

A RESOURCE GUIDE FOR AMERICA'S CAREGIVERS

Caregiving in the age of longevity: A diversity and inclusion perspective

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INTRODUCTION

Caregiving — the new normal

The U.S. population is growing older and living for longer than ever before — transforming our society, health care and retirement systems, and expectations for our later years. There are 73 million baby boomers in the U.S., and 10,000 people in this cohort turn 65 every day.¹ By 2034, it is projected that there will be more Americans over the age of 65 than under the age of 18.²

As a result, caregiving has become the “new normal” for people, families and communities across the country. Today, more than 40 million family caregivers provide care to over 50 million older adults, and these numbers will continue to grow.³ Therefore, every American should be considering the potential for caregiving in their future, whether it’s arranging for their own care or providing care for older relatives — ideally, *before* the need arises.

Caregiving is an underestimated need

7 in 10 Americans turning 65 today will need care for prolonged periods in their lives.

4 in 10 Americans age 50+ believe they’re likely to ever need care.

These caregiving needs will likely be greater than those faced by previous generations. Many older adults will now need care and financial resources for 20, 30 or even 40 years after traditional retirement age. Indeed, seven in 10 Americans turning 65 today will need care for an extended period of time at some point in their older years⁴ — yet most are not accounting for this possibility, as only four out of 10 over the age of 50 believe they will ever need care.⁵ Instead, most are expecting their families to shoulder

the burden if a care need does arise: More than 68% of Americans believe they will be able to count on their family members to care for them.⁶

However, few families are currently planning for or fully prepared to meet the demands of care, especially its financial aspect. Many prospective caregivers already have childcare responsibilities, effectively “sandwiching” them between the needs of their parents and their children. Additionally, at a time when the responsibility for later life financial security has shifted to the individual, only one-third of adults over the age of 40 has set aside any money to fund their long-term care needs,⁷ and only 11% of Americans over the age of 65 has long-term care insurance.⁸ As a result, the staggering cost of long-term care will be beyond the reach of many families, especially for caregivers who must also raise children, save for retirement, and pay daily expenses.

There is a pressing need to educate, equip and empower older adults, current caregivers and future caregivers to better plan for and manage their caregiving journeys.

Our Resource Guide is intended to help address this need. It outlines the most common types of caregivers and the unique challenges for each group, including women, spouses, adult children, long-distance caregivers, dementia caregivers, those in the LGBTQ+ community and financial caregivers. The Resource Guide then provides practical steps that can help all caregivers to plan for and manage care, as well as a list of key external resources.

66%
of all family caregivers
in the U.S. are women,
and women are twice
as likely as men to be
providing care from
the age of 40 through
their 60s.^{10,11}

Who are the caregivers?

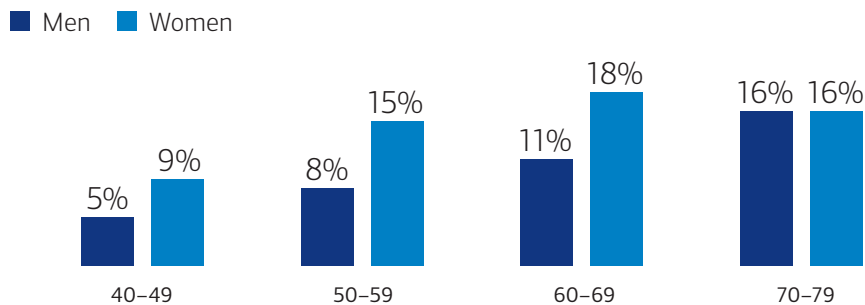
Caregivers are as diverse as the American population itself—coming from all walks of life, all ethnicities, genders and sexual orientations. They all face common caregiving challenges and impacts, such as the demands on their time, physical and mental health, and finances. They also all experience the joys of caregiving, as research shows that caregiving can provide a sense of purpose and improve the caregiver’s feelings of well-being.⁹

Each distinct group of caregivers—such as spouses, adult children, long-distance caregivers and others—also faces unique challenges that will shape their journey. Below, we examine the most common caregiver groups and specific considerations and research for each.

Women as caregivers

Caregiving disproportionately affects women, including wives, daughters and daughters-in-law. Sixty-six percent of all family caregivers in the U.S. are women, and women are twice as likely as men to be providing care from the age of 40 through their 60s.^{10,11} Women are often the sole provider of many different types of care, including hands-on physical care, care coordination and financial care. However, there is some evidence that the proportion of male-to-female caregivers is becoming more even among younger generations.¹²

Caregiving prevalence by gender and age



Source: Annual Prevalence, National Academies Press, 2016. *Families Caring for an Aging America: Proportion Caring for Older Adults 65+*.

