



AARP Family Caregiving Guide

Look inside for:

5 Key Steps for Your Caregiving Journey

General Needs Assessment to Help
Evaluate Your Situation

A Simple Goals and Needs Checklist





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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 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.

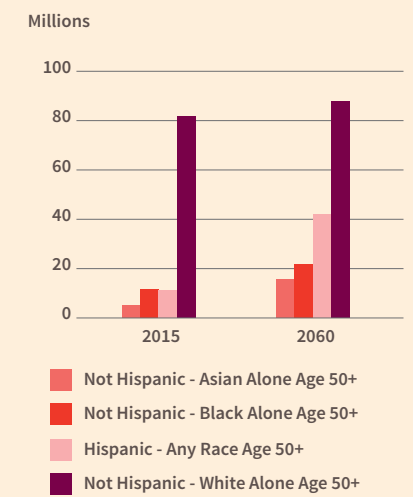
Make a plan. Putting together a family caregiving plan now will help you respond more quickly and effectively should the need arise. It can also provide some peace of mind. A plan helps everyone get on the same page and keeps the focus on what's best for your loved one.

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.

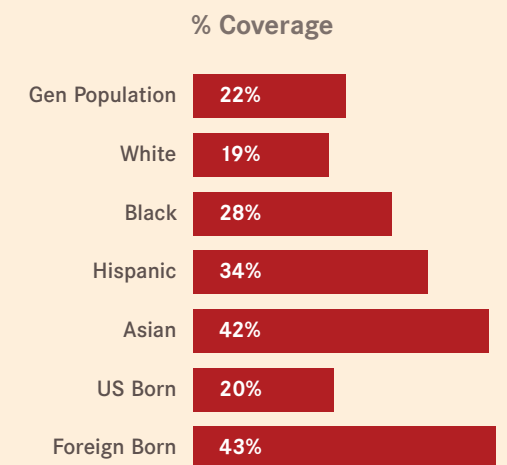


Growth and Diversity of the 50+ (2015-2060)



Source: U. S. Census Bureau, 2014. National Population Projections, Population Division.

Incidence of Caregiving for elders (Age 45-55)



Source: Belden, Russonello & Stewart and Research/Strategy/Management, 2001. "In the Middle: A Report on Multicultural Boomers Coping With Family and Aging Issue". AARP Research Report.

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 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 and not prepared to 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. Your loved one may be hesitant to share the details of their finances or health, but approach them with respect and explain your intentions.



investments, insurance coverage and loans. Find out whether they have *long-term care insurance* and funds or assets that can be used to cover potential care needs.

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.

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*, pays 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,



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 or with limited time 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 your 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 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 OK 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 age 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. Oftentimes 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 agency on aging can help you identify the appropriate services and connect you with 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.*

10 Questions to Ask Before Hiring a Health Aide

No one with a need for a home health aide should be afraid to seek necessary care. But how do you ensure that your loved one is in safe hands? Lee Lindquist, M.D., chief of geriatrics at the Northwestern University Feinberg School of Medicine, offers these 10 questions to ask when vetting home-care agencies.

1. How do you recruit home health aides, and what are your hiring requirements?
2. Do you do criminal background checks on prospective aides? How about drug screening?
3. Are health aides certified in CPR, or do they have any health-related training?
4. Are the aides insured and bonded through your agency?
5. What competencies are expected of the aide? Lifting and transfers? Personal care skills (bathing, dressing, toileting)? Training in behavioral management, cognitive support?
6. How do you assess what the aide is capable of doing?
7. What is your policy on providing a substitute home health-care aide in the event a regular care provider cannot perform the services in your contract?
8. If there is dissatisfaction with a particular home-care provider, can he or she be replaced "without cause"?
9. Does the agency provide a supervisor who is responsible for regularly evaluating the quality of home care?
10. Does supervision occur over the telephone, through progress reports or in person at the home of the older adult?



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.



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 flextime 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 your loved one's doctor know that you are their primary caregiver and you need information on their 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 you and your loved one can sign giving providers permission to discuss their care with you. If your loved one has a durable power of attorney for health, be sure his or her medical providers have a copy in their medical files.

The Caregiver Advise, Record, Enable (CARE) Act, which has passed in many states recently, generally requires hospitals to:

- Provide your loved one the opportunity to designate a family caregiver when admitted.
- Inform you when your loved one is to be discharged to another facility or back home.
- Give you explanations and live instruction of the medical tasks—such as medication management, wound care and transfers—that the family caregiver will perform at home.

You can check if your state has passed the CARE Act and read the latest news about other AARP Advocacy initiatives on www.aarp.org/SupportCaregivers.

Learn more about the CARE Act and get your free wallet card to keep with your insurance card, so you have important information about the CARE Act when you need it. Visit www.aarp.org/walletcards.

