



PREPARE

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CARE

A Planning Guide for Families





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Introduction

Are you using your lunch hour or leaving work early to run errands for your parents? Giving up a promotion because it would mean longer hours you don't have? Spending more time tending to mom's prescriptions than your own?

It may start with driving your mother to get groceries or going with her to the doctor. Later, you may find yourself taking more time off work, preparing meals or handling her bills.

As our parents 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

Family caregiving often happens while we are in the prime of our working life with children of our own relying on us too. Being sandwiched with these demands can take its toll on our jobs, our families and our health.

No matter where you are in the continuum of caregiving — just beginning to anticipate a need, helping coordinate a big move, or taking care of your parents full-time in your home — having a good framework in which to consider your loved one's needs will make the process easier.

This guide is a practical tool to help you care for your parent(s). You'll find information, resources, and checklists to help you get organized and find the support that you and your parents 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 approach the emotions and responsibilities of caregiving alone. While other family members are likely sources of support, don't overlook friends, colleagues and club or organizational affiliations as resources too.

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

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. But keeping up your energy and maintaining your health are critical in order to care for your loved one. It's no less important to make a plan to take care of yourself than to create a caregiving plan for others.

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

A lot of uncertainty can be avoided if you talk with your loved ones before something happens. It's easy to put off these conversations because it's hard to accept our parents are aging. Plus, we're busy. It never seems like the right time to bring up what we think will likely be a difficult topic. You may be surprised to find your parents have been meaning to have the talk too and are relieved when you take the lead.

Look for an opening. You might come up with an ice breaker or opening 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 that causing problems with reading or driving?"

Try not to anticipate what your parents 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 parent's wishes. Every caregiving plan must center on the wishes of the person receiving the care. A plan should never be made without the participation, knowledge, and consent of your loved one. A person with a cognitive impairment should participate as much as possible.

Once you've brought up the subject, bring in a few other trusted family members to be part of the process and have a nuts-and-bolts conversation.

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

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

It's important to have a point person to keep the process going 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 with the parent, or simply is a take-charge person. Expect that there may be conflicts and don't be afraid to talk them out. 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. Parents 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 & needs checklist on page 23 to help you identify concerns related to your parent'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 parents about housing, health care and other expenses. One thing that caregivers often find surprising is that unless your parents have long-term care insurance, most health insurance, including Medicare, pay for little, if any, of the cost of help with daily activities such as bathing, dressing or eating. Ask them to review their bank accounts, investments, insurance coverage, and other loans with you. Determine with your parents whether they have funds or assets that can be used to cover potential care needs.

Counter resistance. Your mother might say, "I just don't want to talk about it." Sometimes parents are private by nature or one spouse might be protective of the other's limitations. It's also hard to admit they need help, especially from their own children — who they taught to drive and balance a checkbook.

Be sensitive to the possible reasons behind their push back — but don't give up. It's hard for your parents to discuss what they may see as being a burden on their children. 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 parents shut you out and you think they truly need help, ask a trusted family friend, doctor or faith leader to approach them about your unease. If you feel your parents are at immediate risk or unsafe in their living situation, you may need to contact adult protective services* or the police to get involved. This extreme situation underscores the importance of planning early to avoid a forced intervention.

Form Your Team



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

willing members that you may not have thought about, such as neighbors or friends from your parent's 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. At this stage, you and your siblings need to pull together to provide care for your parents. 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. Opening up the lines of communication 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 parent'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 team of family and friends. Armed with the information you gathered from going through our goals & needs checklist on page 23 with your parents, 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 who is going to do what. Be sure to ask your parents their preference for who does what task. For instance, there might be a comfort level with one person handling financial affairs over another. This might take place in a face-to-face family meeting, over a conference call, or through a series of emails where everyone is copied. Keep all parties in the loop so there are no hurt feelings, surprises or missed opportunities.

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 broader plans for the future. Use the goals & 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 parents say that they will likely 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.

Once the issues have been hashed out, a written summary can reinforce your parent'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 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 change. How your parents' needs unfold may differ from what you expected.

Find Support

It's okay to reach out for extra support; it benefits your parents and you. If you've discovered the scope of care your parent needs is beyond what you or your team can provide or maybe you're not sure what is needed, you might consider getting help from an organization in your community.

