

PREPARE TO CARE

A PLANNING GUIDE FOR FAMILIES

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Real Possibilities





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INTRODUCTION

Caring for a family member or close friend is one of the most important roles you'll play. It may start with driving your loved one to get groceries or going to the doctor. Later, you may find yourself taking more time off from work, preparing meals or handling bills.

No matter where you are in the journey of family caregiving—just beginning to anticipate a need, helping coordinate a big move, or taking care of a family member 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 to help you care for your family member or close friend. 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, and 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 the conversation. Many people wait until a crisis occurs before they 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.

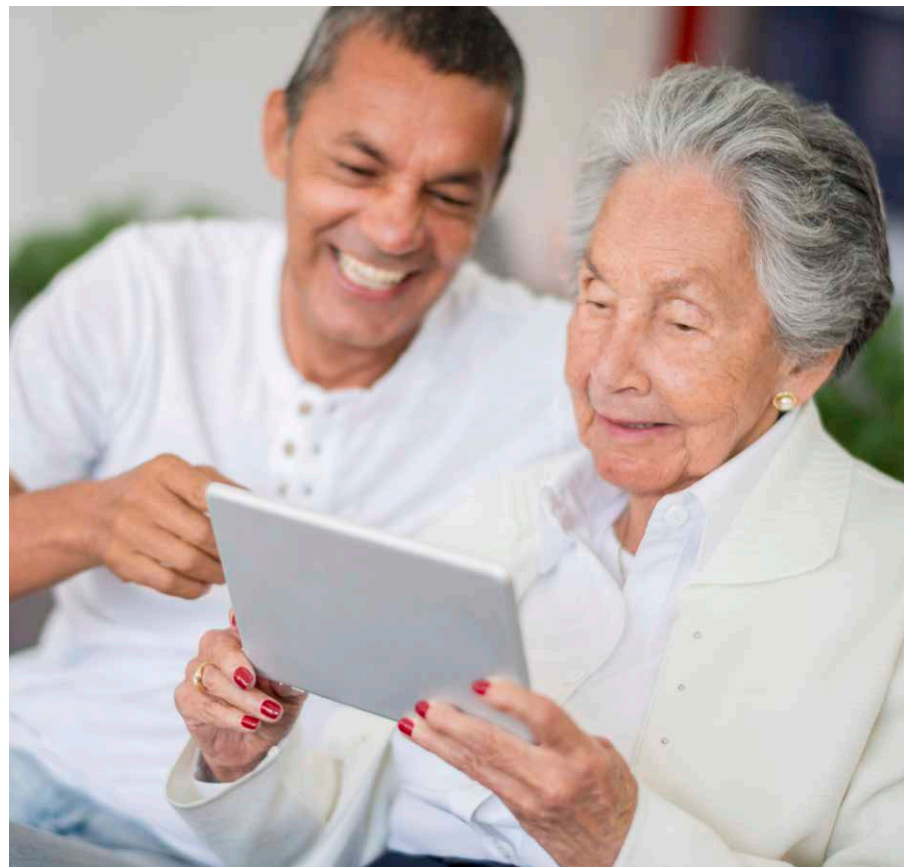
Form your team. No one should try to approach the responsibilities of caregiving alone. While other family members are likely sources of support, don't overlook friends, colleagues, clubs or religious and other organizational affiliations as resources too.

Make a plan. Putting together a family 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.

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

Caring for a family member or close friend is one of the most important roles you'll play.





START THE 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. Plus, we're busy. 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.

Look for an opening. You might use an article you've read about 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?"
- "I just read an article about gathering all your important papers. Sometime can you show me where yours are and what you'd like us to do just in case?"
- "As time goes on, do you think you will want to stay in this house? It might be difficult with all the stairs."
- "You mentioned your eyes are bothering you. Is this causing problems with reading or driving?"

Try not to anticipate what your loved one might say or how they will react. Just get the conversation started. It will likely take place over time. Be open. Express your love and concern and, most importantly, listen.

Respect your loved one's wishes. Every family 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 participate as much as possible.

Once you've started the conversation, you may wish to bring in a few other trusted family members or friends to be part of the process.

Before meeting, you and the other family members should consider...

- Who is the best person to start or lead the conversation?
- What are your own feelings and outlook on the situation?
- What are your goals or what is the best outcome you think might happen as a result of the conversation?
- What are you prepared to do and not do?
- What is most difficult for you about having this conversation about the person you care about?

It's important to have a point person to keep the process moving and make sure people understand what's been decided. In most families, 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. Better now, than in a time of crisis.

It is also sometimes helpful to engage the help of an outside facilitator, such as a social worker or minister to help keep everyone focused, manage potential disagreements and communicate difficult subjects during the meeting.

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.



We've inserted a goals and needs checklist on page 23 to help you identify concerns related to your loved one's home, health, finances, and legal needs.

