

# Overcoming Barriers to Care for LGBT Elders with Alzheimer's

By Marcy Adelman

LGBT people with Alzheimer's must plan ahead in order to guarantee quality dementia care.

Jim and Fred have been a couple for thirty-three years. They had been together for fifteen years, when Fred's personality began to change. But it was another four years before they got the diagnosis: Alzheimer's.

Fred's chief caregiver? Because they weren't legally married, and still are not, would Jim be prevented from making day-to-day and life-and-death decisions? Might he even be stopped from being able to see his partner?

## Because they weren't legally married, would Jim be prevented from making day-to-day and life-and-death decisions?

For Jim, the news was doubly challenging. He had no idea what to do about the disease. And he didn't feel confident that service providers would understand their relationship. Jim was really concerned about how doctors, in-home care providers, and others would react to the couple being gay. Would he not be allowed to remain as

The American public has become very aware and afraid of Alzheimer's. More than 5 million individuals live with it, and that number is expected to triple over the next few decades as more people are living longer (Alzheimer's Association, 2015). Alzheimer's is the sixth leading cause of death in the United States and remains the only leading cause of death for which

there is no cure (Alzheimer's Association, 2015).

Yet for LGBT older adults, Alzheimer's can evoke a double stigma: living with dementia and being LGBT (Adelman, Nolan, and Haskell, 2013). As with everyone else, LGBT older adults fear losing themselves and their memories, being embarrassed or devalued, or simply being avoided. Mostly, people are frightened of becoming completely dependent upon the care of others.

In addition, LGBT elders do not know how professional caregivers will treat a gay or lesbian couple or transgender person. Will they and their relationship be respected? Will they receive a lesser quality of care? Will they someday be forced to have a roommate or have to live in a facility with other residents who are openly

hostile? These fears act as barriers to care.

A 2014 report by the San Francisco LGBT Aging Policy Task Force found that even in the San Francisco Bay Area, LGBT older adults living with Alzheimer's—and their caregivers—are underrepresented in local Alzheimer's support programs. (San Francisco Lesbian, Gay, Bisexual, and Transgender (LGBT) Aging Policy Task Force, 2014).

## Ensuring Access to Quality Dementia Care

Three actions can help ensure that the estimated 1.5 million to 3 million LGBT older adults nationwide will have, if needed, access to the same quality of dementia care and comfort available to everyone (Espinoza, 2014).

First, mainstream service providers—first responders, medical, homecare, daycare, memory clinics, and residential providers—can be trained to interact with LGBT people living with Alzheimer's in ways that make them feel recognized, understood, and respected. Receiving culturally competent and dementia-competent training geared toward LGBT elders can give professionals the tools to create a trusting and effective care relationship. Many LGBT older adults have the same concerns as Jim, and are more likely to access dementia services if they feel confident

that they and their loved ones will not be overlooked or devalued, but instead treated with dignity and respect.

Second, LGBT organizations that serve older adults and LGBT community centers can reduce barriers to dementia services by requiring and providing dementia competency training for staff, offering Alzheimer's education and awareness programs, and referring clients to LGBT-affirming dementia care resources. These actions would increase opportunities for early diagnosis and planning and help people living with Alzheimer's to delay institutionalization by living as well as possible and as long as possible in their homes and communities.

Even with additional competencies in both mainstream and LGBT providers, contemplating or receiving an Alzheimer's diagnosis can feel

overwhelming and frightening. At a recent educational program at the San Francisco LGBT Center, one gay older adult spoke as if he had already given up. "I'm here because I think I have Alzheimer's," he said. "I don't know what to do about it. I don't know if there is anything to do about it." But there are things he can do.

The third action to overcome barriers to care is for LGBT people to plan ahead while still healthy, even before receiving a diagnosis. They should make financial, medical, and legal arrangements; and they should identify either an elder law attorney who knows the person's care wishes and can make medical or financial decisions when he or she cannot, or a trusted caregiver who is capable of providing or arranging the care desired. This relieves LGBT elders of the burden of making these arrangements when their health is

## The Ten Warning Signs of Alzheimer's Disease

1. Memory loss that disrupts daily life
2. Challenges in planning or solving problems
3. Difficulties completing familiar tasks
4. Confusion with time or place
5. Trouble understanding visual images and spatial relationships
6. New problems with words, in speaking or writing
7. Misplacing things and losing ability to retrieve steps
8. Poor judgment
9. Withdrawal from activities
10. Changes in mood and personality

For more information on the ten warning signs of Alzheimer's, go to [www.alz.org/alzheimers\\_disease\\_10\\_signs\\_of\\_alzheimers.asp#signs](http://www.alz.org/alzheimers_disease_10_signs_of_alzheimers.asp#signs).

→ **ABSTRACT** LGBT elders face added stigma when anticipating an Alzheimer's disease diagnosis. They fear in-home care providers may not be open to their relationships with loved ones, and that institutional care providers, and even doctors, may not accept their lifestyle or chosen caregivers. This fear and apprehension make care decisions more difficult. Instead of fearing and delaying diagnosis, planning ahead for quality care is even more crucial for this population. | **key words:** *LGBT older adults, Alzheimer's, caregiving, stigma, care planning*

compromised and they are at their most vulnerable.

LGBT elders especially benefit by planning ahead. They are more likely than heterosexual older adults to be single, childless, and living alone (Fredriksen-Goldsen et al., 2013). Unlike heterosexuals, who rely upon family and adult children for support, LGBT older adults are more likely to rely upon close friends.


But close friends, usually similar in age, may become unavailable as they face their own health challenges. Even when friends and partners are available to provide direct care, unlike legally recognized family members, they are at a disadvantage in acting on behalf of their friends. These unique features of the LGBT community put LGBT people living with Alzheimer's without

caregivers—or without *empowered* caregivers—at risk of not having full access to needed services and supports.

By being proactive and choosing trusted people to act on their behalf, LGBT older adults can help assure that their wishes are followed and their comfort care is arranged.

### Conclusion

Dementia and aging services that are LGBT-affirming can have a major positive impact on the underserved LGBT older adult population. At the same time, LGBT organizations that acquire greater awareness of aging and dementia issues can be critical for bringing their communities to key services. An early diagnosis gives people extra time to respond and prepare for successful care. The ten warning signs of Alzheim-

er's Disease (see sidebar on page 39) can reveal when it is time to ask for a medical opinion. With or without a diagnosis, advance planning can help people stay in their homes, receive the best care, and maintain quality of life for longer. Planning also can provide another valuable benefit—greater control over one's own life—and that can make a huge difference in a person's well-being. 

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