Facing the Challenges of Eldercare

KENTUCKY PERSONNEL CABINET

Kentucky Employee Assistance Program

The purpose of this guide is to provide information for accessing eldercare resources.

Eldercare providers have to wear many hats and are faced with decisions in multiple life areas. This guide addresses these issues. The Table of Contents has a link to each section and each can be read as needed.

The following information has been compiled from a variety of resources for reader's convenience. Some information and sources may have changed since initial compilation.

Table of Contents

1. *KNOWING WHEN YOUR PARENT NEEDS HELP*
Signs of At-Risk Behavior in Seniors 4
2. *EDUCATION AND PLANNING*
Preparing for Down the Road: A Planning Guide 5
Exploring Your Options: An Overview of Types of Care 6
How much does Elder Care Cost 8
What Insurance Doesn't Cover 10
3. *COMMUNICATING WITH YOUR PARENT*
Communicating with Your Parent 12
The Do's and Don'ts of Communicating 16
4. *FORMING A TEAM*
Involving the Whole Family in Caregiving 20
Tips for Holding the Family Meeting 22
5. DETERMINING WHAT'S NEEDED
Determining what's needed 24
a. Helping stay at home
Elder Safety at Home 28
Adapting the Home for Alzheimer's Sufferers 34
Home Care Agency Checklist 36
Hiring a Home Care Worker 38
b. Living with you
Can Your Loved One Live with Your Family? 42
Moving Your Elder in With You 44
Respite Care: Getting a Break 48
c. Assisted living
Guide to Assisted Living Facilities 52
d. Residential care
Evaluating Residential Care 55
Easing the Transition: Moving into Residential Care 57
6. LOCATING SPECIFIC RESOURCES 60
7. LEGAL and FINANCIAL CONCERNS
Getting Your Affairs in Order 62
Free Legal Advice for KY Seniors 66
Financial Matters 67
A Quick Guide to Understanding Medicare 68
Is a Reverse Mortgage a Good Idea for My Parents? 71
8. HEALTH & PRACTICAL CARE TIPS
When Your Loved One Resists Care 72
Managing Problem Behaviors 74
Behaviors in Dementia 77
101 Things to Do with A Person with Alzheimer's 80
9. WORK AND CAREGIVING
Balancing Work and Caregiving 81
The Family and Medical Leave Act 83
10. CARE FOR THE CAREGIVER
Managing the Stress of Caregiving 85
Overcoming Negative Emotions 86
Overcoming Caregiver Stress 87

1. Knowing When Your Parent Needs Help

Signs of At-Risk Behavior in Seniors

Most seniors continue to function well through most of their lives. There is normal expected age-related cognitive and physical decline. At some point this can become a safety issue for the senior. There are signs/symptoms that may indicate either expected age-related decline or more serious problems. Regardless of origins it is important for the senior to be evaluated medically to determine problem, cause, prognosis, and treatment if needed.

Indicators that may be suggestive of a senior at risk:

Confused, Disoriented
Forgetful
Hearing problems
Problems chewing food
Problems paying bills
Cannot afford transportation
Social isolation
Not sleeping well, Not eating well
Withdrawn
Gait problems, Falls
Decline in hygiene/appearance
Mail is unopened
Tantrum behavior
Yard or pets neglected
Violence physically or verbally
Rapid weight loss
Tics, slurred words
Talk of suicide
Poor judgment/ insight
Anxiety, tenseness, excessive worries
Problems with gross or fine motor movements
Short term memory loss
Disregarding conventional rules of social conduct and behavior, problems thinking abstractly, planning, initiating, sequencing, monitoring, and stopping complex behaviors.

2. Education and Planning

Preparing for Down the Road: A Planning Guide

We could all be better prepared. The good news is, if you're planning for future long term care needs you're already ahead of the game. You may be managing current needs now and starting to think how your situation could change over time. Or, you may have little experience with chronic conditions or long term care and want to anticipate future needs for yourself and a loved one. Getting involved before a crisis strikes allows you to be more thoughtful in exploring your options.

Think through your needs

Planning for potential needs can be anxiety-producing, but keep in mind that by thinking thought these issues now, you will feel more confident and prepared should a crisis situation present itself. Here are some steps you can take to begin preparing for future needs:

- **Open a dialog with your elder family member.**
- **Compile a binder of critical information.**
- **Review health insurance coverage.**
- **Investigate advance directives now.**

Prepare for an emergency

- **Identify your informal emergency support network.**
- **Get emergency support for someone home alone while you're in the planning phase.**

Do a home assessment to see if modifications can meet future needs

- **Identify your informal emergency support network.**
- **Take a critical look at the home environment.**
- **Prepare for home modifications.**
- **Explore options for future home care needs.**

Learn about local support services

- **Begin gathering info about the types of services available so you'll know what's out there when the time comes to use them.**

Whatever you do now can save you and your family from having to make difficult decisions under duress. Keep the lines of communication with your elder open; planning may take some time. Use this time to show a vulnerable elder that you care about his future and that you can take steps to plan for long-range needs.

Exploring Your Options: An Overview of Types of Care

Once it is determined that a loved one requires some degree of assistance, it is important to become familiar with the various levels of care and services available. Options exist to meet the needs of both the care recipient and the caregiver and can often be used in combination. This section briefly reviews the care services continuum.

Home Care-Home care provides individuals with a wide variety of supportive services that enable them to remain in their own home. Services may be medical or non-medical. In-home care also allows hospital patients to be discharged earlier because recovery can be handled in the home. Home care can be accessed through home care agencies or through less formal arrangements with an independent home care provider.

- Nursing care
- Personal care (e.g., assistance with bathing, toileting, and dressing)
- Monitoring of medications
- Physical, speech, respiratory therapies
- Strategies to compensate for physical limitations
- Assistance with meals
- Housekeeping
- Companionship and supervision

Adult Day Centers-Adult day services are community-based programs designed to meet the needs of frail elders or cognitively impaired adults (e.g., Alzheimer's disease or stroke). Adult day care centers provide a safe and caring setting for individuals who can no longer be left at home alone. Services include a mixture of health, social and support programs offer services in the evenings and/or the weekends. The primary advantage of adult day care is that it allows care recipients to remain in their community, while simultaneously allowing primary caregivers to continue working.

Services may include:

- Meals
- Social interaction with others
- Social activities
- Therapeutic recreation
- Emotional support
- Transportation to and from home
- Health monitoring or rehabilitative therapies

Respite Care-Respite means giving the regular caregiver a break from constant caregiving responsibilities. Respite care covers a range of possible care options, in-home, adult day care or other group setting, as well as overnight in a residential care facility. Respite services are typically short-term, temporary or intermittent ongoing services with a dual purpose; to help the caregiver take time off and provide necessary care or supervision for individuals with chronic illnesses, disabilities or dementia (e.g., Alzheimer's disease).

Hospice Care-Hospice provides services and care at home or in a health care facility for terminally ill individuals and their families. Care is usually supervised by the persons' physician who works in collaboration with a team of professionals (e.g., nurses, social workers, therapists), clergy, home care aides and volunteers. Hospice care seeks to manage pain and discomfort while creating an environment that encourages the individual and family members to openly grieve, talk, grow, and enjoy each other while remaining physically and emotionally close until the very end. People do not usually enter hospice care until their projected final six months of life.

Residential Care-About 1 in 20 Americans is cared for in a nursing home, and this likelihood increases with age. There is no easy rule of thumb to determine if residential care is your best choice. This will depend on a combination of factors including your loved one's health condition, preferences, the abilities and stamina of the home caregiver, and your family's financial resources.

Residential care is global term covering a variety of facility types where the person lives and receives care services. Residences like assisted living facilities can provide independent living with apartment-style units and built-in care services. Skilled nursing homes are the most restrictive level or residential care offering round-the-clock nursing care to individuals with more complex medical needs.

How Much Does Elder Care Cost?

You know that your older adult needs significant help. Perhaps now you want to compare the costs of getting her help at her (or your) home with the costs of relocating your elder to a care facility. These figures certainly vary by type, quality and geographic region. Be sure to check with each service or facility about **their** specific fees. Also, some services are covered by insurance plans or government benefits, while others are paid for privately.

Nursing homes
There is s significant range in nursing home costs (depending on location, size, etc.). It is an expensive level of care-expect to pay an average of $227 per day. Medicare will pay for nursing home costs under certain conditions-for a limited period of time after a hospitalization. It does not cover these costs for an elder who permanently lives in a nursing home. Medicaid covers nursing home costs. Some long term insurance plans also cover nursing home expenses. In some instances, the Veterans' Administration provides nursing care (check with your local Veterans' facility).

Assisted living facilities
Assisted living facilities (which go by various names) range widely in cost, from $2600-$5750 per month, which includes all levels of assistance available at assisted living facilities. These services and facilities are not covered by health insurance plans, Medicare or Medicaid. Some long term care insurance policies cover assisted living facilities.

Independent living facilities
Independent living and retirement housing settings vary in quality, and therefore, in cost. This is often one of the most expensive long-term care solutions. Insurance plans and benefits such as Medicare do not cover these costs; they are typically paid for out-of-pocket.

Home care and home health care
Home health care is covered by Medicare and health insurance plans when a physician provides a qualifying diagnosis. This is usually on a short term basis only, offers medical or nursing care and does not constitute personal or household help. If you pay for this service privately, it averages about $21 an hour.

Home care is a service provided to elders who require help with everyday activities in order to remain living at home. It is not covered by health insurance policies or Medicare. Some LTCI plans, Medicaid (in certain circumstances) and the Veterans' Administration (in some cases) cover home care costs. Most often, elders pay privately for this service—an average of $21 per hour.

Adult day care programs
Day care programs vary in cost. Some programs specialize, such as in dementia care, or provide added services, such as transportation. Some charge $38 per day and others as much as $125 per day or more. Insurance plans and government benefits generally do not pay for this service. They are paid for privately. Some local Veteran's facilities offer adult day care programs, often at no charge. Be sure to ask each program if they have sliding scale fees, based on your loved one's ability to pay.

Senior centers
Independent seniors who would benefit from socialization and nutritional programs can utilize local senior centers at no charge. Often, a charge for lunch or transportation service is made based on the elder's ability to pay.

Geriatric care managers
The services of a geriatric care manager are usually paid for privately. They charge $50 to $200 per hour and some charge for an initial assessment. Under some circumstances, health insurance companies supply their own care managers to at-risk elders (this is often short term).

Emergency response service
An emergency response service, which includes a variety of options, typically costs $25 to $100 per month. This type of service is typically paid for out-of-pocket.

Medication reminder service
You can pay a service to call your elder to remind him/her to take their medications for approximately $15-25 per month. An alternative is a dispensing device that can be programmed and offers alerts for errors. Insurance plans do not cover this service.

Meal delivery programs
This service is paid for privately (insurance does not cover them), but many local programs (administered through senior centers and not-for-profit agencies) are subsidized with government grants, and have a nominal charge to elders. Each meal may cost between $2 and $5 and often the program will bill monthly. Private companies also provide this service with charges at a much higher range.

Companion/visitor programs
Many communities offer free programs where volunteers visit seniors living alone. They are not appropriate for older adults who require significant care, but if your elder would benefit from a "friendly visit" service, you may find this type of program at local churches, city recreation departments, civic or youth groups, the YMCA/YWCA, etc.

Transportation services
Insurance policies, including Medicare, will pay for ambulance transportation to take an elder to an inpatient facility (this is usually a hospital) for medical emergencies. Transportation to regular outpatient appointments or any other destination is not covered. If an ambulance is used without medical justification, it is likely that our elder's insurance company will not pay for it.

Many communities have Para transit services, which provide transportation to elderly and disabled people (with or without a wheelchair). This is often free or costs the elder several dollars per ride (many programs bill monthly). Contact your county transit department about specific charges and how to qualify.

Web-based Technology Monitoring services
One option emerging is that of using technology to help someone at a distance tell how things are going, using some sort of passive monitoring system. Private pay costs vary depending on degree of monitoring.

What Insurance Doesn't Cover

Many health care products are not covered by insurance policies and seniors must pay for these items out-of-pocket. How much do seniors spend? The following are approximate costs for various products. You will need to check with individual providers about their specific prices.

Medical-Related Items

Incontinence products

Adult diapers are not covered by health insurance or Medicare. If an elder resides in a nursing home, they are covered by Medicaid and many long term care insurance policies. Many seniors pay out-of-pocket for incontinence pads.

Diabetes products

Most diabetes and blood sugar testing supplies (in fixed quantities) are provided by doctors and hospitals and are covered, by Medicare and insurance (and Medicaid and some long term care insurance plans, when the elder resides in a nursing home). You can purchase additional products in drugstores, for varying out-of-pocket costs.

Injection supplies

Injection supplies (in fixed quantities) are covered by insurance plans and Medicare (and Medicaid and some long term care insurance plans, when the elder resides in a nursing home). If your elder needs additional supplies (for example, syringes) they are usually purchased privately for $30 to $50 (the higher end reflect models designed for those with impaired vision).

Eyes drop dispenser

An out-of-pocket expense

Eyes, Ears and Teeth

Did you know that vision, hearing and dental services (and products) are not covered by Medicare? In addition, health insurance plans and Medigap plans may cover some, but not all, of these items.

Special plans

Seniors can purchase specific insurance policies (such as a private dental plan) to cover exams and products, like dentures or eyeglasses. Premium prices vary from plan to plan, depending on the extent of coverage. The specific policy your older adult chooses determines how much coverage he gets for related products.

Paying out-of-pocket

These are approximate estimates. You will need to check with local providers to help your elder plan their health care budget.

Dentures
Hearing aids
Eyeglasses
Routine Exams

Costs for Non-Medical Services

Often, a way for an older adult to remain in her (or your) home is to make several modifications around the house. What do home modification projects cost? The following are a few examples of what you can expect to pay. These are approximations only. Check with local providers for exact prices.

Safety equipment

Grab bars can be installed in an elder's bathroom and around the house to prevent falls. Safety bars range from $30 to $80, not including labor installation expenses. Shower (or bathtub) benches cost between $40 and $130, depending on whether you choose a bench with a seatback or extra padding.

Wheelchair ramps

You can purchase portable wheelchair ramps (that fold into a carrying case for travel) for between $150 and $800, depending on the width and length of the ramp. The cost of hiring a contractor to install a wheelchair ramp into a step entry doorway varies based on location.

Stair lifts

Many families in bi-level homes install stair lifts, so their elder in a wheelchair can have mobility throughout the house. A stair lift affords a wheelchair-bound person as much of her normal life as possible (and avoids turning the living room into a bedroom). This is an expensive project and affects the value of your home, so do your research. The cost of a stair lift depends on the model you choose and the details of installation (length of the staircase, etc.). A ballpark figure is $2000.

Large number telephone

For around $50, you can purchase a telephone with larger numbers for an older adult's home. These phones are ideal for people with visual impairments.

Reachers

After rehabilitating from a stroke or a fracture, and older adult's ability to perform everyday activities are often compromised. A reacher is used to pick up items more than an arm's length away (particularly useful when an elder is lying in bed). Reachers are generally covered by Medicare or an insurance plan when an elder has been admitted to a health care facility with a qualifying diagnosis. In this case, the facility may give your elder one, or you can ask for one. If not, your elder can buy one. Reachers can be purchased at medical supply stores for approximately $15 to $18.

3. Communicating With Your Parent

Most people find it hard to talk to their elderly parents about caring for them when they can no longer care for themselves. But, it's important to talk about elder care early – if possible, before your parents need your help.

Getting Started

When discussing issues of health, competency, finances and living arrangements for the last years of a parent's life, eldercare experts emphasize the importance of being sensitive to their feelings.

Instead of directly asking, "So, do you have long-term care insurance?" or "We've noticed you are having trouble taking care of yourself," begin the discussion in the context of a relative or friend's experience. For example, "This is what happened to Aunt Alice. We want to be better prepared." Or put the discussion in the context of your own life, such as, "I'm starting to plan for the time when I might have trouble taking care of myself. This is where my documents are. I've signed a health-care proxy. Have you made any of these plans yourself?"

It helps if you "own" the problem. Avoid saying "You know, Mom, since you had a stroke, you really can't take care of yourself anymore; you need help." Instead, try saying, "Since you had the stroke, I can't sleep or concentrate at work. I'm so worried about you being on your own and being able to take care of things. Would you help me by coming to talk with someone who can help?" Most elders are not going to be resistant if it is expressed in the context of putting their adult children at ease.

In some cases, prior to the onset of any difficulties, the elder may want to engage in the "it" conversation to ensure that their wishes are understood and that their children will act accordingly when the time comes.

While many adult children don't end up playing an active role in their elder relative's planning process, eldercare experts point out the importance of knowing who to go to when the time comes – the attorney, the health-care surrogate, and so on. Listen to the responses you get, and let your parents know you care about them and want to be able to follow through with their wishes.

Because it is not always easy to bring up these topics, approaches might include:

*Saying you are beginning your own family's estate planning and need their advice.
*Assuring you do not want to take over their affairs, but are concerned that needs will be met, especially if a crisis occurs.
*Giving them a list of questions and scheduling time to talk later.
*Admitting you are worried about their driving, for example, and offering to find alternate arrangements. In many instances, caregivers encounter resistance from parents who are embarrassed or who don't want to be a burden.

Above all, approach the subject with dignity.

Ask if Your Parents Have Their Wishes in Writing

Documents called advance directives let your parents give instructions about their future medical care, to be used if they are incapacitated. The two basic types of advance directives are a living will and a durable power of attorney for health care.

-Living will: A living will puts in writing your parents' wishes about medical treatment. The living will is consulted if a person is dying, un conscious, incoherent, or unable to communicate. It guides family and doctors in decisions about how to use medical treatment to delay death.
-Durable power of attorney for health care: In a durable power of attorney for health care, your parents can appoint someone to make medical decisions when they cannot.

