



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

Are you spending more and more of your time tending to your family member or close friend's needs? It may start with driving your mother to get groceries or helping to sort through bills. Later, you may find yourself taking time off work to help prepare meals or go with her to the doctor. As our loved ones age, it's likely a matter of when, not if, they will need our help. Nearly 44 million Americans—1 in 5 adults—are family caregivers for a relative or friend over age 50.¹ According to a nationwide AARP study, Asian Americans and Pacific Islanders (AAPIs) are almost twice as likely to care for their elders than the general population.² Respect for one's elders is a value common to AAPIs; as is family togetherness, demonstrated by the fact that AAPIs are also twice as likely as Whites to live in households with at least two adult generations.³

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

² Caregiving Among Asian Americans and Pacific Islanders Age 50+ Executive Summary. AARP Report. November, 2014.

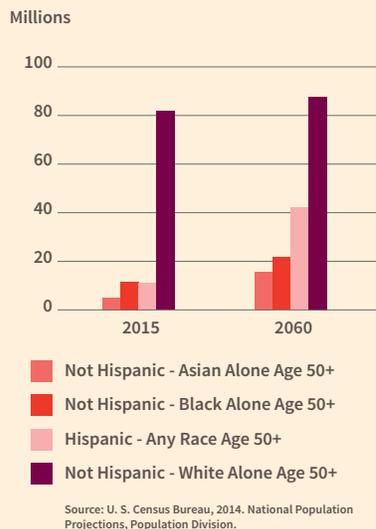
³ Hua, "Asian Americans More Likely to Have Multigenerational Households." NBC News, August 25, 2015.

Since two-thirds of AAPIs age 50 or older are immigrants, they may have traditional cultural expectations that can be a challenge to meet by their more Western acculturated children who are attempting to balance work-life with raising children of their own. AARP's study found that the vast majority (73%) of AAPIs, more than any racial or ethnic group, believe that caring for parents is expected of them. The study found that AAPIs were more likely to take charge of caregiving for their elders: they are more likely to talk to doctors (54% vs. 36%), contribute financially (51% vs. 27%), and handle paper work or bills (41% vs. 33%) than the total population of the same age or compared to Whites, Blacks, and Hispanics.⁴

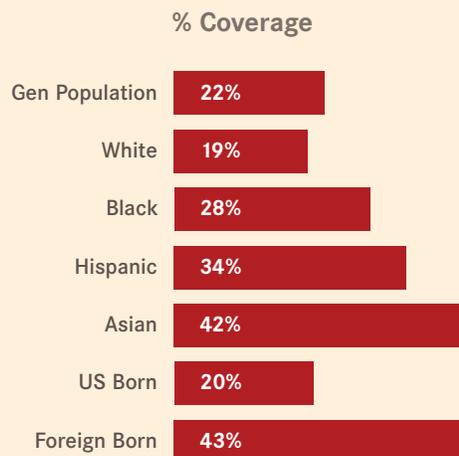
Caring for one's loved ones as they age is one of the cultural ways AAPIs honor and show respect for their elders. This guide is a practical tool to help you care for them. You'll find information, resources, and checklists to help you get organized and find the support that you might need.

⁴ Caregiving Among Asian Americans and Pacific Islanders Age 50+ Executive Summary. AARP Report. November, 2014.

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



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.

The guide provides five important actions for you to consider in the care of your loved one:

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, you may be forced to make important decisions without careful consideration.

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, extended relatives and family associations, religious organizations, and culturally relevant social services 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 ones.



Find support. There will be many issues that arise during your caregiving experience that require additional information and resources. Don't hesitate to reach out to organizations and professionals with experience in caring for older people.

Care for yourself. As a *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.