Locate community resources. A variety of support services are available to people ages 60 and over and their caregivers throughout the United States. Your local area agency on aging can typically help connect you to services such as home-delivered meals, transportation, adult day services centers, care management, and more. Check into the services offered in your community through the Eldercare Locator* at www.eldercare.gov.

Consult a professional. Often times a parent's needs can be complex especially when health, emotional and financial issues fall into play. A geriatric care manager, who is often a nurse or social worker, can help you sort things out and determine what is needed, find services, and arrange and monitor the care. Perhaps your workplace has an Employee Assistance Program



that can help connect you to professionals and services in your community or you can find them through the Eldercare Locator*.

Hire help. If you see that your mom 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 parent might be eligible 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. See our checklist of what to ask at the AARP Caregiving Resource Center* at www.aarp.org/caregiving.

Secure their safety. The main goal is often to keep your loved one as independent as possible and in their own home. As your parents 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 at the AARP Caregiving Resource Center* at www.aarp.org/caregiving.

Housing with supportive services. If your parents 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, group dining, 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 several 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.



Care for Yourself

Don't overlook the impact of caregiving 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 time². 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 at a distance³. The following resources and strategies can help:

- *Geriatric care managers* can guide you through care choices and help monitor the care when you don't live nearby.
- 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 parent is safe.

² Caregiving in the U.S., The National Alliance for Caregiving and AARP, 2009.

³ Ibid.

- Try to make repeated travel for caregiving easier. Consider keeping a few clothing items and some basic necessities at your parent'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. No running back over. Keep a journal of your parent's appointments, including dates, who was present and what was discussed; consider using online calendars and reminders; carry on your person contact information for their doctors, insurance companies, and neighbors. 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 friends⁴. Often employers are sympathetic to the plight of caregivers, but many employees are hesitant to be open with their supervisors about their responsibilities. Find out if your company has policies or programs to support caregivers. There may be benefits or services that can help ease your situation. Think about taking advantage of flex-time or working from home to help open up your schedule. If you need more time off, consider asking whether you are covered by the Family and Medical Leave Act. 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 parents or travelling repeatedly to see them. Try to calculate these costs when budgeting with your parents. If possible, stay in the workforce to increase retirement income later.

Advocate for you. Consider telling your doctor that you are a caregiver for someone and this extra work has increased your stress level. Discuss ways to manage stress. Let your parent'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 parent

can sign giving their doctor or other professionals permission to discuss their care with you.

Recognize your emotions. How you came into the role as a caregiver can influence how you feel about the experience. Perhaps you have always been close to your parents 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 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.

Heal yourself. Caregiving can be emotionally draining and lead to feelings of frustration, doubt, 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 a hot bath. Treat yourself to something fun. Not every minute of your day needs to be scheduled to take care of your children, parents 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 parents, but there are community services that can help the caregiver. Don't feel guilty about needing time off or help with understanding complex information; and remember that your parent 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*.

⁴ Caregiving in the U.S., The National Alliance for Caregiving and AARP, 2009.

Glossary

Activities of Daily Living (ADLs)

Basic tasks of everyday life that include dressing, bathing, eating, transferring (i.e., from bed to chair) 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 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 (AAA) or for older people and adults with disabilities (ADRC) within a specific geographical area. Both agencies provide information, resources, assistance, and links to community services.

Assisted Living Residences

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

Community Meal Program

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

Conservator

A person appointed by a court to handle someone's affairs when that person cannot handle them him or herself. A conservator usually handles only financial affairs.

Continuing Care Retirement Communities

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

Discharge Planner

A professional who assists patients and their families in developing a plan of care for a patient following a hospital or nursing home stay.

DNR: Do Not Resuscitate Order

An order written by a doctor to fulfill a patient'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.

Extra Help

An assistance program for people with Medicare who need help paying their part of the costs of Medicare Part D prescription drug coverage.

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.

Geriatric Care Manager

A professional who performs an assessment of a person's mental, physical, environmental, and financial conditions to create a care plan to assist in arranging housing, medical, social, and other services.

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.

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: 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 be in a terminal condition and not 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

The national health insurance program for people age 65 and older, and for some younger persons with disabilities. Medicare covers hospital stays, doctor visits, prescription drugs and other health care related services.