Free resources for advance directives. If they are concerned about the legal costs of preparing an advance directive, don't worry. You can get free forms and instructions for your state (advance directives are regulated by states) from your local hospital, bar association, or state office on aging.

A free service called the U.S. Living Will Registry lets people register their advance directives, organ donor documentation, and emergency contact information. The files are stored in a computerized system that makes them available to healthcare providers 24 hours a day. The registry sends advance directive registration labels for people to stick to their insurance card and driver's license.

Consulting a lawyer about advance directives. Many people find it helpful to consult a lawyer who is familiar with end-of-life issues. From advance directives to financial matters, an attorney can offer valuable, no-nonsense information when you need it most. The attorney will ensure that advance directives have been completed and distributed properly.

Whom to notify about advance directives. Once the advance directives are completed, make sure that the appropriate people have copies. Your parents' doctors should have copies of the living will, and the person who is named durable power of attorney should have a copy of that document, as well as the living will. If applicable, the lawyer and the caregiver also should have copies of both. Ask your parents if someone else, such as a close friend or religious leader, should receive copies of the advance directives.

It's also important to discuss parent's wishes with other family members. If you predict conflict over the subject, have a meeting that includes a trusted family friend, religious leader, or social worker. Everyone involved should know what the parents' care will consist of and what role he or she will play. Family members should keep each other up to date on your parent's condition.

Ask if your parent would like you to keep a record of important medical information.

If you are a primary caregiver, you need to maintain as much information as possible about your loved one's medical situation. You may feel like you're snooping, but you need an accurate picture of your parent's medical condition, especially in case his or her health deteriorates. You may need to ask about:

* Medical history
* Instructions that the doctor gives your parent.
* Discharge planning after hospitalizations (you may need to request permission to get a copy of the discharge orders, including what medications your parent should take after discharge).
* Your parent's pharmacy information (get a printout of his or her prescriptions and the reasons that they were prescribed).

Ask your parent if they would like to share their financial plans.

The first step to getting your parents' finances in order is deciding how involved you want to be. Are you going to drive them to the bank or are you going to pay their bills and handle their state planning?

If your mother or father can't handle finances due to a physical problem, you can still partner with them to tackle their finances. If your parent is having cognitive difficulties, is confused with budgeting, or can't maintain his or her finances properly, you may have to take control of the financial affairs. This can be quite difficult – especially if your parent doesn't want to relinquish this role. A good way to handle this is to act as a helper. Explain in a gentle but direct manner that you'll simply follow your parent's wishes and make sure that no bills are left unpaid.

What's their financial situation? If you receive permission to manage your parents' finances, you need to take stock of their income, investments, and expenses. If you discover that their finances have been managed poorly, get advice from a bank or investment counselor.

Find out what types of income they receive, how often it's paid, and whether it's easy to access. Make an inventory of Social Security, pensions, annuities, stock investments, mutual funds, savings, home equity, antiques, and other valuables. Have the values of your parents' assets, such as their home, assessed and keep the values handy.

Legal steps for handling finances. If you choose to handle your parents' finances, certain measures will entitle you to act on their behalf.

- **Power of attorney.** A power of attorney is a legal instrument that lets you handle business or financial affairs on your parents' behalf. For example, you can sign checks for them or make mortgage decisions. It makes you the agent, or attorney-in-fact, for your parents.
- **Representative payee.** Through the Social Security Administration, you can become a representative payee, which means that you receive Social Security payments for someone who can't handle his or her money.

What to do if money is tight. If your parents' finances are tight there are steps you can take to make sure they get the care they need.

- **Federal, state, and local services.** To find out what services are available in your area, contact your local AAA's information and referral department, call the Administration on Aging's Elder Care Locator (1-800-677-1116), or visit BenefitsCheckUp. For additional resources, contact your parents' health insurance company.
- **Reverse mortgage.** A reverse mortgage, sometimes called a home equity conversion mortgage, is literally a reversal of the normal mortgage process. A person age 62 or older who owns his or her home outright sells the home's equity to a bank (without selling or giving up the house). In exchange, the homeowner receives monthly checks from the bank. These loans are often described as "second pensions" tied to a home's value and are most appropriate for older people in need of cash who don't plan on moving.
- **Pharmaceutical assistance.** Pharmaceutical assistance programs help make prescription drugs and other services more affordable. These programs are often run at a state level.
- **Tax/rent rebates.** Tax/rent rebates are sometimes available from the state's department of revenue for older adults and others who may be eligible by income. Recipients get a rebate on property taxes or rent. They also may receive subsidized transportation and housing.

(Find additional information in Section 7. Legal and Financial Concerns)

Discuss community healthcare options

Your parents are likely to need more care as they age. You need to know the community healthcare services that are available to them. Talk to your parents about what they want and talk to their physician about what they need. Have a family meeting and as much as possible allow parent to feel in control. As eldercare needs rise, having a team approach will benefit everyone.

The Do's and Don't of Communicating with Aging Parents

Communication is skill and art. Skills are specific types of verbal and nonverbal actions that help you get the results you want, including cooperation, joint decision making, and finding solutions to difficult issues. The art part is taking the skills and figuring out how to apply the skills to a specific situation. Your job as a caregiver is to decide what to use and how to use it.

When you are talking with aging parents and have some concern about how the communication may go, you are most likely talking about an important topic or an emotionally loaded topic. Important topics may be things such as figuring out where older parents should live, what kinds of help (if any) they need, who needs to know about their finances, what types of health care services they should have, whether or not they have an up to date will or even whether or not someone else should have some legal power to act in their behalf, such as power of attorney or conservatorship.

Emotionally loaded topics are almost anything that leads to strong emotions being experienced and communicated. In any family, there are a specific and unique set of emotionally laden topics, including (but not limited to): who spends the holidays with whom, who is the favored child, who should get possession of various personal items in an estate, who has to take responsibility for care giving, and what is a fair share to be paid for gifts or care by various members of the family.

As a caregiver, you undoubtedly have a series of specific issues that you want to communicate about with your older family member. Some of these are emotionally laden, some are not. Some are easy to discuss in your family situation, some are not. Generally, when there is an emotionally laden and important issue, the following guidelines can help you focus your efforts to get the best out of a difficult situation.

The situation changes dramatically when the older adult has limitations, including dementia. A dementia patient would need more specific guidelines and principles, some of which will be addressed in a future article in this series. However, many of the principles listed below hold regardless of the cognitive limitations of your older family member.

Be prepared for the discussion to end before you want it to. Make every attempt to treat the discussion as a door opener, that is, an opportunity to get the ball rolling, rather than the time everything has to be decided upon.

While hardly a complete list of all the nuances of family communication, these guidelines may help you evaluate how you want to have discussions as well as be an informal checklist to evaluate how you did after a discussion about an emotionally laden topic. Remember, these guidelines have to be applied by you in your situation. They will potentially take many forms, you have to be the final judge on how to apply these principles and ideas.

Do's for emotionally laden situations

Think ahead of what you need to get (vs. what you hope to get) from discussions: That is, what is your bottom line? Do you need to get your parent(s) to tell you EVERYTHING about their possessions or do you really need to get them to confer with a competent attorney? Do you need to get your family member into a nursing home or do you need them to be evaluated by a competent agency, physician or other provider who may come up with options that may work for your older relative?

Do's

Answer the following question (and it's a very important one): *Are you doing this WITH the older adult or FOR them?* That is, do they have both a say and veto power in the discussion? If the older relative has veto power, then he or she may disagree with you or even do something you are very uncomfortable with. At the same time, if it is really their decision, then you should not try to coerce or manipulate them into the decision.

- Think ahead as to when and where to have the conversation. Pick a place and time when older relatives can hear what you are saying without family and holiday distractions. I know of individuals who have actually made a special trip to another city to visit their parents just to have an important conversation.
- Use "I" statements. Literally, this means beginning any declarative sentence with the word "I". This means talking about "My view", "My perception", and especially "My feelings" rather than talking as if you have a corner on the truth and anything your parent says not only contradicts you but is wrong… "I" statements can lead to negotiation and sharing, "You" statements may lead to war.
- Consider having a mutual ally present when beginning important and emotionally laden discussions. Having someone who is trusted by both parties may make things easier.
- Be clear about the topic of discussion with your family member.
- Give the others time to process and think about what you are presenting. Going too fast can lead to misunderstandings. You may have to have more than one conversation about an emotional topic.
- Respect the rights of the others to agree and disagree.
- Stand your own ground. That is, you can be assertive and clear about your beliefs and your point of view without denying others their rights and own perspectives.
- Be aware of your own feelings and reactions to the situation and the others involved. Sometimes, this may mean taking time to go over your likely reactions and figuring out how to enhance reactions that might help the conversation move along and, at the same time, find ways to keep inflammatory reactions in check.
- Practice the conversation with a "coach", someone who can listen to you and let you know how you are coming across. A coach can be a spouse, significant other, family member or friend. If you practice, be sure to ask your coach what behaviors or actions you have that might give the wrong message to your older relative.

Don'ts for emotionally laden situations

- Don't blame others in either word or tone of voice. We often forget that our internal tension or concern may come across as judging others or being defensive, which in turn leads to their not paying attention to our care and thoughts about them.
- Don't do all the talking. A general rule is to occupy no more than ½ of the airtime. It is important to listen and acknowledge the others' concerns and questions. You don't have to answer each and every point when it is made.
- Don't go in with a fearful attitude, it will become your message. Being clear about your goals and having practiced what you want to say can help decrease anxiety.
- Don't overload the table with old issues and hurts. A major mistake made in these conversations is that once the initial point is agreed upon, too much is attempted too quickly. It helps some people to think of their old history as a museum, don't show all of the items at once, limit your exhibits.
- Don't believe that disagreement means someone does not love someone else. I would even go so far as to suggest that a parent's defensiveness (or our own) also does NOT mean that someone does not love someone else. Too often, people mistake defensiveness as a lack of love.
- Don't believe that a quick agreement means the others will agree with you after reflection. People may go away from an involved encounter and think things over again, be prepared to revisit tough issues several times.
- Don't go in with a "someone has to win" attitude, you are usually working together. People who are naturally competitive may find themselves competing with their aging parents rather than working together even with the best of intentions. One way around this is to be clear that the goal is for the "team" of both of you to figure out what is best for the ENTIRE family.

4. Forming a Team

Involving the whole family in caregiving

Usually one person assumes the role of primary caregiver to older parents because he or she is closest geographically, closer to the parent emotionally, or a take-charge person. If you are that person, don't try to do it alone. You need help and the more help, the better. Involving others gives your parents a broader base of support and relieves you of some of the caregiving. The more help you get, the less likely you are to burn out. Just as important, involving your siblings and other immediate family show them they are important to the family and valued as family members. It gives them, too, the opportunity to show their love for their parents or grandparents. Most caregivers do get help. Many feel that other family members do their share. Working with family members constructively can sometimes be a challenge. In times of stress, we often have less to give to each other. Old family roles and resentments can surface. There are ways families can overcome barriers to cooperation and create the supportive network they and their parents need.

Involving your parents is crucial.
Unless your parents are severely mentally incapacitated, such as with Alzheimer's disease, they should always retain decision-making power and be central part of all discussions and actions surrounding their care. Otherwise, it can be difficult for adult children to find solutions and assistance that their parents will find acceptable. Talk with your parents about the importance of working together in meeting their needs. Your parents are probably concerned about being a burden and losing control of their lives. Talk openly about the issues and agree on ground rules. Establish limits so parents won't have unrealistic expectations.

Involve siblings and other close family.
Family meetings can get everyone involved – and keep them involved – in providing care.

- Limit participation to siblings or others directly involved in care. People who cannot attend in person can participate by phone.
- Develop a series of questions and concerns such as health, legal economic or housing issues. Include problems that may have occurred in giving or getting help and following the schedule.
- Every few months, reassess your parents' situation.
- Bring up anything new that has arisen since the last meeting. Discussing such issues openly avoids hurt feelings and suspicions and gets problems solved.
- Choose a neutral party to moderate, if necessary, to keep meetings constructive.
- Have a clear agenda for each meeting and agree on rules of conduct at the outset.
- Avoid arguing. Stick to facts, not opinions or generalities. Don't try to resolve old family wounds.
- Focus on the task of taking care of the parent.

Involve your spouse.
- Keep you marriage a priority and make time to be together.
- Be specific about how your spouse can help. Suggest particular tasks you need done. Thank him or her for all efforts.
- Encourage you spouse to talk about his or her feelings, recognizing that your caregiving responsibilities also affect your spouse in a major way.
- Will your spouse support you emotionally through the caregiving process?

Involve your children
- Be honest with your children about the situation and answer their questions.
- Take time to listen to their concerns.
- Spend time doing something fun with them, no matter how tight the time is.
- Ask them if they'd like to help out with your parents sometimes. Even a toddler can make Grandma feel loved. Teenagers may drive their grandparents to the store or on errands.

There's a job for everyone.
As a family, list what needs to be done and plan for it. Your parents and others who will take on key responsibilities should be involved in planning. This organized approach reduces the stress that comes from "loose ends." It ensures that your parents get all the assistance they need. Back-up plans, where possible, are a good idea. In fact, being available for back-up duty is a valuable role someone may be willing to play. Be sure to write down your plans and schedules, and give all those involved a copy.

A sibling who lives far away can still help with jobs such as paying bills, talking with doctors, researching local agencies, or calling regularly. People with young children can cook meals occasionally, bring the children for visits as appropriate, and take Mom and Dad on errands with the children in tow. Perhaps the children could also help with tasks appropriate to their ages. Don't accept excuses for not helping without suggesting something else a person could do.

Who else to involve?
Immediate family and close friends are obvious choices. More distant relatives, less close friends, neighbors, and community organizations can also provide support. Suggest that these people help in small ways, such as walking the dog, running an errand, watering the lawn and garden.

Contact community and other non-family sources of help. Determining who could do what tasks could be a joint effort among those involved in helping the older persons.

- Ask a friend of your parent to pick up groceries or get books from the library.
- A neighbor's child might visit after school.
- A local teenager might be available to do your yard work.
- A civic group could provide volunteer home repair or transportation services.
- Those your parent sees often (paper delivery person, barber/beautician, apartment superintendent) could call you if anything seems wrong.
- Friends can provide backup child transportation when you need to be with your parent.
- Is there a group of people in similar situations? Perhaps you could start a cooperative arrangement in which you share mutual tasks, such as information gathering and coping strategies.

The Challenges - Overcome your reluctance to ask for help.
- You might hesitate to ask your sibling for help, fearing he or she will refuse and that confrontation will harm your relationship.
- Your husband/wife is already fixing more meals at home, doing more with the children, and having less of a social life because of your responsibilities.
- You don't even know your parent's friends. How can you ask for help?

These feelings are natural and, in some cases you may be right to hold back. However, some people may need only a little encouragement to take on a task. Others may feel hurt or left out if you don't ask for their help.

Sharethecare.org offers support and creative ideas for building a caregiving team.

Tips for Holding the Family Meeting

Including family members who are willing to provide care – either by performing an assigned task or providing financial support – and who will be involved directly or indirectly in your relative's care. In addition, spouses or partners whose lives will be significantly affected by the plans that you're making should also attend the meeting.

Set clear, reachable goals for each meeting.

Be clear and realistic about your relative's condition before the meeting. This is not the time to get stuck on making everyone face up to the fact that Aunt Mindy has dementia. The meeting is the time to plan what to do about her dementia. Sooner or later, however, regardless of whether everyone has accepted that the problem exists, you'll have to have a meeting.

You'll probably need to meet more than once, so state this at the outset. This will help keep people from feeling tense or worried that everything has to be accomplished at once.

Don't try to make a decision about every issue at one meeting. Some problems will warrant further research and thought. For example, you may need to make some phone calls about a particular service before deciding who in the family has to do more.

Plan an agenda and stick to it. Each family member should include a short list of what they wish to discuss during the meeting. The leader of the meeting should put these in order and let everyone know all the topics that will be discussed at that particular meeting.

Discuss what type of help your relative needs. Be detailed. Don't just say, "Father needs help in the morning." Be specific. "He needs someone to lift him out of bed. But he can shower with a bath chair. He needs help getting out of the shower. He can dress himself, but it takes him awhile. He likes to do this on his own. Then he wants someone to help him settle in his favorite chair while he has his tea and toast."

Choose a "facilitator"-the person who runs the meeting. This is not necessarily the person who does all the talking. In fact, this person's role is to make sure that everything on the agenda receives attention.

Each person should be given a chance to talk. The others must listen without interrupting. Then, constructive responses should be given. Don't denigrate someone else's idea. Instead, think of another way to solve the problem. Look at their idea to see what parts of it might work. Make suggestions about how something could be done differently.

By the end of the meeting you should have:

- ◊ designated the family advocate. This person is the liaison between the agencies and individuals who are taking care of your relative and the family. When there is a problem, for example, the social worker will get a phone call from the family advocate, not from all twenty members of your family. This also ensures that communication is clear.
- ◊ compiled a telephone list of family members and their phone numbers. Each person calls the person who is listed after them on the list with information received from the family member listed just above them. This way one person doesn't have to call everyone.
- ◊ scheduled the next meeting. Remember to make a copy of what was discussed in the meeting and give a copy to everyone who attended.

Reassess your plans periodically to make sure that things are still working well. Recognize that situations change in our lives. While your sister may have been able to come over in the morning to help your mother in the past, now that she has a new job and has to be at work thirty minutes earlier, stopping by to help Mom is really too stressful for her now. Can another arrangement be made?

If you can't get your siblings to accept shared responsibility, then at least get your parents to adjust to the coming reality that you will bear a disproportionate amount of the eldercare load. Explain to your parents that you will need more of their living or after-death estate than your siblings to compensate you for using a larger portion of your current living estate to care for them. That's only fair. Use language that is as diplomatic or as straight-forward as you will need.

