

Prepare to Care

A Planning Guide for Caregivers in the LGBT Community

Look inside for:

5 Key Steps for your caregiving journey

General Needs Assessment to help evaluate your situation

A simple Goals & Needs Checklist

Additional LGBT Caregiving Resources





Caring for a spouse, partner, close friend, or family member is one of the most important roles you could ever play. It may start with driving your loved one to get groceries or going to the doctor. Later, you may find yourself taking more time off from work, preparing meals, or handling bills. As our loved ones age, it's likely a matter of when, not if, they will need our help.

If your loved one identifies as lesbian, gay, bisexual or transgender (LGBT), you will likely face extra challenges around caregiving. LGBT older adults are twice as likely to be single and four times less likely to have children than their non-LGBT counterparts.¹ Many are estranged from their biological families which means they're less likely to have traditional caregiver support.

LGBT older adults instead typically rely on *families* of choice for support. It is very common for a close friend, an ex-partner, or a younger relative (such as a niece or nephew) to become the primary caregiver. These relationships often go unrecognized legally and even socially, which can make it difficult for someone to be identified as a caregiver or to perform tasks and access services on their loved one's behalf.

Moreover, because LGBT older adults often rely on close friends of similar age for caregiving, these caregivers may be unable to provide longstanding support as they develop their own health impairments. Given this, and the lack of support from biological family, many LGBT older adults experience isolation and loneliness.

Also, many LGBT older adults are fearful or distrustful of medical and social service providers and isolate themselves from others rather than risk experiencing discrimination. A 2010 study revealed that they access services, like senior centers, meal programs and benefits at only 20% the rate that their non-LGBT peers do.² Many wish to keep their sexual orientation or gender identity secret altogether. If they enter a long-term care system, 78% of LGBT seniors choose to stay in the closet.³

These are just some of the reasons that LGBT-friendly caregivers are so important and why your loved one may need you to step into this critical role. No matter where you are in the process of caregiving, having a good framework to help guide both you and your loved one will make it easier.

We've outlined five important steps to help support you and your loved one in your caregiving journey. We've also provided a General Needs Assessment (pages 8 and 9) and a Goals & Needs Checklist (page 14) to help you evaluate your specific caregiving situation.

We hope the information, resources and checklists in this guide will help you get organized and provide the support that you need along the way.

¹ Out and Visible: The Experiences and Attitudes of Lesbian, Gay, Bisexual and Transgender Older Adults, Ages 45-75. LGBT Market Research. Retrieved from <http://sageusa.org/resources/publications.cfm?ID=214>.

² LGBT Movement Advancement Project (MAP) and Services and Advocacy for Gay, Lesbian, Bisexual, and Transgender Elders (SAGE). Improving The Lives of LGBT Older Adults (March 2010). Page 5. www.lgbtaging-center.org/resources/pdfs/ImprovingtheLivesofLGBTOlderAdultsFull.pdf.

³ National Resource Center on LGBT Aging. LGBT Elders in Long-Term Facilities: Stories From the Field. (April 2011). Page 6. http://www.lgbtagingcenter.org/resources/pdfs/NSCLC_LGBT_report.pdf



STEP 1) START THE CONVERSATION

Many people wait until a crisis occurs before they talk with their loved ones about important issues like healthcare preferences or finances. A lot of uncertainty can be avoided if you talk with your loved one before something happens. If the person you're caring for is not your partner/spouse or legal family member it is important to get their permission before taking on any significant caregiving responsibilities. It's not always an easy conversation, but here are some tips to start the dialogue.

Look for an opening.

You might use an article you've read or something you saw on the news to raise the topic of future care, such as "I just read an article about gathering all your important papers in one place. Is there someone who knows where those are and could get to them in an emergency?" Try not to anticipate what your loved one might say or how they will react. Just get the conversation started. Express your love and concern and, most importantly, listen.



Counter resistance.

Your loved one might say, “I just don’t want to talk about it.” Some people are private by nature. It’s also hard for some people to admit they need help. Be sensitive, but don’t give up. If it doesn’t go well, try again. Start small, discussing just one aspect of your concerns.

Respect your loved one’s wishes.

A caregiving plan should never be made without the participation, knowledge and consent of your loved one. Once you’ve started the conversation, you may wish to bring in a few other trusted family members, members of the community, or friends to be part of the process.

Size up the situation.