Wives tend to be the sole caregivers for their husbands regardless of the level of care the spouse requires, and many do not have a supporting care team. The heavy burden of spousal care more often falls on wives because women tend to outlive men by four to five years¹³ and to be younger than their spouses by about two to three years.¹⁴ In cases where there is no spouse, adult children usually provide care. Thirty-one percent of eldercare hours provided by family are provided by daughters versus only 16% of hours provided by sons.¹⁵

Women caregivers face significant physical, mental and emotional, professional and financial effects. More women than men report that it is difficult to balance caregiving with other responsibilities (66% vs. 59%), and they are almost twice as likely to report feeling overwhelmed.¹⁶ There are also disproportionate time demands: Women who work outside of the home spend, on average, 60% more time caring for an older loved one than do their male counterparts.¹⁷

The health consequences of caregiving are particularly concerning. Consider these statistics:

- Women caregivers are twice as likely to forego needed health care compared to women who are not caregivers.¹⁸
- Women caregivers are more likely to have had one or more chronic health conditions than women who are not caregivers.¹⁹
- Wives who spend nine or more hours per week providing care are twice as likely to develop coronary heart disease.²⁰
- Women caregivers have higher rates of depression, anxiety and other mental health conditions compared to women who are not caregivers.²¹



Caregiving also has a disproportionate impact on women’s financial health. When a woman leaves the workforce to provide care, she loses an average of \$324,000 in total wages and benefits, compared to \$284,000 for a male caregiver²² — and this total does not account for retirement plans, HSAs and other benefits. Women are also likely to become caregivers regardless of salary level, while male caregivers tend to be lower wage earners.²³ And women are also three times more likely to retire earlier than expected to become full-time caregivers.²⁴ Over the long term, caregiving may also have a detrimental effect on the accumulation of Social Security benefits or pensions, leading to decreased income in retirement. Mary Ellen Eady, Work Life Specialist at Emory University states,

“Employers can play an important role in helping caregivers, especially women, to manage the financial strain that can be a result of family caregiving responsibilities. By offering benefits such as flexible work hours, telecommuting opportunities, caregiver benefits and support groups, employers can make great strides toward a more flexible and inclusive environment for their working caregivers.”

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Mary Ellen Eady, MPA,
Work Life Specialist,
Emory University
Human Resources

Spousal caregivers

Caring for a spouse can present unique physical, financial and emotional challenges, especially if the caregiving need arises suddenly, such as a life-changing illness. In addition to providing daily care, the spousal caregiver is likely to be called upon to make decisions that affect the care recipient's independence and quality of life. In many cases, the caregiver must also become the sole family breadwinner, simultaneously managing the loss of their loved one's income and paying for new medical expenses.

At the same time, spousal caregivers must contend with the changing dynamic of the spousal relationship. This may cause friction between the couple, with feelings of loneliness, anger, resentment, guilt and isolation. Many spousal caregivers may experience the traditional stages of grief, even though their spouse is still alive.

Adult children caregivers

After the spouse, adult children are most often called upon to provide care to an aging parent. As described above, these adult children may already be providing care or financial support to their own children, straining their time and financial resources.

Additionally, when multiple adult children are providing care, they often face several specific challenges. Siblings may be hesitant to start the caregiving conversation with each other and their parents. They may also have different ideas about what caregiving plans and choices are best for their parents and about who will provide which types of care.

While it is important for siblings to work as a team, sometimes complex sibling relationships may affect caregiving. Without realizing it, siblings may fall into the roles that they had when they were growing up. Additionally, each adult child's ability to provide care may change over time. Siblings may feel that they are unfairly shouldering the majority of care or, alternatively, that they have been excluded from caregiving decisions and responsibilities.

Long-distance caregivers

Fifteen percent of all caregivers are "long-distance caregivers"—defined as living at least an hour from the care recipient.²⁵ These caregivers commonly conduct two main care activities: gathering information (using websites and other resources) and coordinating services.²⁶ Unlike their counterparts who live in close proximity to the care recipient, long-distance caregivers have the additional stress of coordinating care from afar, while still juggling their work and the needs of their immediate family.



Caregivers for those with Alzheimer's disease and other dementias

More than 16 million Americans provide care to a person with Alzheimer's disease or other dementias.²⁷ Caring for a person with Alzheimer's disease is not only physically taxing but also emotionally draining. These caregivers provide more hours of care per week and, in many cases, support their care recipient for a longer period of time. They are also more likely to perform medical tasks in addition to running errands, managing finances and, most importantly, keeping their loved one safe and secure. Because of the progressive nature of the disease, Alzheimer's patients are likely to move through many different levels of care over several years. The caregiver is often challenged with many difficult decisions. Alister Bazaz is senior vice president, Credit and Lending at Bank of America. A business executive, father and caregiver to his wife, Alister reflects on his caregiving journey.

“As a spousal caregiver with a wife diagnosed with early onset Alzheimer's disease, I made the decision to give my wife as normal a life as possible until such time as it became impossible to. Having a supportive employer in Bank of America, I was able to use flexible work arrangements and spend more time with her while she still had cognitive ability. Knowing that time was not on our side, we tried to do as much as possible outside of the home. It was very hard to let others take care of her the way our daughter and I had at home. In essence, at that point, I became aware that I had been “fired” as a caregiver . . . by life. It was a tough transition to accept at first but one quickly sees that professional care was the right approach. If we had not had thoughtful financial planning, that might not have even been possible.”