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.

National Family Caregiver Support Program

A federally funded program available in local communities that provides a range of supports to assist family caregivers who care for their loved ones at home. Services may include caregiver education, training, information, counseling, links to community services and respite.

Nursing Homes

A nursing facility that provides intermediate 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.

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 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.

Physician Orders for Life-Sustaining Treatment (POLST)

A form that states what kind of medical treatment patients want toward the end of their lives. Available in some states. See www.polst.org for more information.

Respite Care

A break from providing care for a loved one. It can be provided by either family and/or friends or 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 covered-work who is either disabled or age 62 or over, as well as certain family members are eligible.

Supplemental Security Income (SSI)

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

Resources

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

Your one-stop shop for information, tools, and resources while caring for a loved one.

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

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

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.

Aging with Dignity: www.agingwithdignity.org or 1-888-5WISHES (1-888-594-7437)

Information and instruction on developing a living will and having conversations with family.

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 elders and their 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.

American Bar Association Commission on Law and Aging: <http://new.abanet.org/aging>

Information on legal issues effecting older adults and referrals to lawyers in your area.

Assisted Living Federation of America: www.alfa.org

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

Caring Connections: www.caringinfo.org

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

Centers for Medicare & Medicaid Services: www.cms.gov

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

Helpful consumer information on eligibility and benefits. Online tools help you search and compare nursing homes, hospitals, home health agencies, health plans, and Medicare prescription drug plans in your area. The tools also rate performance.

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

Information about eligibility and benefits for veterans and their families.

Eldercare Locator: www.eldercare.gov or 1-800-677-1116

A national public service that connects you with local resources for older people and their caregivers.

Family Caregiver Alliance: www.caregiver.org or 1-800-445-8106

Tools and resources for family caregivers and a Family Care Navigator with information on services in your state.

LeadingAge: www.leadingage.org

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

National Adult Protective Services Association:

www.apsnetwork.org/Abuse/index.html

Find public adult protective services agencies in every state and D.C. Consumers can report abuse online. Immediate dangerous situations should be directed to 911 or local police.

National Alliance for Caregiving: www.caregiving.org

This organization offers research and reviews books, videos, websites, and other material to help family caregivers and professionals.

National Alliance for Hispanic Health: www.hispanichealth.org or 1-866-783-2645

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

n4a: www.n4a.org/answers-on-aging

A membership organization of local Area Agencies on Aging and Title VI programs. Provides answers to questions about home- and community-based services for seniors and family caregivers.

National Association of Professional Geriatric Care Managers: www.caremanager.org

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

National Association for Home Care & Hospice: www.nahc.org/consumer/home.html

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 Family Caregivers Association: www.thefamilycaregiver.org or 1-800-896-3650

Information, educational materials, and support for family caregivers. Includes www.familycaregiving101.org, a project to educate and assist family caregivers.

Resources *(continued)*

National Hospice and Palliative Care Organization: www.nhpco.org or 1-800-658-8898

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

National Long-Term Care Ombudsman Resource Center: www.ltombudsman.org

An organization that connects you with a local ombudsman, who is a person advocating for quality care for residents of nursing homes and other long-term care facilities, and helping to resolve complaints.

National Respite Locator: www.archrespite.org

A service that helps people locate respite services.

NIH Senior Health: www.nihseniorhealth.gov or 1-800-222-2225

Fact sheets from the U.S. National Institutes of Health on a range of health topics can be viewed online or ordered for free.

Pioneer Network: www.pioneernetwork.net/consumers

An organization working to transform long-term care services to be more responsive to every person's unique needs.

SAGECAP: www.sageusa.org/sagecap

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

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

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

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

Your local SHIP offers one-on-one counseling assistance for people with Medicare and their families. Go to the website or call Medicare at 1-800-633-4227 to find your state SHIP.

**The Consumer Voice for Quality Long-Term Care:
www.theconsumervoice.org/familymember**

An organization working to improve the lives of people in nursing homes and other long-term care facilities. Find a local ombudsman online.

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

With time constraints, we often find ourselves focusing solely on the needs or tasks that need to be addressed for our parents. It is equally important to begin the conversation about what is most important to your loved ones as they grow older and what strengths do they bring to bear.