Review finances. 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. One thing that family caregivers often find surprising is that most health insurance, including *Medicare*, pay for little, if any, of the costs of care in a nursing home, *assisted living residence*, or help with daily activities such as bathing, dressing, or meals. Ask them 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.

Counter resistance. Your loved one might say, "I just don't want to talk about it." Some people are private by nature. It's also hard for some people to admit they need help, especially if it's from their own children. If your first conversation doesn't go well, try again. Start small, discussing just one aspect of your concerns. If your loved one shuts you out, ask a trusted family friend, doctor or faith leader to approach them about your unease.



FORM YOUR TEAM

Caring for a family member or friend can be too big of a job for one person. Trying to do everything yourself may lead to burnout and problems with your health and well-being. Instead, reach out to form a larger network of friends, family and community resources that can help you with your loved one's care. Your loved one can help you identify willing members that you may not have thought about, such as neighbors or friends from the faith community.

Look for team members. Team members need not all live nearby or have huge blocks of time to be of value. Family or friends living at a distance with limited schedules can pitch in behind the scenes with meal organizing, bill paying, or financial assistance. The computer whiz in the family could set up an electronic calendar for dinner delivery or chores. 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.

Build and support your team. Putting a supportive 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.



MAKE A PLAN

The most effective family caregiving plans are made with the person you are caring for 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 team members to help manage the workload.

By now, you should also have an idea of the willing caregivers on your team. It's now time to figure out your plan. Be sure to ask your caregiving team members about their preferences for who does what task. For instance, they might be more comfortable with one person handling financial affairs over another. Assigning tasks can take place in a face-to-face family meeting, over a conference call, or through a series of emails.

The plan doesn't have to be extensive or fancy. You can never anticipate every detail or scenario. The plan should include immediate needs as well as plans for the future. Use the goals and needs checklist as your guide. Options for addressing needs will depend on finances, the willingness of your support team and the availability of community resources and services. (See

sample caregiving plans beginning on page 34.) For example, if your loved one wants to move in the next year or so, you can assign someone the task of researching locations and facilities. Someone else might offer to spend some weekends helping them sort through their belongings.

A written summary of the plan can reinforce your loved one's wishes and needs. Set up a system for communicating with everyone on the team. The point person should be well organized and an in-depth planner who can work through conflicts between the team members. There are a number of roles that people can help with; for example, you might want an assertive advocate to communicate with medical professionals or insurance companies. Be open to modifications as the situation and team members' ability to help may change. How your loved one's needs unfold may differ from what you expected.

FIND SUPPORT

It's okay to reach out for extra support. If you've discovered the scope of care that is needed 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 60 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 services* centers, care management, and more. Check into the services offered in your community through the Eldercare Locator* at www.eldercare.gov.

Consult a professional. Often times a loved one's needs can be complex especially when health, emotional and financial issues come into play. A nurse or social worker can help you determine what is needed, find services, and arrange and monitor the 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 services through the Eldercare Locator.



Hire help. If you see that your loved one needs help with daily activities, you can explore the range of home care services available. Some home care workers do housekeeping, meal preparation, laundry, and shopping. Others provide more hands-on help with bathing, dressing, and transferring from one position to another, which usually requires special training, a license, or certification depending on the laws in your state. Your local 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. Get references to ensure good quality. Visit the AARP Caregiving Resource Center* at www.aarp.org/caregiving for more information on how to hire and find help.

Secure safety. The main goal is to help your loved one stay as independent as possible and in their own home. As your loved one has more difficulty getting around or their vision or hearing fades, some simple changes can be made to make the home safer. Handrails, grab bars, night lights and adjustable shower seats can make a house safer and more comfortable. The AARP Home Fit Guide at www.aarp.org/homefit offers solutions that range from simple fixes to improvements that require skilled expertise.

Find 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, group dining, laundry service, and more. Not all types of housing are available in every community. Our Glossary includes common definitions for the different types of housing alternatives available.

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 www.aarp.org/caregiving. If selecting a nursing home, go to Medicare's Nursing Home Compare page at www.medicare.gov.*

