AARP®

LGBTQ Community Caregiving Guide

A Planning Guide for Caregivers in the LGBTQ Community

Look inside for:

5 Key Steps for Your Caregiving Journey

General Needs Assessment to Help Evaluate Your Situation

A Simple Goals and Needs Checklist

Additional LGBTQ Caregiving Resources

sage | Advocacy & Services for LGBT Elders

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INTRODUCTION

Caring for a spouse, partner, close friend, or family member is one of the most important roles you'll play. As our loved ones age it's likely a matter of when, not if, they will need our help. Nearly 44 million Americans—1 in 5 adults—are caregivers for a relative or friend over age 50.[1] 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.

If your loved one identifies as lesbian, gay, bisexual or transgender (LGBTQ), you will likely face extra challenges around caregiving. LGBTQ older adults are twice as likely to be single and four times less likely to have children than their non-LGBTQ counterparts.[2] Many are estranged from their biological families which means they're less likely to have the traditional caregiver support that many older adults rely on.

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[1] Caregiving in the U.S., The National Alliance for Caregiving and AARP 2009.

[2] Out and Visible: The Experiences and Attitudes of Lesbian, Gay, Bisexual and Transgender Older Adults, Ages 45-75. *LGBTQ Market Research*. Retrieved from **sageusa.org/resource-posts/out-visible-the-experiences-and-attitudes-of-lesbian-gay-bisexual-and-transgender-older-adults-ages-45-75-by-the-numbers-full-report**.

LGBTQ older adults instead typically rely on *families of choice* for support and 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 for an older LGBTQ adult who needs assistance. 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 LGBTQ 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 LGBTQ older adults experience isolation or loneliness. Indeed, LGBTQ older adults are more likely to live alone than heterosexual cisgender peers.[3] Caregivers for LGBTQ older adults should be mindful of this as they prepare to care.

It's also important for caregivers who are not part of the LGBTQ community to be mindful of the particular challenges LGBTQ people have faced. Just a few decades ago homosexuality was considered a mental illness and a crime in the United States. Housing, employment, and healthcare discrimination were common. Those experiences were traumatizing for many. For LGBTQ people who live in less welcoming communities, discrimination may still exist. As a result of past, or present, experiences many LGBTQ older adults today are fearful or distrustful of medical and social service providers and isolate themselves from others rather than risk experiencing further discrimination. Many wish to keep their sexual orientation or gender identity secret altogether. If they enter a long-term care system, 78% of LGBTQ seniors stay in the closet.[4]

Great diversity exists within the LGBTQ community, and each of our groups—racial, ethnic, immigration status—has its own distinct cultural beliefs, attitudes, and practices around healthcare and caregiving. It's important to remain aware of these nuances, as well as the fact that race, class, religious affiliation, location, and gender expression can also affect our access to care and impact the healthcare journey as a whole.

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[3] Kim, H-J., & Fredriksen-Goldsen, K. I. (2016). Living Arrangement and Loneliness among Lesbian, Gay, and Bisexual Older adults. *Gerontologist*, 56(3), 548-558; Persson, D. I. (2009). Unique Challenges of Transgender Aging: Implications from the Literature. *Journal of Gerontological Social Work*, 52(5), 633-646; Wallace, S. P., Cochran, S. D., Durazo, E. M., & Ford, C. L. (2011). The Health of Aging Lesbian, Gay, and Bisexual Adults in California. *Policy Brief UCLA Center for Health and Policy Research*.

[4] National Resource Center on LGBTQ Aging. *LGBTQ Elders in Long-Term Facilities: Stories From the Field*. (April 2011). Page 6. **LGBTQagingcenter.org/resources/pdfs/NSCLC_LGBTQ_report.pdf**

This guide is a practical tool created to help you. Here you'll find information, resources, and checklists to help you get organized and find the support that you might need.

However, there are also commonalities among different groups. Isolation, widespread financial insecurity, and significant health disparities among LGBTQ people compound the need for assistance but LGBTQ older adults don't tend to reach out for it; a 2010 study revealed that LGBTQ older adults access services, like senior centers and meal programs, and benefits, like housing assistance or food stamps, at only 20% the rate that their non-LGBTQ peers do.[5] That's why 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 journey of caregiving—just beginning to anticipate a need, helping coordinate a big move, or taking care of a loved one full-time—having a good framework to help guide both you and your loved one will make the process easier.

This guide is a practical tool created to help you. Here you'll find information, resources, and checklists to help you get organized and find the support that you might need. Words in italics are described in greater detail in the Glossary, organizations identified with an asterisk are listed in the Resources section. The guide follows five important steps that will help see you through your caregiving journey.

START A CONVERSATION. Many people wait until a crisis occurs to talk about their values and preferences, wishes for health care, or details of their finances. If you wait until a fall, accident, or serious diagnosis, big decisions may be driven by assumptions. A crisis can also lead to hastily-made decisions rather than ones that are carefully thought-out. Before entering into a caregiving role it's a good idea to ask outright about being a part of your loved one's caregiving team. Clarifying this ahead of time will make it much easier to navigate a crisis if one does occur.

[5] LGBTQ Movement Advancement Project (MAP) and Services and Advocacy for Gay, Lesbian, Bisexual, and Transgender Elders (SAGE), *Improving The Lives of LGBTQ Older Adults* (March 2010). Page 5. **LGBTQagingcenter.org/resources/pdfs/ImprovingtheLivesofLGBTQOlderAdultsFull.pdf**.

MAKE A PLAN. Putting together a caregiving plan now will help you respond more quickly and effectively should the need arise. It can also provide some peace of mind. A plan helps everyone get on the same page and keeps the focus on what's best for your loved one and for you. If you are not your loved one's legal spouse or next of kin you will likely need to put legal documents in place in order to carry out parts of this plan. It is important to take care of these before an emergency arises so that your loved one is able to state and verify their own wishes.

FORM A TEAM. You will be more effective as a caregiver if you don't try to do it alone. Find others who can help you, whether they're friends, family members, community groups, or professional service providers. While other family members are likely sources of support, don't overlook friends, colleagues, clubs or religious and other organizational affiliations as resources too. Stay focused on your loved one; it will be more effective if the team recruited is closely connected to the person in need of caregiving.