The average person with dementia requires 171 hours of care per month—over 100 hours more than someone without dementia.²⁸ Dementia caregivers are likely to be employed, and they are working, on average, 35 hours per week.²⁹ Two-thirds of these employed dementia caregivers struggle to balance work and caregiving and report that their caregiving responsibilities affected their work in some way.³⁰ Thirty-five percent of dementia caregivers say that their health has declined as a result of their caregiving responsibilities versus just one in five non-dementia caregivers.³¹

“As a spousal caregiver to my wife, who was diagnosed with Early Onset Alzheimer's Disease, I found that the transitions to different levels of care during our journey were tough. If not for thoughtful financial planning, these transitions may not have been possible.”



Alister Bazaz
Senior Vice President
Credit and Lending
at Bank of America

Caregivers in the LGBTQ+ community

There are approximately 2.7 million LGBTQ+ older adults in the United States,³² who face unique needs and challenges for care. Older LGBTQ+ adults are twice as likely to be single and living alone, and three to four times less likely to have children.³³ Instead, many in the LGBTQ+ community have developed a social network of partners, friends and neighbors who they consider to be their “family of choice.” Often, these families of choice will provide social, emotional, physical and financial support. However, these caregivers may not be afforded legal recognition or protection, and service providers may not think to include them as caregivers because they are not part of a traditional family.

To help address this issue, most states have adopted some version of the CARE (Caregiver, Advice, Record and Enable) Act, which requires that hospitals ask patients at admission whether they would like to designate a caregiver. Most versions of the CARE Act require a hospital to record the name of the caregiver in medical records, inform the caregiver when the patient is being discharged, and train the designated caregiver to perform any medical tasks that may be needed once the care recipient returns home.

Beyond the hospital, many LGBTQ+ caregivers have difficulty finding supportive health care and service providers for their loved ones. Many fear inadequate treatment or discrimination and, as a result, may postpone seeking out services providers, assistance or support.



Financial caregivers

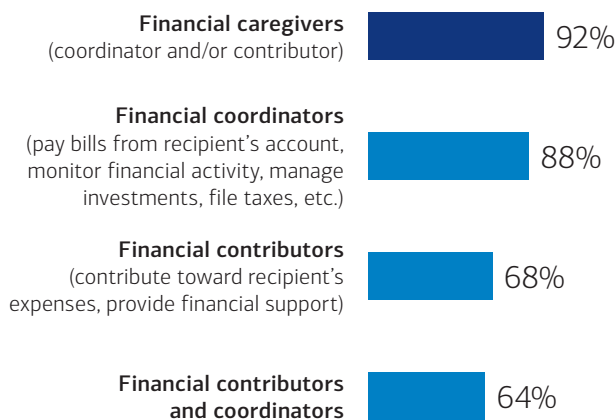
One of the most common types of care is the management of an older loved one’s financial affairs, as 92% of caregivers say that they are performing at least one aspect of financial caregiving.³⁴ Financial caregivers can be categorized as financial contributors and/or financial coordinators.

Financial contributors

Financial contributors are caregivers who use their own money to help pay for the cost of care. Sixty-eight percent of caregivers say they are providing financial support to their loved one,³⁵ and caregivers spend an average of \$7,000 per year on caregiving. This money goes toward meeting the personal, medical and household needs of the care recipient.³⁶

The financial burden varies for different caregivers. Caregivers for people with Alzheimer’s or other dementias spend, on average, 54% more than the average caregiver.³⁷ Spousal caregivers spend 68% more than average, and long-distance caregivers spend 71% more than the national average.³⁸

Percentage of caregivers who are ...

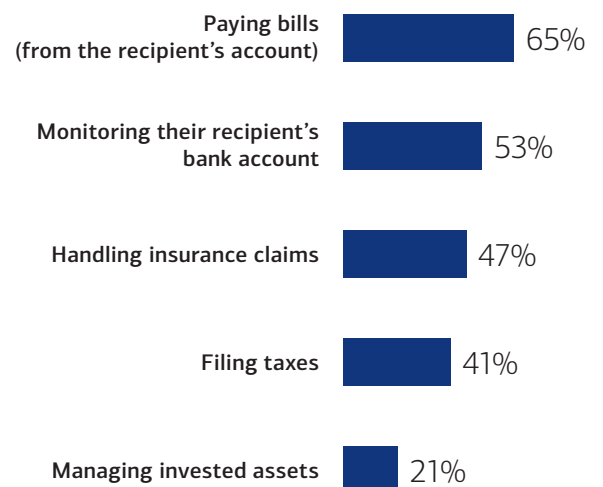


Base: Caregivers (select all that apply).

Financial coordinators

Financial coordinators are those caregivers who manage financial tasks for the care recipient. These tasks can include paying bills, balancing checkbooks, handling insurance claims, filing taxes and managing investments. In some cases, financial coordinators may end up taking over the entire management of their loved one’s financial affairs.

Financial coordinator tasks



Base: Caregivers (select all that apply).

Unfortunately, caregivers who do not adequately prepare for this role can face challenges. One in four financial coordinators report that they struggle to be granted permission from banks to access financial accounts, and nearly one-half of financial caregivers do not have the legal authority to perform their role.³⁹

Financial coordinators will typically find that their level of involvement escalates over time. The Age Wave/Merrill Study, *The Journey of Caregiving: Honor, Responsibility and Financial Complexity*, found that, after two years of care, 53% of care recipients need full assistance with their finances and only 12% are independently managing their own finances.⁴⁰



Practical steps for caregivers

Caregivers, older Americans and families can take several key practical steps to help prepare for and manage the needs of caregiving. The information below can empower current and future caregivers to navigate their journeys.

