

How LGBTQ Adults Arrange to Age at Home

Clearly written instructions and legal documents that name who will carry out your wishes are critical

By Terry Ann Donner

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Seven million adults in the U.S. will identify as LGBTQ by 2030. Alienated from family because of their sexual orientation or identity and often childless, older LGBTQ adults must rely on aging partners or spouses for care.





By not appointing a legal decision-maker in a health care power of attorney, LGBTQ older adults can find themselves in a position where estranged family members are making health care decisions for them. | Credit: Getty

A 2022 study found that 60% of older LGBTQ adults fear discrimination or abuse because the current health care system fails to train providers to treat these patients in a culturally sensitive manner. Other studies have found that health care providers are more likely to neglect or mistreat older LGBTQ adults as their health declines.

As a result, older LGBTQ adults often delay or decline to pay for home care, which can lead to serious health issues and early institutionalization.

Many try to "re-closet" themselves, hiding photos, removing their partner's personal items from their bedrooms or identifying partners as siblings or cousins.

When older LGBTQ adults do retain home care, hospice or other long-term care services, they often try to hide their LGBTQ status.

The Cost of Staying Home

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Many older adults living with one or more chronic illnesses need assistance with basic activities of daily living (ADLs), including bathing, eating, grooming, toileting and walking. They may also require help with cooking, housekeeping, grocery shopping, medication reminders and transportation. Non-medical home care agencies provide caregivers trained to give this type of assistance.

However, home care is expensive. The average hourly rate for non-medical home care is \$26. If you require care 24 hours per day, your average monthly cost would be \$17,472, making such care unaffordable, especially for older LGBTQ adults.

The Importance of Planning

Older LGBTQ adults are twice as likely to live in poverty as their heterosexual counterparts, and often cannot afford home care without qualifying for benefits through the Aged, Blind and Disabled Medicaid program.

Michael and James are in their mid-70s, have been partners for years and live in Michael's home.

Michael has made provisions to bequeath James the house and his investment account when he dies. They are both estranged from their biological families.

Due to his chronic obstructive pulmonary disease, Michael uses oxygen 24 hours a day and cannot walk more than 100 feet. James has become Michael's caregiver, taking him to appointments, running errands, preparing meals, performing household chores and helping him to bathe.

Life Changes in a Moment

Michael and James do not trust home care agencies, so Michael pays James \$15 per hour to help him with his ADLs. Neither has health care or financial powers of attorney.

One morning while James was running errands, Michael's feet became entangled in the tubing attached to his oxygen concentrator. He fell, hit his head, and remained on the floor, confused and cold, until James returned several hours later.

In the emergency room, James identified himself as a "friend" and provided Michael's basic medical and insurance information. He also gave the name of Michael's estranged sister when he was asked about Michael's next of kin.

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Once it was determined that James was not Michael's spouse or biological family, James was given very little information about Michael's care.

James visited Michael every day but was told to contact Michael's sister for information.

Estranged Family Takes Over

Michael remained confused and required assistance with his ADLs. When James contacted Michael's sister, she was angry that James had left Michael home alone.

Several days later, James was informed that Michael was being transferred to a nursing home near his sister. Once he was admitted, his sister filed to become his legal guardian. After a court approved her request, she sent James a 30-day eviction notice.

"LGBTQ older adults can find themselves in a position where estranged family members are making health care decisions for them."

So, in short order, James lost his partner, his home, his income from caregiving and his potential inheritance. Proceeds from the sale of Michael's house and his investment account were spent on nursing home care.

'Must Have' Documents for LGBTQ Older Adults

Frank C. Krasovec Jr., an estate planning attorney in the Cleveland office of Hahn Loeser & Parks LLP, explains that "even in an emergency, individuals who are not your spouse or a biological relative are not able to make health care decisions for you without a health care power of attorney."

Krasovec asserts that "by failing to appoint a legal decision-maker in a health

care power of attorney, LGBTQ older adults can find themselves in a position where estranged family members are making health care decisions for them."

The following legal documents are important for everyone, but especially for LGBTQ older adults who often rely on partners or friends, rather than relatives.

1. Healthcare Power of Attorney

This document allows you to name an agent to make health care decisions for you when you are incapacitated.

Given the discrimination experienced by older LGBTQ adults, sexual advance directives should be included in this document. By recording who they wish to be intimate with, LGBTQ older adults can preserve the right to have relations with their partner or spouse.

2. Living Will

This directive tells your physicians what types of life-sustaining measures you consent to.

3. HIPAA Authorization

A HIPAA authorization allows a health care provider to share your protected health information with the people or entities that you name in the document.

4. Durable Power of Attorney

This document allows for the appointment of an agent to make financial decisions. The agent can pay bills and do anything with your assets that you can do.

Your agent should be able to apply for Medicaid and other government benefits

on your behalf. However, many states require a durable power of attorney to expressly give your agent the power to do so.

If your power of attorney also has specific and express instructions on the matter, your agent should also have the authority to establish certain trusts or make gifts to himself or others for Medicaid planning purposes.

5. Caregiver Agreement Between Unmarried Partners

This agreement allows you to pay a partner for providing caregiving services.

If drafted properly, it should not lead Medicaid to deny benefits alleging the payments were improper transfers.

The agreement also should prevent estranged family members from accusing a partner of theft.

What is my recourse if the caregiver you send is uncomfortable with my sexual orientation, and disrespects me or my partner?

Securing Supportive Home Care

When interviewing home care agencies, it is prudent to ask the following questions to assess whether a home care agency can meet the needs of older LGBTQ adults.

- Has the owner or the staff had any training on the specialized needs of

LGBTQ older adults? SAGE, a national nonprofit providing advocacy and services to older LGBTQ adults, offers training to home care agencies and other health care providers to reduce discrimination. Older LGBTQ adults can also search on SAGE's website for the nearest certified provider.

- What is my recourse if the caregiver you send is uncomfortable with my sexual orientation, and disrespects me or my partner?
- Does the agency have LGBTQ clients? Can the owner reach out and ask if I may speak to them about the services?
- Are there any LGBTQ caregivers?
- Will staff call me by my preferred name and pronoun?

Who we love should not affect the quality of the care we receive as we age. Access to culturally sensitive care should be a right afforded to every LGBTQ adult, and they should be proactive in signing legal documents that allow them to choose an agent who will make decisions that protect their right to age at home with a partner of their choosing and supportive care.

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