FIND SUPPORT. Many issues may arise during your caregiving experience that require additional information and resources. Don't hesitate to reach out to organizations and professionals with experience in helping family caregivers.

CARE FOR YOURSELF. As a caregiver, it's easy to forget about your own needs. But keeping up your energy and maintaining your health are critical in order to care for others. It's just as important to plan for self-care as it is to create a plan for others' care. Educate yourself about what the aging process looks like—not just day-to-day needs, but also health management and advocacy that may be necessary while navigating the healthcare system. Be honest with yourself about what you're agreeing to, and understand your own capacity for helping before stepping into a caregiving role.

Note: Words in *italics* are described in greater detail in the Glossary, and organizations identified with an asterisk (*) are listed in the Resources section.

START A CONVERSATION

A lot of uncertainty can be avoided if you talk with your loved one before something happens. It's easy to put off these conversations because they can be difficult. It never seems like the right time to bring up what we think will likely be an uncomfortable topic. You may be surprised to find your loved one has been meaning to have the talk too and is relieved when you take the lead.

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. Many people find it difficult to ask for help; taking the first step and clearly offering to be a part of your loved one's support system is one of the most caring things you can do.

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'm starting to think about estate planning, do you have any advice?"
- "As time goes on, do you think you will want to stay in this house [or apartment]? It might be difficult with all the stairs."
- "You mentioned your eyes are bothering you. Is this causing problems with reading or driving?"
- "I just read an article about gathering all your important papers. Is there someone who knows where those are and could get to them in an emergency? Would you like me to be that person?"

Try not to anticipate how she or he may react. Just get the conversation started. It will likely take place over time. Be open, express your support and concern and, most importantly, listen. Another more personal opening might be discussing a friend who has declined, gone into care, or has passed away recently.

RESPECT YOUR LOVED ONE'S WISHES. Every caregiving plan must center on the wishes of the person receiving the care. A plan should never be made without the participation, knowledge, and consent of your loved one. A person with a cognitive impairment should still participate as much as possible.

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COUNTER RESISTANCE. Your loved one might say, "I just don't want to talk about it" or look for ways to put off the conversation. Be sensitive, but don't give up. It's hard for them to discuss what they may see as being a burden to you. If your first conversation doesn't go well, try again. Start small, discussing just one aspect of your concerns.

It may take time for your loved one to come around but continue to emphasize that you care about them and want what's best for them. Introducing a trusted professional's opinion – someone who can serve as an impartial third-party and is familiar with the caregiver experience – may help reduce resistance among loved ones.

CONCERN FOR THEIR SAFETY. If your loved one shuts you out you may be able to approach a trusted family member or another friend with your concerns. If your loved one is isolated and you are concerned for their safety, revisit the plan with the care team and your loved one. Reach out to their healthcare providers for input, intervention, and resources. It's best to have people who are personally involved and invested in your loved one's interests. As a later step, if necessary, you can place a call to your local *Area Agency on Aging*, a go-to for community-based services, personal emergency response services, and transportation, among others. Revealing your loved one's LGBTQ identity is not a requirement.

Once your role in assisting your loved one has been established, you can begin to address specific concerns:

SIZE UP THE SITUATION. Figuring out what your loved one's priorities are – where they want to live and the nature of the care needed – will help you determine the next steps. It can lead you to find resources ahead of time. They may be hesitant to share the details of their finances or health, but approach them with respect and explain your intentions. Consider a tiered designation—instead of an assumption of current decline, determine if this is early planning, a response to acute illness or hospitalization, or something else.

We've inserted a checklist of goals and needs to help you identify concerns related to your loved one's home, health, finances, and legal needs.

REVIEW FINANCES. Older LGBTQ adults are at greater financial risk than their non-LGBTQ 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.[6] Money can be a particularly sensitive subject, but it's often at the heart of many decisions you'll make with your loved one about housing, health care, and other expenses. 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*. It also does not cover most help with daily activities such as bathing, dressing, or meals.

Ask your loved one to review their bank accounts, investments, insurance coverage, and other 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. Also, note that veterans may have additional access to healthcare and caregiving assistance.

[6] LGBTQ Aging Aging: A Review of Research Findings, Needs, and Policy Implications (April 2016). Page 8. **williamsinstitute.law.ucla.edu/wp-content/uploads/LGBTQ-Aging-A-Review.pdf**.

MAKE A PLAN

The most effective caregiving plans are made with the care recipient at the center of the discussion. Armed with the information you gathered from going through our goals and needs checklist, you can begin to explore the options available in the community and bring in other team members to help manage the workload.

The plan doesn't have to be extensive or fancy. You can never foresee every detail or scenario. The plan should include immediate needs as well as broader plans for the future. Use the goals and needs checklist as your guide. Options for addressing needs will depend on finances, the willingness of any support team, and the availability of community resources and services. A written summary of the plan can reinforce your loved one's wishes and needs. However, be open to modifications as their situation changes. Your loved one's needs may unfold differently than you had initially anticipated.

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. Take notes to help you keep track of this; you can refer to them later if you need to interact with those people on your loved one's behalf. Remember, due to a lifetime of discrimination, some LGBTQ people feel that they need to return to the closet as they age. Always be sensitive to their concerns.

BE AWARE OF LEGAL OBSTACLES. Many LGBTQ caregivers emphasized the importance of knowing your loved one's rights and ensuring that all the required paperwork/legal documents are complete. 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. *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. Also become knowledgeable about a *release of information (ROI)* and a *do not resuscitate (DNR)* directive. Each of these documents vary somewhat from state to state, but most are fairly easy to complete and do not require legal assistance. Visit **aarp.org/advancedirectives** to find free, downloadable, state-specific *advance directive* forms and instructions.

Another document, generally called a power of attorney, authorizes someone to conduct banking and other business on behalf of a loved one. 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, contact your local *Area Agency on Aging* for resources.

It is important to get this paperwork done before something unexpected happens: not having the proper documents in place can mean that decision-making reverts to a family member with whom your loved one may not have a close relationship, or to professionals who never knew your loved one at all.