Proactively discuss care and prepare key contacts and documents

All older Americans should proactively discuss their potential caregiving needs and preferences — ideally before the need arises. This can help to prepare potential caregivers for their role, equip them to make difficult decisions, and reduce their stress.

Before there is an immediate need, older adults should provide information on where to locate important records and documents, contact information for doctors, attorneys, accountants and financial advisors, and any other helpful information for coordinating and monitoring care. Putting these basic pieces in place will help to alleviate confusion and ensure everyone is on the same page when a care need arises.

Useful resources include:

- The Merrill “Family Album” is a comprehensive document that can help to gather relevant information for caregiving. This editable PDF may be obtained through any Merrill Financial Advisor.
- The Family Caregiver Alliance website provides a one-pager titled, “Where to Find My Important Papers,” which may be helpful in collecting information. This can simplify communications with government agencies, attorneys and physicians, as well as provide help with banking and other financial transactions. A downloadable PDF is available at caregiver.org/where-find-my-important-papers.

Arrange legal documents

Every adult should have the legal documents listed below in place before a caregiving need arises. This is especially important for those in the LGBTQ+ community, who may face unique obstacles due to laws and regulations that are not designed for same-sex couples:

- **Will**—A will provides for the distribution of a person’s assets, as well as instructions regarding any surviving minor children. In the case of an LGBTQ+ couple, if the same-sex partner is not named as a beneficiary in a will (or as a joint tenant on property), they may find that all of the property of the deceased is unintentionally left to children, parents, siblings or other biological family members. A will is also the only form of testamentary document in which a guardian of a minor child may be appointed. Therefore, if an LGBTQ+ person has a minor child who has not been adopted by the same-sex partner, it is critical that a will is executed. This is also the place to leave instructions regarding the minor child’s education and where the minor child will reside.⁴¹
- **Revocable trust**—A trust, like a will, provides for the orderly distribution of assets. A trust can also have language addressing the trustee’s wishes regarding incapacity. This may be executed prior to death.⁴²
- **Durable power of attorney**—Under a durable power of attorney, the designated agent will assume the legal authority to manage property and financial affairs. This is a particularly important document for LGBTQ+ care providers and care recipients. Without this document, the LGBTQ+ partner may find that they are legally unable to take care of legal and financial transactions on behalf of their loved one who has become incapacitated.⁴³

Advance directive for health care—While not a pleasant topic of discussion, your loved one’s wishes for his/her own care must be communicated and documented. Kai Walker, Head of Inclusion Transformation at Bank of America underscores the importance of these documents. “Caregiving continues to be a labor of love for many—unexpected events occur and we’re living longer than ever before. Continuing to provide guidance and resources to support family members or loved ones as they navigate the caregiving process is vital and beneficial to providing clarity for everyone involved.”

There are two types of advance directives:

- **Living will**—Details the type of medical treatment a person wants at the end of their life, in the event that they cannot speak for themselves. It details a person’s wishes regarding specific decisions, such as whether to administer mechanical ventilation or feeding tubes.⁴⁴
- **Durable power of attorney for health care**—Appoints a person to make medical decisions on behalf of another person. The appointed person advocates on behalf of the patient and acts as the patient’s spokesperson in the event the person cannot speak for themselves.⁴⁵

“Continuing to provide guidance and resources to support family members or loved ones as they navigate the caregiving process is vital and beneficial to providing clarity for everyone involved.”



Kai Walker
Head of Retirement
Research and Insights and
Inclusion Transformation
Bank of America



Hold an initial family meeting

When a care need arises, those who will be providing care should meet to develop a care plan (see below), which outlines a care recipient's needs and lays out who will take responsibility for each of those needs. Ideally, this family meeting will take place before there is a crisis situation. As with all care plans, caregivers should involve the care recipient in the decision-making process, if at all possible, and respect their wishes for their own care.

The meeting should include the potential care recipient (and spouse if applicable), and all family members who are stakeholders in their care. In the case of adult children, each child may have a different idea about what is best for their parents, and their parents may have different preferences that the children are not even aware of. It is critical to discuss all of these ideas and feelings, in order to develop a care plan that both serves the interests of the care recipient and is feasible for all caregivers.

Develop a care plan

To develop a care plan, caregivers should seek a complete and accurate medical diagnosis and/or update from the care recipient's physician, including an assessment of both physical and cognitive health. The caregivers can then determine what the care recipient is capable of doing independently, what they can do with minimal help, and what they cannot do at all.



They can then create a checklist of care needs and a resulting care plan. This should include activities and responsibilities like:⁴⁶

- household chores
- grocery shopping, cooking and cleaning
- personal hygiene
- transportation
- medical appointments
- assistance and advocacy
- financial coordination assistance
- legal issues that may still be pending (e.g. durable powers of attorney, health care directive, health care proxy, wills, trusts)
- medication management
- safety inspection
- necessary home renovations, including installation of ramps and grab bars
- trips to an adult day care center or senior center
- a list of family and friends who can check in
- emotional support

Once this information is obtained, caregivers can create a Care Notebook to keep track of needs and responsibilities.

