

GUIDE

Alzheimer's Disease: Caregiving Challenges



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NATIONAL ALLIANCE FOR CAREGIVING

Established in 1996, The National Alliance for Caregiving is a non-profit coalition of national organizations focusing on issues of family caregiving. The Alliance was created to conduct research, do policy analysis, develop national programs, and increase public awareness of family caregiving issues. Recognizing that family caregivers make important societal and financial contributions toward maintaining the well-being of those for whom they care, the Alliance's mission is to be the objective national resource on family caregiving with the goal of improving the quality of life for families and care recipients. www.caregiving.org

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This guide will help IF you or a loved one:

- Want to understand the nature and progression of Alzheimer’s disease.
- Are looking for guidance on how to address the behavioral changes that accompany dementia.
- Need to find ways to communicate effectively with a family member who has dementia.
- Are searching for resources to ensure a family member with Alzheimer’s disease receives proper care.

NORMAL FORGETFULNESS? OR ALZHEIMER’S DISEASE?

Some people may worry that if they lose their keys, forget someone’s name, or find it difficult to pay attention to more than one thing at a time that this may be a sign of Alzheimer’s disease. However, that level of forgetfulness is usually just a normal sign of aging. Alzheimer’s disease, on the other hand, is progressive and affects both memory and the individual’s ability to manage daily activities.

If someone you love has Alzheimer’s disease, you are not alone. There are presently an estimated 5.3 million Americans with the disease.¹ Meeting the challenge begins with getting a proper diagnosis, then learning what to expect and developing a plan that is appropriate to each stage of the disease. Reading this guide is a good place to start understanding the nature of the illness and how you as a caregiver can help meet your loved one’s needs.

¹ 2010 *Alzheimer’s Disease Facts and Figures*, Alzheimer’s Association, accessed via Internet 7/2010 at: www.alz.org/documents_custom/report_alzfactsfigures2010.pdf.

Assess the Situation

IF YOUR LIFE IS TOUCHED BY ALZHEIMER'S DISEASE . . .

Alzheimer's disease is a gradual degenerative brain disease. Typically, it changes an individual's:

- Personality and behavior.
- Ability to manage daily activities and learn new things.
- Capacity to remember, think, and use language appropriately.

The disease progresses at a variable rate but always on a downward slope.

YOU ARE NOT ALONE

For each of the estimated 5.3 million Americans affected by Alzheimer's², there are one to four caregivers involved with helping.³ In other words, millions of people are experiencing much of what you are going through.

For caregivers, adjusting to the changes in a person you love can cause your emotions to run the gamut: you may feel sad, worried, angry, or resentful some days and empathetic, understanding, and accepting other days. Try to be good to yourself and ask for help when you need it. There are resources available to assist you.

LEARN THE SIGNS AND SYMPTOMS OF ALZHEIMER'S DISEASE

Although Alzheimer's disease manifests itself differently in every person, there are some common changes. See the sidebar on page 3 for guidelines.

GETTING A CORRECT DIAGNOSIS IS VITAL

Although Alzheimer's disease is a major cause of dementia, it is not the only cause. Dementia can also result from thyroid dysfunction, Vitamin B12 deficiency, depression, medication interactions or side effects, and more. These forms of dementia may be reversible with proper treatment.

Other forms of dementia such as vascular dementia (restricted blood flow to the brain) or dementia caused by multiple small strokes are not reversible, but these conditions progress differently than Alzheimer's disease.

² 2010 *Alzheimer's Disease Facts and Figures*, Alzheimer's Association, accessed via Internet 7/2010 at: www.alz.org/documents_custom/report_alzfactsfigures2010.pdf.

³ *About Alzheimer's: Statistics*, Alzheimer's Foundation of America, accessed via Internet 7/2010 at: www.alz.org/documents_custom/report_alzfactsfigures2010.pdf.

Know the Signs of Alzheimer's Disease

The changes will vary from person to person — these are guidelines, not rules.

Dementia: This is a set of symptoms associated with an illness. Alzheimer's disease causes irreversible dementia, which is a progressive permanent loss of mental capabilities. It interferes with a person's work life, social interactions, and daily activities.

These changes will vary from person to person and can include:

Significant Memory Loss: This is not the normal forgetfulness of aging like, "I cannot find my keys" or "I cannot recall your name." With Alzheimer's, memory loss and decreased cognitive function result in other difficulties such as getting lost in familiar places and decreased capacity for learning and understanding.