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 AARP's online caregiving community at www.aarp.org/caregivingcommunity 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 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 working 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 age 60 and over and their 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 affect 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, has a disability 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 (HCPA Health Care Proxy)

A special kind of durable power of attorney 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 look at and receive it. The law 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 people 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 copays 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 Home

A nursing facility that provides intermediate care, such as 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 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 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 888-971-2013.

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

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

AARP Care Guides: www.aarp.org/careguides

Take the stress out of caregiving with these targeted, easy-to-use guides.

AARP Local Caregiver Resource Guides: www.aarp.org/caregiverresourceguides

Local resources that help make caregiving easier.

AARP Caregiving Tools: www.aarp.org/caregivingtools

AARP's suite of web-based tools will help you find services, keep track of health records and more.

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.

AARP Online Caregiving Community: www.aarp.org/caregivingcommunity

Join our community & connect with other caregivers like you.

Administration on Community Living (ACL): www.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.

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

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

American Cancer Society: www.cancer.org or 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: www.diabetes.org or 800-342-2383

Resources and research to prevent, cure and manage diabetes.

American Heart Association: www.heart.org or 800-242-8721

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

Argentum: www.argentum.org

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

Care.com: www.care.com

Improving the lives of families and caregivers by helping them connect in a reliable and easy way.

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

Information, educational materials and support for family caregivers.

CaringInfo: www.caringinfo.org

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

Eldercare Locator: www.eldercare.gov or 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.elizabethdoletfoundation.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 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 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 affecting 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.healthymamericas.org or 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 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 of Social Workers: www.socialworkers.org

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

Resources (continued)

- National Clearinghouse for Long-Term Care Information:** www.longtermcare.gov
Information and tools to help plan for long-term care needs.
- National Hospice and Palliative Care Organization:** www.nhpco.org or 800-646-6460
Provides free consumer information on hospice care and puts the public in direct contact with hospice programs.
- National Multiple Sclerosis Society:** www.nationalmssociety.org
Offers resources and support to navigate the best life through the challenges of MS.
- National Parkinson Foundation:** www.parkinson.org or 800-473-4636
Events, research progress and resources for those affected by Parkinson’s disease.
- National Respite Network:** www.archrespite.org
A service that helps people locate respite services.
- NIH Senior Health:** www.nihseniorhealth.gov or 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 800-772-1213
Help and information on eligibility and benefits are available online from 5 a.m. to 1 a.m. ET Monday through Friday; 5 a.m. to 11 p.m. ET Saturday; and 8 a.m. to 11:30 p.m. ET Sunday. Phone help is available 7 a.m. to 7 p.m. ET Monday through Friday.
- State Health Insurance Assistance Program (SHIP):** www.shiptacenter.org or 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 Affairs:** www.caregiver.va.gov or 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:** 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.
- 2-1-1:** www.211.org
A free and confidential service that helps people across North America find the local resources they need.



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	Strengths
_____ To remain healthy and active	_____ Able to advocate for self
_____ To stay/move near family	_____ Adequate savings and/or income
_____ To remain in my own home for as long as possible	_____ Low-maintenance single-story home
_____ To stay active with religious or community groups	_____ Family and friends nearby
_____ To maintain hobbies	_____ Relationships with family
_____ To be around people	_____ Other
_____ 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	

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 supervising 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? (attach copy of documents)t	Contact Name
	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		
	Other		
	Passwords		



HOME MAINTENANCE CHECKLIST

X	Home Item	Where Is It Kept? (attach copy of documents)	Contact Name
	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: <i>(does not apply to an Advantage plan with drug coverage)</i>		
	Other Health Insurance Policy (Medigap): Company: Premium: Payment schedule:		
	Veterans 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

MEDICATION CHART

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**, www.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) 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 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 (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	End of day	Daughter Mary	Call and review pill box
	2. Go to doctor’s appt	1:00 p.m.	Daughter Ann	Drive to appt, get prescriptions, set in pill box
Tuesday	1. Go grocery shopping	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
	2. Check on medications			
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	Today	Daughter Mary	Call agency to see if meals will be delivered next Monday
	2. Check on medications	End of day	Daughter Mary	Call and review pill box
Friday	1. Check on medical bill payment	Today	Daughter Mary	Make call to insurance provider about payment Call Peggy to fill in for Monday lunch
	2. Ask Daughter-in-law Peggy to bring lunch on Monday			
Saturday	1. Take over supper 2. Drive to beauty parlor 3. Check on medications	Afternoon	Daughter Ann	
Sunday	1. Manage medications	Evening	Mary	Review medications and place in pill box for the week Drive Mom to service
	2. Take to faith services	9:00 a.m.	Al	
	3. Arrange for visitor or outing	1:00 p.m.	Niece Beth	

Caregiver Resources

Visit the AARP Caregiving Resource Center for information, tools
and resources for caring for a loved one at

www.aarp.org/caregiving
or call **877-333-5885**

For Spanish resources visit

www.aarp.org/cuidar or call **888-971-2013**

Download a brochure? Tell us what you think. www.aarp.org/preparetocaresurvey