Figuring out what your loved one’s priorities are, such as where they want to live or the nature of the care they will need will help determine the next steps. They may be hesitant to share the details of their finances or health, but if you approach them with respect and explain your intentions, the conversation will likely be smoother. We’ve inserted a checklist of goals and needs on p. 14 to help you identify concerns related to your loved one’s home, health, finances, and legal needs.

Review finances.

Older LGBT adults are at greater financial risk than their non-LGBT peers because of disparities in earnings, employment and opportunities to build savings over a lifetime. They also lack access to legal and social programs that are traditionally established to support aging adults.⁴

Ask your loved one to review their bank accounts, investments, insurance coverage and loans. Find out whether they have long-term care insurance and funds or assets that can be used to cover potential care needs. Look into Medicaid early on to find out if your loved one qualifies for supplemental services. Caregivers are often surprised to learn that most health insurance, including Medicare, pays for little—if any—of the costs of care in a nursing home or assisted-living facility.

⁴ LGBT Aging: A Review of Research Findings, Needs, and Policy Implications (April 2016). Page 8. <http://williamsinstitute.law.ucla.edu/wp-content/uploads/LGBT-Aging-A-Review.pdf>.

STEP 2) FORM YOUR TEAM

Caring for a family member or friend is too big of a job for one person. Trying to do everything yourself may lead to burnout and problems with your health and well-being. Instead, form a network of friends, family and community resources that can help you with your loved one's care. Putting a supportive team together can strengthen both you and your loved one's ability to deal with any issues that emerge.

Look for team members

Team members need not live nearby or have huge blocks of time to be of value. Family or friends living at a distance or with limited time can pitch in behind the scenes with meal organizing, bill paying or financial assistance. You may feel hesitant to ask others for help, but some people may need only a little encouragement to take on a task—and they may even feel left out if they are not asked. Be specific about the type of assistance needed, as many people just don't know what to do.

Build a team

Identify the people who will be the core members of the team, get your loved one's permission to involve them, and then bring them together for a conversation to figure out who is willing to assist. Discuss specific tasks that each team member is willing will take on. Expect that there may be conflicts and don't be afraid to talk through them. It's better to do so now and not in a time of crisis.

Caregiving on your own

Although a caregiving team is ideal, you may find yourself in a situation where there are few people who can participate in your loved one's care, or whose help your loved one will accept. If this is the case, it may be helpful to reach out to local agencies that provide supportive services. Social workers, doctors, etc. can be important members of a care team. You may also involve some of your own friends or family members, who can support you by taking simple caregiving tasks like grocery shopping or errands off your plate.

STEP 3) MAKE A PLAN

Putting together a caregiving plan will help you respond more quickly and effectively should the need arise. It can also provide some peace of mind. A plan helps get everyone on the same page and keeps the focus on what's best for your loved one. The plan doesn't have to be too detailed. You can never foresee every scenario.

Get started by filling out the General Needs Assessment on pages 8 and 9 and the Goals & Needs Checklist on page 14. Once you've gathered this information, here are some tips to create a plan.

Gather your resources and assign tasks

Explore the options available in the community and bring in team members to help manage the workload. Be sure to ask your caregiving team members about their preferences for who does what task. Assigning tasks can take place in a face-to-face family meeting, over a conference call or through email.

Respect privacy

If your loved one is open about their sexual orientation or gender identity to some people but not everyone, it may be helpful to have a private conversation about who can or should have access to that information and who should not. Always be sensitive to their concerns.

Think both short and long term

The plan should include both immediate and future needs. Options for addressing needs will depend on finances, the willingness of your support team and the availability of community resources and services.



Communicate with the team

Set up a system for communicating with everyone on the team. It's important to have a clear leader to keep the process moving. The point person should be well organized and an in-depth planner who can work through possible conflicts between team members. A conference call or team meeting on a quarterly (or monthly) basis can help ensure that everything is on track and people feel supported as they support your loved one.

Document your plan

A written summary of the plan can reinforce your loved one's wishes and needs and make sure everyone is working toward the same goals.

Be aware of legal obstacles, discrimination, and anti-LGBT attitudes

Many LGBT caregivers have emphasized the importance of knowing your loved one's rights and ensuring that all the required paperwork/legal documents are complete before something unexpected happens. Keep in mind that if you are not your loved one's legal spouse or next of kin you will likely need specific legal documents in place to carry out parts of this plan. Otherwise, decision-making may revert to distant or estranged family members.



