



Family Caregiver Guide

A Guide to LGBT Caregiving

Caregiving is often challenging. Those who provide or manage the care of someone with a serious or chronic illness may feel emotional distress and physical strain. Caregivers can experience financial difficulties and find it hard or frustrating to coordinate care. Caregiving also offers many rewards. These rewards include the affirmation of love and respect between the caregiver and person being cared for.

People who are lesbian, gay, bisexual, or transgender (LGBT)—whether they are caregivers or the ones in need of care (and, often, both are LGBT)—may encounter special challenges. This guide looks at some of those challenges, including a change in care setting, such as an admission to a hospital followed by a discharge to home or a nursing home rehab program.

In this guide, the term “family caregivers” refers to all people who provide or manage the care of someone who is chronically or seriously ill. Family caregivers may be part of the patient’s family of origin or family of choice. For this reason, this guide may refer to the person you are caring for as your “family member.”



This guide has been prepared by the United Hospital Fund’s Next Step in Care campaign, in collaboration with Services and Advocacy for GLBT Elders (SAGE) and the SAGECAP (Caring and Preparing) program.

You Are Not Alone



Sometimes one caregiver is caring for a partner, an LGBT friend, and a parent at the same time.

About one in five adult Americans (as well as many teens and even children) is involved in caregiving. As a group, LGBT individuals are particularly likely to be caregivers. This is because many are single and/or childless. Their families of origin may see them (or they may see themselves) as someone most available to care for older family members. Many have formed close attachments to others in the LGBT community. They understand the need of individuals who are aging or ill for emotional and practical support from familiar people.

Special History of Caregiving in the LGBT Population

In the early years of the HIV/AIDS epidemic, gay men and lesbians were the main, and sometimes only, caregivers for their friends and loved ones. This experience made a deep impact on the generation that lived through it and may now need care. Some may remember the stigma and fear. Others may focus on the community taking care of their own.

Having experienced rejection and disrespect in health care settings, many older LGBT individuals avoid seeing a health care provider until a serious problem arises. Others have found a primary care provider who is comfortable with LGBT patients. These LGBT-friendly health care professionals may not be available when your family member has a medical emergency or is admitted to a hospital or nursing home. Problems can also arise when your family member needs health care services at home.

Emergency Rooms (ERs) and Hospitals

All caregivers should have the same rights, responsibilities, and obligations, but some LGBT caregivers report problems in carrying out this role. It is often not possible to select health care providers who are LGBT-friendly – especially when your family member goes to an Emergency Room (ER) or hospital. If the hospital admission is planned, you may be able to select a

hospital (within insurance and geographic realities). Do not select a hospital based only on what you hear from others. While one person may have had a good experience in a certain hospital, another might not. So much depends on the many physicians, nurses, and social workers you meet along the way.

Your family member's primary care doctor may not be the one directing care in the hospital. That role has been increasingly taken over by "hospitalists" – doctors who are trained in critical care, see patients only in the hospital, and are available at all times of the day and night. But hospitalists do not have continuing relationships with patients. In fact, you may not even see the same hospitalist each day.

It is important for hospitalists to communicate with the patient's primary care doctor. To encourage this, tell the primary care doctor that your family member has been hospitalized and ask that he or she talk with the hospitalist in charge. This communication can help prevent errors (about medication or other medical issues) and aid in discharge planning. It also can be reassuring to know that your family member's trusted physician is actively involved in his or her care.

Legal Documents



To find state-by-state legal requirements for advance directives, visit Caring Connections at www.caringinfo.org.

It is always a challenge to navigate an unfamiliar environment, whether that is the ER, hospital or other care setting. It helps to prepare ahead of time. One important way is by getting the necessary legal documents in order. The rights of LGBT individuals to participate in decision making and even visiting the patient in the hospital may be challenged by families of origin or ignored by staff. There is no absolute guarantee against an incident occurring, but there are some ways to make it less likely and to seek recourse if it does.