Consult with a care manager

Geriatric care managers can help to inform the care plan. These professionals focus on needs assessment and care coordination. They can be particularly helpful to long-distance caregivers, as they can provide updates on the care recipient's situation and, as needs change, provide options to address their ongoing care. The National Association of Professional Geriatric Care Managers is a good source to find a credentialed geriatric care manager ([caremanager.org](https://www.caremanager.org)). The local Area Agency on Aging (AAA) may also be able to assist in finding high-quality care managers.

Continue family meetings and update the care plan

After the initial meeting and care plan, family and caregiver discussions should occur on a continual basis. Life is dynamic, and a caregiver's ability to provide care may change. Ideally, caregivers should feel like they are an integral part of the care recipient's care and well-being. Whenever possible, they should feel safe to communicate the ways in which they can contribute and whether changes are needed.

Family meetings, on a regular basis, can be helpful to determine what is needed, what each person can contribute (including both time and money), and what course corrections are necessary to keep things running smoothly.

Organize finances

Caregivers should develop a written financial plan and ensure they have the proper documents to coordinate a care recipient's finances, if necessary.

Without such legal authority, the caregiver may be unable to access necessary funds to manage the support and care of their older loved one. This point alone is enough to justify planning for all aspects of care before there is a crisis. Financial caregivers should work hand in hand with a financial advisor to get the necessary education and assistance with financial management, banking, documentation and support. This will help the caregiver better manage the financial life of the care recipient and their own financial future.



As caregivers plan for the future, they should consider the possibility that they will need to help pay for care. This can help them to avoid the danger of derailing their own plans for later life as they move through their caregiving journey.

Prioritize self-care

Self-care is critical, especially for female caregivers. Caregivers should always remember to care for themselves first. This is the only way to bring their best self to the caregiving role. In particular, caregivers should be realistic about what they can and cannot do. Then, enlist family, friends and professionals to help carry the load.

Build a support network

All caregivers should build a strong support network. This can include family members, friends, neighbors, caregiving professionals and others. This wider circle can then help with care tasks where needed or simply provide emotional support.

In addition, designated caregiver support groups can provide a variety of benefits, including education, emotional support and an empathic group of people who are facing similar experiences and challenges. These support groups can also uncover useful information and resources.

In addition to general support groups, there are also groups for specific kinds of caregivers:

- **Spouses**—Support groups for spousal caregivers, made up of people who are going through similar circumstances, can be an invaluable resource. These groups can provide empathy and advice as the caregiver struggles with conflicting feelings and emotions associated with this most demanding and stressful experience. The Well Spouse Association (wellspouse.org) offers a website, phone groups, mentoring, weekend respite events, online forums and a chat line as support for spousal caregivers.
- **Dementia caregivers**—The Alzheimer’s Association offers several thousand support group meetings nationally each month, which can be found at communityresourcefinder.org. These groups are facilitated by individuals who have received training from the Alzheimer’s Association. These support groups typically meet in person, but there are also virtual support groups available. The Alzheimer’s Association also offers alzconnected.org, a free, online forum to ask questions and seek advice.

Specific steps for dementia caregivers

Dementia caregivers can follow the general steps for all caregivers, but they may also face unique challenges. Guideposts.org offers the following tips for caring for a loved one with dementia:

- **Go where they are**—Validate their feelings. Confusion happens when their brain function declines. Go where they are mentally. Maybe we go where they were 50 years ago. Sometimes we go where they are and stay all day.

- **Do little things that make them feel good**— Pamper them (fix their hair, put on makeup, etc.) Take them outside on trips around the area.
- **Be consistent and reassuring**— Sometimes their dreams are very real to them. Talk things out and help them sort through what has and has not occurred.
- **Say yes to help and support**— Don’t try to take care of someone with Alzheimer’s Disease or dementia by yourself 100% of the time. Get help and get away for breaks.
- **Tap into the joy of music**— Music is one of the memories that holds on the longest with someone with dementia.
- **Keep them socially active as much as possible**— Take them to activities where they can be around other people and be engaged.
- **Don’t take difficult behavior personally**— Use patience, compassion, redirection, laughter and humor.⁴⁷

Specific steps for LGBTQ+ caregivers

LGBTQ+ caregivers may face unique challenges, including finding supportive service providers and navigating the legal system. The best source for finding local service providers who are sensitive to the needs of LGBTQ+ elders and their caregivers is the LGBTQ+ community itself. Asking for referrals to LGBTQ+-affirming health care and service providers is one of the most reliable paths to finding the resources that LGBTQ+ adults may need. Local LGBTQ+ community and senior centers may also be able to provide referrals and support, as well as LGBTQ+ senior advocacy groups. The Gay and Lesbian Medical Association (glma.org) also offers referrals to LGBTQ+-sensitive medical professionals.