- Advance directives, such as a health care proxy or *living will*, ensure that your loved one's wishes will be followed should they become unable to communicate or make medical decisions. Visit **www.aarp.org/advancedirectives** to find free, downloadable, state-specific advance directive forms and instructions.
- Also become knowledgeable about a *release of information (ROI)* and a *do not resuscitate (DNR)* directive. Each of these documents vary from state to state, but most are fairly easy to complete and do not require legal assistance.
- Another document, generally called a *durable power of attorney*, authorizes someone to conduct banking and other business on behalf of a loved one. Often, your loved one's bank has their own forms, and signatures require a notary. You may need the help of a lawyer to draft this document, though that is not always required. If you do not have a lawyer, or don't think you can afford one, visit **www.lambdalegal.org/help** or contact your local *Area Agency on Aging* for resources.



Remember that anti-LGBT attitudes or outright discrimination in services, accommodations, and professional treatment still exist. Organizations like Lambda Legal and the other organizations listed in Resources are available to contact for information and support.

These attitudes may exist in a loved one's family of origin, too. A carefully drafted set of legal documents can be crucial, and a LGBT-affirmative lawyer can be an invaluable resource. Outside consulting by LGBT-affirmative professionals in general can be helpful for resolving family disagreements in favor of a loved one's preferences.

General Needs Assessment

(One for each individual who will need care)

Area of Need	Types of Possible Tasks	Point Person
Home Maintenance and Living Situation	___ Pay rent/mortgage	_____
	___ Home repairs/modifications	_____
	___ Ongoing maintenance	_____
	___ Safety concerns	_____
	___ Grocery shopping & meal preparation	_____
	___ Lawn care	_____
	___ Pet care	_____
	___ Housekeeping	_____
	___ Research alternative living situations	_____
	___ Other: _____	_____
Financial Affairs	___ Paying bills	_____
	___ Keeping track of financial records	_____
	___ Managing assets	_____
	___ Applying for and supervising public benefits	_____
Transportation Needs	___ Driving decisions	_____
	___ Coordinating rides	_____
	___ Locating transportation services	_____
Personal Care	___ Coordinating personal care activities	_____
	___ Help with daily grooming and dressing	_____
	___ Clothes shopping	_____



General Needs Assessment

(One for each individual who will need care)

Area of Need	Types of Possible Tasks	Point Person
Health Care	___ Monitor and record physical and emotional symptoms	_____
	___ Arrange medical appointments, transportation, and someone to accompany as needed	_____
	___ Submit medical insurance and bills	_____
	___ Explain medical decisions	_____
	___ Medication management (fill prescriptions, fill pill boxes, give reminders and dispense medications)	_____
	___ Perform medical tasks (wound care, injections, and catheter)	_____
	___ Obtain medical bracelet and/or medical alert system if needed	_____
Communications	___ Keeping family caregiving team informed	_____
	___ Coordinating team visits	_____
	___ Daily check-in	_____
	___ Obtain cell phone and/or Internet to enhance communication	_____
Socialization	___ Sending greeting and thank-you notes	_____
	___ Arranging for visitors	_____
	___ Arranging outings	_____
Adaptive Devices	___ Ordering, maintaining and paying for adaptive devices	_____
	___ Training on how to use devices	_____
	___ Other: _____	_____

STEP 4) FIND SUPPORT

The LGBT community has a deeply-rooted history of caring for its own, without accepting help from “outsiders.” A distrust of social service providers may be based on very real experiences of discrimination or harassment. However, it’s important to recognize your limitations and that it’s okay to reach out for support. If you’ve discovered that the scope of care is beyond what you or your team can provide, you might consider getting help from your community.

Find welcoming services

You or your loved one may be concerned about whether services will be welcoming to LGBT people. You can start by searching for providers with a SAGECare LGBT aging cultural competency credential at **www.sageusa.org/care**. If those don’t meet your needs, ask for referrals from friends in the community or from a local LGBT Community Center or other LGBT organization. Look at an agency’s advertising, brochures and website for clues that they knowingly and intentionally serve LGBT people.

You can also ask an agency directly if its staff has received cultural competency training, if their non-discrimination policy includes sexual orientation and/or gender identity and if they have experience serving LGBT clients. Ultimately, trust your instincts in choosing a provider that’s a good fit for your loved one and for you. For additional resources about finding LGBT-friendly services, visit the National Resource Center on LGBT Aging at **www.lgbtagingcenter.org**.



Locate community resources

A variety of support services are available to care recipients and their caregivers. Your local Area Agency on Aging can typically help connect you to services such as home-delivered meals, transportation, adult day care centers, care management, and more. Check into the services offered in your community through the Eldercare Locator at **www.eldercare.gov**.