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



START THE CONVERSATION

Each AAPI ethnic group has its own cultural beliefs, attitudes and practices around caregiving; however, there are also commonalities. For example, AAPI families are generally resistant to moving their elders out of their homes and into assisted living or nursing home facilities. In addition, there is a resistance to home visits from health care providers with a strong preference to be cared for by family. Among Chinese Americans, but other AAPI groups as well, there is a reluctance to discuss end of life related issues due to the nature of karma and the belief that talking about bad things can make them occur.⁵ Such cultural beliefs and preferences can make caregiving discussions difficult to have, but it's extremely important to talk with your loved ones to understand their wishes before something happens, like a fall or an accident, that could force serious decisions and timely responses.

Look for an opening. Approaching the conversation with humility, expressing concern for your loved ones' health and a desire to ensure their continued comfort and well-being may help open the door. Try asking a conversation-starting question, such as:

- “I recently read an article in the newspaper about gathering all one's important papers; so I organized mine and filed them in one drawer. Would you like me to help you with yours?”

⁵ Caregiving Among Asian Americans and Pacific Islanders Age 50+ Executive Summary. AARP Report. November, 2014.

Is there a cultural saying that may inspire your loved one to begin planning for the future? For example, there is a Filipino saying “Laging Hangda!” which means “Always be prepared!”

- “Are there too many stairs in your home? Should we look for a single story home for you? Or a condo with an elevator?”

Enlist the help of your loved one’s physician: “Last time we visited your doctor, he spoke a lot about your diet and nutrition. What would you think about food shopping together and we can make some meals that you can heat up on your own when you are hungry?”

Talk about a family friend or relative that may be in a similar situation. “Auntie June told me that she completed her advanced directives. Have you done yours or thought about getting yours done?”

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, ask your loved one who he/she would like to bring in 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. In more traditional AAPI households, the eldest child

(son or daughter) may take a leadership role, but all families have their unique dynamics and relationships. Expect that there may be conflicts and don't be afraid to talk through them. Better now, than in a time of crisis.

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 27 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 caregivers often find surprising is that unless your loved one has *long-term care insurance*, most health insurance, including *Medicare*, pay for little, if any, of the costs of help with daily activities such as bathing, dressing, or eating. Ask them to review their bank accounts, investments, insurance coverage, and loans with you. Determine with the person whether he or she has 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" or look for ways to put off the conversation. Be sensitive, but don't give up. It's hard for them to discuss what they may see as being a burden to you. If your first conversation doesn't go well, try again. Start small, discussing just one aspect of your concerns.

Concern for their safety. If your loved ones have refused your efforts to assist them and you truly believe they are at immediate risk or unsafe in their living situation, ask a trusted family friend, doctor or faith leader to approach them about your concerns. It's important to address safety concerns with people your family trusts to avoid forced intervention from outside authorities.



FORM YOUR CARE 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. Long-distance family or friends 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. If there are grandchildren, consider including them in the caregiving plan. From keeping their grandparents company to mowing their lawn, kids of all ages can provide emotional and practical support if the situation is right. It might be a good way for them to feel they are contributing, not to mention their help may teach them

beneficial lessons in patience and caring from the experience. Involving the kids also reduces your struggle between caring for your parents or them since you are all working together.

Manage sibling issues. If the care is for your parents, you and your siblings need to pull together to provide care for them. The reality is that relationships between parents and children have deep histories and some are healthier than others. The oldest sibling may take charge, yet the younger ones may be more in tune with what the parents want. Others may check out, triggering resentment among the willing siblings. As you sort through the responsibilities, tensions can run high. It may help to have a neutral third party present, such as a counselor or faith leader. Regardless of your family dynamics, it's best not to assume beforehand that all your siblings will agree on what should happen. Communicating with each other early, before a crisis happens, can minimize some of the family tensions. Include your parents in on these discussions and let their wishes be your guide and the center of decision making

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 caregiving plans are made with the loved ones at the center of the discussion and input from your care team. Together, use the information gathered in the Goals & Needs Checklist (page 27) to form your plan. The plan should include what needs to be done and who should do what (see sample plans on pages 38-39). Be sure to ask your loved ones their preference for who does what task. For instance, there might be a comfort level with one person handling financial affairs over another. No matter who gets assigned what tasks, keep all parties in the loop so there are no hurt feelings, surprises or missed opportunities.