AVOID DISCRIMINATION AND ANTI-LGBTQ ATTITUDES. Given that anti-LGBTQ attitudes, or outright discrimination in services, accommodations, and professional treatment still exist, especially in certain areas of the country, it is important to respect your loved one's personal history and desires. In particular, your loved one may desire to fight the resolution of an injustice. Supporting your loved one, as best you are able, is the appropriate course to take. Remember that you are there for them. Legal organizations, listed in Resources, are available to contact for information and support.

Anti-LGBTQ attitudes may also exist within a loved one's biological family. A carefully drafted set of legal documents can be crucial and a gay-affirmative lawyer can be an invaluable resource. Outside consulting by gay-affirmative professionals in general can be helpful for resolving family disagreements in favor of a loved one's preferences.

FORM A TEAM

Caring for a loved one can be too big a job for one person. Trying to do everything yourself may lead to burnout and problems with your own physical and mental health. Instead, reach out to form a larger network of friends, family and community resources that can assume responsibilities for some of your loved one's care.

LOOK FOR TEAM MEMBERS. Your loved one can help you identify willing members that you may not have thought about such as neighbors or family members. If your loved one takes part in an organized community – at a place of worship or a community center, for example – you will likely be able to find people there who are willing to pitch in. Team members need not all live nearby or have huge blocks of time to be of value. Family or friends, even those living at a distance or with limited schedules, can pitch in behind the scenes with meal organizing, bill paying, or financial assistance. For example, a friend or family member who is a computer whiz may be able to set up an electronic calendar for dinner delivery or chores.

Locally, members of the community may be happy to drop off a meal now and then, or help with yard work. If your loved one wants to move in the next year or so, one task can include searching locations and facilities by a person who can visit possible places. Someone else could spend some weekends helping your loved one sort through their belongings.

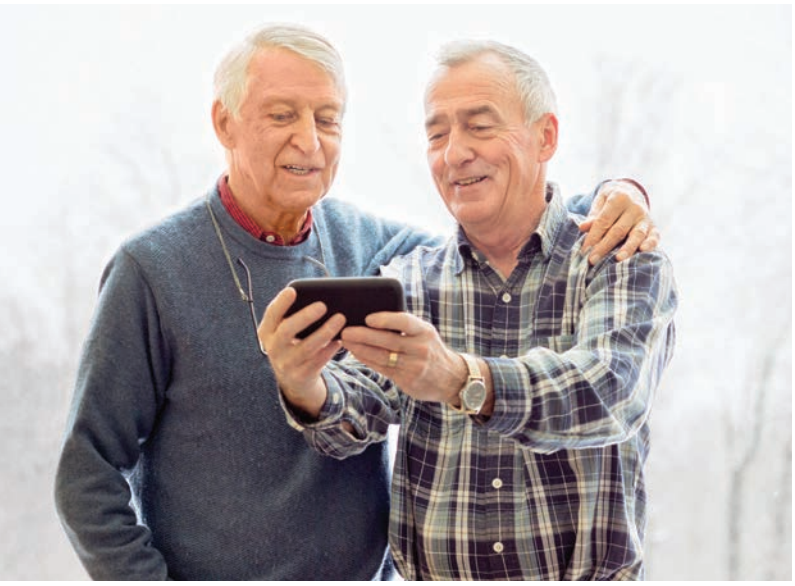
You may feel hesitant to ask others for help, but some people may need only a little encouragement to take on a task – and they may feel left out otherwise. In addition, many people get great satisfaction from helping. Don't feel guilty about asking. Be sure to ask your caregiving team members about their preferences for who does what task and to take your loved one's wishes into account; for instance, they might be more comfortable with one particular person rather than another handling financial affairs.

BUILD AND SUPPORT YOUR TEAM. Putting a support team together that is deep and wide can strengthen both you and your loved one's ability to deal with any issues that emerge. It will also help assure that as team members' ability to help out changes; you will still have support from the larger group. 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 nuts-and-bolts conversation.

If you have been able to pull together a team of people to help it's now time to figure out who is going to do what. This might take place in a face-to-face meeting, over a conference call, or through a series of emails. Agree together and be clear about specific tasks that each team member will take on.

Before meeting, you and the other team members should consider…

- What are your top three concerns for your loved one?
- What are any immediate and long-term needs you may have identified?
- What are your own feelings and outlook on the situation?
- Who is the best person to start or lead the group conversation?
- What are your goals or what is the best outcome you think might result from the conversation?



- What are you prepared to do and what are you unable to do?
- What is most difficult for you about having this conversation regarding your loved one's care?

It's important to have a clear leader to keep the process moving and make sure people understand what's been decided. In most cases, one person assumes the primary role because he or she lives nearby, has a close relationship, or simply is a take-charge person. 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.

Afterward, an ongoing platform for connection and check-in will be important. A point person will still be necessary to keep this process organized and in check. 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. Platforms for ongoing communication such as **caretree.me/families** can be helpful.

Get help wherever you can and try to stay mindful of your own feelings and needs to avoid burnout.

CAREGIVING ON YOUR OWN. Although a caregiving team is ideal, you may find yourself in a situation where there are very few people other than you 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—you'll find more information and suggestions in the "Find Support" section. Social workers, doctors, etc. can be important members of a care team, and the questions listed above can be useful to ask them as well. You may also be able 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. Get help wherever you can and try to stay mindful of your own feelings and needs to avoid burnout.

FIND SUPPORT

The LGBTQ community has a deeply-rooted history of caring for its own, without accepting help from "outsiders," and you or your loved one may be accustomed to that culture. A distrust of social service providers may be based on very real experiences of discrimination or harassment earlier in life. However, it's important to recognize your limitations and recognize that it's okay to reach out for extra support. If you've discovered that the scope of care is beyond what you or your team can provide, or if you're not sure what is needed, you might consider getting help from an organization in your community

LOCATE COMMUNITY RESOURCES. A variety of support services are available to people ages 50 and over and their caregivers throughout the United States. 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 **eldercare.gov**. In addition, SAGENet,* SAGE's network of local affiliates, has 30 locations in 20 states across the country. **sageusa.org/what-we-do/sagenet-national-affiliates**

CONSULT A PROFESSIONAL. Often times a loved one's needs can be complex especially when health, emotional and financial issues come into play. A *geriatric care manager*, who is often a nurse or social worker, can help you sort things out and determine what is needed, find services, and arrange and monitor professional care. Perhaps your workplace has an Employee Assistance Program that can help connect you to professionals and services in your community. You can also find professionals through the Eldercare Locator* at **eldercare.gov**.