Hire help

If you see that your loved one needs help with daily activities, you can explore the range of home care services available. A nurse or social worker can help you determine what is needed, find services and arrange and monitor the care. Some home care workers do housekeeping, meal preparation, laundry and shopping. Others provide more hands-on help with bathing, dressing and transferring from one position to another, which may require certification.

Inquire whether the hired caregiver is familiar and comfortable with LGBT culture and get references to ensure good quality care. Visit the AARP Caregiving Resource Center at **www.aarp.org/caregiving** for more information on how to find and hire help.

Secure safety

The main goal is to help your loved one stay as independent as possible and in their own home. If they have more difficulty getting around or their vision or hearing fades, some simple changes can be made to make the home safer. Handrails, grab bars, night-lights and adjustable shower seats can make a house safer and more comfortable. Here's a website on smart solutions to making your home more comfortable for your loved one:

www.aarp.org/homefit.

Find housing with supportive services. If your loved one has decided that they would prefer to live in a new residence that combines housing with support services, you can look into the variety of housing options that may be available in your community. Begin by making a list of criteria, such as location, group dining and laundry service. Once you know the type of living arrangement desired, visit several facilities, and be sure to talk with residents and their families.

STEP 5) CARE FOR YOURSELF

As a caregiver, it's easy to forget about your own needs. Balancing caregiving with work and other family obligations can be stressful. Keeping up your energy and maintaining your health are critical in order to care for others. It's just as important to make a plan to take care of yourself as it is to create a caregiving plan for others.

Recognize your emotions

Caregiving can evoke a wide range of emotions. You may feel grateful for the opportunity to “give back” to your loved one. You may feel resentful that you have been pushed into the responsibility, or exhausted from being stretched thin by your own work and other obligations. Whatever you're feeling, it's helpful to recognize your emotions and to know that you are not alone in feeling this way. Finding someone to talk to about these feelings can be very helpful.

Take care of yourself

Allow yourself to take a break. Tend to your own needs for exercise, sleep, and healthy eating. Find ways to reduce your stress and make sure to take time to have fun! If you invest in caring for yourself, you often return to your responsibilities renewed and better able to provide care for your loved one.

Work and caregiving

Many of those who are caring for a loved one are also in the paid workforce. Find out if your company has policies or programs to support caregivers. Think about taking advantage of flextime or working from home to help open up your schedule. If you need more time off, consider asking your employer whether you are covered by the Family and Medical Leave Act.

Understand the financial impact

Your personal finances can take a hit from caregiving – from time off of work, cutting back on hours or passing up promotions to buying groceries and paying for prescriptions. Try to calculate these costs when budgeting. If possible, stay in the workforce to increase retirement income later. In general, try to use your loved one's funds rather than your own, in particular because he or she may need to ‘spend down’ their savings in order to qualify for Medicaid.

Caregiving services and support groups

There's comfort in knowing others are experiencing the same ups and downs as you. Others may also give you ideas about strategies and resources available to lighten your load. If you are interested in LGBT-specific services or support, SAGE can help you locate resources in your area or online. Visit **www.sageusa.org** or call the SAGE LGBT Elder Hotline at 1-888-234-SAGE. Online support groups can also be a good way to find a community of caregivers who may be having similar experiences. Some good places to start:



- **www.aarp.org/caregivingcommunity**
- **<https://www.caregiver.org/lgbt-caring-community-online-support-group>**
- **<http://openhouse-sf.org/resources/lgbt-caregiving>**

RESOURCES

Inclusion in this list does not necessarily indicate that an organization or agency is LGBT-affirming. We encourage you to ask questions when seeking services in order to determine whether they will be welcoming. Visit <http://www.lgbtagingcenter.org/resources/resource.cfm?r=4> for tips and suggested questions. Not all resources will be available in your area. Visit resource websites or call to find out more.

AARP Caregiving Resource Center

www.aarp.org/caregiving
or 1-877-333-5885 Your one-stop shop for tips, tools, and resources while caring for a loved one. For Spanish resources visit www.aarp.org/cuidar or call 1-888-971-2013.

American Civil Liberties Union (ACLU)

www.aclu.org
or 212-549-2500
Evaluates and supports civil liberties cases and issues to defend people from government abuse and overreach.

Care.com

www.care.com
A resource to find caregivers you can hire directly.

Caregiver Action Network

www.caregiveraction.org
or 202-454-397 Information, educational materials, and support for caregivers.