Goals	Strengths
<input type="checkbox"/> To remain healthy and active	<input type="checkbox"/> Great negotiator
<input type="checkbox"/> To stay/move near family	<input type="checkbox"/> Adequate savings
<input type="checkbox"/> To remain in my own home for as long as possible	<input type="checkbox"/> Low-maintenance single story home
<input type="checkbox"/> To stay active with religious or community groups	<input type="checkbox"/> Large network of friends
<input type="checkbox"/> To maintain hobbies	<input type="checkbox"/> Close relations with family
<input type="checkbox"/> To be around people	<input type="checkbox"/> Other
<input type="checkbox"/> To move to a residence with support services	
<input type="checkbox"/> Other	
Needs	

First determine if there is an immediate need under each area. If there is not a pressing issue, the team (with your parent) might 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	_____
	_____ Ongoing maintenance	_____
	_____ Safety concerns	_____
	_____ Grocery shopping & meal preparation	_____
	_____ Lawn care	_____
	_____ Pet care	_____
	_____ Housekeeping	_____
	_____ Research alternative living arrangements	_____
	_____ Other: _____	_____
Financial Affairs	_____ Paying bills	_____
	_____ Keeping track of financial records	_____
	_____ Managing assets	_____
	_____ Applying and supervising public benefits programs	_____
Transportation Needs	_____ Driving decisions	_____
	_____ Coordinating rides	_____
	_____ Locating transportation services	_____
Personal Care	_____ Organization of family and professional care providers	_____
	_____ 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	_____ Determine medical or emotional problems	_____
	_____ Make, accompany, drive or make alternate logistic arrangements for doctor's appointments	_____
	_____ 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)	_____
	_____	_____
Communications	_____ Keeping family caregiving team informed	_____
	_____ Coordinating team visits	_____
	_____ Daily check in	_____
Socialization	_____ Sending greeting and thank you notes	_____
	_____ Arranging for visitors	_____
	_____ Arranging outings	_____
Adaptive Devices	_____ Ordering, maintaining, and paying for adaptive devices (e.g., wheelchair, walker, etc.)	_____
	_____ Training on how to use devices	_____
	_____ Other: _____	_____
	_____	_____

PERSONAL INFORMATION CHECKLIST

(One for each individual who will need care)

NAME _____

X	Personal Information	Where is it kept? Contact Name <small>(attach copy of documents)</small>
	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? Contact Name
(attach copy of documents)

Mortgage Company Name: Amount due:	
Rental Management Company: Amount due:	
Rental/Real Estate Agent:	
Gas/Electric/Water Company:	
Cable/Internet/Telephone:	
Homeowners Insurance Agent: Insurance Policy #: Homeowners Premium:	
Garbage Service Garbage Pickup Day is: M T W Th F (circle)	
Home Services: • Handy person • Lawncare • Appliances	
Passwords Computer(s) password clue(s) Phone messages password clue	

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:	
	Veteran's Health System: ID #:	
	Do Not Resuscitate (DNR) Order:	
	POLST form-if available in your state	
	Living Will	
	Durable Power of Attorney for Health Care	



MEDICATION CHART

Prescription Name	Strength	Dosage	Warnings/Instructions



TRANSPORTATION CHECKLIST

NAME _____

X	Item	Notes	Where is it kept?
	Auto(s):	Make(s):	
	Auto Loan Information:	Model(s):	
	Title for Car(s):		
	Auto Insurance Company:		
	Recreational Vehicles:		
	Title:		
	Insurance:		



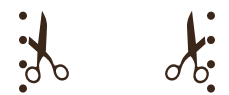
FINANCIAL CHECKLIST

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 parent(s) may have or be eligible for extra 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 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. The team, along with your parents, should 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 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	After work	Son Al	Call Mom for grocery list at lunch, shop after work and drop over.
	2. Check on medications			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	Today	Daughter Mary	Make call to insurance provider about payment
	2. Ask Daughter-in-law Peggy to bring lunch on Monday			Call Peggy to fill in for Monday lunch
Saturday	1. Take over supper	Afternoon	Daughter Ann	
	2. Drive to beauty parlor			
	3. Check on medications			
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





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