LGBT Caregiver Concerns

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 caregivers for a partner, friend or biological family member. While caregiving can be rewarding, it can also be isolating. This brochure will help you navigate community resources and options for support.

The Alzheimer’s Association welcomes and is supportive of all persons regardless of age, race, gender identity, class, ethnicity, sexual orientation, language, physical ability or religion.

While LGBT specific services may not be available everywhere, the Alzheimer’s Association is here to help you find the right care and support options.

Caregiver stress daily checkup

How many of these signs have I had today?

- Denial
- Anger
- Social withdrawal
- Anxiety
- Depression
- Exhaustion
- Sleeplessness
- Irritability
- Lack of Concentration
- Health Problems

Whenever stress is a concern, consult your health professional and contact the Alzheimer’s Association for information and support.
Knowledge about the disease
Symptoms of Alzheimer’s may appear gradually. It can be easy to explain away changing or unusual behavior 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. Don’t delay; some symptoms are treatable. Contact the Alzheimer’s Association for more information about Alzheimer’s disease and related dementias.

Access to healthcare
Due to discrimination and inadequate treatment, LGBT individuals tend to access routine healthcare less often than others. It is important to seek supportive healthcare that has ties to the LGBT community. The Gay and Lesbian Medical Association offers referrals to LGBT sensitive medical providers. LGBT community centers may also have recommendations for medical providers.

Connecting to community resources
Contact your local Alzheimer’s Association office. The staff can help you find LGBT friendly resources in your community. Adult day programs, in-home assistance, visiting nurses and meal delivery are just some of the services that can help you manage daily tasks.

Getting help
Trying to do everything by yourself will leave you exhausted. It may also be particularly isolating and lonely if you do not have good relationships with your family of origin or children. Seek the support of friends, family and social groups. Tell others exactly what they can do to help. Turn to the Alzheimer’s Association 24/7 Helpline 1.800.272.3900 or online message boards at www.alz.org.

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

Legal concerns
It is important for you and your loved one to have legal and financial documents in place to establish your wishes for care as the disease progresses. Legal plans are especially vital for the person with dementia. Medical and financial powers of attorney and hospital visitation authorizations are best filed in advance while the person is still able to make decisions. Complete your own documents to ensure your loved one will be cared for should something happen to you. Contact the Alzheimer’s Association for legal referrals.

Dual caregiving roles
It is common for LGBT caregivers to care for their partner while also caring for friends and family of choice or a relative. 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 provide support and care for you and your loved ones.

Long term care
Long term care has a continuum from living independently at home to a variety of assisted care options. The decision to move a loved one is emotional and difficult for anyone to consider. LGBT caregivers and care receivers face additional challenges such as discrimination. Contact the Alzheimer’s Association for LGBT friendly in-home care and long term care options.

End of life care
When struggling with end of life issues, it becomes essential for LGBT individuals to have advance directives in place. Without advance care planning, legal/institutional practices may present obstacles to providing optimum care for your loved one. The process of grieving often begins before your loved one has died. Consider seeking hospice care to ensure your loved one’s comfort and to provide you with emotional support. It is especially important not to become isolated after the loss of a loved one. Seek emotional and social support from your network of friends and family. Call your local hospice agency to request information on grief counseling or groups in your community.

Coming out
To whom and when you disclose your sexual orientation and/or gender identity is an important and sometimes difficult decision throughout your life. You may worry that service providers will respond negatively to your LGBT identity. Perhaps you feel it’s necessary to stay in the closet to avoid family conflict. Remember to trust yourself in the decision to come out: make sure you are comfortable telling someone and that you have the support you need.