LGBTQ+ caregivers should also be aware of the relevant laws and regulations in their city and state to ensure that both the caregiver and their loved one are protected. All of the above listed documents are important for every adult to execute. However, it is particularly imperative for members of the LGBTQ+ community who are not legally married to make certain that these documents are prepared and filed according to the laws and regulations applicable in each state of residence.

CONCLUSION

Empowering caregivers to adapt and thrive

Our society is just beginning to define the new era of aging and longevity. Today's longer lives are a modern miracle — opening opportunities for older adults to launch new careers, explore new passions and pursuits, and find new meaning in their later years.

However, to fully realize this potential, people must plan for their own care and prepare to step into the role of caregiving — today's new normal. With the right planning, information and support, caregivers can focus on the joys of providing care to an older love one while managing and minimizing the negative impacts and costs.

We hope this resource guide and the full list of external caregiving resources below help American families and caregivers to prepare, adapt and thrive.

Key resources for caregivers

Area Agencies on Aging — The Area Agencies on Aging (AAA) are a network of more than 600 nonprofit organizations nationwide that address the needs and concerns of older Americans at the local level. These organizations are designed to provide services to a specific geographic area and address the unique needs of the older populations whom they serve. These services include nutrition counseling, home-delivered meals (Meals on Wheels), homemaker assistance, group meals and caregiver support, such as respite care and caregiver training. Agencies may also offer other services deemed necessary to encourage independent living as a viable option for seniors.

The first step to engaging with your Area Agency on Aging is to access their [Eldercare Locator \(eldercare.acl.gov/Public/About/Aging-Network/AAA.aspx\)](https://eldercare.acl.gov/Public/About/Aging-Network/AAA.aspx). Typing in the applicable zip code will connect you with several resources, including:

- **Caregiver help desk** — free access to caregiving experts who can help find information on common caregiving challenges. The Help Desk can be reached by dialing their toll-free number: 855.227.3640.
- **Caregiver support group** — a community of caregivers who gather to share information and talk with their peers.
- **Technology for caregivers** — information about new apps and devices for caregivers, including a section (ICAN) specifically designed to help caregivers sort through technology products, as well as apps for elder safety, elder care, medication management and various other tools.

- **Video resource centers** — accessible videos for specific groups of caregivers, including those caring for people with Alzheimer’s, cancer and rare diseases.
- **Toolbox for caregivers** — a video series on various topics, including Managing the Cost of Care, Understanding Medicare, How to Talk to Doctors, and specific videos geared toward those caring for loved ones with Parkinson’s disease and Alzheimer’s disease.
- **Checklists** — a Medication Checklist, Patient File Checklist and Doctor’s Office Visit Checklist.
- Links to tips on financial caregiving, housing, hiring help, transportation issues and how to talk to parents about relinquishing their keys and alternative transportation options
- Links for caregiver support including long-distance caregiving, dealing with dementia and cognitive impairment, family and sibling conflict and discourse, help with emotions and feelings throughout the caregiver journey, balancing work and caregiving responsibilities, and what happens when the caregiving journey ends

AARP (aarp.org) — AARP provides advocacy, information, products, services and discounts geared toward older adults over the age of 50. AARP continues to be one of the foremost authorities and trusted resources in the United States when it comes to issues of aging and quality of life. Highlighted here are only a few of the many resources that AARP offers:

- Prepare to care resource guide — tips for having important conversations on caregiving, ways to assess a loved one’s needs, and organizing important documents. The guide also includes a listing of federal and national resources, tips for caregiver wellbeing, checklists, medication charts and contact lists. This resource guide is available in English, Spanish and Chinese.
- A pamphlet that outlines five steps every caregiver should take
- Guides to managing caregiver stress

- An online chat community to get advice and tips from other caregivers
- Caregiver support line: 877.333.5885
- Advice for working caregivers

Family Caregiver Alliance (caregiver.org) — The Family Caregiver Alliance is a nonprofit organization dedicated to supporting the caregiving efforts of families and friends across the country. Highlighted here are just a few of the many resources that the Family Caregiver Alliance offers. All of these can be found on their website:

- A free guide to long-distance caregiving titled *Handbook for Long-Distance Caregivers: An Essential Guide for Families and Friends Caring for Ill or Elderly Loved Ones*
- **Family care navigator** — a state-by-state searchable database to help locate publicly funded programs: caregiver.org/family-care-navigator
- A fact sheet on community care options, which provides details on the types of resources that may be found in a particular area
- “Holding a Family Meeting” fact sheet — tips for engaging each person involved in the loved one’s care to establish an understanding of goals and tasks to support the care recipient’s and caregiver’s needs
- “Where to Find My Important Papers” — one-page document that may help with information collection to simplify communication with government agencies, banking and other financial institutions and legal, medical and financial professionals: caregiver.org/where-find-my-important-papers

ARCH National Respite Network (archrespite.org) — The ARCH National Respite Network connects caregivers directly to local respite and crisis care services. The network assists in and promotes the development of quality respite and crisis care programs and acts as advocates for respite care.