State laws govern who is able to make health care decisions for patients who cannot do so for themselves. State laws also govern the type of evidence that is required. If you and the person you are caring for live near a state's border or spend a lot of time in another state, it is essential that you have documents establishing you as the responsible person in both states. Being legally married or in a civil union or domestic partnership in one state does not guarantee recognition of this status in another state.

Below is a listing of important health care documents. Make sure that these documents are up-to-date and easy to locate. These documents are useless if they are stored in a lawyer’s office or safe deposit box.

Legal Document Checklist

Document	Purpose	Date signed	Location
Advance directive	Defines person’s wishes for care, especially at end of life; includes health care proxy and living will		
Health care proxy	Names someone to make health care decisions if person is unable to do so because of loss of capacity (temporary or permanent)		
Living will	A type of advance directive that gives personal wishes about types of care		
Financial power of attorney	Gives another person power to manage money; this power can be comprehensive or limited		
Hospital visitation directive	Lists people who are allowed (and not allowed) to visit		
HIPAA release	Gives a hospital or other provider permission to share patient’s medical information with a caregiver or other person (not legally necessary but hospital rules may require it)		

If you go to the ER or hospital, take these documents with you along with the patient’s insurance information and current medication list. See the Next Step in Care Family Caregiver Guide to Emergency Rooms http://www.nextstepincare.org/Caregiver_Home/ER_Visits/ for more information.

Other legal documents that may become important include a will (for personal assets), funeral directives (especially if you or your family member anticipate disagreements, for example, with the family of origin), and beneficiaries for life insurance or other assets not included in a will. This list is only a starting point. It is best to consult an attorney familiar with LGBT concerns and state laws to make sure that these documents are appropriately written.

Medical Directives

In addition to legal documents, you may need medical directives (orders) signed by a doctor. For example, if your family member is being cared for at home and does not want certain emergency procedures (such as CPR or a breathing tube), you will need an out-of-hospital (or community) DNR (Do Not Resuscitate) order or a Do Not Intubate (DNI) order signed by a doctor. These vary by state.

If your family member is about to be transferred from a hospital to another setting, the hospitalist may ask him or her (and you as the health care proxy) to sign a Physician Orders for Life-Sustaining Treatment (POLST). The goal of this document is to make it more likely that an advance directive is honored. But you have to be sure that all the factors have been considered before you or your family member sign the order. For example, when checking “no antibiotics,” does your family member mean “no antibiotics under any circumstances” or “no antibiotics that are intended only to prolong life, not relieve pain”? Or does “no mechanical breathing tube” mean “never” or would your family member be willing to try the machine for a defined time? Be sure that a health care professional answers all your questions before you sign.



While health care staff may not be hostile to LGBT patients or caregivers, they might not even consider or understand that the patient and/or accompanying person are LGBT.

Identifying Yourself

Anyone accompanying a patient to an ER or admission to a hospital or nursing home rehab program will be asked, often many times: “And who are you?” Or perhaps the question will be phrased not so much as a question but as a confirmation: “And you’re the patient’s daughter?” Many hospital staff members still think in terms of poorly defined categories like “immediate family,” which may include various relatives, and “next of kin,” which is a legal term identifying relatives of deceased persons.



Some caregivers want to avoid secrecy about their LGBT identity or relationship. Others prefer to keep this information private. And some choose the path of least resistance and go along with any misunderstanding.

You have a choice in such a situation. If you are caring for a parent, sibling, or other member of your family of origin, then just say so. If you are caring for a partner, or LGBT friend, you can choose to accept the designation assigned to you (“Yes, I’m her sister”) or correct the misunderstanding. Some LGBT caregivers want to clear the air and avoid secrecy. Others prefer to keep this information private. And some choose the path of least resistance and go along with the misunderstanding. But keeping this information private may be emotionally uncomfortable and lead to other issues later on. A lot depends on the feelings of the person being cared for. Based on years of being closeted, older LGBT people may be particularly concerned about disclosures and stigma.