If you see that your loved one needs extra help with daily activities, you can explore the range of home care services available.

HIRE HELP. If you see that your loved one needs extra help with daily activities, you can explore the range of home care services available. Some home care workers assist with housekeeping, meal preparation, laundry, and shopping. Others provide more hands-on help with bathing, dressing, and transferring from one position to another, which usually requires special training, a license, or certification, depending on the laws in your state. Your local *Area Agency on Aging* can help you identify the appropriate services and connect you with local providers. They can also help you determine eligibility for publicly funded services. If you work with a home care agency or hire someone on your own, be sure to ask about licensing, background checks, training, and costs. As important, inquire whether the hired caregiver is familiar and comfortable with LGBTQ culture. Get references to ensure good quality care. Visit the AARP Caregiving Resource Center* at **aarp.org/caregiving** for more information on how to find and hire help.

SECURE THEIR SAFETY. A major goal is to help your loved one stay at home and as independent as possible. As your loved one has more difficulty getting around or their vision or hearing fades, some simple modifications can make the home safer. Handrails, grab bars, night lights, and adjustable shower seats can improve the safety and comfort of the home. The AARP Home Fit Guide* at **aarp.org/homefit** offers solutions that range from simple fixes to improvements requiring skilled expertise.

HOUSING WITH SUPPORTIVE SERVICES. If your loved one has decided that they would prefer to get care 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, options for private rooms, group dining, and laundry service. Our glossary includes common definitions for the different types of housing alternatives available. Not all types of housing are available in every community.

Once you know the type of living arrangement desired, visit several facilities, and be sure to talk with residents and their families. For more information about how to choose the right housing option, go to the AARP Caregiving Resource Center* at **aarp.org/caregiving**. If selecting a nursing home, go to Medicare's Nursing Home Compare* page at **medicare.gov**.

Also, you can refer to the *Long-Term Care Ombudsman* (LTC)* program, which lists complaints resolved and/or not resolved, when looking for long-term care environments. **ltcombudsman.org**

FIND WELCOMING SERVICES. You or your loved one may be concerned about whether some of these agencies and services will be welcoming to LGBTQ people. You can start by searching for providers with a SAGECare* LGBTQ aging cultural competency credential at **sageusa.org/care**. If those don't meet your needs, ask for referrals from friends in the community or from a local LGBTQ Community Center or other LGBTQ organization. Look at an agency's advertising, brochures, and website for clues that they knowingly and intentionally serve LGBTQ 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 LGBTQ 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 LGBTQ-friendly services, visit the National Resource Center on LGBTQ Aging* at **LGBTQagingcenter.org**.

CARE FOR YOURSELF

Don't overlook the impact of caregiving on your own health and wellness. Balancing caregiving with work and other family obligations is often stressful. When asked, caregivers often say the most difficult part of caregiving is the demand on their time. Stress can negatively affect your health, well-being, and ability to provide care. Take time regularly for what's important to you and get help from others.

CAREGIVING AT A DISTANCE. Coordinating care when you don't live in the same community can be time consuming, expensive, and frustrating. The following resources and strategies can help:

- *Geriatric care managers* can guide you through care choices and help monitor the care when you don't live nearby. They are professionals who can assess an individual's mental, physical, environmental, and financial conditions and create a care plan to arrange housing, medical, social, and other necessary services.
- Technology such as *personal emergency response systems (PERS)*, remote monitoring devices, mobile apps with medical records, and electronic calendar reminders can help you juggle your many tasks as well as provide some peace of mind that your loved one is safe. Organization is essential for the long-distance caregiver. Keep a list of all contact information for doctors, insurance companies, and neighbors. It's also important to keep a list of their medications with you.

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. Benefits or services may be available that can help ease your situation. Think about taking advantage of flex-time or working from home to help open up your schedule. If you need more time off, and you're caring for a family member or your legal spouse/domestic partner, consider talking to your employer about whether you are covered by the *Family and Medical Leave Act (FMLA)*, which provides up to 12 weeks of job-protected unpaid leave to care for a spouse, child, or parent with a serious health condition. Some states have additional leave laws that provide more coverage for unpaid or paid caregiving leave.

UNDERSTAND THE FINANCIAL IMPACT. Your personal finances can take a hit from family 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.

ADVOCATE FOR YOU. Consider telling your own doctor that you are a caregiver for someone and this extra work has increased your stress level. Discuss ways to manage stress. Let your loved one's doctor know that you are the primary caregiver and that you need information on their condition and the treatments prescribed. Ask for training if you are expected to handle any procedures at home. Some professionals might be reluctant to share information, especially if a caregiver is not related to their patient. However, most professional offices have a form that your loved one can sign to give their doctor or other professionals permission to discuss their care with you.

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, or enter caregiving reluctantly but discover that it's a chance to mend a broken or distant relationship and experience healing. 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. You may feel that you're the only person your loved one has to lean on for support which can be stressful and isolating. If you cared for friends and loved ones during the AIDS epidemic, you may find that caregiving now triggers difficult memories or emotions. 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. Consider tapping into a caregiving social network such as **caringbridge.org** for support.

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. There are community services to help you in your journey of caregiving. Don't feel guilty about needing time off or help with understanding complex information, and remember that your loved one may also benefit from having a wider circle of care. Consider finding services and support groups available in your community through Eldercare Locator.* If you are interested in LGBTQ-specific services or support, SAGE can help you locate resources in your area or online. Visit **sageusa.org** or call the SAGE LGBTQ Elder Hotline at **1-888-234-SAGE**.