Caregiver Support Services

(caregiversupportservices.com) — Offers services for family caregivers, professional caregivers and caregiver organizations. Offerings include:

- Caregiver support services blog — provides content that promotes self-advocacy and empowers caregivers to achieve optimum wellness
- Pharmacy and wellness consultant
- Monthly caregiver wellness webinars
- Access to events for caregivers, such as a webinar series, virtual conferences and caregiver support programs
- Caregiver assessment tool — helps the caregiver evaluate their own wellness and take better care of themselves
- Caregiver support services bookstore
- Caregiver training courses for home caregivers, nursing assistants, family caregivers, non-medical home caregivers and companions
- Access to “Medicare Interactive” — a state-of-the-art, user-friendly, online resource for information on:
 - Medicare law
 - Medicare home care
 - Prescription drug assistance
 - Therapy services
 - Low-income benefits
 - Up-to-the-minute Medicare counseling system including state-specific Medicare information:
 - Case examples and FAQ’s
 - Links to related websites

E-care diary (ecarediary.com) — Provides online tools to help make the caregiving role more manageable, including:

- help to schedule appointments, medications and reminders
- a place to enter health information
- document storage
- caregiver journal

- Resource Center with a cost calculator and section on financing care, state-specific advanced directives, estate planning documents and medical conditions, with links to resources on Alzheimer’s disease, arthritis, cancer, depression, heart disease and stroke, HIV/AIDS, incontinence, neurological disorders, osteoporosis and pain management

I’m A Caregiver/medicare.gov

(medicare.gov/blog/help-for-caregivers-2019) —

This landing page for caregivers on the Medicare website has caregiver content and links to find out whether certain medical procedures are covered by Medicare, finding someone to talk to and answer questions about coverage, urgent care, and many other issues that caregivers may face.

National Adult Day Services Association (nadsa.org) —

This site can compare long-term care services and help with choosing a long-term care center through a visit checklist.

National Association of Professional Geriatric Care

Managers (aginglifecare.org) — Members of the National

Association of Professional Geriatric Care Managers are listed on this site and can be linked to the caregiver. The site explains care management and how to find the best geriatric care manager for the care recipient’s specific situation. The site offers easy links for families to search for geriatric care management by zip code.

National Institute on Aging’s National Alzheimer’s Education and Referral Center

(nia.nih.gov/health/alzheimers) — Has a section for caregivers that includes tip sheets and resources on behaviors, communication, relationships, safety, caregiver health, legal and financial issues, and managing the stages of Alzheimer’s disease. There is a FAQ section as well as a list of publications on caregiving and papers on the latest Alzheimer’s research.

National Clearinghouse for Long-term Care

Information (longtermcare.acl.gov) — This site is run by the Administration on Aging and is geared toward caregivers or seniors who are considering long-term care. The site answers questions about the nature of long-term care, who may need long-term care, the cost of long-term care (with a state-by-state breakdown), how to pay for long-term care, details on Medicare and Medicaid coverage, and legal help for LGBTQ+ elders. The site also explains why everyone should be planning for long-term care and provides a step-by-step planning process.

Rosalynn Carter Institute for Caregiving

(rosalynncarter.org) — Founded over 30 years ago by former first lady Rosalynn Carter, The Rosalynn Carter Institute For Caregiving is an advocacy, education, research and service unit of Georgia Southwestern State University. It has its own training center, caregiving management certificate program, and scholarship and fellowship opportunities, as well as numerous caregiver resources.

Well Spouse Association (wellspouse.org) — The Well Spouse Association provides peer support and education about the special challenges and unique issues facing spouses who provide care. They sponsor caregiver symposiums and respite weekends, and also provide links to support groups around the country.

National Council on Aging Benefits Checkup

(benefitscheckup.org)

Merrill/Resources — Merrill has conducted several studies in partnership with Age Wave that are relevant to a caregiver's journey. In addition, the Merrill thought leadership team has developed many resources to support these topics. These studies and resources are available on the Bank of America Merrill public website at ml.com or from your Merrill Financial Advisor. A sampling of topics:

- The Journey of Caregiving: Honor, Responsibility and Financial Complexity (study)
- Health in Retirement: Planning for the Great Unknown (study)
- Addressing Memory and Your Family (white paper)
- Our Family Album: Take Steps Today to Care for Your Family Tomorrow (editable PDF)
- How to Talk About Caregiving: A Behavioral Guide to Having A Conversation (white paper)
- A New Opportunity for Employers: Strategies to Support Working Caregivers (white paper)
- Older Adults and Driving Safety (article)
- Finances in Retirement: New Challenges, New Solutions (study)

There are also several books that caregivers can read for more information:

1. Linda Abbit: *The Conscious Caregiver: A Mindful Approach to Caring For Your Loved One Without Losing Yourself*
2. Martin J. Schreiber: *My Two Elaines: Learning, Coping, and Surviving as an Alzheimer's Caregiver*
3. Jahanna Beecham and Katie Ortlip: *Living with Dying: A Complete Guide for Caregivers*
4. Melanie P. Merriman: *Holding the Net: Caring for My Mother on the Tightrope of Aging*
5. Tina M. Marrelli: *A Guide for Caregiving: What's Next? Planning for Safety, Quality, and Compassionate Care for Your Loved One and Yourself*
6. Atul Gawande: *Being Mortal: Medicine and What Matters in the End*
7. Bonnie A. Friedman: *Hospital Warrior: How to Get the Best Care for Your Loved One*
8. Virginia Morris: *How to Care For Aging Parents: A One-Stop Resource For All Your Medical, Financial, Housing, and Emotional Issues*