If you can't convince your parents or siblings to pay you for assuming this tremendous financial load – either by shifting assets from your parent's expected estate or giving cash now – *do not use your own money*. You'll only end up impoverishing yourself or robbing your children of their future.

Work out an agreement, in writing, with your siblings, acknowledging that you've had or tried to have discussions with them about your parents' eldercare, that you're willing to undertake the management of the eldercare, but that it will mean extra expense. Make up a sample projection of costs.

5. Determining What's Needed

Before you can shop for services – or decide to handle eldercare yourself – you have to determine exactly what kind of care your elder needs. It's not as easy as you may think.

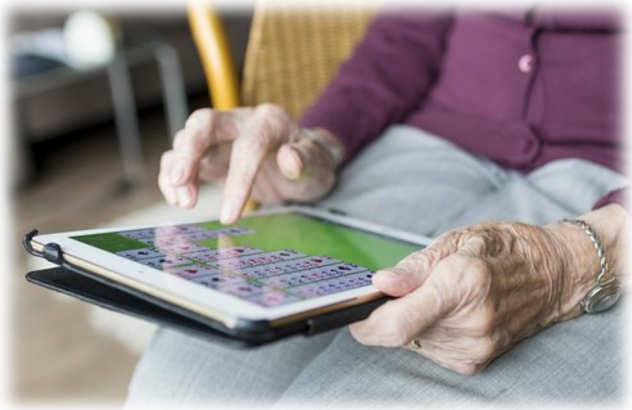
To understand what type of care your relative needs, you need to develop a precise understanding of their abilities. After all, we perform most daily activities automatically, without thinking of them as what they really are – a series of multiple, discrete tasks integrated into complex movement. Take, for example, the action of cooking. To cook, we use our *vision* to identify raw foods and measure, we use *touch* to sense heat and turgidity, our sense of *smell* to determine when something is burning, our dexterity to hold plates and manage hot pots without scalding, wrist and arm strength, and so on. It may seem too simplistic to look at activities in this manner but it is absolutely necessary.

This level of detail may seem painfully tedious but it will help you accomplish their goals. First, you'll avoid overbuying. Breaking down services into components will help you to better identify what you don't need as well as what you do need.

Second, the exercise of identifying exactly what your loved one can accomplish will help you understand his or her frustration in losing parts of the bundle of capabilities that define who they are. Perhaps, more importantly, the process will also help you see what your loved one can still do and to applaud those capabilities.

It should be noted that you do not have to decide which kind of care is needed on your own. If you'd prefer and if you can afford it, you could have an outsider help you make these decisions. "Geriatric care managers" sometimes called "geriatric case managers" will, for a fee, evaluate your elderly loved one's ability to perform activities of daily living, monitor the care provided, and act either as the primary or supplemental family advocate. Such care managers can be especially helpful in those situations where the elderly loved one lives in another town or community, making it difficult for you to interact with and plan for them on your own.

Where do you find a good geriatric care manager? A good place to start is the Aging Life Care Association formerly National Association of Professional Geriatric Care Managers at www.aginglifecare.org .



Detailing the basic activities your relative can perform will not only help you set up a care plan but, as you will see later on, it will also help determine whether he or she is eligible for certain kinds of Federal assistance such as Medicare programs. As precisely as you can, describe the daily activities your loved one finds difficult to perform. Activities should be thought of as *macroskills*, such as eating, which are made up of many different *microskills*. We have constructed the following checklist to help you:

Skills Checklist

Macroskills	Microskills	Level of Need		
		No Help Needed	Some Help Needed	Total Help Needed
Eating	Hold utensils Spoon, fork, or carve food Swallow, chew			
Bathing	Balance to get into tub Balance and strength to get out of tub Strength to turn on/off faucet Flexibility to bathe			
Paying bills and managing money	Memory Ability to calculate to avoid over-spending Basic organizational skills			
Taking medication	Memory Dexterity			
Shopping	Ability to walk or be mobile with walker, wheelchair, or other device Manage money and make change Make decisions			

Other skill concerns:

Skills Checklist

Macroskills	Microskills	Level of Need		
		No Help Needed	Some Help Needed	Total Help Needed
Telephone	Memory Hearing Ability to speak Ability to dial or cradle phone			
Cooking and food preparation	Memory Vision Awareness of temperature Awareness of dietary needs Smell to sense burning or spoilage			
Housekeeping	Physical strength and stamina Agility Vision Memory Awareness to avoid safety hazards, e.g., mixing chemicals such as chlorine and detergent			

a. Helping stay at home

Elder Safety at Home

Technology-Based Elder Care Resources Millions of elderly people live alone, many far from family or others who might watch over them. One option emerging is that of using technology to help someone at a distance tell how things are going, using some sort of passive monitoring system. A passive system does not require the elderly person to do anything to make the system work, as opposed to "active" systems that require the elderly person to take some action, like pushing a button on an emergency response system pendant. Some passive systems put cameras in the older person's home that allow someone somewhere else to see what the camera sees. Others use sensors that can detect motion to alert others if the elderly person is not eating, has not taken their medication, or has fallen. These systems may be used to watch over elderly people who might not realize they need help, like someone with early stage Alzheimer's who might forget to eat or take medications. They can also be used to detect falls or other problems as they happen, or to monitor third parties like home health aides and other home help.

Home Safety for Your Aging Parent Each year, hundreds of thousands of older Americans are injured in and around their homes. Many of these injuries result from hazards that are easy to overlook and could have been avoided. Specific modifications and home repairs can be implemented that will make your aging parent's home safer and more functional. Research suggests that as much as one-third to one-half of all home accidents can be prevented through home modification and repair. The following list is a good place for you to begin a home safety evaluation for your elder—print it out and take it with you the next time you are visiting.

Exterior Approach
*Is the sidewalk in good repair? Would a ramp be helpful?
*If there are steps, are they skid-free? Is a railing properly secured?
*Is the door lock well maintained?
*Is it easy to get the mail?

Interior – General
*Are smoke detectors in working order? Is there at least one on each floor?
*Is the heater in working order? Have the filters been cleaned or changed? Is the heater set at an appropriate temperature?
*Are all space heaters located where they will not get knocked over?
*Are any extension cords or outlets overloaded? Are any outlets warm to the touch?
*Are doorways, hallways and steps unobstructed?
*Are steps well maintained with skid-free surfaces? Are handrails present where needed?
*Is the lighting in the house bright enough (as we age we require more light)? *Is it non-glare? Are there at least a few lights on timers? Is the doorbell loud enough?
*Do electrical cords have safe paths to outlets where nobody has to step over

Telephones and Computers
*Would your elder benefit from phones with large numeric keypads & enhanced audio systems?
*Are emergency numbers posted in large easy-to read print?
*Would your elder use a computer (to communicate with family members, pursuing personal interests, making new friends, etc.)?
*Would an emergency response system be useful in case of a fall?

Living Room
*Is the furniture functional? Can your elder get in & out of chairs & couches easily?
*Are end tables sufficiently stable to support your elder if she suddenly leans on them?
*Are all carpets tacked down (edges should not be sticking up)?
*Are lights non-glare & bright enough for reading?
*Has a professional cleaned the chimney within the last year?

Kitchen Area
*Are all the appliances well-maintained and safe?
*Is it easy for your elder to reach the daily essentials (dishes, pots and pans, food, garbage, etc.)?
*Is there a stable stepstool available for reaching things in high cupboards?
*Do outlets have safety breakers on them?
*Is their sufficient non-glare light?
*Have all drapes and flammables been moved away from the stove?

Bathrooms
*Are all medications (including over-the-counter medications) in easy-to-open containers that are well marked?
*Are faucets easy to turn on & off?
*Are grab bars needed and in place?
*Would a raised toilet seat help?
*Are the bath tub and shower floors covered with a non-stick surface?
*Would a sturdy tub bench or chair be helpful?

Bedroom
*Can your elder get in and out of bed with safety and ease? Is the bed too high?
*Is a light & phone easily accessible from his/her bed?
*Would a nightlight be useful?
*Is the floor uncluttered?

Who can do the repairs?
*Do it yourself
*Hire a handyman or contractor
*Ask about home modification & repair program through your local **Area Agency on Aging**

A day spent identifying and implementing home improvement repairs in your elder's home will bring a considerable amount of peace of mind. If you cannot take time to do an analysis and/or the home improvements yourself, find someone who can.

Key Things to Know and Have on Hand to Ensure Your Elder's Well-Being

If you are the point person for an elderly relative living alone, one of your chief concerns is your elder's safety. You have probably spent time making your loved one's home as safe as it can be, but what if something *does* happen? Whether it's a personal medical emergency, a power outage or a natural disaster, you need an eldercare safety kit.

A Communications Center

Create a communications center in your elder's home to ensure that vital information is easy to find and use on a routine basis, advises Romie Myers, R.N., of FamilyCareGiversOnline, a Web site devoted to supporting caregivers. Many people use the kitchen as a convenient central storage location for this information, she says.

"Emergency workers such as firefighters are trained to go to the kitchen and check the outside and inside of the refrigerator for emergency information," Myers notes. Anyone who routinely comes to the home and provides care should know where the communications center is.

An emergency information sheet is the centerpiece of a plan to help an elderly person cope with a crisis according to Joy Loverde, author of *The Complete Eldercare Planner*. You and your elder should document your network of emergency contacts.

"This list should be posted near every telephone," Loverde says. "But also on the refrigerator. A copy should be given to a trusted neighbor. Every family member should have a copy on their person, in their care and in their home."

According to Myers, many emergency personnel are trained to look for the Vial of L.I.F.E. (Lifesaving Information Emergencies) inside the refrigerator. This is a clear plastic container (such as an empty pill container) with a copy of the important medical and personal information rolled up together with a photograph and stored in the door of the refrigerator, close to the handle. Place a note or a Vial of L.I.F.E magnet on the refrigerator door. The refrigerator will provide some measure of protection to the information sheet in case of fire, flood or other major damage.

Safety Systems

You, your elder and your elder's network should devise a system for checking in on a regular basis so that the caregivers can be altered when something is amiss. This might include a combination of:

A scheduled daily phone call.

Arranging for neighbors to stop by on a daily basis.

Having a neighbor watch the elder's patterns – picking up mail, running errands, etc. – for any worrisome changes.

Using a visual signal. For example, the elder might make a habit of hanging out a flag each morning to say, "All is well."

Using an electronic monitoring system or personal alarm system, if appropriate.

Fire Prevention and Safety

Prevent fires by:

Checking that outlets aren't overloaded.

Discouraging the use of candles.

Using whistling tea kettles and food timers to remind the elder that the stove is on.

Plan an emergency response to fire:

Remind your elder to leave the house and to call 911 before he or she calls you.

Hand or store fully charged fire extinguishers within easy reach. It's best if your elder knows how to use them, but Loverde points out that they should be on-hand even if the elderly person is not strong enough or is anxious about using them. Other people present in the home or neighbors may be able to use them.

Plan and practice at least two escape routes out of each room. Never use elevators. If your elder cannot use stairways make special arrangements for help in advance.

Keep smoke and carbon dioxide detectors clean. Make sure to test them monthly and to change their batteries on a regular schedule.

If your elder can't hear well, Myers suggests purchasing a device that alerts your senior loved one with a flashing strobe light or a vibrating pad under the pillow.

Basic Household Safety

A few basic household items will help keep your elder safe:

Step stool – "This is so an elderly person is not tempted to climb on a chair," Loverde notes.

Extendable gripper – This can be used to pick things up off the floor so an elderly person doesn't have to bend over.

Nightlights – Use these in every bathroom, bedroom and hallway.

Non-slip rugs

Good shoes that grip the floor

Telephones – Loverde recommends large-size key pads that light up in the dark. She also recommends that every house have at least one cordless phone. "And, if an elderly person doesn't shy away from technology," she adds, "cell phones are great in an emergency."

Lighting – Myers suggests installing outdoor lighting to increase visibility around the elder's home.

Basic Emergency Items
In case of emergency, your elder should have these items assembled in a clearly labeled container so that everything can be easily found and ready to go if necessary. "Large toolboxes, with removable trays for better organization, make great safety supply kits," Myers says.

- **First-aid kit** - Make sure that its contents are up to date and appropriate for your relative, Loverde cautions.
- **Two flashlights** with working batteries.
- **A battery-powered radio** - Make sure your elder knows which stations provide information in case of a disaster.
- **Extra batteries** for the flashlights and radio.
- **Extra pair of glasses**
- **Extra hearing-aid batteries**
- **Extra equipment or medical supplies** such as wheelchair batteries or oxygen.
- **Serial number, make and style of medical devices** such as pacemakers.
- **Medical insurance and Medicare cards**
- **Medical alert system** (a wallet card or bracelet)
- **Medical and personal information sheet** - A duplicate of the sheet posted in the elder's communications center.
- **Extra prescription medication**

You and your elder should make plans in case of a power failure. "Find out from the provider of your elder's medical equipment what he or she should do in case of power loss," Loverde suggests. Finally, you should notify your local emergency departments of any illness or disabilities your elder may have. Myers points out that some communities have a "fragile persons" registry or other advance registration.

Disaster Preparedness
The American Red Cross and eldercare experts recommend that you and your elder come up with plans for coping with natural disasters. This involves knowing what disasters could occur in your region and then making two sets of plans: one in case an evacuation is required and the other if residents are instructed to remain in place.
In addition to the basic safety items listed above, your elder should have:

- **A three-day supply of food and water** - The American Red Cross recommends nonperishable food items that are ready to eat and one gallon of water per person per day. Store the water in small containers that an elder can handle.
- **Can opener** - Choose a manual can opener that the elder can handle.

Nonperishable food for pets in the household.

Caregivers' Copies
Make sure that your elder's legal paperwork is in order long before an emergency occurs, Loverde advises. "You need to be sure that the legal documents are in a place that allow you to be part of the decision-making for this person. That means a power of attorney form for finances and health care."
You should keep copies of your elder's:

- Power of attorney
- Advance directive
- Will
- Medical history
- Emergency information sheet
- House and car keys and/or access codes (for alarms, safes, etc.)

Emergency Info

Name: _____
Mailing Address:
_____
_____
Telephone: _____
Date of Birth: _____
Driver's License #: _____
Auto Make & Model: _____
License Plate: _____
Social Security #: _____
Medicare #: _____
Health Insurance Policy #: _____
Allergies: _____
Blood Type: _____
Health Conditions: _____
_____
Medications (drugs, dosage & purpose):
_____
_____

Health Contacts
Doctor: _____
Dentist: _____
Hospital: _____
Pharmacy: _____
Local Agency on Aging: _____
Nursing or Homecare Agency: _____
_____
Insurance Provider: _____
_____

Network
Family: _____
_____
_____
Friends: _____
_____
_____
Neighbors: _____
_____
_____
Senior Center: _____
Social Worker: _____
Clergy: _____

Service Providers
Landlord: _____
Electrician: _____
Electric Co.: _____
Gas Co.: _____
Water Co.: _____
Plumber: _____
Cable Provider: _____
House-sitter: _____
Pet-Sitter: _____
Attorney: _____
Accountant: _____
Banker: _____
Insurance Agent: _____
House Alarm Co.: _____
Locksmith: _____

Adapting the Home for Alzheimer's and Dementia Sufferers

What kinds of home adaptations are necessary? If a person with Alzheimer's disease or some other form of dementia lives at home, caregivers must adapt the environment to ensure the safety of the senior and other household residents. It is important, of course, to take all the usual precautions, such as having smoke alarms and a fire extinguisher; making sure appliances and heaters function properly; and keeping extra food, flashlights and blankets on hand in case of earthquakes, power outages or other emergencies. However, Alzheimer's and dementia sufferers often do not recognize obvious dangers. These structural and design changes will help keep them safe:

- In the bathroom, install safety locks on cabinets containing medicines, household cleaning agents, razors and other potentially dangerous items. In the kitchen, put safety locks on drawers or cabinets containing matches, liquor, knives, household cleaning agents, scissors and any other potentially dangerous items.
- Put safety knobs on your stove, or install a timer so the stove can only operate during certain hours.
- Lower the temperature on the water heater to 120 degrees and label all hot-water faucets clearly with large, red letters. All seniors are at greater risk for scalding because of thinner skin and slower reaction times, and a person with dementia who may not recognize the danger even more so.
- Remove locks from bathroom and bedroom doors. A senior with Alzheimer's might lock a door and then not remember how to unlock it.
- Remove all clutter, throw rugs and other potential obstacles. Make sure hallways are clear and easy to navigate.
- Decorate with solid colors whenever possible. Patterns can confuse someone with Alzheimer's.
- Keep the home well-lighted at night. Waking up in total darkness can disorient.
- Place additional locks on doors a senior might use to leave the house and wander off. Locate the locks high up on the door or somewhere else difficult for the senior to find.
- Place solid black mats on the floor in front of doors leading outside. These can appear as deep holes to an Alzheimer's patient and may keep them from passing through the door.
- Check outside the house for potentially dangerous items such as saws, lighter fluid, power tools and paint. Put such items in a locked garage or tool shed.
- If you have a swimming pool, take precautions to prevent the senior from falling or wading in. Install a firm pool cover or put up a fence with a locked gate.

Other safety considerations In addition to home adaptations, keep in mind a few other safety considerations when dealing with seniors suffering from Alzheimer's or dementia:

- Do not allow them to smoke unattended.
- Make sure the senior wears an ID bracelet containing medical information and a phone number. Sometimes police find Alzheimer's or dementia patients wandering far from home and are unable to immediately identify the person and locate the family.
- Determine whether its time the senior stopped driving. Someone in the earliest stages of Alzheimer's or dementia may still be able to drive relatively safely, but at some point you will likely have to step in and prevent them from continuing. This may involve the drastic step of removing the keys or even disposing of the car. Ask a physician for guidance in making the decision and talk with the senior about this potentially difficult transition.
- It is important for seniors to stay engaged and involved in activities of interest to them as long as possible, but a moment will arise when not just driving but other tasks - such as shopping or going to appointments alone must simply be deemed too dangerous. Because the illness follows a different course in each individual, it is part of the caregivers responsibility to continually reassess the situation and determine when a senior can no longer safely perform a particular function.