Confusion: A person with Alzheimer's will have difficulty performing familiar tasks such as cooking or paying bills.

Changes in Communication: People with Alzheimer's may sound vague or seem withdrawn — more in their own world, less likely to initiate conversations. They may also repeat things or ask the same questions over and over.

Loss of Judgment and Orientation: Your loved one may no longer seem to recognize dangerous situations. For example, he or she may leave pots on the stove until they burn or leave the front door wide open when leaving the house.

Personality Changes: Your previously even-tempered spouse or parent may become irritable, anxious, or depressed.

SEE YOUR PRIMARY CARE PHYSICIAN, A GERIATRIC SPECIALIST, OR A MEMORY ASSESSMENT CENTER

If the dementia is caused by Alzheimer's disease, some medications may help delay the progression of the symptoms for a time. If medications are begun early in the course of the disease, they may be able to slow down its course. Your primary care physician, a geriatric specialist, or a memory assessment center can help you determine if your loved one's dementia is caused by Alzheimer's disease.

Identifying the problem is the first step toward planning for needed care and learning about resources that may help both you and your family member.

STAGES OF ALZHEIMER'S DISEASE

Just as the symptoms are different from person to person, the stages of Alzheimer's disease also vary. The lines between each stage are not clear-cut, but you can expect to see some of the following as time goes on. Thinking about the disease in stages may help you focus on one set of needs at a time.

Early Stages

The individual may not need to have much physical assistance, but will experience memory and personality changes like these:

- Forgetfulness
- Irritability
- Anxiety
- Depression
- Errors in judgment
- Difficulty managing new or complicated tasks

Later Stages

- Physical needs increase.
- Behaviors may become more difficult to manage.
- Higher levels of care are needed.

Understand the Options

DEALING WITH CHANGING BEHAVIORS AND ABILITIES

Helping a person with dementia often requires a caregiver to alter his or her response to the person's behavior, make adjustments in the person's environment, or do both.

Your caregiving options will change as the disease progresses, and how you take care of a loved one with Alzheimer's disease should be tailored to the current degree of impairment.

Be patient with yourself as a caregiver. Caregiving is a process, and you will learn as time goes on. With an illness like Alzheimer's, where needs change over time, the caregiver must be especially flexible.

 **See also the guides: *The Caregiving Journey and Navigating the Health Care System.***

Understand that despite your best efforts there may be times when nothing seems to work. Do not be afraid to ask for assistance from doctors or other health care professionals.

SUGGESTIONS FOR CAREGIVERS: STRATEGIES FOR MANAGING YOUR NEW REALITY

As you may have noticed, your family member does not understand as well as he or she used to, so one of the first adaptations you make will be in how you communicate.

Communicating Effectively

Patience and understanding are more important than ever. Your loved one wants to understand you, but simply may not be able to follow what you are saying. Always treat someone with Alzheimer's disease with respect and as an adult, even though the person's behavior may seem childlike or his or her ability to communicate appears limited.

Ways to Improve Communication

Focus

- Face your family member when you speak so he or she can focus on your words.
- Speak slowly.
- Limit distractions such as the TV or other conversations.
- Use simple words and explanations. Break down the message into steps or parts.
- Ask one question at a time. Wait for the answer. Avoid open-ended questions as these can be difficult to answer.

Tone

- Use a calm, relaxed tone as if you have all the time in the world, especially when you do not.
- Use positive statements, e.g., what he or she can do, not what your loved one cannot do.

Reinforce

- Use gestures or demonstrations to show what your words mean.
- If your loved one is still able to read, write reminders or post signs.

Communication Tips

What to Avoid Saying	Why
Giving logical explanations and lengthy reasoning.	Your loved one cannot follow them, so this becomes frustrating.
Asking questions that require factual answers.	Since your loved one may not know the answers, your questions will only frustrate him or her.
Saying "You're repeating yourself" or "Don't you remember?"	Because of memory deficits, your loved one cannot help repeating the same information or asking the same questions, so this will only offend or frustrate him or her.
Talking about your family member as if she or he were not present.	Consider how you would feel in the same situation.

Acknowledge the Role of Feelings in Your Communications

Words may fail your loved one, but feelings — his or hers and yours — remain and are expressed nonverbally.