Online support groups can be a good way to find a community of caregivers who may be having similar experiences. Some good places to start:

- **aarp.org/caregivingcommunity**
- **caregiver.org**
- **openhousesf.org**

Cancer specific:

- **LGBTQcancer.org**
- **cancercare.org/support_groups/116-LGBTQ_caregiver_support_group**

As you seek out caregiving resources, you are likely to see the term "family caregiver" used frequently. In general, this term serves to distinguish unpaid loved ones like you from paid professional caregivers such as home health aides. In most cases, "family caregiver" is meant to include close friends and families of choice, and caregiver services and resources are available to all unpaid caregivers, not just family members. You should feel free to take advantage of those resources and to identify yourself as a caregiver regardless of your relationship to the care recipient.

Share your caregiving story with others at iheartcaregivers.org.

GLOSSARY

ACTIVITIES OF DAILY LIVING (ADLS)

Basic tasks of everyday life that include, but are not limited to, dressing, bathing, eating, and toileting.

ADULT DAY SERVICES

Structured, comprehensive programs, including a variety of health, social and related support services during any part of the day but for less than 24 hours, provided at local centers for adults who need some supervision and/or support.

ADULT PROTECTIVE SERVICES

A public agency that investigates reports of abuse and neglect of vulnerable adults and that usually works with law enforcement. Situations of immediate danger should be directed to 911 or the local police.

ADVANCE DIRECTIVES

A document (or set of documents) that enables someone to make their wishes clear regarding medical treatment in advance of needing said treatment. See *Health Care Power of Attorney* (Health Care Proxy) and *Living Will*.

AREA AGENCY ON AGING (AAA) OR AGING AND DISABILITY RESOURCE CENTER (ADRC)

An agency designated by the state with the responsibility for planning and coordinating services for older people and sometimes for adults with disabilities within a specific geographical area. Both agencies provide information, resources, assistance, and links to community services.

ASSISTED LIVING RESIDENCES

Housing for those who may need help living independently, but who do not need skilled nursing care. The level of assistance varies among residences and may include help with bathing, dressing, meals, and housekeeping.

CERTIFIED NURSE ASSISTANT (CNA)

A professional who helps patients or clients with healthcare needs under the supervision of a Registered Nurse.

COMMUNITY MEAL PROGRAM

Balanced nutritious meals served at community locations for those ages 60 and over as well as their younger spouses.

CONSERVATOR

A person appointed by a court to handle the affairs of someone who cannot do so independently. A conservator usually handles only financial affairs.

CONTINUING CARE RETIREMENT COMMUNITIES

Housing that offers a variety of living options and services including independent living, assisted living, and skilled care, often all on the same campus and designed to meet a person's changing needs.

DISCHARGE PLANNER

A professional who assists individuals and their families or caregivers in developing a plan of care for an individual following a hospital or nursing home stay.

DNR: DO NOT RESUSCITATE ORDER

An order written by a doctor to fulfill an individual's expressed medical care wishes during a medical emergency.

DURABLE POWER OF ATTORNEY FOR FINANCES

A legal document that allows one to designate another trusted person to make financial decisions on one's behalf. The designation "durable" means that it will stay in effect if you become unable to manage your own financial affairs.

FAMILY AND MEDICAL LEAVE ACT (FMLA)

A law that requires some employers to let an employee take unpaid time off work (up to 12 weeks) for illness, having/adopting a baby, or caring for an ill family member. Your job or its equivalent is guaranteed when you return. If you work for a small employer or are a new employee, or if you're caring for someone who's not a spouse or legal relative, you may not qualify for FMLA. Check with your employer for details about your eligibility.

GLOSSARY

FAMILY CAREGIVER

Anyone (not just a family member) who provides unpaid assistance to another person who is ill, or disabled, or needs help with daily activities.

FAMILY OF CHOICE

Diverse family structures that include but are not limited to life partners, close friends, and other loved ones who are not biologically related or legally recognized but who provide social and caregiving support to an individual.

GERIATRIC CARE MANAGER

A professional who assesses an individual's mental, physical, environmental, and financial conditions and creates a care plan to arrange housing, medical, social, and other necessary services.

GUARDIAN

A person appointed by the court who is responsible for the care and management of an individual determined to no longer have decision-making capacity.

HEALTH CARE POWER OF ATTORNEY (HEALTH CARE PROXY)

A special kind of durable power of attorney in which one appoints another person to make health care decisions in the event that one should become unable to do so.

HEALTH INSURANCE PORTABILITY AND ACCOUNTABILITY ACT (HIPAA)

A federal law that protects private health information, setting rules and limits on who can access this information and permitting its release as needed for patient care.

HOME HEALTH AGENCY

An agency often certified by Medicare to provide health-related services in the home such as nursing, occupational, speech, or physical therapy, social work, and/or personal care.

HOME HEALTH AIDE

An individual who helps someone with bathing, dressing, grooming, assistance with meals, and light housekeeping.

HOMEMAKER SERVICES

A service that provides assistance with general household activities such as meal preparation, cleaning, laundry, and shopping.

HOSPICE CARE

Professionally coordinated support services, including pain and symptom management, social services, and emotional and spiritual support for terminally ill people and their families. The care can be provided at home as well as in other settings such as hospitals and residences.

INSTRUMENTAL ACTIVITIES OF DAILY LIVING (IADL)

Basic tasks of everyday life that include, but are not limited to: managing money, shopping, telephone use, travel in the community, housekeeping, preparing meals, and taking medications correctly.

IN-HOME CARE

In-home care is a service that provides caregivers who will come into the home to assist with activities of daily living, including light housekeeping, grocery shopping, meal preparation, and grooming. Some provide additional services related to help with personal care for toileting and bathing.

LIVING WILL (PART OF A HEALTH CARE DIRECTIVE)

A legal document that specifies a person's wishes about lifesaving medical treatments should he or she have a terminal condition and become unable to communicate those wishes.

LONG-TERM CARE INSURANCE

Insurance that can pay part of the cost of care received in the home, assisted living residences, nursing home, and other designated services depending on the policy purchased.

GLOSSARY

LONG-TERM CARE OMBUDSMAN

A person who investigates and resolves complaints on behalf of residents of nursing homes and other long-term care facilities.

MEDICARE

A federal health insurance program for people age 65 and over, and for some younger persons with disabilities. Medicare covers hospital stays, doctor visits, prescription drugs and other health care related needs. Medicare does not cover long-term care.

