FACT SHEET: LGBT Caregiving

Most caregivers don't realize they are caregivers. You may just be helping out a friend or "doing what spouses do," but guess what? If you're providing any kind of ongoing support to a friend or loved one who needs assistance - cooking meals, taking them to the doctor, helping them bathe, or even just checking in on their wellbeing - you are a caregiver!

YOU define your family. The term family caregiver is increasingly being used to refer to those who care for family members and loved ones, in order to distinguish them from paid caregivers such as nurses, aides, or in-home health assistants. In most cases, the "family" in family caregiver is defined very broadly, and is meant to include close friends, unmarried partners, and anyone else who YOU consider family.

LGBT Caregivers are more likely to be caring in isolation and more likely to be within the same age cohort as the people they're caring for. For both of these reasons, finding others who can assist, including professional service providers, is an important way to make sure that a loved one's care won't lapse due to caregiver burnout or health problems.

LGBT people become caregivers more often. Mom is sick. Your sister's busy with her high-powered career, your brother's busy raising his kids, and you end up taking on the bulk of Mom's care. Sound familiar? You're not alone. LGBT baby boomers and Millennials tend to take on the care of their aging parents at a disproportionate rate. Even if partnered, families often see LGBT adults as single and rely on them for caregiving. And though we may not be seen as the "sandwich generation" if we don't have kids, we're often caring for friends and members of our community at the same time, which results in the same sort of juggling act.
Caregivers tend to have poorer mental and physical health than non-caregivers. For a population that already experiences health disparities, this is a serious concern. It's important to take care of yourself, even though you may be focused on caring for someone else. Keeping up with regular medical appointments, getting emotional support when you need it, and making time for things you love to do will help you to be a better caregiver for your loved one.

Financial disparities can be exacerbated by the costs of caregiving, both direct (paying for medication) and indirect (missing work). Most LGBT older adults do not have the financial means to fully support themselves should they need long-term medical care. And with fewer people sharing the care, more money is coming out of each individual caregiver's pocket.

Many LGBT people have already been caregivers, especially during the AIDS crisis. If caring for a loved one now brings up difficult memories or feelings for you, it may help to find someone you can talk to.

A majority of states have passed versions of the CARE (Caregiver Advise, Record, Enable) Act, which requires hospitals to ask each patient, at admission, if they'd like to designate someone as a caregiver. This generally does NOT have to be a spouse or biological family member; the patient can designate whomever they want. The hospital then has the responsibilities to notify the designated caregiver about discharge planning, and to provide instruction on tasks the caregiver may need to perform at home. Check with your local AARP office for details about the CARE Act in your state.

Advance Directives such as a health care proxy, living will, and power of attorney are critical for anyone whose primary caregiver is not a legal "next of kin" - generally a spouse, parent, or child. Whatever the relationship, a caregiver can assume the rights to make medical decisions, manage finances, and settle a loved one's affairs when necessary, IF that loved one puts their wishes in writing in advance. Check with your local Area Agency on Aging or your state health department for information on these types of legal documents.

Information taken from the National Resource Center on LGBT Aging and the SAGECAP Program
Reviewed by AlzOC June 2022