Balancing the senior's need for independence with legitimate concerns about their own and others' well-being is one of the most heart wrenching aspects of caring for someone with Alzheimer's. The constant vigilance can exhaust even the most attentive and loving caregiver. Physicians, nurses and other professional caregivers - as well as family members, friends and others in the care giving support network - can help you make these assessments as the diseases progress.

Home Care Agency Checklist

If you are looking for home care via a home care agency, this checklist will help you judge the quality and scope of services provided when you contact an agency in your community.

Pre-screen for the basic scope of services. You'll save time if you know what type of care services you're looking for. Use the following points to help you get a handle on your basic level of need. Check which service your loved one requires:

- ☐ **Medical care** (e.g., wound care, injections, monitoring health conditions like diabetes or blood pressure or heart disease, assistance with medical equipment like dialysis, catheter, tube feeding or a ventilator).
- ☐ **Rehabilitation** to improve or retain function, speech therapy or help Swallowing, respiratory therapy, or help getting around the house or using assistive equipment.
- ☐ **Personal care** (e.g., help with bathing, toileting or incontinence, eating, dressing, getting out of bed)
- ☐ **Housekeeping** (e.g., preparing meals, doing dishes, laundry)
- ☐ **Chore work** (e.g., shopping, errands)
- ☐ **Nighttime care** Make sure you know what hours you will need care for (day, evening, all-night, etc.).
- ☐ **Transportation assistance** Will the worker be expected to transport your loved one to activities, shopping, medical appointments, etc.? If so, will the worker drive her own car? Your car?
- ☐ **Companionship** Is it important for the person to provide good company?

Get the basics on their business practice

- ☐ How long has your agency been in business?
- ☐ Do workers provide nursing care, non-medical care (personal care, chore or companionship) or both?
- ☐ Can your agency accommodate my loved one's needs? Note: describe person's diagnosis, age, special needs (e.g., administering medications, using home medical equipment).
- ☐ What are your fees (per hour, per day or per visit)?
- ☐ How many hours in a minimum shift? What about a maximum shift? Can a shift be split?
- ☐ Must the client have a doctor's authorization to receive home health care?
- ☐ Is a nurse or a therapist required to evaluate the client's needs? Will they consult with their MD?
- ☐ Are there any restrictions against accompanying the client outside the home or driving a car?
- ☐ Does your agency carry malpractice insurance?

Ask about worker qualifications and training

- ☐ Are all your home care workers licensed or certified? If not, what qualifications do workers have?
- ☐ Do you screen your workers? If so, what type of background checking is done?
- ☐ Are workers trained? If so, does the training include:
  - Safe bending and lifting practices?
  - CPR/first aid?
  - Infection control? Managing incontinence? Catheter care?
  - Communicating with someone who is confused or forgetful?
  - Managing difficult behaviors (e.g., wandering paranoia, or memory loss?)
  - Bathing someone in the tub/shower or in bed?
  - Preserving client dignity?
- ☐ Can you furnish references for your workers? If not, do you have any client satisfaction survey results?

See how their service quality measures up

- ☐ Are workers supervised? If so, by whom?
- ☐ Is there a written care plan specifying the home care worker's routine duties?
- ☐ Does the elder/family have input into the plan? Are there regular conversations about the client's case?
- ☐ Will a supervisor visit or call the home? To whom can the client/family ask ?'s or make complaints?
- ☐ How does the agency follow-up on/resolve problems or complaints?
- ☐ Can a known agency worker be requested, if there's a problem with the first one?
- ☐ How fast can agency respond to an emergency need? Are workers available 24/7?
- ☐ Can a replacement worker be called if the worker does not come or cannot complete a shift?

Learn about financing and payment

- ☐ Do you accept Medicaid? Do you accept Medicare?
- ☐ Do you accept private health care or long term care insurance?
- ☐ Does the agency pay the worker's social security and taxes? If not, do I need to pay this?
- ☐ What is the cost for overtime, if the worker stays late?
- ☐ When is payment due? (e.g., at the end of each visit? weekly? monthly?
- ☐ Does payment go to the agency? Or the home care worker directly?
- ☐ Are there any additional costs for travel time or extra services (e.g., doing laundry or errands)?

Hiring a Home Care Worker

You can find a home care worker from a variety of sources including a home care agency. You can also advertise for a home care worker in the help wanted or classified section of a local newspaper, at a senior center, community center, church or synagogue, or via a college paper or bulletin board, particularly at a school of nursing. Some community newspapers or newsletters also feature ads from individuals seeking employment as a household helper.

Step 1: Place an ad
A sample ad could read something like this:

Female needed part-time for personal care and housekeeping for older disabled woman. Flexible hours.
Call 555-1234 after 6:00 pm.

Home Helper needed for chores. Must have drivers license and car. Non-smoker with time available in mid morning to mid afternoon weekdays.
Call 555-4321 early morning is best.

Step 2: Screen candidates
You don't have to meet with everyone who responds to your listing. Before you set up an interview, make sure to ask a few prescreening questions so that the person understands the basic duties and schedule and you get an idea about the prospective worker's prior experience or training. In addition, be ready to provide basic information such as:

- ◊ How many hours of work (total per week or per month) are needed
- ◊ What days and times of day are needed
- ◊ Specific job duties (include driving, if appropriate)
- ◊ Salary, benefits, frequency of pay
- ◊ Other specifics (e.g., non-smoker only, must speak fluent English)

Step 3: Interview candidates
Interviewing is the pivotal part of your hiring process. This is where you ask more detailed questions and begin to evaluate which candidate is best suited to do the job. Use the following questions to gain a better understanding of the person you're interviewing:

- ◊ Where have you worked before? Do you have experience with an elderly or disabled person?
- ◊ Do you know about _____(ask about a specific illness or condition)?
- ◊ How do you feel about working for an elderly or disabled person?
- ◊ Tell me a little about yourself, your interests and hobbies.
- ◊ Do you have any health or physical problems which might hinder you on the job? (ask about lifting, bending, ability to drive, push a wheelchair, etc.)
- ◊ What other obligations do you have (e.g., school, part-time job) that will affect your schedule?
- ◊ Do you have your own car and car insurance? Would you be able to transfer someone from a wheelchair into a car?
- ◊ Are you comfortable cooking for someone else? How do you feel about cooking and eating food that someone else wants?
- ◊ How do you handle someone who is upset, angry or fearful?
- ◊ If appropriate: Do you have experience being around someone with memory problems? How do you handle someone who is confused?
- ◊ What made you choose this kind of work?
- ◊ Is there anything that makes you uncomfortable or angry?
- ◊ How do you feel about smoking, drinking or using drugs?
- ◊ Is there anything in the job description that you would not do?
- ◊ What time commitment are you willing to make? When could you begin work?
- ◊ Do you have any questions about the job duties, schedule, or salary?
- ◊ Is there anything else you would like to add?
- ◊ Please give me two work-related references and one personal reference.

Step 4: Evaluate the Interview
After interviewing a candidate, take a little time to note down your impressions or concerns. Try to do this immediately so the person is still fresh in your mind. This is a time for your "gut reaction" to kick in. So, use the following questions to guide you in choosing:

- Did the person arrive on time?
- Did I have a good feeling about the person/pleasant rapport?
- Did we agree on the job duties and schedule?
- Did the person provide the requested references?
- Did I tell the person when I would notify her?
- Was there anything about the person that made me uncomfortable?

Step 5: Check References
Once you have narrowed your choices, be sure to do some background checking on any candidate. Use the following questions to check with prior employers:

This is a reference for _____

Provided by _____ Date _____

Relationship to applicant _____ phone #_____

- How long have you known the applicant?
- What was her position?
- Please tell me about the responsibilities on the job?
- What is your impression of her as a worker?
- Is the person reliable? Punctual?
- Did she show initiative or wait to be told what to do?
- Does the person listen well? Follow instructions?
- Is she trustworthy?
- Does she show good common sense?
- Were there any problems on the job?
- Were you aware of any problems with drugs or alcohol?
- Would you recommend this person?

Step 6: Sign on the Dotted Line

Employer name_____

Employee Name_____

Date of Hire_____

Salary_____ (per hour, week, month)

Terms of Payment_____ (e.g., weekly, monthly)

Hours of Employment_____to_____on_____days
(changes in schedule or hours to be negotiable)

Employee's Social Security
#_____

Employee Duties (fill in):

Personal Care:	Household Chores:
1.	1.
2.	2.
3.	3.
4.	4.
5.	5.
6.	6.
7.	7.
8.	8.
9.	9.
10.	10.
11.	11.
12.	12.

Non-Acceptable Behavior/Reason for Termination:

Signed:

Employer Name_____ Date_____

Employer Name_____ Date_____

Hiring a home care worker requires patience and trust, and your instincts will be important. Beyond that, your time spent screening applicants and checking their references beforehand will greatly improve your chances of finding someone.

b. Living with you

Can your loved one live with your family?

1. Evaluate your elder's feelings about moving in with you. Would they feel they're a burden to you? Would they be bothered by the activities of you children? Would they feel isolated? Would they enjoy being in your home?

2. Evaluate your elder's personal qualities.

YOUR ELDER'S PERSONAL QUALITIES

Please check the closest response.
My elder family member is:

Column 1	Column 2
_____active	_____lazy
_____candid	_____manipulative
_____content	_____dissatisfied
_____cooperative	_____demanding
_____easy to talk to	_____difficult to talk to
_____encouraging	_____controlling
_____friendly	_____disagreeable
_____generous	_____selfish
_____good-natured	_____temperamental
_____happy	_____sad
_____independent	_____dependent
_____kind	_____discouraging
_____self-motivated	_____mean
_____social	_____antisocial
_____flexible	_____stubborn
Total_____	Total_____

-If most of the lines checked are in column 1,
your elder should be easy to live with in your home.
-If most of the lines checked are in column 2,
your elder may be difficult to live with in your home.

3. Evaluate your elder's care needs. Can you provide or arrange for adequate care in your home to meet these needs?

Financial activities
_____organizing and paying bills
_____handling basic banking activities

Homemaking activities
_____laundry
_____housecleaning

Meal preparation
_____assistance with meal preparation
_____assistance with eating
_____meals-on-wheels needed
_____special diet needed

Mobility
_____walks without assistance
_____uses walker or cane
_____no balance problems
_____balance problems
_____uses furniture to maintain balance
_____uses wheelchair
_____bedridden
_____needs med equipment/supplies

Nursing care
_____blood pressure check
_____dressing changes
_____injections
_____medication management
_____other_____

Personal care
_____bathing
_____brushing hair and teeth
_____dressing
_____incontinence care
_____personal hygiene
_____other_____

Supervision
_____daytime
_____nighttime
_____twenty-four hours per day

Transportation
_____to medical appointments
_____to social activities

4. Evaluate your family's feeling about your elder moving in. Does each member understand the changes that will take place?

Do you still feel living with your family is the best choice for your elder?
If you answer yes then begin making plans for this transition and use all available resources for the new situation.
If your answer is no begin evaluating alternative environments for care.

Moving Your Elder in With You: Practical Tips & Suggestions

If you are considering having your elderly parent or relative move into your home, you are not alone. When you consider all the lifestyle adjustments, role changes, and changes in relationships that will ultimately occur by having your elder move in with you, the prospect may seem daunting. So, before you make a quick decision, it is important to look at all the issues facing everyone involved.

When I was 17, my elderly grandmother moved in with my family. I look back on that time with a mix of emotions. I would not have traded the time I spent with my grandmother, but I also know how stressful it was for all of us.

In my situation, my grandmother's long-time companion had died suddenly, and my grandmother was no longer able to live on her own. She was partially paralyzed; therefore, there were mobility issues to consider in trying to determine where she should live. We eventually decided she should reside with us.

I remember the night my dad brought my grandmother to our house. She sat in the hall looking lost, broken and lonely. It was an awkward time for all of us. Looking back, I understand the range of emotions she must have been feeling. She had lost her best friend, had to deal with leaving her own house and she had to face moving into a different house in a different state. And as if that were not enough, she also had to live with a family with an unfamiliar lifestyle.

Living Arrangements. After you determine that you are emotionally ready to make the move, you must examine the living arrangements. When my grandmother moved in with us, one of the biggest adjustments she had to make was being restricted to the lower level of our house. Because of her partial paralysis, she could not navigate the stairs. Her bed, television, and a few other pieces of furniture were set-up in our back room. The only other rooms she had access to were the bathroom and the family room.

She was very upset that she could not prepare her food or cook in the kitchen. This issue turned into an emotional one for the whole family. This is one important issue that we should have resolved before she moved in with our family.

___ Is there enough room in your home for everyone to live comfortably?
___ Do any minor or major changes need to be made to accommodate any disability or mobility problems your parent or relative may have?
___ Have you reviewed the home for safety traps and potential problems?
___ Are you taking into account all privacy issues?
___ What, if any, furniture will your relative bring with him or her?
___ If your elder has Alzheimer's Disease or other form of dementia, will wandering be a problem? Should doors and windows always be secured?
___ Can you identify "Danger Zones" that should be restricted?
___ Can you identify "Safe Zones" where your elder is free to wander and explore?
___ Are there areas of the home where family members can separate themselves from the stresses of caregiving?

Financial Caregiving. As you take on more responsibility for your elder's well-being, you may find yourself managing her financial affairs. This is a doubly challenging responsibility since it presents the additional burden of spending time writing out bills, balancing accounts and managing investments. It also may require you to delve into very private matters that parents and relatives rarely share with their children.

___ Have you considered automatic payment of recurring bills?
___ Do all siblings understand and participate in the financial matters?
___ Have you researched low-cost or free assistance services?
___ Do you regularly meet with other family members to agree on new expenditures or to keep them apprised of accounts?
___ Have you discussed responsibility for out-of-pocket expenses with your siblings and your elder?

Assistance. Another important issue to resolve is whether your elder will need assistance during the day. This is especially important if the rest of your family works or goes to school outside the home.
___ If assistance is required, what arrangements can be made?
___ If your parent requires no daily assistance, will you be able to take off from work to take him to appointments or care for her when she is ill?

Relationship Changes. Role changes may be one of the hardest factors to deal with. I know it was for my grandmother and my dad. Essentially, my grandmother became one of the kids. She had to abide by the rules of the household, and although she was free to voice her opinions, she lacked the authority she once had to make final decisions. I can only imagine how difficult this must have been for her.

It was also difficult for my dad to assert his authority over his mother. He struggled with trying to keep the house running smoothly without restricting her so much that she resented him or the situation.

___ Are you prepared for role reversals that may occur? For example, your elder may no longer feel like the "parent."
___ Are you prepared to make rules that may not always be warmly received by your elder?

Emotional Space. Emily Carton, MA, LISW a Washington, DC area geriatric social worker for more than twenty years, says the biggest complaints people have when they take on this responsibility is that they have no time: they're exhausted and they do not get enough sleep. This is especially true for those who care for parents or relatives with special needs such as those with Alzheimer's Disease or other dementia.

___ Will you be able to cope with encroachment on your privacy? Some of us require more emotional space than others and may resent having someone around all the time.
___ Also, will you be afraid to be yourself? You must consider how you will feel having to be the source of care and entertainment for your new dependent.

Activities. It is extremely important for each of you to feel you are not restricted because of the arrangement.

___ Will you be able to support your parent or relative's outside interests?
___ If he enjoys going to baseball games, will you be able to take him or make arrangements for him?
___ Will your elder occasionally leave home to go to a senior center or visit with other older friends?
___ Will you be able to continue your own activities?

Respecting Yourself and Your Elder. Above all else, you must always remember to respect yourself. You must frequently pat yourself on the back for taking on such a big responsibility. If stress and resentment build up from time to time, you must have a support system in place to help you out. This move is not something you can do without the support of others.

You must also remember to respect your elder. Your elder spent most of his or her life raising and nurturing you, and is deserving of your praise. Although at times it may be difficult, your relative should not be made to feel as though she is a burden.

Your Elder's Contributions to the Family. Consider how much your parent can contribute to the family. Think of all the experiences your mom or dad has had that can be shared with you and your children. You can learn about parts of your family tree that you never knew about or events in history that you have only read about.

Carton, through her experience as a geriatric social worker, says many caregivers look at the situation as a "gift you can give back to your parent" for the gift they gave you at the beginning of your life.

As a teenager, I developed a deep friendship with my grandmother. We talked and laughed all the time. I learned so much about her personality - things I never would have learned by visiting her twice a year as we had done before she moved in.

She was there for some of the most important days of my life. She helped me get ready for my senior prom and graduation. I look back on those days with fond memories, and I am thankful I had the time with her. Despite the stresses on our family, I believe the overall experience was positive for the entire family.

Respite Care: Getting a Break

What is respite care?
Respite care means giving caregivers a break. It's more of a concept than a specific type of care. Anyone with a little experience knows that caring for someone who depends on you requires patience and stamina. The hours are long and it can be a frustrating and anxiety-provoking experience, for even the most patient person. Respite care offers temporary or intermittent ongoing care through a range of in-home and out-of-home service options. In essence, respite serves a dual purpose of keeping the care recipient safe while giving the caregiver time away from constant caregiving responsibilities.

Respite care can be informal. For example, another family member or a friend can take over caregiving duties for a few hours or a few days a week. More formal arrangements can be made using a paid home care worker, either hired independently or through a home care agency. Most home care agencies can arrange for overnight, or even 24-hour care for a period of time.

Other good sources of respite include adult day care centers, or special community-based respite programs for respite care during daytime hours. For individuals who require nursing care, many nursing homes can also provide short-term stays for respite care.