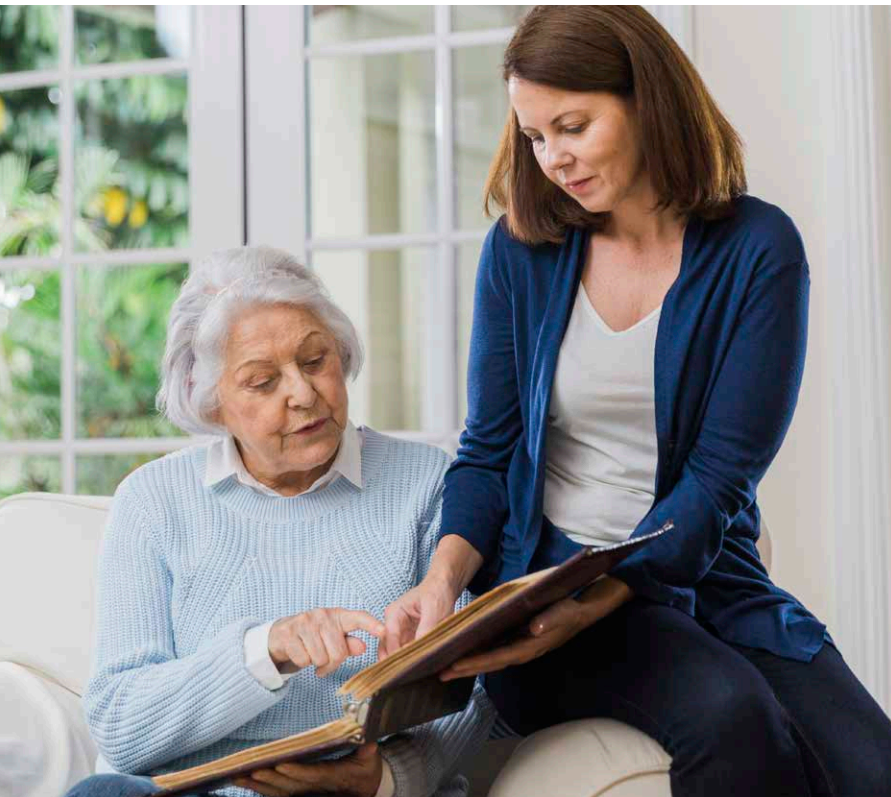


CARE FOR YOURSELF

Don't overlook the impact of caregiving on you. Balancing caregiving with work and other family obligations can be stressful. When asked, family caregivers often say the most difficult part is the demand on their time. Stress can negatively affect your health, well-being, and ability to provide care. Schedule regular time 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:

- Social workers, nurses and other professionals can guide you through care choices and help monitor the care when you don't live nearby.
- Technology such as *personal emergency response systems*, 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 too.



Download AARP's Caregiving app* at www.aarp.org/caregivingapp to help you manage your to-do list, calendar of appointments and support scheduling.

Download AARP's Rx app* at www.aarp.org/rxapp to help you manage your loved one's medications. You can also use it to help you manage your own medications.

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, consider asking whether you are covered by the *Family and Medical Leave Act*. Many people are covered by the Act, but if you work for a small company or haven't worked for your employer long, you may not be eligible for this program.

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 prescriptions. Try to calculate these costs when budgeting. If possible, stay in the workforce to increase retirement income later.

Advocate for you. Let the doctor know that you are the primary caregiver and you need information on your loved one's condition and the treatments prescribed. Ask for training if you are expected to do procedures at home. Some professionals might be reluctant to share information. But, most professional offices have a form that your loved one can sign giving their doctor or other professionals permission to discuss their care with you.

Recognize your emotions.

How you came into the role as a caregiver can influence how you feel about the experience. Perhaps you have always been close to your loved one and you see this role as your chance to give in return the loving care they gave to you and your family. Others may have been pushed into the responsibility and feel resentful because they are stretched with their own work and children. Then there are those who enter caregiving reluctantly, but discover it's a chance to mend a broken or distant relationship. However you arrived to this responsibility, it's helpful to recognize your emotions.



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 take the time to care for yourself, you often return to your responsibilities renewed and better able to provide care for your loved one. To cope, consider tapping into social networks such as www.facebook.com, www.caringbridge.com, and others for support.

Caregiving services and support groups. There's comfort in knowing others are experiencing the same ups and downs as you. It may also give you ideas about other strategies and resources available to lighten your load. There are community services that can 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. Find services and support groups available in your community through Eldercare Locator.*

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, usually works with law enforcement. Immediate dangerous situations should be directed to 911 or the local police.

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 or for older people and 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 do not need skilled nursing care. The level of assistance varies among residences and may include help with bathing, dressing, meals, and housekeeping.

Community Meal Program

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

Conservator

A person appointed by a court to handle someone's affairs when that person cannot handle them him or herself. 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, designed to meet a person's changing needs.

Discharge Planner

A professional who assists individuals and their families 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

The durable power of attorney for finances is a legal document that allows you to give authority to another trusted person to make financial decisions on your behalf. The designation durable means that it will stay in effect if you become unable to manage your own financial affairs.

Employee Assistance Program (EAP)

An employee benefit program offered by many employers. EAPs are intended to help employees deal with personal issues that impact their job performance, health, and well-being. EAPs generally include short-term counseling and referral services for employees and their household members.

Family and Medical Leave Act

A law that requires some employers to let you 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 equivalent is guaranteed when you return. If you work for a small employer or are a new employee, you may not be able to get the leave.