CenterLink

www.lgbtcenters.org
Locate your nearest LGBT Community Center.

Family Caregiver Alliance

www.caregiver.org
or 1-800-445-8106
Tools and resources for family caregivers, including the Family Care Navigator, a state-by-state list of services and assistance.

GLBTQ Legal Advocates & Defenders (GLAD)

www.glad.org or
1-800-455-GLAD Advocates for LGBT people by working to end discrimination through litigation.

Lambda Legal

www.lambdalegal.org/issues/seniors or 1-866-542-8336
Aims to achieve full civil rights for LGBT people through education, policy, and litigation.

Medicare

www.medicare.gov
or 1-800-633-4227 Provides information about the Medicare program and how to find Medicare plans and providers. Caregivers can also find a tool on the website to compare home health care agencies and nursing homes.

National Academy of Elder Law Attorneys

www.naela.org

A professional association of attorneys who specialize in legal services for older adults and people with special needs. Find information on legal issues effecting older adults and a database of elder law attorneys by state.

National Alliance for Caregiving

www.caregiving.org

This organization is dedicated to improving the quality of life for caregivers and those they care for through research, innovation, and advocacy.

National Center for Lesbian Rights

www.nclrights.org

Legal Helpline: 1-800-528-6257
Focuses on LGBT equality through litigation, legislation, policy, and public education.

National Resource Center on LGBT Aging

www.lgbtagingcenter.org

An online clearinghouse of educational resources related to LGBT aging that includes resources for caregivers.

SAGE (Services and Advocacy for Gay, Lesbian, Bisexual & Transgender Elders)

www.sageusa.org

The oldest and largest LGBT aging organization in the U.S. For support and information, call the SAGE LGBT Elder Hotline at 877-360-LGBT or SAGE@LGBThotline.org.

SAGECAP

www.sageusa.org/sagecap

A program that provides counseling, information, support groups and more to gay, lesbian, bisexual, and transgender caregivers.

SAGECare

www.sageusa.care

SAGECare provides training and consulting on LGBT aging issues to service providers. SAGECare offers the added benefit of providing qualifying agencies with a national credential to help consumers identify them as LGBT-friendly.

Transgender Law Center

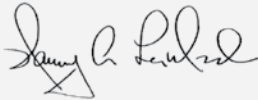
www.transgenderlawcenter.org

or 877-847-1278 Focuses on changing law, policy, and attitudes so that all people can live safely, authentically, and free from discrimination, regardless of their gender identity or expression.

LGBT discrimination is an aging issue that has threatened the health, financial security, and personal fulfillment of too many 50-plus older adults. LGBT individuals should not face discrimination from the entities that 50-plus adults traditionally rely upon for support, such as healthcare institutions, housing centers, meal providers, senior centers, and other vital government services.

Civil rights and equal opportunity in employment, housing, public accommodations, and government services are essential to foster communities where people of all ages can live and thrive without fear of prejudice and bigotry. On this historic date, which marks fifty years of LGBT advocacy since Stonewall, AARP is pleased to support the Equality Act, and urges Senate action to better the lives of LGBT older Americans.

Sincerely,

A handwritten signature in black ink, appearing to read 'Nancy A. LeaMond'.

Nancy A. LeaMond
Executive Vice President and Chief Advocacy and Engagement Officer



Goals & Needs Checklist

Use this list to start the conversation about what is most important to your loved ones and what strengths they bring to bear.

Goals

- ___ To remain healthy and active
- ___ To stay/move near family
- ___ To remain in my own home for as long as possible
- ___ To stay active with religious or community groups
- ___ To maintain hobbies
- ___ To be around people
- ___ To move to a residence with support services
- ___ To move to a more accessible home (one story or apartment with elevator)
- ___ To be financially secure and/or to budget for future needs
- ___ To travel/visit home country
- ___ Other:

Strengths

- ___ Able to advocate for self
- ___ Adequate savings and/or income
- ___ Low-maintenance single-story home
- ___ Family and friends nearby
- ___ Relationships with family
- ___ Other:

Needs

First determine if there is an immediate need under each area. If there is not a pressing issue, prioritize the tasks to be addressed and develop a timeline.

Caregiver Resources

Visit the AARP Caregiving
Resource Center for information,
tools and resources.

General: **AARP.org/caregiving**
or call 877-333-5885

LGBT: **AARP.org/pride**
or call 866-Pride-50

Spanish: **AARP.org/cuidar**
or call 888-971-2013