Who needs respite care?
Caregivers do. The main goal of respite is to prevent caregiver burnout. If you are a caregiver, you will need to protect your own health in order to provide the best level of care for your loved one. This means setting aside some time for yourself, making sure your own needs are met including getting to regular doctors appointments, running errands, and maintaining contacts in the community: in a sense having time off to "recharge your batteries."

It may be hard to admit, but a caregiver who is under too much stress from the constant demands of caregiving cannot provide adequate care. Without a break, the caregiver's health can suffer leaving two people who need care instead of one. Your ability to cope is essential to caring over the long run.

Some signs that may signal a need to arrange for respite care include:

- Increased anxiety
- Loss of sleep
- Physical strain (e.g., frequent colds, high blood pressure, back strain)
- Increased irritability
- Feelings of anger towards the care recipient
- Exhaustion
- Feelings of isolation from friends or outside activities

Where can you find respite care?
Programs actually called respite are relatively few and far between. Some states and local communities offer specialized "respite care" programs, though these vary considerably in size and scope. Your local Area Agency on Aging may be able to assist you in locating a program in your area. Since, these programs differ substantially, be sure to ask about who can be served including eligibility restrictions based on age, diagnosis, income, and other factors.
Many services and programs offer respite care to meet a variety of needs, preferences and budgets. Determine first whether or not you want care provided in your own home (if you reside with the care recipient), in the community (by day), or overnight in a facility. Once you have made your decision, you can explore the following care options:

Family and Friends
Volunteers
Home Care Agencies
Adult Day Care Centers
Senior Centers
Skilled Nursing Facilities

Family and Friends -- If you have family members who have offered their support, contact them to see if they can schedule a few hours or a few days a week to assist. If your care recipient has friends in the area who are able to provide you with some relief, contact them as well. Whoever you choose, make sure you go over all duties and responsibilities before you leave, and answer any questions. Also, remember to leave emergency numbers in plain view for the respite caregiver.

Volunteers -- It may be possible to locate a volunteer to provide periodic respite care. Check with local volunteer programs such as the Volunteers of America, senior centers, religious groups, or United Way. Volunteers should not be expected to handle complex care needs, but may be helpful in providing companionship or supervision of a homebound elder for a brief period of time. Explicit instructions should be given to make sure the volunteer understands what needs to be done and who to contact in case of an emergency.

Home Care Agencies -- If you choose to use a home care agency to provide respite care in the form of a homemaker or a home health aide, make sure you give the agency a complete overview of your care recipient's physical and mental status. Once the agency sends over a homemaker or home health aide to your residence, you should go over a list of duties with them and answer any questions they might have. Again, always leave emergency contact numbers in plain view.

Adult Day Care Centers -- If you decide that what you really need is respite several days a week outside of your home during the day time, you should contact an adult day care center. Adult day care centers are generally open weekdays, typically for 8-hour days and serve one hot meal and snacks during that time. Some centers are open on Saturdays as well. Many charge on a sliding scale depending on income. Most centers are staffed with social workers and activity coordinator or recreation therapists and provide social and recreational activities and help with basic activities of daily living. Some centers also employ nurses and physical therapists and offer personal care, health monitoring and rehabilitation. Specialized programs also cater to the needs of people with dementia. It can take several weeks to complete the enrollment process, so don't wait to sign up until the last moment.

Senior Centers -- If an elder does not require individualized care, a senior center offers relevant social or recreational activities that can be used as respite care. The main goal of a senior center is to provide diverse activities for active seniors including painting, cards, outings, lectures, dancing, movies, book sales, bingo and bridge. Transportation is often available.

Skilled Nursing Facilities (SNF) -- Some SNFs (nursing homes) accept individuals on a short-term basis for respite care. SNFs usually are equipped to admit people with dementia or other chronic health conditions requiring 24-hour care or supervision. The staff at any facility will need a current medical history before agreeing to provide respite care for anyone. Respite beds in a skilled nursing facility are often hard to come by and many make respite spots available only when they have empty beds. Be aware that not all nursing homes have openings for respite care and few may be willing to take Medicaid for respite beds. Make sure to contact the facility in advance and also to confirm a respite arrangement.

Who pays for respite care?
Paying for respite depends on the type of care selected. Informal arrangements are low cost or no cost. Varying hourly or daily rates apply for respite care at home, in a day program or a short stay in a nursing home.

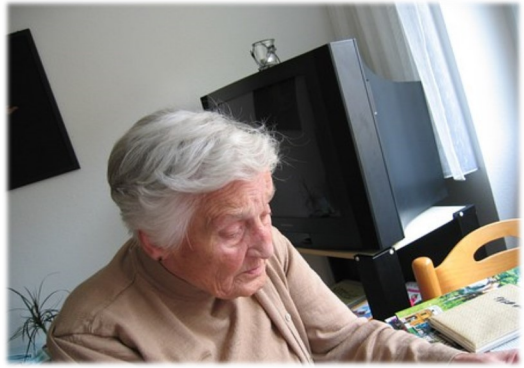
⇒ Relief care from family members, friends or volunteers is free.
⇒ Some states subsidize the cost of dedicated respite services for qualifying individuals (e.g., low-income Medicaid-eligible, frail elder, Alzheimer's disease, etc.). Community-based respite centers may even be free.
⇒ Independent providers (private individuals for hire) typically charge about $8-$15 per hour. Home care agencies generally charge from $15- $30 an hour (most have a 4-hour minimum).
⇒ Senior Centers are a good low cost alternative for healthy active elders, most programs are free, but offer little individualized attention.
⇒ Adult day health centers utilize a sliding scale, with fees averaging about $45 per day. Some may accept Medicaid reimbursement, if medically-oriented services are provided. This cost often includes transportation to and from the center.
⇒ Skilled nursing facility rates vary from state to state and may be reimbursable by Medicaid for qualified low-income persons. Private rates vary.

Few health insurance companies cover respite expenses. However, designated long-term care insurance may have a provision for respite care assistance. Be sure to check your policy coverage.

c. Assisted Living

Guide to Assisted Living Facilities

What is an assisted living facility?



Assisted living facilities (ALFs) are a category of residential care designed for individuals who do not require skilled nursing care, but could benefit from personal care assistance and support services. ALFs come in many shapes and sizes covering a range of living arrangements from small group homes with shared rooms to luxury private apartments. The definition of an ALF can vary from state to state, so it is very important for you to carefully check out services offered, building type and layout, state regulations and licensing requirements and financing options.

The following ALF models will give you a sense of the possibilities:

Board and care model: offers room and board in either a private home or larger building. Meals are in a common dining area. These facilities offer somewhat less independence and privacy since residents do not have the option to cook their own meals and my not have their own bathroom.

Hospitality model: offers apartment-style living and hotel-type services with limited personal care assistance for toileting, getting up from a chair, or assistance eating. Residents have a high-degree of independence but may not be able to stay if their care needs worsen.

Aging-in-place model: offers apartment-style living with more intensive personal care services which are more likely equipped to assist those in wheelchairs, or residents requiring more help with toileting and incontinence, getting out of bed or chair, or help eating. In some cases, services may come just short of **skilled nursing facilities.**

Specialized dementia care model: offers a greater number of staff per residents, specialized staff training and activity programs and building safety which includes secured exits and enhanced visual cues (like signs or pictures) to help residents feel more oriented in unfamiliar surroundings. These ALFs may or may not provide private apartments or private resident rooms.

A rapidly-growing segment in senior housing, there are currently an estimated 25,000 to 30,000 ALFs throughout the U.S. housing up to a million residents, primarily older adults.

What services are available?
Services vary widely from residence to residence. However, most ALFs offer a minimum package of support services including:

* 24-hour on-call staff to help with activities of daily living (e.g., bathing, dressing, toileting, walking, or getting out of a chair or bed)
* Emergency call buttons in each unit
* Medication management (administering medication or reminding residents to take prescribed medications)
* Housekeeping and laundry
* Meal services in dining hall (however, residents also have the option of preparing their own meals in their own kitchen-equipped units)
* Social and recreational activities
* Additional services (typically for an extra cost) such as beautician or barber services, newspaper subscriptions, non-medical transportation

What eligibility criteria apply?
Because the definition of an ALF can vary considerably from state to state, eligibility will also vary. However, as a rule of thumb, ALFs are not nursing homes and don't offer medical services or skilled nursing. Therefore, individuals with serious medical conditions or heavy care needs may not be appropriate for an ALF. Be sure to ask questions of any facility to regarding the restrictions or exclusions for:

* Full time use of wheelchair
* Constant supervision for someone with memory problems
* Hands-on care for feeding, toileting, catheter, or lifting
* Payment by public benefits (e.g., individuals eligible for Medicaid or Supplemental Security Income-SSI)

Are ALFs licensed?
Licensing requirements vary by state. Not all states require ALFs to be a licensed category of residential care, although some states do mandate staff training and certification. In addition, some ALF residences institute their own training programs or certification requirements to ensure quality care. All ALFs are subject to state and local building code and fire safety regulations. Because licensing requirements vary, you may with to contact your **state long term care ombudsman's office** to inquire about ALFs in your state.

How much does an ALF cost?
Costs vary considerably depending on the services provided, size of units, location and geographic region. Most facilities receive payments on a month-to-month contract, but some may require an initial lump sum payment.

It is important to note that the "basic service package" included in the monthly rate varies. There may be additional fees for "a la carte" services which increase the monthly rate. Therefore, interested persons should be sure to check out the complete costs for all services offered.

In recent years there has been a movement in some states to construct more affordable ALF units increasing the accessibility of this residential option to low-income elders.

Who pays for ALF care?
The vast majority of ALF residents (about nine in 10) pay privately – either the residents themselves or their families. Medicare does not pay for ALF care.

Home owners have additional financing strategies available including estate planning and reverse mortgages. Individualized legal and financial planning can be provided by a qualified elder care attorney. If you're planning for future needs, a long term care insurance policy may be able to help you cover the cost of an ALF.

Other financial assistance options are sometimes available. For example, some state with special federal Medicaid waivers, allow low-income Medicaid-eligibles to receive reimbursement for services provided in an ALF. However, room and board typically must be paid by the person's supplemental security income (SSI), pension or other means.

Making the "right" decision
An ALF is an exciting option for individuals who want to maximize their independence while in the safety of a residential setting. Talk with your loved one about his/her preferences. In addition, bear in mind that this option may not be appropriate for everyone. Consider the specifics of your loved one's care needs.

d. Residential Care

Evaluating Residential Care

Once you have decided to use residential care and have carefully reviewed the range of residential care options, you should:

- Identify your loved one's specific needs and preferences
- Establish a budget
- Determine when to make the move

Consider other criteria important to your situation (e.g., location)

After answering the above, you're ready to start your search. Whether you're looking for a board and care home, assisted living facility or nursing home, look for a place where your loved one will feel safe and secure, while maximizing independence, as appropriate.

Steps to take when selecting residential care:

Step 1: Identify the possibilities
Take the time to adequately research potential providers. Facilities are not evenly distributed geographically, so you will need to identify what is available in your community.

Step 2: Review the possibilities
Review your choices. The spectrum of quality and cost is substantial. As soon as you compile a list of potential providers, you and your loved one should begin the evaluation process as soon as possible. You can establish certain "cut-off" criteria based on distance from home, cost and level of care. This will help you narrow your search.

You can ask some initial questions by phone:

- What is your availability? Do you have a waiting list?
- What are you fees? What type of financing do you accept?
- Would your facility provide the care needed for _____(describe loved one's health condition)
- Is the facility fully wheelchair accessible?
- (If an issue:) Are pets allowed?

Step 3: Plan a site visit
If possible, plan a site visit to each facility under consideration. Site visits can be scheduled or unscheduled. You may wish to schedule a site visit the first time and plan to interview the facility administrator in person. Include your loved one in the process, if appropriate.

An un-announced visit can be conducted at a future date to give you confidence that what you saw the first time is accurate. When touring the facility, speak with the director, as well as some staff members and residents. In addition to your checklist, you can interview staff and residents individually.

Questions to ask when interviewing facility staff:

- How do you like working here? What makes a good day for you?
- Are daily schedules individualized? Do residents awake on there own accord and decide their own bed-times and outdoor times?
- Is the facility restraint free?
- What is the staff turnover rate?
- What does a resident do on a normal day?

Questions to ask facility residents:

- What makes a good day for you?
- Do you like any of the regular activities?
- Do you know the other people here – staff and residents?
- Is the food okay? Can you choose what you want to eat?
- Do you have any complaints?

Step 4: Do your homework
Before making a decision, it's a good idea to check out a facility's history. You can learn about any previous complaints filed or past citations from the Long Term Care Ombudsman's office. In addition, you can speak with residents on the premises, or ask to be put in touch with the resident's council or family council, if one exists.

Step 5: Make a decision
By following the above steps you should have a solid impression of your preferred choices.
Your other top considerations will include:

- Costs
- Available services and amenities
- Location
- Your gut reaction (or the preference of your loved one)

The move into residential care is very difficult life transition and trying to replace a loved one's former home can create unrealistic expectations. Be discriminating, but keep an open mind. Equally important, be supportive in helping a loved one with the change in living arrangement. Ultimately, the more prepared you both are, the smoother the transition will go. The work that you put into the process of evaluating a care facility should help you feel secure that you are making the best decision possible under the circumstances.

Easing the Transition: Moving into Residential Care

Once you've made the decision to use residential care, everything else should be easy, right? Not necessarily. While you may feel some sense of relief in finding a facility, you will still need to prepare emotionally and in practical terms for the move itself and your loved one's transition to a new living arrangement.

Offer support and reassurance

The most difficult part of moving may not be the packing or transportation. It's likely to be the emotional preparation for your loved one and the family. Leaving the comfort of home, the company of family and losing independence are emotionally-charged issues. Reassure your loved one that he/she will not be abandoned and that he/she is still loved. Make sure he/she knows that cherished pets or plants that cannot go along will be well cared for. Allow him/her to grieve. And, although you may be in the role of supporter, remember that you too will need to process the complex feelings regarding the move.

What to pack

What to pack depends largely on what type of facility your loved one will be moving into. Individuals going into a skilled nursing facility (or other residence with room and board accommodations) will bring the least since residents' rooms should be completely furnished. Nonetheless, a special chair or other small furniture item may be permitted, as space allows. Check on the house rules for plants. Some potted plants may be restricted as a potential allergen or toxic substance, if a bedroom is shared with other residents.

Packing recommendations include a two-week supply of clothing with an emphasis on comfortable, easy-fit and dressing. If incontinence is an issue, make sure clothing is easy to remove and that ample changes of clothes are packed.
In addition, be sure to bring along personal items like framed photos, photo albums or scrapbooks, reading materials and toiletries like cosmetics or special hair care items or lotions. Other "warm fuzzies" might include a personal pillow, afghan or comforter from home.

Expensive jewelry or other valuables are best left at home or in a bank safe deposit box. To minimize the risk of theft, anything of value should be inventoried and documented with the facility at the time of admission. You can also check with the facility to ensure there is a secure place for personal, legal and financial documents belonging to the resident.

Using Movers

If you're moving into an assisted living facility with a private apartment, you'll need to move furniture as well as clothing and personal items. Unless you have family members with strong backs who are up for the task, hire professional movers. If you don't know who to call, the facility may be able to recommend a moving company. It's a good idea to shop around. Call two or three companies to check prices and availability. Find out if they'll pack for you or if you need to pack everything (e.g., kitchen items) yourself.

Settling in

Leave time on moving day to help your loved one settle in. Unpacking personal items like family photos, scrapbooks or other treasured items will make the person feel more comfortable. In addition to setting up the room, you should plan to tour the facility and meet staff and other residents. You can request guest meals in the dining hall for extra family members on moving day. Also, make sure you know how to reach your loved one by phone-and he/she knows who to go to for questions or to get basic needs met. To make leaving more comfortable, schedule the next visit or outing before you go.

Helping a confused person

How you deal with orienting your loved one will differ greatly if he/she is forgetful or confused. A confused person can become more disoriented in a new environment and may not understand her new surroundings. Further, it may be impossible to prepare him/her ahead of time. Speak with staff before your arrival (and while you're there) to help minimize difficulties. Some families moving a loved one with moderate to severe dementia rely on well-intentioned deception (i.e., offering few details about the move before it happens). You can focus on offering comfort and compassion and reassuring the new resident that you'll be back soon.

You may find that regular visits without the burden of constant caregiving can help nurture your ongoing relationship with your relative. There's no one "right" way to make the transition work, so think through what strategy is most appropriate for your family.

Establishing a smooth transition

Make sure you have an opportunity to meet with the nursing assistants, the ones who provide hands-on care at the facility. Your ability to create a rapport between these caregivers and your loved one will mean the difference between the new resident having a personal relationship with staff and being one more nameless person on the shift.

Family members can help individualize care by helping staff get to know the new resident. Some families write a personal biography of their loved one including their history, names of children, siblings, etc., personal likes and dislikes (especially food), and tips for daily care (e.g., mom only drinks with a straw, or he/she always takes a bath-never a shower). Anything that will personalize care and help staff meet individual needs can be enormously helpful.

Visiting and ongoing contact

Leaving your loved one in the facility will be tough. It's unlikely that he/she will feel "at home" in the first days or weeks in a new place. The transition period will likely occur over several months. Your ongoing phone calls and visits will help immeasurably. In addition, by getting to know the Activities Coordinator you can learn about social activities that can help your loved one feel less isolated. If the new resident is able to develop a sense of community or other interests, it will lessen fears and wanting to go home.

Dealing with complaints

A new living arrangement necessarily means compromises, so be ready for some things to be less-than-perfect. Listen to your loved one's complaints - major and minor. Complaints about food are common and may require a conference with the facility administrator or kitchen staff. More serious complaints (either your loved one's or yours) can be addressed to the facility administrator, family council (if there is one) or contact the Ombudsman Office. The ombudsman is charged with investigating complaints in nursing homes and reporting facility violations.
It won't be easy, but by helping your loved one make this important life transition, you can continue to show that you care.