MEDICARE SAVINGS PROGRAM

An assistance program for people with Medicare who need help with paying their Medicare expenses, such as premiums, co-pays, and deductibles for Medicare Parts A & B.

MEDICAID

The federal/state funded health and long-term care program for people with limited income and assets. Medicaid is administered by the states within federal guidelines so eligibility and coverage may differ from state to state. For long-term care services, states have additional eligibility rules.

NURSING HOMES

Facilities that provide immediate care – assistance with personal care and activities of daily living – and/or skilled 24-hour medical, nursing, and rehabilitation care, often during a transition from hospital to home. The latter may also be called a skilled nursing facility.

PALLIATIVE CARE

Professionally coordinated services that focus on the physical, mental, social, and spiritual needs of those with life-threatening illness and their loved ones. Palliative care seeks to maintain the patient's highest level of comfort, pain management, and quality of life. Note that palliative care is not the same as hospice.

PERSONAL EMERGENCY RESPONSE SYSTEM (PERS)

A portable electronic device with a call button that a person can use to summon help in an emergency.

RELEASE OF INFORMATION (ROI)

A legal authorization to release health records to a designated individual..

RESPITE CARE

A temporary break from providing care for a loved one. Respite care can be provided by friends or family or through services such as attending an adult day services center. You can also have a paid home-care worker come to the home, or find an accommodation in a nursing facility for a short stay.

SOCIAL SECURITY

A benefit earned by eligible workers that provides guaranteed inflation-adjusted monthly income for life. A person with the required number of quarters of – who has thereby paid into Social Security to later earn benefits – is eligible at age 62 or if disabled. Certain family members may be eligible for benefits as well.

SUPPLEMENTAL SECURITY INCOME (SSI)

A monthly cash benefit for people who are 65 years of age and older, disabled, or blind, and who have limited income and assets.

ADDITIONAL RESOURCES

Inclusion in this list does not necessarily indicate that an organization or agency is LGBTQ-affirming. We encourage you to ask questions when seeking services in order to determine whether they will be welcoming. See the above discussion on Finding Welcoming Services, and visit **LGBTQagingcenter.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
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 **aarp.org/cuidar** or call **1-888-971-2013**.

AARP ADVANCE DIRECTIVE FORMS
aarp.org/advancedirectives

> Free, downloadable state-specific advance directive forms and instructions.

AARP MEDICARE Q&A TOOL
aarp.org/medicareqa

> An easy-to-use online tool that provides answers to frequently asked questions about Medicare.

AARP HEALTH LAW ANSWERS
healthlawanswers.org

> An online tool designed to help you understand what the health care law means for you and your family and where to go for information in your state.

AARP LONG-TERM CARE COST CALCULATOR
aarp.org/costcalc

> Find and compare the costs of home care, assisted living, and other services throughout the United States.

ADMINISTRATION ON COMMUNITY LIVING
acl.gov

> The federal agency responsible for advancing the concerns and interests of older people. The website has a variety of tools and information for older adults and family caregivers.

AGING LIFE CARE ASSOCIATION
aginglifecare.org

> This association can help you find a private geriatric care manager in your community.

ALZHEIMER'S ASSOCIATION
alz.org or 1-800-272-3900

> Resources, tools, and a 24-hour helpline for people with Alzheimer's disease and their families.

AMERICAN CANCER SOCIETY
cancer.org or 1-800-227-2345

> From basic information about cancer and its causes to in-depth information on specific cancer types – including risk factors, early detection, diagnosis, and treatment options.

AMERICAN DIABETES ASSOCIATION
diabetes.org or 1-800-342-2383

> Resources and research to prevent, cure, and manage diabetes.

AMERICAN HEART ASSOCIATION
heart.org or 1-800-242-8721

> Resources that will help you better care for someone who has heart disease or who has had a heart attack, heart surgery or a stroke.

AMERICAN CIVIL LIBERTIES UNION (ACLU)
aclu.org or 212-549-2500

> Evaluates and supports civil liberties cases and issues to defend people from government abuse and overreach.

ARGENTUM
argentum.org

> Formerly the Assisted Living Federation of America. Information and resources on assisted living options and how to find them..

CARE.COM
care.com

> A resource to find caregivers you can hire directly.

ADDITIONAL RESOURCES

CAREGIVER ACTION NETWORK
caregiveraction.org or 202-454-3970

Information, educational materials, and support for family caregivers.

CENTER TO ADVANCE PALLIATIVE CARE
getpalliativecare.org

Provides comprehensive information about palliative care and has a searchable provider directory of hospitals.

CENTERLINK
LGBTQcenters.org

Locate your nearest LGBTQ Community Center.

DEPARTMENT OF VETERANS AFFAIRS
va.gov or 1-800-827-1000

Information about eligibility and benefits for veterans and their families.

ELDERCARE LOCATO
eldercare.gov or 1-800-677-1116

A public service of the U.S. Administration on Aging that connects caregivers to local services and resources for older adults.

ELIZABETH DOLE FOUNDATION
elizabethdolefoundation.org

Created to help American military caregivers by strengthening the services afforded to them through innovation, evidence-based research, and collaboration.

FAMILY CAREGIVER ALLIANCE
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)
glad.org or 1-800-455-GLAD

Advocates for LGBTQ people by working to end discrimination through litigation.

LAMBDA LEGAL
lambdalegal.org/issues/seniors or 1-866-542-8336

Aims to achieve full civil rights for LGBTQ people through education, policy, and litigation.

LEADINGAGE
leadingage.org

Consumer information on long-term care facilities and services, and how to access them.

LONG-TERM CARE (LTC) OMBUDSMAN
ltcombudsman.org

Long-term care ombudsmen are advocates for residents of nursing homes, board and care homes and assisted living facilities. Ombudsmen provide information about how to find a facility and what to do to get quality care.

LOTSA HELPING HANDS
lotsahelpinghands.com

A website that helps organize and coordinate caregiver help, including a calendar and reminders.

MEDICARE
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
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
caregiving.org

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

ADDITIONAL RESOURCES

NATIONAL ASIAN PACIFIC CENTER ON AGING
napca.org

Educates, empowers, and advocates on behalf of Asian American and Pacific Islander aging community. Offers toll-free helplines in English, Chinese, Korean and Vietnamese.