Family Caregiver

Anyone who provides unpaid assistance to another person who is ill, disabled, or needs help with daily activities.

Guardian

A person appointed by the court who is responsible for the care and management of another person who has been determined to be no longer capable of making decisions for him/herself.

Health Care Power of Attorney (Health Care Proxy)

A special kind of durable power of attorney called a Health Care Power of Attorney (HCPA) in which you appoint another person to make health care decisions should you become unable to do so.

Health Insurance Portability and Accountability Act (HIPAA)

A federal law that gives you rights over your health information and sets rules and limits on who can look at and receive your health information. It also permits the release of personal health information needed for patient care.

GLOSSARY *(continued)*

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 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 is provided at home and in other settings.

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.

Living Will (Part of a Health Care Directive)

A legal document that communicates a person's wishes about lifesaving medical treatments should he or she have a terminal condition and not be able to communicate their health care 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.

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 and possibly 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. It 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

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

Palliative Care

Professionally coordinated services that focus on physical, mental, social, and spiritual needs of those with life-threatening illness and their families. It seeks to maintain the highest level of comfort.

Personal Emergency Response System (PERS)

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

Respite Care

A temporary break from providing care for a loved one. Respite care can be provided by either family and/or friends through services such as attending an adult day services center. You can also have a paid home-care worker come to the home.

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 in Social Security is eligible at age 62 or if disabled. Certain family members may be eligible for benefits as well.

Supplemental Security Income (SSI)

SSI provides a monthly benefit to people who are 65 years of age and older, disabled or blind, and who have limited income and assets.

RESOURCES

AARP Caregiving Resource Center: www.aarp.org/caregiving or 1-877-333-5885

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

AARP Caregiving app: www.aarp.org/caregivingapp

Helps you manage your to-do list, calendar of appointments and support scheduling.

AARP Rx app: www.aarp.org/rxapp

Helps you manage your loved one's medications. You can also use it to help manage your own medications.

AARP Advance Directive Forms: www.aarp.org/advancedirectives

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

AARP Medicare Q&A Tool: www.aarp.org/MedicareQA

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

AARP Health Law Answers: www.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 I Heart Caregivers: www.aarp.org/iheartcaregivers

Share your caregiving story and connect with others.

AARP Long-Term Care Cost Calculator: www.aarp.org/longtermcarecosts

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

Administration on Aging (AoA): www.aoa.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.

Alzheimer's Association: www.alz.org or 1-800-272-3900

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

Assisted Living Federation of America: www.alfa.org

Information and resources on assisted living options and how to find them.

Caregiver Action Network: www.caregiveraction.org or 202-454-3970

Information, educational materials, and support for family caregivers.

Caring Connections: www.caringinfo.org

A national engagement initiative to improve care at the end of life.

Department of Veterans Affairs: www.va.gov or 1-800-827-1000

Information about eligibility and benefits for veterans and their families.

Eldercare Locator: www.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: www.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: www.caregiver.org or 1-800-445-8106

Tools and resources for family caregivers, including the Family Care Navigator, a state-by-state list of services and assistance.

LeadingAge: www.leadingage.org

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

Medicare: www.medicare.gov or 1-800-633-4227

Provides information about the Medicare program and how to find Medicare plans and providers. Caregivers will also find a tool on the website to compare home health care agencies and nursing homes. The official U.S. Government site for Medicare.

National Academy of Elder Law Attorneys: www.naela.org

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

National Alliance for Caregiving: www.caregiving.org

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

National Alliance for Hispanic Health: www.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 for Home Care & Hospice: www.nahc.org

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

National Association of Home Builders: www.nahb.org/caps 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.

RESOURCES *(continued)*

National Association of Social Workers: www.socialworkers.org

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

National Clearinghouse for Long-Term Care Information: www.longtermcare.gov

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

National Hospice and Palliative Care Organization: www.nhpco.org or 1-800-646-6460

Free consumer information on hospice care and puts the public in direct contact with hospice programs.

National Respite Locator: www.archrespite.org

A service that helps people locate respite services.

NIH Senior Health: www.nihseniorhealth.gov 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: www.rosalynncarter.org

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

SAGECAP: www.sageusa.org/sagecap

An organization providing counseling, information, support groups and more to gay, lesbian, and bisexual and transgender caregivers.

Social Security Administration: www.ssa.gov or 1-800-772-1213

Information on eligibility and benefits is available from 7 a.m. to 7 p.m., Monday through Friday.

State Health Insurance Assistance Program (SHIP): www.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: www.theconversationproject.org

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

Veterans Administration: www.caregiver.va.gov or 1-855-260-3274

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

Village to Village Network: www.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.

CAREGIVER RESOURCES

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tools, and resources for caring for a loved one at

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