6. Locating Specific Resources

Help at Home

Home and Personal Care. Home-care aides do chores such as cleaning the house, grocery shopping, and laundry. Personal care is non-medical help with such activities of daily living (sometimes called "ADLs") such as bathing, dressing, or using the toilet.
Where to look for resources: KY Aging and Disability Resource Center (877-925-0037 http://chfs.ky.gov/dail/adrc/; online; KY Home Care Association http://www.khca.net/search-by-county.html.

Home Safety. Modifications you make to a house to make it "user-friendly" for elderly.
Where to look: **https://www.aarp.org/home-garden/housing/info-03-2010/fs168.html**

Meal Services. Home-delivered meal programs offer nutritionally balanced meals to those who can no longer shop for groceries or cook. Many Senior centers often offer lunch and the opportunity to eat with other people.
Where to look: Ky Dept. for Aging and Independent Living **http://chfs.ky.gov/dail/NutritionProgramfortheElderly.htm**; yellow pages

Companion and Telephone Reassurance Services. Volunteers make regular visits or phone calls to older adults who can't get out of the house. The volunteer checks on the person and keeps him or her company, providing regular contact for older people who are alone.

Home Observation. Some communities train mail carriers or utility workers to spot signs of trouble at the homes of older adults. When they have concerns, such as accumulated mail or trash, they report it to an agency that checks on the older person.

Home Health Care. Home health care is designed to address health care needs prescribed by a physician and provided by licensed professionals. This includes skilled nursing care, personal care, rehab therapy, & giving medicine.
Where to look: Medicaid home health services http://chfs.ky.gov/dms/hhs.htm#service

Personal Emergency Response Systems (PERS). A PERS is a simple device worn by a person to call for help in emergencies. When the user pushes the button on the PERS, it sends a message to a hospital or police station. Someone then checks on the person. A variety of options are available for purchase online.

Hospice Care. Hospice services include medical care, counseling, and pain control for terminally ill patients and their families. Hospice services are usually provided in patients' homes. They help the entire family, caregivers and the patient cope with issues related to the terminal illness.
Where to look: KY Assoc. of Hospice and Palliative Care www.kah.org 888-322-7317

Help in the Community

http://www.eldercare.gov/Eldercare.NET/Public/Index.aspx
Senior Centers. Many communities offer a variety of activities in centers designed for older adults.
Where to look: DAIL http://chfs.ky.gov/dail/AreaAgenciesonAging.htm; yellow pages

Transportation. Many communities provide transportation to medical appointments, senior centers, or shopping. These services are usually free. Some may have a small fee. Other transportation services, such discount taxi programs, van services or volunteer drivers are often available, too. Find local community resources online.

Adult Day Centers. For the older person who needs supervised assistance, these centers offer many services in group settings. Services may include health care, recreation, meals, and rehabilitative therapy. These centers meet the needs of people with mental or physical limitations. While there is usually a cost, many offer sliding rate scales and some financial assistance.
Where to look: http://chfs.ky.gov/dail/adultday.htm; yellow pages
Respite care. Respite care provides time off for family members who care for someone who is ill, injured, or frail. It can take place in an adult day center, in the home of the person being cared for, or even in a residential setting such as an assisted living facility or nursing home.
Where to look: www.eldercare.gov

Residential Resources

Assisted Living. If your loved one is in good physical health but needs help with bathing, eating, or remembering to take meds then AL might be an option.
Where to look: www.eldercare.gov; yellow pages

Nursing Homes. Nursing homes are for people who need extensive & extended health or personal care.
Where to look: www.eldercare.gov; yellow pages
Nursing Home Rating Comparison guide – Compare Local Nursing Homes click here

Paying for Services

Medicare. This program provides medical coverage for most people over the age 65. Medicare covers limited skilled nursing home care and home-care benefits.
Where to look: www.medicare.gov 1-800-Medicare.

Medicaid. A state and federally funded program to help people with low incomes pay for medical care. Medicaid may help pay for nursing home care and sometimes services at home. It's important to check with your local Medicaid office for eligibility.
Where to look: http://www.cms.gov/home/medicaid.asp; in KY http://chfs.ky.gov/dms/services.htm 1-800-372-2973

Private Long-Term Care Insurance. This type if insurance pays for care in nursing homes, assisted living facilities, and/or home care depending on the policy. The older you are when you purchase your coverage, the higher your costs, and it is not affordable for some.
Where to look: http://insurance.ky.gov/Documents/2008LTCguideComplete010709online.pdf

Additional Resources

Additional information may be found at www.AARP.org
AARP is a nonprofit, nonpartisan organization that helps people 50 and older improve the quality of their lives.

Eldercare Locator. The U.S. Administration on Aging can help you find local services for legal assistance and prescription assistance.
Where to look: **www.aoa.gov**

Benefits Check-up Answer a few confidential questions and this database tells you which federal, state, and local programs you might be eligible for and how to apply. The site is provided by the National Council on Aging.
www.benefitscheckup.org

Eldercare Management Services. These fee-for-service providers will meet with families to develop eldercare plans. May advertise at senior centers, the yellow pages and on-line.

7. Legal Concerns and Financial Concerns

Getting Affairs in Order

When an aging family member suddenly needs help with daily living tasks or must enter a nursing home, the emotions of such a change can interfere with a family's ability to make decisions. The decision making process can seem overwhelming, particularly if legal concerns are involved. While dealing with your parent's legal concerns may seem difficult, you need not feel overburdened. The best defense against confusion and uncertainty in coping with legal issues is to prepare in advance of change. The information in this section offers some suggestions for preparing you and your parents for the day they may need your assistance in handling their legal affairs.

Relatives and friends sometimes must help older people manage their legal or financial affairs temporarily or even gradually assume these responsibilities. Often the person who provides care has little knowledge of vital information and records. If papers are in order, the task is much simpler. The following suggestions can help most people begin creating a financial and personal records file.

Personal Records File A personal records file should include the following information:

- Full legal name/Social Security number/Date and place of birth
- Legal residence
- Names and addresses of spouse and children (or location of death certificates if any are deceased)
- Location of will or trust; Location of birth certificate and certificates of marriage, divorce, and citizenship
- List of employers and dates of employment;
- Education and military records;
- Religious affiliation, name of church or synagogue, and names of clergy (if desired)
- Memberships in organizations and awards received;
- Names and addresses of close friends, relatives, doctors, and lawyers or financial advisors
- Requests, preferences, or prearrangement for burial.

A family member or friend should know the location of this personal records file and the location of all important papers and documents, although it is not necessary to reveal the contents of wills or trusts.

Financial Records File In making a financial records file, list information using this outline:

- Sources of income and assets (pension funds, interest income, etc.);
- Social Security and Medicare information;
- Investment income (stocks, bonds, and property);
- Insurance information (life, health, and property), with policy numbers;
- Bank accounts (checking, savings, and credit union);
- Location of safe deposit boxes;
- Copy of most recent income tax return;
- Liabilities--what is owed to whom and when payments are due;
- Mortgages and debts -- how and when paid;
- Credit card and charge account names and numbers;
- Property taxes; and
- Location of personal items such as jewelry or family treasures.

Having this information available can help you or a family member plan for any change in later years--retirements, a move, a death in the family--and can help you or a family member make wise decisions.

Legal Definitions

Power of Attorney This is a legal device which permits one individual (the Principal) to give to another person (the attorney-in-fact) the authority to act on his or her behalf. The person with power of attorney is then authorized to handle banking and real estate, pay bills, incur expenses, and handle a wide variety of legal affairs for a specific period of time. This can continue indefinitely as long as the person granting power of attorney remains competent and is capable of granting power of attorney. This kind of power of attorney expires when the Principal becomes comatose, mentally incompetent, or dies.

Durable Power of Attorney Most people feel more secure knowing that, in the event of incapacity, a trusted person and not the courts will make decisions and carry out their wishes. A Durable Power of Attorney gives a specified person this right despite the physical or mental incompetence of the elder. It terminates only upon the death of the grantor (Principal) or if revoked by a legally appointed guardian or by the grantor if he or she remains competent.

Guardianship or Conservatorship A guardianship or conservatorship, arranged through an attorney, blocks a person from acting on his or her own behalf. This arrangement is useful when a person is incapable of managing financial and/or personal affairs, or does not know that he or she is managing poorly, and this incapability poses a major threat to his or her well-being. All guardianships must be approved by a court and actions taken by a guardian are overseen by the court.

Social Security Representative In the event a parent or older person cannot sign a Social Security check, the Social Security office will appoint a person, institution, or community association as representative payee. The name on the Social Security check is changed from the direct beneficiary's to the payee's, and the payee is then responsible for distributing the money on behalf of the beneficiary. Social Security checks can also be directly deposited in most situations.

Will A will is a legal declaration of how the deceased wants his or her money, property, and other possessions disposed of after death. A will also can be used to determine guardianship of minor children and to set up trusts for heirs who may have an inadequate knowledge of how to manage inherited money or property. Without a doubt, every person with property of any value should have a will. However, many people delay thinking about death and then die intestate, that is, the State distributes their estate according to the laws of the State. When drawing up a will, a parent and older person should make a list of his or her resources and clarify and write down his or her wishes. The parent and older person must choose an executor and witness to the will. The parent and older person also has the responsibility to review it periodically, to keep it up-to-date, and to see that it is stored in a safe place. You should know where your parent or older person's will is kept.

Living Will A living will is a document that allows people to state, while they are still able, their wishes regarding the use of extraordinary measures or procedures to keep them alive when it is evident that they are dying. The living will may also appoint someone else (a relative, friend or attorney) to direct health care if the person signing the living will is unable to do so. In most cases, people who sign living wills want to be certain that they will not receive unwanted or unwarranted treatment if death is near and they have no reasonable expectation of recovering. Others may want to make clear that they want to be at home when death is imminent, or that they want to donate their organs after death.

Legal Aid There are a few programs that will provide low-cost legal services to a parent or older adult. Legal aid offices are set up to provide low income individuals with legal services if they meet eligibility guidelines.

Free Legal Advice for KY Seniors

The Legal HelpLine for Older Kentuckians is a service of the Access to Justice Foundation (AJF). It is a service intended to help elderly Kentuckians with legal issues. The service provides legal advice and assistance to persons age 60 and older and their caregivers. **The toll-free number is 1-800-200-3633.**

Who can call? Calls by older Kentuckians and their children or caregivers are welcome.

How does it work? The Legal HelpLine is a telephone advice and referral service. Calls are answered or returned in the order they are received. If the attorneys are busy, callers need to leave their name, phone number (including area code) and a brief message about the type of question they need help with.

What kind of questions can the HelpLine answer?
Frequent topics are:

Medicare and Medicaid
Wills and basic Estate planning
Working with bill collectors
Credit card debt
Home repair problems
Power of Attorney
Guardianship
Living Wills and Advance Healthcare Directives

Does it cost me anything?
No. The call is toll-free and the attorneys can provide advice and limited assistance at no charge. Some problems are too complex to be handled through the HelpLine. In those cases, an attempted referral will be made to an attorney who has agreed to take the case for free or a reduced rate, or to a social service agency.

The HelpLine provides basic advice about Living Wills, Health Care Surrogacy appointments and Durable Powers of Attorney. Referrals to attorneys who will prepare these documents for free can also be provided.

Legal HelpLine for Older Kentuckians/Access to Justice Foundation
535 West Second Street
Suite 101
Lexington, KY 40508
1-800-200-3633 (Toll-Free)
859-233-4747 (voice)
859-231-5356 (fax)
rcooke@ajfky.org (email)

Financial Matters

The information in this section briefly discusses financial considerations that you and your parent or older person may wish to consider. The information is in no way intended as financial advice nor as a comprehensive overview of parent or older person financial concerns. Instead, this section is intended to introduce you to or remind you of some common financial topics that concern parents or older persons.

Social Security--The General Idea The basic idea behind Social Security is a simple one. An individual pays taxes to the system during his or her working years, and the individual and members of his or her family receive monthly benefits when he or she retires or becomes disabled. Or, survivors collect benefits when an individual dies.

Here's An Important Point Social Security is **not** intended to be an individual's only source of income. Instead, it is meant to be used to supplement the pensions, insurance, savings, and other investments accumulated during the working years.
There are three types of Social Security benefits:

*Retirement Benefits provide retirement income to retired workers and their families
*Survivors Benefits provide income security to family members upon the death of a breadwinner
*Disability Benefits provide protection against the loss of family income due to the disability of a breadwinner.

Signing Up For disability, survivors, and SSI benefits, your parent or older person should apply as soon as he or she is eligible. When signing up for retirement, Social Security asks that an individual do so about three months before he or she wants the benefits to start.

When Individuals Need Help Handling Their Benefits Sometimes Social Security or SSI recipients are not able to handle their own financial affairs. In those cases, the Social Security Administration turns to a relative, a friend, or another interested party to handle a person's Social Security matters. This person becomes the "representative payee." All Social Security or SSI benefits due are made payable in the payee's name on behalf of the beneficiary. Contact the Social Security Administration for more information.

For further information about any
Social Security Program, or to apply,
Call SSA's Toll Free Number

1-800-772-1213
Monday - Friday
7 a.m. - 7 p.m.
(Eastern Standard Time)

Tax Information
Contact the Internal Revenue Service (IRS) toll free at **1-800-829-3676** to receive assistance in filling out tax forms for older persons. The IRS will refer you to a volunteer tax assistant in your area.

Veteran's Benefits Some seniors may qualify for VA benefits, including adult day care and long-term care placement. Refer to **www.va.gov** or appropriate state agency for more info.

A Quick Guide to Understanding Medicare

Medicare is a health insurance program administrated by the federal government. It is designed to help those over the age of 65. However, individuals with certain disabilities are also entitled to it. In addition, those with Lou Gehrig's disease and advanced kidney failure are eligible for Medicare.

Understanding the different types of Medicare can be confusing. Here is a brief overview of the different Medicare "parts" and a few optional plans:

Medicare Part A When you check into a hospital or long-term care facility, the admission is covered under Medicare Part A. Short-term health care and hospice care all fall under the auspices of Medicare Part A. It is free for participants, and most people are automatically enrolled at the age of 65.

Medicare Part B When you visit your doctor, have outpatient tests, or receive other medical care that doesn't require checking into the hospital or long-term care facility, Medicare Part B kicks in. Though coverage is available for everyone who qualifies for Part A, Medicare Part B requires an annual deductible and a monthly fee.

Medicare Part D Prescription drug plans fall under the umbrella of Medicare Part D. The plans are run by private insurance companies, so the amount of coverage may vary from one plan to another. Financial help might be available for those who can't afford the full cost of the prescription plans.

What about Other Medicare Plans? There are several other plans that are often considered part of Medicare, but might not be. Here are a few of the most common plans often mistaken for Medicare:

- **Medicaid.** This is not part of the Medicare plan. Medicaid is for those who have medical need but have low incomes and cannot afford medical care.
- **Medigap**. These plans are administered by private insurance companies and cover the costs that Medicare does not. The cost depends upon the plan chosen.
- **Medicare Advantage.** These are Medicare plans, but they are managed by private insurance companies. They might restrict the doctors you can see, and they usually cost more. However, these plans can combine Medicare Part A, B, and D into one package, which might make several aspects of care easier.

How Do You Qualify for Medicare? If you are 65 years or older, a permanent resident of the United States, and worked in Medicare-covered employment for at least ten years, you should be eligible for Medicare. If you receive Social Security benefits, you can get Medicare Part A without having to pay premiums. If you qualify for Part A, you automatically qualify for Part B as well.
Medicare can be confusing, but your Social Security office is trained to help you with any questions you might have. If you have any questions about eligibility, coverage, and what you might have to pay, contact them at your earliest convenience.

For Questions about Medicare and insurance coverage in KY for Seniors contact
SHIP 1-877-293-7447

The SHIP program provides health insurance information, counseling and assistance to seniors and disabled individuals. This service is provided at no charge by local, well-trained counselors.

Understand Medicare Home Care Benefits

For many caregivers and families who are searching to find out more information on how they can care for their elders and loved ones, it can seem like a daunting task. One of the most important distinctions that have to be made on your information gathering quest is to know the difference between Medicare covered Home Care vs. all other forms of home care.

What is Medicare Home Health Care? Home Health Care is skilled nursing care and certain other health care services that you get in your home for the treatment of illness or injury. One of the services offered to senior citizens by Medicare is Home Health Services. Medicare recipients must qualify for services, and must be recommended by the individual's primary care physician or specialty care physician. Medicare beneficiaries who feel they may need Medicare home care should always look into whether they can actually qualify for Medicare home health services. It is not a general personal care or chore-worker service. Rather, Medicare home care covers limited, specifically defined at-home care related to diagnosed medical conditions, and sometimes includes personal care services.

These Medicare home health services must be prescribed by a physician, and provided through a licensed home health agency. The beneficiary must have a medical condition, or combination of conditions, that require periodic services from a skilled nurse or therapist. A plan of care will be developed that describes the specific services covered. Eligibility and coverage are evaluated strictly so the beneficiary's conditions and care needs must be aired fully.

Medicare Home Health Care Qualifications It is common for an elderly person to need assistance upon discharge from a hospital or in-patient rehabilitation stay. That individual's physician, sometimes in concert with family members and the patient him/herself, would determine the in-home health care need and complete paperwork that refers the patient to home health care.

Other common situations include the slow physical decline elderly people experience; when that decline includes inability to care for oneself on a daily basis—but nursing home care is not yet required—the physician may recommend home health care for just those tasks the senior is unable to perform.