- 1 U.S. Census Bureau. "2020 Census Will Help Policymakers Prepare for the Incoming Wave of Aging Boomers." December 10, 2019.
- 2 U.S. Census Bureau. "2020 Census Will Help Policymakers Prepare for the Incoming Wave of Aging Boomers." December 10, 2019.
- 3 AARP/NAC, 2015. "Caregiving in the U.S."
- 4 U.S. Department of Health and Human Services, 2017. "How Much Care Will You need?"
- 5 Age Wave/Merrill Lynch, 2014. "Health in Retirement: Planning For the Great Unknown."
- 6 Thompson, T. et al, 2013. "Long-term Care: Perceptions, Experiences and Attitudes Among Americans Age 40 and Older," Chicago, IL: The Associated Press NORC Center for Public Affairs Research.
- 7 Associated Press-NORC Center for Public Affairs Research, 2017. "Long-term Care in America: Views on Who Should Bear the Responsibilities and Costs of Care."
- 8 American Association for Long-term Care Insurance, 2013.
- 9 Gambini, B., wellspouse.org. "Burdens of Spousal Caregiving Alleviated by Appreciation," August 28, 2017.
- 10 Annual Prevalence National Academies Press, 2016. "Families Caring for an Aging America: Proportion Caring for Older Adults 65+."
- 11 National Academies of Science, Engineering, Medicine, 2016. "Number of Years and Percentage of Adult Life Spent Caring for an Older Adult."
- 12 National Academies of Science, Engineering, Medicine, 2016. "Number of Years and Percentage of Adult Life Spent Caring for an Older Adult."
- 13 U.S. Census Bureau, 2016. American Community Survey.
- 14 Census Bureau. 2015. Current Population Survey.
- 15 Center for Retirement Research, Boston College, 2017. "How Much Long-Term Care Do Adult Children Provide?"
- 16 Age Wave/Merrill. "The Journey of Caregiving: Honor, Responsibility and Financial Complexity." 2017.
- 17 SHRM/Home Instead, 2017. "Daughters in the Workplace Report."
- 18 Collins, S. C. & Joseph, S. Informal Caregiving. Retrieved November 9, 2019. From commonwealthfund.org/publications/other-publication/1999/may/informal-caregiving.
- 19 Ibid.
- 20 Ibid.
- 21 Cannuscio, C. C.; Jones, C.; Karachi, I.; Colditz, G.A.; Berkman, L. & Rim, E. "Reverberations of family illness: A longitudinal assessment of informal caregiving and mental health status in the Nurses' Health Study." American Journal of Public Health, (August, 2002). 92(8), 1305-1311.
- 22 MetLife, 2011. "Study of Caregiving Costs to Working Caregivers."
- 23 Ibid.
- 24 Age Wave/Merrill Lynch, 2014. "Health and Retirement: Planning for the Great Unknown."
- 25 healthinaging.org. Health in Aging Foundation. 2020.
- 26 Rosenblatt, R. and Van Steenberg, Carol. Family Caregiver Alliance. 2014. *Handbook for Long-Distance Caregivers: An Essential Guide for Family and Friends*.
- 27 alz.org/alzheimers-dementia/facts-figures.
- 28 Bott, et al, 2017. "Dementia Care, Women's Health and Gender Equity: The Value of Well-Timed Caregiver Support." JAMA Neurology, Vol 7 4(7).
- 29 AARP/NAC, 2015. "Caregiving in the U.S."
- 30 NAC/Alzheimer's Association, 2017.
- 31 Ibid.
- 32 Fredriksen-Goldsen.K.I. (2016). "The Future of LGBT Aging: A Blueprint for Action in Services, Policies and Research." Generations. 40(2), 6–15.
- 33 Family Caregiver Alliance. "Caregiving in the Lesbian, Gay, Bisexual, and Transgender (LGBT) Communities." caregiver.org. Accessed March, 12, 2020.
- 34 Age Wave/Merrill. "The Journey of Caregiving: Honor, Responsibility and Financial Complexity." 2017.
- 35 Ibid.
- 36 AARP, 2015. "Family Financial Caregiving: Rewards, Stresses and Responsibilities."
- 37 Ibid.
- 38 Ibid.
- 39 Ibid.
- 40 Age Wave/Merrill. "The Journey of Caregiving: Honor, Responsibility and Financial Complexity." 2017.
- 41 Family Caregiver Alliance. "Legal Issues for LGBT Caregivers: FCA Fact Sheet."
- 42 Ibid.
- 43 Ibid.
- 44 Ibid.
- 45 Ibid.
- 46 Rosenblatt, R. and Van Steenberg, Carol. Family Caregiver Alliance. 2014. *Handbook for Long-Distance Caregivers: An Essential Guide for Family and Friends*
- 47 Guideposts.org/caregiving/alzheimers-and-dementia/everyday-coping-for-caregivers/7-tips-for-caring-for-a-loved-one-with-dementia.


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