The plan doesn't have to be elaborate or fancy. You can never anticipate every detail or scenario. The plan should include immediate needs as well as broader plans for the future. For example, if your parents say that they will likely move in the next year or so, you can assign someone the task of researching locations. Someone else might offer to spend some weekends helping them sort through their belongings.

Once the issues have been sorted through, a written summary can reinforce your loved one's wishes and needs. Set up a system for communicating with everyone on the team, perhaps by email.

The point person needs to be well-organized and an in-depth planner who can work through conflicts between 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. Executing a *durable power of attorney for health and for finances* at this time can also help identify who will assume responsibility for decision-making when/if the need arises. Be open to modifications as the situation and team members' ability to help change. How your loved one's needs unfold may differ from what you expected. Consider setting up a regular care team gathering, perhaps once a month, in person or through a conference call to foster continued support and involvement.

FIND SUPPORT

It's okay to reach out for extra support; it can benefit your loved ones and you. From a cultural perspective, you may feel shame or guilt about asking for help, but if you've discovered that the scope of care your loved one needs is beyond what you or your team can provide or perhaps you're not even sure what is needed, consider getting help from an organization in your community. Many AAPI families tend to be private about family concerns and try to manage everything within the family unit, but failing to get support when you and your loved one need it can make matters worse.



Locate community resources. A variety of support services are available to people ages 60 and over and their caregivers throughout the United States. In some regions, there are ethnic community-based organizations that provide services in AAPI languages. Your local Area Agency on Aging may be able to connect you to organizations that provide culturally relevant meals, activities for elders, transportation and help accessing services and benefits for your loved one. 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 dealing with health, emotional and financial issues. A community health worker or social worker can help you sort things out and determine what is needed, find services, and arrange and monitor the care. Some regions have AAPI community health workers who may speak your family's language and be sensitive to your culture. Your workplace may have an Employee Assistance Program that can help connect you to professionals and services in your community or you can find them through your local Area Agency on Aging or the Eldercare Locator*.

Hire help. If you see that your loved one needs extra help with daily activities, you can explore the range of home-care services available. Some home-care workers 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 Area Agency on Aging can help you identify the appropriate services and connect you with local providers. They can also help you determine if your loved one might be eligible for publicly funded services. In some states, trusted family members can be

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?

trained and licensed to provide home care for their loved one. 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 (see our checklist of what to ask on page 37). Get references to ensure good quality.

Secure their safety. The main goal is often to keep your loved one as independent as possible and in their own home. As your loved ones have more difficulty getting around or their vision or hearing fades, there are some simple changes that can be made to make the home safe. Handrails, grab bars, night lights and adjustable shower seats can make a house safer and more comfortable for an older loved one. You can find a detailed home safety checklist in the AARP Home Fit Guide at www.aarp.org/homefit. The guide also offers solutions that range from simple fixes to improvements that require skilled expertise.

Find housing with supportive services. If your loved ones have 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 determining the level of support needed beyond housing. Make a list with your criteria, such as location, ethnic meal availability, bilingual staff, laundry service, and more. Our Glossary includes common definitions for the different types of housing alternatives available. Not all types of housing are available in every community.

Once you know the type of living arrangement needed, visit facilities and be sure to talk with residents and their families. For more information about how to choose the right facility for your loved one, 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.