These four conditions must be met before home health services can be prescribed and covered by Medicare:

1. Your doctor must decide that you need medical care in your home, and make a plan for your care at home; **and**
2. You must need at least one of the following: intermittent (and not full time) skilled nursing care, or physical therapy or speech-language pathology services or continue to need occupational therapy; **and**
3. You must be home bound or normally unable to leave home & leaving home takes a considerable and taxing effort. A person may leave home for medical treatment or short, infrequent absences for non-medical reasons; **and**
4. The home health agency caring for you must be approved ("certified") by the Medicare program.

What Does Medicare Home Health NOT Cover?

*Round the clock care at home
*Prescription medication
*Homemaker services- shopping, cooking, cleaning etc.
*Home delivered meals
*Personal care by an aide (bathing) when it is the only care needed
*Medical services or supplies that Medicare doesn't pay for
*20% of the Medicare-approved cost for Medicare-covered equipment

Medicaid is Different than Medicare

Medicare and Medicaid are different and separate programs. Medicare is a federal health insurance program primarily for older adults. Medicaid is an assistance program for people with low incomes.

Medicare doesn't cover most long term care expenses, but learning how to maximize its benefits is an essential step toward meeting the costs of aging. In most states, Medicaid covers nursing home costs and provides some assistance to qualified caregivers. Even if your loved one is financially comfortable today, it's a good idea to learn about Medicaid.

Medicaid is a government assistance program that serves financially needy people regardless of age. Benefits vary by state, but at minimum, Medicaid covers the same services as Medicare. Many caregivers ignore Medicaid, assuming that their loved ones will never meet the financial eligibility requirements. That's often a mistake—the cost of long term care can quickly drain even a substantial savings account, making Medicaid a necessity.

To qualify for Medicaid, a person must not exceed strict limits on income and assets. Check with your state's Medicaid program office for details and to learn how gift-giving and other factors can affect eligibility. In KY 1-800-372-2973

Understanding Medicare Plan Part D

Some of the following tips may help you or an elderly loved one untangle the confusing web of technical jargon and exceptions to eligibility for the Medicare Part D program.

1. **Speak with your Physician.** Since more than 41 million seniors are eligible for Medicare Part D, their physicians are commonly asked about Medicare Part D eligibility and prescription coverage which varies by each coverage option. Many physicians are prepared to help their patients find the answers to these questions using mobile devices or searching the internet.

Many practitioners offices use free software applications like Epocrates RX Drug and Formulary Reference, to find out which medications are covered by each health plan. These programs also help to identify generic or less expensive alternatives. In addition, the software is designed to help determine which Medicare health plan will best suit each patient's medical and financial situation. Potential drug interactions will be flagged as well.

2. **Check with helpful internet sites.** There are several government websites designed to help seniors determine what kind of coverage they may be eligible for and which prescriptions may be covered. A user friendly site developed to help seniors is www.healthcare.gov. Make note of all prescription or non-prescription medications you are currently taking as well as any medical diagnosis you've received before starting your search. This will help you determine which plan will best suit your needs.

3. **Talk with friends and family members.** Ask a friend or family member to help you in your search, and check with other seniors who have enrolled in a Medicare Part D plan. Their experience could help you navigate finding the right coverage.

Is a Reverse Mortgage a Good Idea for My Parents?

With all of the recent attention given to reverse mortgages, you may be wondering if it makes sense for your elderly parents to apply for one of these loans. Under the right circumstances a reverse mortgage can be a wonderful financial tool that can provide another source of income for folks over 62. But there are pros and cons to taking out a reverse mortgage that need to be considered very carefully.

First, adult children should always consult with their parents before making financial decisions for them unless their parents are physically and/or mentally unable to be involved. If you are the authorized legal representative for your aging parents, you can request a reverse mortgage counseling session. Counseling allows you to take a look at your parents' overall finances to decide whether a reverse mortgage is a smart option.

Why Consider a Reverse Mortgage?

Reverse mortgages are paid as a lump sum of cash, through regular payments, or a combination of both. Your parents have the option of choosing how they want to receive their money, as well as how to spend it. Reverse mortgages are popular because the money received doesn't have to be repaid until a homeowner dies or moves. These loans also typically don't require income or credit checks.

When Are Reverse Mortgages a Good Option?

Some folks are better candidates for using a reverse mortgage to tap into home equity than others. Your parents may see real benefits from a reverse mortgage if they:

- Own their home free and clear or have a low mortgage balance
- Are over 70, since the older they are the more money they can receive
- Need extra cash to help pay medical costs, credit card debt, or other bills

Want to use the proceeds from a revere mortgage to downsize to a smaller home

When Are Reverse Mortgages a Bad Option?

Don't jump on the reverse mortgage bandwagon without considering how a loan may impact the overall finances of your aging parents. A reverse mortgage may not be a good idea if:

- Your parents' home has lost a lot of equity during the housing downturn since this can lower the amount of an appraisal
- Your parents aren't that old and really don't need the money right now. Waiting a few years means they should be able to qualify for a larger payout when they apply for a reverse mortgage
- The mortgage lender pressures them to purchase annuities or other expensive financial products
- Your parents plan to move from their home in a few years. Money received from the reverse mortgage typically has to be paid back when they leave their home
- Your parents want to leave their home to you as an inheritance

Being the caregiver for aging parents isn't easy. In addition to knowing where to go for good medical care, it's important to know where to turn for help with important financial decisions. A reverse mortgage is just one of the tools that may be able to help manage your parents' finances more effectively.

When Your Loved One Resists Care

How many times has your mother refused to change her clothes? Has your father resisted getting out of bed? Has your wife pushed you away when you tried to brush her teeth? Many times a caregiver will be particularly frustrated by her loved one's refusal to help himself. At times she can't help but think that the person she cares for "36 hours a day" is going out of his way to make her miserable! The increasing irrationality of individuals with dementia makes it even harder on the caregiver. Individuals who resist care and assistance are trying to communicate to you. If dementia, stroke, vision loss, hearing loss or other illness limits one's ability to speak and convey information effectively, body language and physical actions take on a greater role in communication. Refusal to accept care, physical contact or participation in an activity is the individual's way of telling you something.

When your loved one resists care, step back calmly and think:

- Are there any environmental factors such as lighting, shadows, noise, commotion or other external influences that are causing the problem now?
- Before you say something, think about what you are going to say. Check your emotions and frustration before you speak. Your increased frustration can contribute to your loved one's agitation.
- Put yourself in her shoes. Use your knowledge of her personal background to pinpoint patterns and reasons for her reaction.
- Is this confrontation worth escalating? Choose your battles wisely. A head-to-toe bath is not necessary every day or even more than once each week. Similarly, clothes do not have to be changed every day if they are not soiled.

Refusal to accept care or engage in once-pleasurable activities is a sign that something is amiss. The caregiver can assess the situation for specific complicating factors and make adjustments if necessary:

- Refusal to get out of bed: illness – Assess physical factors such as injury from a fall, bruises, temperature/fever, urinary tract infection, or oral infection. Keep a thermometer handy and know how to use it. Make a point every day or so of inspecting skin for dryness, sores or bruises. Catching skin or mouth sores early on will limit long-term damage and illness.
- Refusal to join family or participate in even small activities: environmental – Assess for too much noise, harsh lighting, or specific individuals who cause distress. Correct these distractions and integrate positive factors such as music, aroma, comfortable fabrics and warmer room temperatures.
- Refusal to perform tasks and activities: depression – The inability to fully perform tasks for oneself can cause an individual to avoid those situations. Assist them as much as possible while encouraging them to do as much for themselves without embarrassment. This is time-consuming, but it is the best route for enhancing self-esteem and independence.
- Refusal to take medication: physical side effects – Sometimes side effects result from medication that are unbearable to the recipient. Learn what possible side effects can occur from the drugs your loved one takes. Consult with the doctor to see if over-the-counter anti-nausea, anti-diarrhea, or anti-dizziness products can be taken with prescription medications. Perhaps the medication can be taken at bedtime or mealtime to reduce side effects. When administering the medication, tell your loved one how it will help them and use distraction if side effects occur.
- Refusal to bathe or change clothes: embarrassment – Limit other people's presence (even their voices), approach in a non-threatening way, undress/bathe one area at a time and keep the rest covered, speak calmly and tell your loved one what you are doing each step of the process. Talk about pleasant memories and stories as you are bathing/dressing.
- Refusal to eat or clean teeth: illness, incapacity – Oral hygiene is essential for elderly persons since poor hygiene can make eating painful and compromise nutrition. Don't let oral health get to a point where it is a problem. The sense of taste declines with age, so make efforts to improve the flavor of food, make it appear appetizing, and ensure that portions are of the right size and consistency. You may need to provide pre-cut portions or thickened liquids. See if better shaped utensils and plates help your loved one feed herself.

You may have to use your own creative ideas to get around resistance. One caregiver's mother often refused to settle down for dinner. So the caregiver helped her mother get dressed up a bit with a nice sweater, a brooch and her purse. The two dined out on the patio without incident. If your loved one still resists care even after adjusting for other factors, remember that confronting your loved one at that time of heightened emotions may make both of you more agitated. Take a time-out and attempt the task later.

Managing Problem Behaviors

Anyone who has an elder with Alzheimer's Disease knows that the hardest part of caring for the individual comes from the problem behaviors that can occur as a result of the disease. In some people, problems begin in the early stages of the disease and last until they die. Others seem to live in their own little world and are passive and easy to deal with. Sometimes "problem" behaviors are in the eye of the beholder. A behavior that may be problematic for one caregiver may not concern another. The key for dealing with behavior problems is for caregivers to have a positive attitude and be flexible. This article focuses on reducing or eliminating problem behaviors once they occur. Alzheimer's Disease is not just a disease of memory loss. People with Alzheimer's Disease also show symptoms of:

- Language problems;
- Problems with judgment, reasoning, sequencing and planning;
- Problems with perception;
- Loss of motor skills;
- Inability to carry out daily activities;
- Personality changes

All of these deficits lead to changes in behavior that can range from simple repetitive behaviors and lack of interest in past hobbies to extreme agitation and violence. Some of the problem behaviors seen in people with Alzheimer's Disease include:

- Anxiety; Easy Frustration;
- Wandering; Rummaging;
- Stealing other's property;
- Pacing; Inability to remain quiet;
- Disorientation to time, place and/or person;
- Constant demand for attention;
- Repetitive speech and/or actions;
- Restlessness and fidgeting;
- Inappropriate toileting; Undressing; Feeding problems;
- Inappropriate sexual behavior;
- Emotional outbursts; Screaming; Cursing;
- Combativeness; Hitting, kicking and biting;
- Lack of interest in surroundings/activities;
- Disturbance of sleep/wake cycle;
- Hostility; Being uncooperative;
- Paranoid ideas; Hallucinations; Delusional ideas;
- Resisting care or refusing care;
- Mood swings; Sadness, hopelessness or despondency;
- Catastrophic reactions (when a demented person has an extreme reaction, often due to sensory overload)

Understanding Problem Behaviors Difficult behaviors can be more easily understood if caregivers remember that:

1. All behavior has meaning: It is most important to remember that all behavior has meaning, even if it's sometimes hard to determine what that meaning is. Caregivers can't think like a person who has Alzheimer's Disease because caregivers are capable of logically thinking through their own behaviors. People with Alzheimer's Disease don't follow logic and can be very difficult to understand.

2. There is always a cause for a behavior and a result of the behavior: Behavior always has a cause and a result. For instance, a person may start to pace for multiple reasons. He may have a generalized feeling of anxiety or he may be searching for something. The behavior's result can be anything from a decrease in the feeling of anxiety to finding a way out of the house in order to search further.

3. Behavior does not occur in a vacuum: There are always outside influences that modify behavior. They can come from people or from the environment. For instance, a person with Alzheimer's Disease who is a resident of a nursing facility might become agitated when a message from a staff member is heard over the loudspeaker. Since these influences change from moment to moment, behavior also may change from moment to moment.

Stage One: Early

Behavioral problems often occur early in the disease, before a caregiver is even aware that the person is afflicted. For instance, the person may become easily angered when a mistake is made due to memory loss. One person may lash out verbally at the caregiver when it is pointed out that she forgot to pay a bill. Another may become very angry when he asks why a favorite relative hasn't visited lately and is told she was just there the day before.

Stage Two: Middle

As the disease progresses, behavioral problems may become more frequent and severe. Some people in Stage Two become very paranoid and suspicious, accusing their caregivers of stealing things or being unfaithful. Some people have sleep disturbances and begin to wander from home.

Stage Three: Late

The person may yell inappropriately & may resist a caregiver's attempts to help with bathing, dressing or other personal care.

Guidelines for Dealing With Behavior Problems

- Everything surrounding a person could contribute to the behavior problem;
- A thorough assessment of the elder, the environment and the caregiver by a trained professional is necessary in order to plan for intervention;
- Think ahead and plan for situations that could result in problem behaviors;
- Trying to argue or reason with a person who has Alzheimer's Disease only results in frustration for both the caregiver and the elder. It is not possible to win an argument with a person who has Alzheimer's Disease;
- Distract and divert whenever possible;
- Keep the routine the same. Changes in routine are upsetting to people with Alzheimer's Disease and can cause behavior problems;
- Promote a sense of security and comfort when problem behaviors occur. Problem behaviors often happen because a person is frightened and unable to make sense out of the environment;
- Use positive reinforcement such as food, smiles, a gentle touch, personal attention and lots of praise. These tools are more effective than negative reactions;
- Allow a person with Alzheimer 's disease some sense of control. Being able to save face is important even in a person who is very confused;
- Maintain a calm manner when confronted with threatening behaviors. This can defuse a very tense situation and help a person become less fearful;
- Keep things simple. Complex situations only cause frustration and can escalate behavior problems;
- If a caregiver becomes frustrated and angry, it is best to find someone else to handle the problem and have the caregiver leave the immediate area or take a break (respite). An angry caregiver will only intensify problem behaviors;
- Caregivers should practice ways to reduce stress when they become frustrated and angry. Deep breathing or talking to someone can be helpful. Remember that stress comes from many sources, including personal life;
- Behavioral problems result from the disease. Don't take things that the person says and does personally. It is the disease speaking;
- Be creative when seeking solutions to difficult behaviors;
- Use good common sense when attempting to solve problem behaviors;

Keep a sense of humor even in the most difficult situations. Humor will help you cope with the frustrations of caring for a loved one with Alzheimer's Disease.

Behaviors in Dementia

Dementia can result in behaviors that caregivers find challenging, such as confusion, aggression, hoarding, sundown syndrome, and wandering. The following are suggestions to help manage these troublesome behaviors. All of these suggestions are actions you can take at home without a clinician's assistance. Many people who find caring for a person with dementia stressful are relieved when they realize that they can take actions that may help.

First Step Suggestions

- Stick to a regular daily routine
- Surround the person with familiar objects
- Plan the schedule around the person's prior routine (i.e. morning shower, dinner every evening at 5pm)
- Determine the time of day when your elder is most capable of performing a certain activity
- Evaluate the home for safety:
  - Safety bars on the wall near the toilet and bathtub
  - Night lights in hallways and stairs
  - Use non-slip rugs and shower stools
  - Lower the bed to reduce the risk of falls

Confusion

- Use memory aids: large calendars and clocks, lists of daily routines, reminders about safety measures, name tags on important objects. Use pictures if the person no longer understands words. Paint the bathroom door a bright color. Make memory books. Limit the number of choices offered. Lay out clothes to wear, limit wardrobe and colors, eliminate accessories, avoid buttons and zippers.
- Ask questions with yes/no questions.
- Indicate desired response through positive statements: "stand still" rather than "don't move".
- Get the person's attention before touching her. Say her name and make eye contact.
- Keep instruction simple and precise. Cut down on distraction during the task.
- Provide only as much guidance as necessary, then stop guiding.
- Give reassurance but avoid distracting the person.
- Treat each step as a separate task. Not "It's time for your shower". Rather, "Take off your shirt. Good. Now take off your socks."
- Allow sufficient time for the task.

If the task can't be completed, focus on what has been accomplished and give praise for it. Thank the person for helping you.

Aggression

- Make sure that the behavior is not being caused by a physical or medical condition (infection, pain, drug interactions).
- Review all medications every six months for need, effectiveness, and safety.
- Look for triggers, such as too much noise, too many tasks.
- Don't argue if accused or insulted.
- Use soothing words, then change the subject or redirect their attention. "I know you're frightened", not "I am not trying to hurt you."
- Encourage purposeful, calming activities, such as sorting and folding laundry, watering plants, dusting, polishing, vacuuming, etc.

Rummaging, Hiding, and Hoarding

- Place a sign that says "no" on places you want the person to stay out of.
- Lock doors and closets.
- Make duplicate of importance things (glasses, keys).
- Keep the house neat; don't leave things lying around.
- Look for patterns: If the person keeps taking the same thing, try giving her one of her own.
- Fill a top drawer with "rummagable" items and let him enjoy it.
- Keep the person's closet open at all times with everyday items in plain view. Identify favorable hiding places, and look through waste/garbage cans when looking for lost items.

Sundown Syndrome: Late Afternoon/Early Evening Agitation, Confusion, or Restlessness

- Leave lights on and close blinds to shut out the darkness.
- To avoid overstimulation; reduce activity and distractions, turn off the radio before speaking to her; don't invite many evening guests.
- Encourage afternoon naps to reduce fatigue and agitation.
- Offer a soothing bath or play classical music.
- Provide more activity earlier in the day to use up energy and reduce stress. Schedule activities that must be done (such as bathing and medical appointments) early in the day.

