimer's Association hosts an online support group for people living with the disease and caregivers, including a message board for the LGBT community and allies at **alzconnected.org**.

### 7. PARTNER WITH LOCAL LGBT COMMUNITY GROUPS AND POLITICAL ORGANIZATIONS.

Building relationships with leaders in your local LGBT community is a great way to begin to develop trust. Many LGBT people turn to one another for recommendations for providers and supports. These relationships are an important way to reach LGBT older adults and caregivers through word-of-mouth.

### 8. ADVOCATE FOR NONDISCRIMINATION PROTECTIONS.

It is still legal to discriminate against LGBT people in many parts of the country. Your organization can take a public stand to demand that local leaders work to protect LGBT people.

### 9. COLLECT INFORMATION ON SEXUAL ORIENTATION AND GENDER IDENTITY.

Collecting demographic information on sexual orientation and gender identity helps you to know if you are reaching the LGBT community and can aid advocates in understanding the specific needs of LGBT people. For more information, see A Practical Guide to Collecting Data on Sexual Orientation and Gender Identity from the National Resource Center on LGBT Aging at **Igbtagingcenter.org**.

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#### Sources

- Alzheimer's Association and SAGE, Issues Brief: LGBT and Dementia.
- Jason Flatt, Ph.D., MPH, et al. Dementia Prevalence Among Sexual Minority Older Adults. Funder: U.S. National Institute on Aging.
- Hanneke Rhodius-Meester, M.D., et al. Median Survival in Memory Clinic Cohort Is Short, Even in Young Onset Dementia. Funders: Alzheimer Nederland; Stichting Dioraphte.
- Yvonne Leung, Ph.D., et al. 100 Years and Beyond: Investigating the Prevalence of Dementia in Centenarians and Near-Centenarians from 17 Population-Based Studies. Funder: The Dementia Momentum Initiative.