You may worry that being explicit about your identity or your relationship will result in your family member being harassed or getting inadequate care, even though that should not happen. Unfortunately, poor care (such as failure to keep the patient clean or assist in feeding) can have many causes, and you have to be alert to this no matter what you decide about identifying yourself. The best defense against poor care is your own vigilance. This includes being present in the hospital or other care setting, establishing yourself as the person most responsible for the patient at home, and identifying the most cooperative staff members. While you cannot always be present, it helps to visit during different shifts, call in, and ask informed questions.

There is a difference between poor care and disrespectful care:

- ▶ Poor care is unacceptable as it affects the patient’s physical well-being.
- ▶ Disrespectful care, such as hostile remarks or anti-gay joking, is unacceptable because it diminishes the patient’s dignity.

Disrespectful care is not limited to LGBT individuals. Members of minority groups, people with dementia or mental illness, people who do not speak English—all may experience times when they are subject to demeaning labels or insults. This can affect not only patients but also hospital staff who may be the target of verbal or physical abuse, such as when patients refuse to be treated by someone of a different race or religion. No one — patient, caregiver, or staff — should be treated this way. Yet these incidents do occur because hospitals and ERs are often places of high emotion, drama, and tension.

What should you do if this happens to you or your family member? A lot depends on the situation and your tolerance for bad behavior. Try to distinguish between remarks that are, as best

you can tell, intended to be hurtful, and those that are due to curiosity or a lack of knowledge. You might be able to stop this by letting the other person (staff, patient, or patient's family) know that you are concerned by their attitude or speech. If this doesn't help, ask to speak with the head nurse (assuming that he or she was not involved), the hospital's patient advocate, or the director of nursing. If all else fails, contact the administrator in charge.

Hospital stays are often very short. The offending staff member may never be seen again or the rude roommate may be discharged that day. It may not make sense to make a major complaint at the time, but know that you can do so later. If the incident affects your family member's health or causes a lot of emotional distress, then you may want to pursue the matter right away.

Discharge Planning

Most hospital stays are very short. Therefore, early in the admission you need to start thinking about what happens after discharge. Do not wait for the social worker on the unit to find you. Instead, find the social worker as soon as you can. If you are an experienced caregiver, you may already know what works best for you and your family member. You may have had good or bad experiences with a certain nursing home rehab program or home care agency. If you are new to being a caregiver, you will have to quickly learn about discharge options.



When your family member is “medically stable,” he or she is considered ready for discharge. This does not mean that all is well. It simply means that a different type of care is appropriate.

If there are ongoing medical issues that need monitoring or there is a need for physical or cardiac rehab, the recommendation will likely be a transfer to a skilled nursing facility. Many older LGBT individuals refuse this recommendation, fearing isolation and discrimination. Their fears have to be taken seriously. However, going home may not be realistic, even with home care services.

The social worker may give you a list of discharge options without making any recommendations. If so, you need to quickly investigate these options as the time frame can be very short. A stay in a rehab program may last weeks instead of days, so you want to try and find a welcoming LGBT environment. Check nursing home websites for hints that suggest inclusiveness, such as photos of multicultural patients and staff. Call the admissions director for the institution's policies for LGBT patients and staff training about cultural sensitivity. Your research may reassure

your family member that this is a safe place to be. Of course, the quality of care and location are also critical factors. Weigh pros and cons along with what is known and unknown when making this important choice.

Unpleasant incidents may occur in nursing homes, with remarks by staff or roommates or other patients. Many patients in these programs have some form of dementia or are on medications that may cause them to lose control over their inhibitions. They may say things that they never would have said if they were not confused. Still, you and your family member should not be subject to any disrespect.

- ▶ It may be necessary to change roommates.
- ▶ If a staff member makes such remarks, tell his or her supervisor.
- ▶ If the situation involves the patient's choice of clothing, gender appearance, or another characteristic that defines him or her as LGBT, then the facility's administration should be informed.