NATIONAL ASSOCIATION FOR HISPANIC HEALTH
hispanichealth.org **or 1-866-783-2645**

The Hispanic Family Health Helpline and its Su Familia provide free and confidential health information for Hispanic families.

NATIONAL ASSOCIATION OF HOME BUILDERS
nahb.org **or 1-800-368-5242**

A web-based directory of Certified Aging-in-Place Specialists who can identify and/or provide home modifications that make a home accessible, safer, and more comfortable.

NATIONAL ASSOCIATION FOR HOME CARE & HOSPICE
nahc.org

Consumer information on how to select a home care provider or hospice.

NATIONAL ASSOCIATION OF SOCIAL WORKERS
socialworkers.org

This organization maintains a directory of licensed social workers at helppro.com/nasw.

NATIONAL CAUCUS AND CENTER ON BLACK AGING
ncba-aged.org

Helps to protect and improve the quality of life for minority and low-income seniors.

NATIONAL CENTER FOR LESBIAN RIGHTS
nclrights.org
Legal Helpline: 1-800-528-6257

Focuses on LGBTQ equality through litigation, legislation, policy, and public education.

NATIONAL CLEARINGHOUSE FOR LONG-TERM CARE INFORMATION
longtermcare.gov

Information and tools to help plan for future long-term care needs.

NATIONAL HISPANIC COUNCIL ON AGING
nhcoa.org

The leading national organization working to improve the lives of Hispanic older adults, their families, and their caregivers.

NATIONAL HOSPICE AND PALLIATIVE CARE ORGANIZATION
nhpco.org **or 1-800-646-6460**

This organization provides free consumer information on hospice care and puts the public in direct contact with hospice programs.

NATIONAL INDIAN COUNCIL ON AGING
nicoa.org

Advocates for improved comprehensive health and social services and economic well-being for American Indian and Alaska Native Elders.

NATIONAL RESOURCE CENTER ON LGBTQ AGING
LGBTQagingcenter.org

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

NATIONAL RESPITE NETWORK
archrespite.org

A service that helps people locate respite services.

NIH SENIOR HEALTH
nia.nih.gov/health **or 1-800-222-2225**

Fact sheets from the U.S. National Institutes of Health can be viewed online or ordered for free.

ROSALYNN CARTER INSTITUTE FOR CAREGIVING
rosalynncarter.org

Created to support caregivers – both family and professional – through efforts of advocacy, education, research, and service.

ADDITIONAL RESOURCES

SAGE (SERVICES AND ADVOCACY FOR GAY, LESBIAN, BISEXUAL & TRANSGENDER ELDERS)

sageusa.org

> The oldest and largest LGBTQ aging organization in the U.S., providing direct services in New York City and across the country through a network of SAGE affiliates. For support and information, call the SAGE LGBTQ Elder Hotline at **1-888-234-SAGE** or **SAGE@LGBTQhotline.org**. Operated by the GLBT National Health Center, this hotline offers peer-support to callers who are often very isolated, sometimes still closeted, and in need of a caring, non-judgmental person to talk with. Hotline operators don't give advice – instead, they listen and they care!.

SAGECARE

sageusa.care

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

SOCIAL SECURITY ADMINISTRATION

ssa.gov or 1-800-772-1213

> Information on retirement and disability benefits, including how to sign up for Social Security.

STATE HEALTH INSURANCE ASSISTANCE PROGRAM (SHIP)

shiptacenter.org or 1-877-839-2675

> Your local SHIP offers one-on-one counseling assistance for people with Medicare and their families.

THE CONVERSATION PROJECT

theconversationproject.org

> Created to help people talk about their wishes for end-of-life care.

THIS CARING HOME

thiscaringhome.org

> A resource that provides ideas for home modifications.

TRANSGENDER LAW CENTER

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.

VETERANS ADMINISTRATION

caregiver.va.gov or 1-855-260-3274

> Provides supports and services for families caring for veterans. Connects caregivers with local caregiver support programs for veterans.

VILLAGE TO VILLAGE NETWORK

vtvnetwork.org

> An organization that helps communities start Villages, which are membership-based groups that respond to the needs of older people within a geographic area. Find Villages across the U.S. online.

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.

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 maintaining public benefits	_____ _____ _____ _____
Transportation Needs	____ Driving decisions ____ Coordinating rides ____ Locating transportation services	_____ _____ _____
Personal Care	____ Coordinating personal care activities ____ Help with daily grooming and dressing ____ Rides to hair stylist ____ 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	

PERSONAL INFORMATION CHECKLIST
(One for each individual who will need care)

NAME _____

X	Personal Information	Where is it kept? Contact Name (attach copy of documents)
	Social Security Card	
	Birth Certificate	
	Marriage Certificate	
	Death Certificate (for Deceased Spouse)	
	Divorce Papers	
	Military Records Branch of Service VA ID#: Discharge Papers:	
	Driver's License/Organ Donor Card	
	Passport/Citizenship Papers	
	Address Books (names and addresses of friends and colleagues)	
	Lists of church & community memberships and contact information	
	Information on waiting lists or contracts with retirement communities or nursing homes	
	Information on funeral arrangements	
	Pet Care: Vet, Sitter, Walker	
	Beautician/Barber	
	Lawyer	
	Passwords	
	Other	

HOME MAINTENANCE CHECKLIST

X	Home Item	Where is it kept? Contact Name (attach copy of documents)
	Mortgage Company Name: Amount due:	
	Rental Management Company: Amount due:	
	Rental/Real Estate Agent:	
	Gas/Electric/Water Company:	
	Cable/Internet/Telephone:	
	Home Security Company:	
	Neighbor's Contact Information	
	Homeowners Insurance Agent: Insurance Policy #: Homeowners Premium:	
	Garbage Service/Garbage Pickup Day is: **M T W Th F** (circle) Recycle Service Pickup Day is: **M T W Th F** (circle)	
	Home Services: • Handy person • Lawn care • Appliances	
	Passwords Computer(s) password clue(s) Phone messages password clue Cell phone	