Wandering

- Distinguish between aimless and goal-directed wandering. Study patterns: specific time of day, need to go to the bathroom, hunger, boredom, lost item, agitation due to overstimulation or medication side effect.
- Remind the patient to use the restroom every two hours.
- Provide an outlet: a walk, activity, a memory book, music.
- Minimize stress by reducing noise, distraction, and light; provide a stuffed animal for cuddling.
- Leave lights on at night.
- Place a bed alarm-a flat strip laid under the sheets that alarms when the person gets out of bed.
- Get motion sensors for the hallway outside the person's bedroom.
- Place child safety gates at top of stairs, porches, decks (sometimes two are required for height), lock doors or place child-resistant "over-locks', and secure windows.
- Experiment with footwear, some wander when wearing shoes but not slippers.
- Attach bells and alarms to outside doors.
- Make sure person carries ID/ wears ID bracelet; register with Alzheimer Association Wander Registry, alert neighbors.
- As last resort, consult with healthcare providers about medication, restraints, or a nursing home.
- Call police if the person wanders away.

101 Things to Do with a Person With Alzheimer's Disease

Clip Coupons
Sort Poker Chips
Count Tickets
Rake Leaves
Use the carpet sweeper
Read out loud
Bake Cookies
Look up names in the phone book
Read the daily paper out loud
Ask someone with a child to visit
Listen to Polka music
Plant seeds indoors or out
Look at family photographs
Toss a ball
Color pictures
Make homemade lemonade
Wipe off the table
Weed the flower bed
Make cream cheese mints
Have a spelling bee
Read from the Reader's Digest
Fold clothes
Have a friend visit with a calm pet
Cut pictures out of greeting cards
Wash silverware
Bake homemade bread
Sort objects by shape or color
Sing old songs
"Tell me more" when they talk about a
Put Silverware away
Make a Valentine collage
Play favorite songs and sing
Take a ride
Make a cherry pie
Read aloud from Ideals magazine
Play dreidels
Make a basket of socks
Take a walk
Reminisce about 1st day of school
String Cheerios to hang outside for birds
Make a fresh fruit salad
Sweep the patio
Color paper shamrocks green
Fold towels
Have afternoon tea
Remember great inventions
Play Pictionary
Paint a sheet
Cut out paper dolls
Identify states and capitals

Make a family tree poster
Color a picture of our flag
Cook hot dogs outside
Grow magic rocks
Water house plants
Reminisce about the first kiss
Play horse shoes
Dance
Sing Favorite hymns
Make homemade ice cream
Force bulbs for winter blooming
Make Christmas cards
Sort playing cards by their color
Write a letter to a family member
Dress in your favorite football team's color
Pop popcorn
Name the presidents
Give a manicure
Make paper butterflies
Plant a tree
Make a May basket
Make homemade applesauce
Finish famous sayings
Feed the ducks
Mold with play dough
Look at pictures in National Geographic
Put a puzzle together
Sand wood
Rub in hand lotion
Decorate paper placemats
Arrange fresh flowers
Remember famous people
Straighten out underwear drawer
Finish Nursery Rhymes
Make peanut butter sandwiches
Wipe off patio furniture
Cut up used paper for scratch paper
Take care of fish tank
Trace and cut out leaves
Ask simple trivia questions
Finish Bible quotes
Paint with string
Cut out pictures from magazines
Read classic short stories
Put coins in a jar
Sew sewing cards
Put bird feed out for the birds
Clean out a pumpkin
Reminisce about a favorite summer
Roll yarn into a ball
Make a birthday cake

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9. Work and Caregiving

Balancing Work and Caregiving

You have a stressful deadline at work, and your father woke you up every night this week. The home nurse didn't come on time, and your supervisor asked why you were late to work again. Your parent needs full-time care, but you can't afford to quit your job or take time off. You feel you're letting your coworkers down. If you care for an older parent, those stories sound familiar. You face problems like them every day. At times you're distracted on the job, emotionally drained, and physically exhausted. Work is a financial necessity, but caring for parents or others often conflicts with doing your job well.

Support from Your Employer

Nearly 22 million American workers are caregivers for their loved ones. They care a lot about their jobs. They also take their family commitments seriously. Naturally, family caregiving sometimes interferes with workplace responsibilities. Despite this, a recent study by AARP found that most employers are sympathetic to these caregiving demands. However, many workers are reluctant to be open with their supervisors about their caregiving responsibilities. They fear it will affect their job security or career prospects.

Since 1993, federal law offers some support for working caregivers though the Family and Medical Leave Act (FMLA). This allows eligible workers up to 12 weeks a year of unpaid leave for family caregiving without loss of job security or health benefits. Although valuable, FMLA does not help those who cannot afford to take unpaid leave. It also has restrictions, such as company size and the amount of time a worker has been employed that keep many from being covered.

Coping with Double Demands

Balancing work and family is never easy. Each working caregiver's job is different and, even within the same company, different mangers may be more or less supportive of you. But there are effective things to do that can help you better manage your caregiving and work responsibilities. Consider the follow-

Balance

Contact your EAP for info on resources and to learn about stress management.

Ask your personnel department to give you information on the Family Medical Leave Act. If appropriate, ask them to send a copy to your supervisor.

Take advantage of flex-time policies. Ask for a flexible schedule if a formal policy is not in place. Offer to work less desirable shifts when most people want to be off. This flexibility on your part shows your employer that you are committed to your job.

Whenever possible, avoid mixing work with caregiving. If you have to make phone calls or search the Internet for information related to your parent's needs, do it on your lunch break.

Manage your time well at home & work. Set priorities & then accomplish the most important items on your list first. Delegate responsibilities at work and at home; others can almost always take some of the burden. Pace yourself & don't do so much in one area that you can't be effective in another.

Get all the support you can from community resources.

Take care of your own needs. Pay attention to your health. Eat right, get enough sleep, and exercise. Try to make time to enjoy yourself even when your schedule is packed. Fun is important. Take a break when the pressure gets too great; even a short walk or hot bath can help relieve the stress. Talk to someone about your feelings and needs: an EAP counselor, a professional counselor, or a member of the clergy.

Consider talking to your supervisor or manager at work about your caregiving issues. It's better for them to understand the reasons you're coming in late or seen preoccupied than to let them draw their own conclusions. Chances are that your company will appreciate your honesty and sense of responsibility toward your family and your job.

Be sure to thank those at work for the consideration and assistance you receive. To help someone else who has heavy family or other responsibilities, perhaps you could agree to take on an extra assignment or special project when you do have time.

The Family & Medical Leave Act

"Family and medical leave is a matter of pure common sense and a matter of common decency. It will provide Americans what they need most: peace of mind. Never again will parents have to fear losing their jobs because of their families."—President Clinton, Family and Medical Leave Act Signing, February 5, 1993

What is the Family & Medical Leave Act?
The Family & Medical Leave Act (FMLA) is legislation that entitles eligible employees to take up to 12 weeks of unpaid, job-protected leave in a 12-month period for specified family and medical reasons. The FMLA applies to all public agencies, including government employers and public schools, and private sector employers who employ 50 or more employees. The legislation is significant because it is the first federal law to allow employees the right to time off from work for family or health issues without fearing demotion or loss of employment.

Am I Eligible?
You're eligible to receive FMLA benefits if you:
1. Work for a covered employer;
2. Have worked for that employer for a total of 12 months;
3. Have worked at least 1250 hours over the previous 12 months; and
4. Work at a location where at least 50 employees are employed within 75 miles.

What Entitles Me To Take FMLA Leave?
If you're eligible, you're entitled to leave for one or more of the following reasons:
1. The birth and care of a newborn child;
2. Placement of a son or daughter for adoption or foster care;
3. To care for an immediate family member (spouse, child or parent) with a serious health condition; or
4. To take medical leave if you are unable to work because of a serious health condition.

If you and your spouse work for the same employer, you are entitled to a combined 12 weeks of family leave for any of the above reasons. If you take leave for the birth and care of a newborn child or for placement for adoption or foster care, you must conclude the leave within 12 months of the birth or placement. Some employers will also allow leave for a death in the immediate family, although that is not written into the act.

Do I Have to Take All the Leave at Once?
No. Under certain circumstances, you can take FMLA leave in blocks of time or by reducing your normal weekly or daily work schedule. The leave can be taken intermittently whenever it is medically necessary to take care of an ill family member or if you are seriously ill and unable to work. The largest portion of leaves taken under the FMLA have been for seven or fewer days.

What Happens to My Health Benefits?
As long as you are covered under group health insurance before you take your leave, your employer is required to maintain that insurance on the same terms as if your were still working. If necessary, you will need to make arrangements to pay for your share of your health insurance premiums while you're on leave. If, for reasons other than health or family issues, you do not return to work after the FMLA leave (such as finding another job and accepting it while on leave), your employer can collect its cost of health care during the leave.

Will My Job Be Safe While I'm Gone?
The FMLA requires that when you return from leave, you must be restored to your orig or to an equivalent job with equivalent pay and benefits, as well as other terms of empl Also, if you take FMLA leave, you cannot lose any benefit that you earned or were ent before you took the leave, and the leave cannot be counted against you under a "no fau tendance policy (with limited exception). However, if your employer has a legitimate terminate your employment while you are on leave (planned downsizing, poor job perf mance), the FMLA probably won't protect your job.

In general, employers have been supportive of employees' use of the FMLA, and are g more supportive as awareness of the act increases. Most realize that a company's succ pends on flexible, smart, committed, and loyal employees, and surveys have indicated employers see the FMLA and similar leave programs as advantageous because they im employee morale, decrease turnover and increase loyalty.

How do I take FMLA Leave?
If you're planning on taking FMLA leave, your are required to provide 30 days notice employer, if the need is foreseeable and such notice is reasonable. Your employer may you to provide medical certification supporting your need to take leave, as well as peri tus reports during your leave. If those requirements are not met, leave may be denied start of the leave may be delayed. Your employer is responsible for giving you specifi information regarding your rights and responsibilities under the FMLA and what could in circumstances such as your failing to return to work after FMLA leave. It is illegal employer to prevent you from exercising the rights granted to you under the FMLA.

What if I Don't Quality for the FMLA?
If you don't qualify for FMLA (for example, your employer doesn't have 50 employee are other options. Many smaller businesses have developed arrangements with employ take leave without pay. Even if your employer can't guarantee you your position wher turn, you can continue to receive your medical benefits through the Consolidated Omn Budget Reconciliation Act, more commonly known as COBRA. This act protects you and insurance benefits even if you are terminated or move to another job elsewhere.

Of course, the FMLA is not the only way to take leave. The FMLA encourages emplo provide more generous leave rights, and many employers have leave policies that go b what's covered by the FMLA under a collective bargaining agreement or employment plan, giving even more flexibility. You can also combine options, such as taking FML and disability, or combine FMLA leave with vacation time that you've earned. To det the best approach to taking leave check with your employer, and, if available, your em Human Resources Department.

For more information, visit the FMLA Fact Sheet on the Department of Labor homepa
http://www.dol.gov/dol/topic/benefits-leave/fmla.htm

10. Care for the Caregiver

Managing the Stress of Caregiving

A study conducted by the National Alliance for Caregiving and AARP found that more than half of those who provide major care for parents experience stress and strain. Studies show that experiencing stress is not just unpleasant – it can negatively affect your health, well-being, and ability to provide care. When you are caring for others taking care of yourself and your needs is like doing regular maintenance on your car. It is critical to staying in shape over time. Managing your stress will improve your physical and mental health to benefit yourself, your elderly loved ones, and others who depend on you.

Take Care of Your Health
*East nutritious meals. Don't give in to stress-driven eating or drinking.
*Get enough sleep. Make rest a priority.
*Exercise regularly, even if it means finding someone else to provide care while you walk or go to exercise class.
*Get regular medical checkups. If you have any symptoms of depression (extreme sadness, trouble concentrating, apathy, hopelessness, thoughts about death), see a doctor right away. Depression is an illness that can, and should be treated.

Involve Others Make a list of jobs you need help with. They could include household chores, home repair or maintenance, driving, paying bills, finding information on services you need. Maybe it's simply giving you a break by staying with Mom while you get away for awhile. Ask friends, neighbors and other family members if they could give some time to helping out.

Maintain Social Contacts Isolation increases stress. Having fun, laughing, and focusing on something besides your problems helps you keep your emotional balance.

Get Help From Community Services and Organizations
*Consider a geriatric care manager to coordinate your parent's care. Support could include home health aides, shopping assistants, housekeeper, a handyman, meal services, and referral programs.
*Perhaps volunteers from faith-based organizations could visit or help with driving.
*Respite care can give you some time off.
*Adult day centers, which usually operate five days a week during business hours, provide care to older people in a group setting – including health monitoring, transportation, nursing care and therapeutic recreation.

Talk about it
Research suggests that keeping your feelings bottled up can harm your immune system and lead to illness. Talk to friends and family about your feelings. Share experiences with coworkers in similar situations. See a professional counselor. Join a caregiver support group to share emotions and experiences, seek and give advice, and exchange practical information.

Deal Constructively with Negative Feelings
When feeling resentful, think about how to change things. Recognize the anger-guilt-anger cycle, and stop it immediately by forgiving yourself for being angry. Then distance yourself from the situation, figure out what caused the anger, and decide how you can respond more constructively the next time. Hold a family meeting to resolve conflicts with relatives. And recognize your accomplishments as a caregiver instead of dwelling on your shortcomings.

Overcoming Negative Emotions

In this article we will look at how caregivers cope with the emotional stresses that may come with being a caregiver to a loved one with a chronic condition.

As we mature, we each develop an individual style of dealing with our emotions. Our personal style becomes set fairly early on, so that, without even thinking, we react to various emotional stimuli in our own particular way. For example, the person who, when frustrated goes into a rage, versus the person who keeps his frustration inside and develops a headache.

We learn our emotional reactions by example, by being taught and by experience, that is, finding out what works for us. This is not necessarily a conscious, cognitive process. For many of us we would have to stop and think, "Well, what do I do when I am afraid, frustrated, etc." Our emotional response then is automatic, not necessarily rational and not always adequate. With that as a foundation, the caregiver comes to the role more or less prepared to deal with emotions, although she is almost never prepared enough for the enormous emotional challenges that will be encountered.

It therefore serves us well to take a more concrete, problem solving approach to caregiver emotional reactions, rather than assuming that our usual way of coping with negative emotions will suffice.

Coping When Things Don't Go Smoothly

The emotions caregivers experience my be fear, anxiety, frustration, anger and depression. Unrealistic expectations can set the caregiver up for disappointment, frustration and anxiety. Logically then a good starting point is an accurate assessment of what one can expect when caring for someone who is chronically ill, and what the caregiver can expect of herself in terms of her contribution.

What is the goal? If you set unrealistic expectations of a cure, or expect to turn back the clock, you will sink before you begin. However, even assuming you have accurately assessed these two factors, it is still helpful to take a problem solving approach to the emotions you may feel.

Let us first look at how we learn to deal with emotions. As noted above, early on we develop our own style. As part of that style, we use psychological defenses in order to deal with feelings, especially unacceptable or threatening feelings. We develop preferred defensive styles when we are young.

Defenses, despite their bad rap, are not necessarily negative. They prevent us from being overwhelmed by emotions since they can give us time to regroup. For example, when a family hears the diagnosis of Alzheimer's Disease in a loved one, they may initially respond with denial – "It's not Alzheimer's Disease. He's just getting older and having some memory problems." Denial here gives time for a breather and a gathering of resources. Denial, like other psychological defenses only becomes a problem when it goes on and on and interferes with coping and problem solving.

Another defense, rationalization, is an attempt to justify something that is not reasonable in order to make it acceptable. For example, the caregiver who is depressed by the restrictions of taking care of a loved one, rationalizes that no one else can do the job as well and therefore continues feeling trapped and overworked. Psychological defenses are used to deal with emotions but too often do not provide enough of an answer.

Overcoming Caregiver Stress

Practically, the obvious first recommendation for overcoming caregiver stress, whether it is physical, emotional, or time limitations, is to take care of yourself. Caregivers hear this often. It is not a new idea. It's just that caregivers don't take time because they're too busy to figure out what this means for them. Taking time to meet your needs has tremendous payoff in terms of your ability to deal with emotional stress. This means making sure you have adequate rest, nutrition, and exercise. More specifically it may be helpful to take time for one of the relaxation techniques such as yoga or mediation.

To successfully use any activity for stress reduction, however one must plan and set up a specific realistic time when it can be done. Similarly, time away at an activity, which brings pleasure, must be planned. Whether the activity is a brief extended venture, it won't happen by just saying you should do it. You must make a definite plan and follow through.

Develop a support system, that is a community of friends, relatives, and professionals who will be resources for you. Make a list of people:

- On whom you can rely on for specific tasks and assistance,
- On whom you can share your feelings,
- Who can help with transportation,
- Who can stay with your loved one for a while,
- With whom can you go out and have a good time, and
- To whom you can go when you need professional help.

To deal with emotions more specifically, you must become proactive so that the same emotional stress does not repeatedly wear you down. Usually it is certain situations with impaired loved one that are the trigger for upsetting emotional reactions. You won't always be prepared and in control but being aware and planning ahead can help.

There are also steps that are useful in understanding and dealing with your feelings.

1. Identify the feeling. You must first know what it is that you feel. Anxiety, anger, depression are qualitatively different and have different antecedents.
2. Admit you have the feeling even though it is unpleasant and accept that it is yours.
3. Take a step back and gain some distance from the situation. Go to the next room. Take a walk.
4. Analyze. Use the time to figure out what triggers the feeling. What is it about a situation that makes you feel a certain way? How do you react? What does the situation mean to you?
5. Talk about your feelings with someone who you trust, or write them down to express them. Sometimes writing helps one to understand, and begins the problem solving process. Talk to a professional if you are getting overwhelmed.
6. Make a plan. Figure out what you can do differently when you recognize that feeling again. Make the plan very concrete. It's like dieting. You can't just say I'm going to start tomorrow. You have to know specifically what you will change and how.
7. Remember there must be a balance between your needs and those of your loved one. Be comfortable with your limits. This means accepting what you are realistically able to do. Remember to be a good caregiver and to go beyond caregiving, your life must continue and be meaningful.

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