Housing Options:

- > *Assisted Living Residences*
- > *Continuing Care Retirement Communities*
- > *Home Health Agency*
- > *Hospice Care (In-Home and In-Facility)*
- > *Independent Living*
- > *In-Home Care*
- > *Memory Care Communities*
- > *Nursing Homes*



CARE FOR YOURSELF

Don't overlook the impact caregiving has on you. Balancing caregiving with work and other family obligations is often stressful. When asked, *caregivers* often say the most difficult part is the demand on their time.⁶ 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. Nearly one-quarter of people caring for elderly relatives do so from a distance.⁷ The following resources and strategies can help:

- *Community health 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.

⁶ Caregiving in the US., The National Alliance for Caregiving and AARP, 2009.

⁷ *Ibid.*

- Try to make frequent travel for caregiving easier. Consider keeping a few clothing items and some basic necessities at your loved one's home. You can also investigate deals with airlines, rental cars, and hotels that can make booking easier and rewarding.
- Organization is essential for the long-distance caregiver. Keep a journal of your loved one's appointments, including dates, who was present and what was discussed; consider using online calendars and reminders; always carry contact information for their doctors, insurance companies, and neighbors. It's also important to keep a list of their medications with you too.

Work and caregiving. More than 26 million American workers are also caregivers for their parents or older relatives and friends.⁸ Often employers are sympathetic to the demands of caregivers. Find out if your company has policies or programs to support caregivers. You may be able to take flex-time or work from home to help open up your schedule. If you need more time off, see if you are covered by the Family and Medical Leave Act. Most 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 included, and you may not be able to afford to take unpaid leave.

Understand the financial impact. Your personal finances can take a hit from caregiving — from time off of work, cutting back on hours, or passing up promotions to buying groceries and prescriptions for your loved ones or frequently visiting them. Try to calculate these costs when budgeting with your loved ones and the care team. If possible, stay in the workforce to increase retirement income later.



⁸ *Ibid.*



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 their 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 explanation 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.

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 ones and you see this role as your chance to give in return for the loving care they gave to you and your family. Others may have been pushed into the responsibility as a cultural obligation or expectation, 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 and experience healing through their role. However you arrived to this responsibility, it's helpful to recognize your emotions and realize that you are a role model for what it means to be family for the young people in your life.

Take care of yourself. Caregiving can be emotionally draining and lead to feelings of frustration, resentment, guilt and anger. Allow yourself to take a break. Tend to your own needs for exercise, sleep, and healthy eating. Find ways to reduce your stress — whether it's taking in a good movie, walking with a friend, or carving out time for meditation. Treat yourself to something fun. Not every minute of your day needs to be scheduled to take care of your children, parents, close friends, or work. You run the risk of burning out if you don't listen to your own needs. 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 ones. 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. We mentioned community services to help your loved ones, but there are community services that can help caregivers. 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. The National Family Caregiver Support Program provides information, education, training, referral to local services and respite to the caregivers of people ages 60 and over. Consider finding your local program through the 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.

Advance Directives

Legal documents that allow you to spell out your decisions about end of life care ahead of time. They give you a way to tell your wishes to family, friends, and health care professionals and to avoid confusion later on.

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.

Asian American and Pacific Islander (AAPI)

A term used in the United States to include both Asian Americans and Pacific Islander Americans.

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 Health Worker

A person who is a liaison and provides cultural mediation between health care/social services and the community to facilitate access to services and improve the quality and cultural competency of service delivery.

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.

Durable Power of Attorney for Health Care

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

Independent Living

Housing that offers a simplified lifestyle for adults with limited-care needs. Sometimes referred to as retirement communities.

In-Home Care

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

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.

Memory Care Communities

Housing that specializes in providing care to aging adults with Alzheimer's, dementia, and other cognitive issues.

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 Asian American and Pacific Islander: www.aarp.org/AAPI

The group part of AARP dedicated to connecting unique tools and programs to the AAPI community.

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 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.

Asian & Pacific Islander American Health Forum: www.apiahf.org

Works with AAPI communities to influence policy and strengthen their community-based organizations to achieve health equity for AAPIs.