If a longer stay in the nursing home becomes necessary, the response of the administration to your complaint is a good guide as to whether this setting will work over time. Every facility must prominently post telephone numbers for reporting abuse to state agencies and state ombudsmen (programs that mediate disputes). Discrimination is abuse and should be reported, especially if corrective actions are not taken right away.

Home Care

Going home from a hospital or nursing home rehab program is common. Your family member may resist having "strangers in the house," but your own limits as a caregiver may make this necessary. Choosing an LGBT-friendly home care agency involves asking similar questions to choosing a nursing home rehab program. One difference is that with home care you will see just a few professionals (a nurse and perhaps a physical, occupational, or speech therapist) and possibly a home care aide. Interactions are more personal because they take place in the home.

Remember that your family member's home (and yours, if that is the case) is your personal space. You should feel comfortable displaying photos, objects, or books that identify you and your family member as LGBT. You may have to make adjustments to fit medical equipment. But you should not have to make

adjustments to avoid questions from a nurse, aide, or therapist. Ask for a change if you are not satisfied with someone's service or attitude. It may take a few tries to find the right home health care team.

Perspectives on Caregiving



Caregiving requires being an informed, persistent and, when necessary, forceful advocate for your family member.

Caregiving is often seen only as emotional support, which is essential. But caregiving is more than that. Being present is the best way to protect your family member's dignity and rights and to make sure that his or her care is competent and considerate. Be prepared for situations that might occur and be flexible when problems arise. Assure your family member that you will be present all along the way.

Finally, find support for yourself. This can be from other LGBT caregivers or friends. It can also be from more general support groups, such as those for certain diseases. You may find that you have much in common with non-LGBT caregivers. There can be a lot you can learn from them. And a lot you can teach other caregivers as well.

Resources to Learn More

National Resource Center on LGBT Aging:

www.lgbtagingcenter.org

This is the country's first and only resource center aimed at improving the quality of services and supports offered to lesbian, gay, bisexual and transgender older adults. The website includes links to information about caregiving, end-of-life decisions, legal support, and other topics. You can find a map of local resources at www.lgbtagingcenter.org/resources/area.cfm.

SAGE and the National Center for Lesbian Rights' (NCLR) *Planning with Purpose: Legal Basics for LGBT Elders*

www.lgbtagingcenter.org/resources/resource.cfm?r=33

Includes information about relationship recognition, finances, health care, long-term care, Medicare and Medicaid, planning for the care of minor or disabled children, inheritance, elder abuse, and discrimination against LGBT elders.

Nine Tips for Finding LGBT-Affirming Services

www.lgbtagingcenter.org/resources/resource.cfm?r=4

Includes nine helpful tips on finding an LGBT-affirming service provider.

Services & Advocacy for GLBT Elders (SAGE) and SAGECAP (Caring and Preparing)

www.sageusa.org

SAGE is the country's largest and oldest organization dedicated to improving the lives of LGBT older adults. SAGE provides direct services in the greater New York City area as well as telephonic assistance to LGBT caregivers nationally to connect them to local resources in their communities.

Lambda Legal's *Take the Power: Tools for Life and Financial Planning*

www.lambdalegal.org

also: www.lgbtagingcenter.org/resources/resource.cfm?r=42

Toolkit includes information about creating wills and protecting medical and end-of-life decisions. The goal is to help create a more secure future for you and your family.

Next Step in Care

www.nextstepincare.org

Free, downloadable, easy-to-use guides and checklists to help support family caregivers and increase communication between caregivers and health care providers, plus an extensive list of national, disease-specific and other resources. All caregiver materials are in English, Spanish, Russian, Chinese.

Family Caregiver Alliance

www.caregiver.org

Materials for all family caregivers, with specific information, discussion groups, and online support groups for LGBT caregivers.