HEALTH CHECKLIST

PHARMACY Name **PHONE #**

LOCATION

PHARMACY Name **PHONE #**

LOCATION

DOCTOR Name **PHONE #**

ADDRESS

DOCTOR Name **PHONE #**

ADDRESS

DOCTOR Name **PHONE #**

ADDRESS

DOCTOR Name **PHONE #**

ADDRESS

DENTIST Name **PHONE #**

ADDRESS

HOME CARE AGENCY **PHONE #**

ADDRESS

HEALTH CHECKLIST (continued)

X	Item	Where is it kept? Contact Name
	Medicare Original or Medicare Advantage (company name): ID Number:	
	Medicare Prescription Drug Coverage (company name): ID Number: *(does not apply to an Advantage plan with drug coverage)*	
	Other Health Insurance Policy (Medigap): Company: Premium: Payment schedule:	
	Veteran's Health System: ID #:	
	Do Not Resuscitate (DNR) Order:	
	Physician Orders for Life-Sustaining Treatment (POLST) form—if available in your state	
	Living Will/Advance Directives	
	Durable Power of Attorney for Health Care	

MEDICATION CHART

Prescription Name	Strength	Dosage	Warnings/Instructions

TRANSPORTATION CHECKLIST

NAME

X	Item	Notes	Where is it kept?
	Auto(s):	Make(s):	
	Auto Loan Information:	Model(s):	
	Title for Car(s):		
	Auto Insurance Company:		
	Recreational Vehicles: Title: Insurance:		
	Transportation Services (such as ACCESS van or local cab service):		

FINANCIAL CHECKLIST

X	Item	Where is it kept? Contact Name
	Bank Records (checking/savings accounts), Pin number clues — online banking and accounts with passwords and clues	
	Trusts	
	Will	
	Durable Power of Attorney for Finances	
	Any rental agreements or business contracts	
	Complete list of assets & debts	
	List of routine household bills	
	Federal & State Tax Returns (past 3-5 years): Tax Preparer:	
	Records of any personal loans made to others:	
	Financial Planner or Broker:	
	Life Insurance Policy or Policies:	
	Disability Insurance (long- and short-term):	
	Long-Term Care Insurance:	
	Safe Deposit Box(es):	Location(s): Number(s): Keys:

PUBLIC BENEFITS CHECKLIST

Your loved one may have or be eligible for help with paying for food, heating bills, property taxes and more. Use **AARP BenefitsQuickLINK**, **aarp.org/quicklink**, to find out about programs in your state.

X	Item		
	Food Assistance, (i.e., SNAP/FNS)	☐ YES	☐ NO
	Low Income Home Energy Assistance (LIHEAP)	☐ YES	☐ NO
	Supplemental Security Income (SSI)	☐ YES	☐ NO
	Property Tax Assistance	☐ YES	☐ NO
	Extra Help Paying for Medicare Part D (prescription drug coverage)	☐ YES	☐ NO
	Medicare Parts A, B and D Premium Support	☐ YES	☐ NO
	Medicaid (help with long-term care and medical care) Number & Identification Card	☐ YES	☐ NO
	Transportation Assistance	☐ YES	☐ NO

SAMPLE CAREGIVING PLAN

A caregiving plan can be simple or as detailed as you and your team desire. Use this simple plan to determine the goals, steps, person responsible and timing together. Try to include a self-care goal for yourself and your team.

Name:	Date Started:
Team Members:	
Contact Info:	

Need	Steps	Person Responsible	Timeframe
1. Better understand and manage Mom's medical care.	**Meet with Mom and doctor** a. Create chart of medications to be taken when (make multiple copies for team); translate medication regimen for mom in mom's primary language, perhaps create a pictorial aid as well b. Buy pill organizer c. Get calendar to mark all appointments d. Mom signs form giving doctor permission to discuss medical care with me and my sister e. Take notes at each appointment in journal—get written instructions from doctor f. Confirm follow-up/appointments		
2. Move Mom to a new home.	a. Determine amenities/services needed (including language needs and meal needs) b. Determine budget c. Research locations d. Research facility types e. Sort through stuff to be sold or given away		
3. For the caregiver: Relax with friends once a week.	a. Call Mary on Monday for a movie on Friday		

SAMPLE DETAILED WEEKLY CAREGIVING PLAN

For daily tasks or those done on a regular routine, try something like this weekly schedule shown below (it can be made into a daily or monthly schedule):

Caregiving Week of:

Day	Tasks	When	Person(s) Responsible	Plan
Monday	1. Check whether medications have been taken 2. Go to doctor's appt	End of day 1:00 p.m.	Daughter Mary Daughter Ann	Call and review pill box Drive to app't, get prescriptions, set in pill box
Tuesday	1. Go grocery shopping 2. Check on medications	After work	Son Al	Call Mom for grocery list at lunch, shop after work and drop over. Check pill box when dropping off groceries. Look in fridge for spoiled food.
Wednesday	1. Check on medications	End of day	Daughter Mary	Call and review pill box
Thursday	1. Check on home-delivered meals on the holiday 2. Check on medications	Today End of day	Daughter Mary Daughter Mary	Call agency to see if meals will be delivered next Monday Call and review pill box
Friday	1. Check on medical bill payment 2. Ask Daughter-in-law Peggy to bring lunch on Monday	Today	Daughter Mary	Make call to insurance provider about payment Call Peggy to fill in for Monday lunch
Saturday	1. Take over supper 2. Drive to beauty parlor 3. Check on medications	Afternoon	Daughter Ann	
Sunday	1. Manage medications 2. Take to faith services 3. Arrange for visitor or outing	Evening 9:00 a.m. 1:00 p.m.	Mary Al Niece Beth	Review medications and place in pill box for the week Drive Mom to service

NOTES

NOTES

LGBTQ Community Caregiving Guide

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

General:
aarp.org/caregiving | 877-333-5885

LGBTQ:
aarp.org/pride | 866-Pride-50

Spanish:
aarp.org/cuidar | 888-971-2013

AARP®

sage | Advocacy & Services for LGBT Elders

601 E Street, NW | Washington, DC 20049
AARP Caregiving Support: **877-333-5885**
aarp.org/caregiving

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