Assisted Living Federation of America: www.alfa.org

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

Association of Asian Pacific Community Health Organizations: www.aapcho.org

An association dedicated to promoting advocacy, collaboration, and leadership that improves the health status and access of medically underserved AAPI communities.

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.

Diverse Elders Coalition: www.diverseelders.org

Created to ensure that the needs and perspectives of vulnerable elders are heard. This coalition advocates for policies and programs that improve aging in communities as racially and ethnically diverse people; American Indians and Alaska Natives; and LGBTQ people.

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 Asian American and Pacific Islander Mental Health Association: www.naapimha.org

This organization promotes the mental health and well-being of AAPI communities and strives to raise awareness of the role of mental health in an individual's health.

National Asian Pacific American Families Against Substance Abuse: www.napafasa.org

An organization dedicated to addressing the alcohol, tobacco and other drug issues of AAPI populations.

National Asian Pacific Center on Aging: www.napca.org

An organization that advocates on behalf of the AAPI aging community, to educate AAPI seniors and the general public on the unique needs of the AAPI aging community.

RESOURCES (continued)

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.

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.archrespice.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 7:00 a.m. to 7:00 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.

GOALS & NEEDS CHECKLIST

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

Goals

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

Strengths

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

Needs

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



GENERAL NEEDS ASSESSMENT
 (One for each individual who will need care)

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



GENERAL NEEDS ASSESSMENT (One for each individual who will need care)

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



PERSONAL INFORMATION CHECKLIST

(One for each individual who will need care)

NAME _____

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



HOME MAINTENANCE CHECKLIST

X Home Item	Where is it kept? Contact Name <small>(attach copy of documents)</small>
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: <ul style="list-style-type: none"> • 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

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:	
	Veteran's Health System: ID #:	
	Do Not Resuscitate (DNR) Order:	
	Physician Orders for Life-Sustaining Treatment (POLST) form— if available in your state	
	Living Will/Advance Directives	
	Durable Power of Attorney for Health Care	



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)	<input type="checkbox"/> YES	<input type="checkbox"/> NO
	Low Income Home Energy Assistance (LIHEAP)	<input type="checkbox"/> YES	<input type="checkbox"/> NO
	Supplemental Security Income (SSI)	<input type="checkbox"/> YES	<input type="checkbox"/> NO
	Property Tax Assistance	<input type="checkbox"/> YES	<input type="checkbox"/> NO
	Extra Help Paying for Medicare Part D (prescription drug coverage)	<input type="checkbox"/> YES	<input type="checkbox"/> NO
	Medicare Parts A, B and D Premium Support	<input type="checkbox"/> YES	<input type="checkbox"/> NO
	Medicaid (help with long-term care and medical care) Number & Identification Card	<input type="checkbox"/> YES	<input type="checkbox"/> NO
	Transportation Assistance	<input type="checkbox"/> YES	<input type="checkbox"/> 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
<p>1. Better understand and manage Mom's medical care.</p>	<p>Meet with Mom and doctor</p> <ul style="list-style-type: none"> a. Create chart of medications to be taken when (make multiple copies for team); translate medication regimen for mom in mom's primary language, perhaps create a pictorial aid as well b. Buy pill organizer c. Get calendar to mark all appointments d. Mom signs form giving doctor permission to discuss medical care with me and my sister e. Take notes at each appointment in journal—get written instructions from doctor f. Confirm follow-up/appointments 		
<p>2. Move Mom to a new home.</p>	<ul style="list-style-type: none"> a. Determine amenities/services needed (including language needs and meal needs) b. Determine budget c. Research locations d. Research facility types e. Sort through stuff to be sold or given away 		
<p>3. For the caregiver: Relax with friends once a week.</p>	<ul style="list-style-type: none"> a. Call Mary on Monday for a movie on Friday 		



SAMPLE DETAILED WEEKLY CAREGIVING PLAN

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

Caregiving Week of:

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



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**

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