- **Understand what nonverbal messages you are sending.** Even if your family member cannot understand your words, your body language and tone of voice say volumes. For example, smiling, hugging, or waiting patiently expresses a calm, soothing, loving message. Hands on hips, raised eyebrows, and an irritable voice convey frustration and impatience. Both messages affect your loved one.
- **Try to understand your loved one's feelings.** Try to focus on the feelings being expressed and what might have caused them, not the actual words or lack of words. If she or he seems happy, smile; if upset, try to comfort or distract.

- **Don't take it personally.** Sometimes it may be hard to recognize that the confusion and personality changes you see are the result of the disease — especially when you are having trouble communicating. Try to keep in mind that your loved one cannot help the behavior; he or she is not acting that way on purpose.
- **Observe your family member's reactions.** Through experience, you will sense how your family member sees your body language. Be patient as you gradually gain that understanding. Recognize your need to make adjustments as his or her reactions may change over time.

PROMOTING SAFETY AND INDEPENDENCE

Do not expect your family member to take responsibility for his or her own safety. You will need to anticipate potential hazards and adjust the environment to minimize or eliminate them prior to a problem occurring.

Take Steps to Promote Safety

Simple home safety steps include adding grab bars in the bathroom, removing scatter rugs, making sure lighting is adequate throughout the home, and lowering the temperature of the hot water heater to prevent burns.

Pay Attention to the Physical Environment

- **Structure:** Keep things in the same place. Familiarity and predictability are important.
- **Simplicity:** With your family member's permission, remove clutter.
- **Safety:** In the later stages of the disease, it may be necessary to install locks on doors above eye level, remove knobs, or disconnect stoves to prevent harm to your family member.
- **Security:** The environment should provide a sense of security. If there is something your family member really wants, keep it as long as it is not dangerous.

Remove Potential Hazards

Someone with Alzheimer's may no longer know what is safe and what is not. Check your home to reduce potential hazards:

- Find a safe place for items such as matches, cleaning products, poisonous substances, medication, and razor blades.
- Consider ways to safeguard structures such as stairs, ladders, and swimming pools.
- Rethink your loved one's ability to smoke, cook, and use power equipment and hot water.

 **See also *The Essentials: Falls and Fall Prevention*.**

SAFETY AND DRIVING

As your family member's Alzheimer's progresses, he or she will lose many of the skills needed to drive safely. Observe your family member over time to accurately assess his or her skills.

Watch for these signs:

- Lack of judgment.
- Slow response time.
- Disregarding lights or stop signs.
- Having near misses, accidents, or fender benders.
- Driving too fast or too slowly.
- Forgetting how to find familiar places.
- Getting angry or confused while driving.

What seems obvious to you may not be obvious to your family member, so you may need strategies to keep him or her from behind the wheel:

- If possible, involve your family member in the discussion about driving. Let him or her know a ride will always be available.
- Involve your family doctor. He or she is often more effective in convincing a family member not to drive.
- You may need to experiment with ways to distract your family member from driving, e.g., by saying you will be following a new, unfamiliar route or suggesting he or she deserves the opportunity to sit back and enjoy the scenery, while someone else drives.
- As a last resort, you may need to hide the keys and disable or sell the car.

CHALLENGING BEHAVIORS

Alterations in behavior are often the most upsetting and difficult aspects of Alzheimer's caregiving — especially for family members. The behaviors are not willful or spiteful. They are part of the illness and may occur because a person is attempting to convey a need or feeling. If your loved one exhibits any of the difficulties on the following chart, consider the suggested options. Sometimes medications are needed to manage behaviors when other interventions have not been completely successful.

Behavior	Definition and Cause	Options
Agitation	Anxiety and worry, which may be manifested by pacing, restlessness, and irritability. Your family member may not be able to tell you what is wrong. It may be related to a variety of issues, including uncertainty about what is going on, losing an item that is important to him or her, too much activity, or too many people all at once.	<ul style="list-style-type: none"> • Avoid disruptions in daily routine. • Move at your family member's pace in any routine. • Listen, reassure, and use a calm tone of voice. Reduce commotion and noise. • Distract or redirect your family member to another activity or place.
Repetitive Actions or Speech	Asking the same questions repeatedly or doing some action like folding a towel over and over. The person may be anxious or bored.	<ul style="list-style-type: none"> • Distract with music or exercise. • Ignore the behavior or answer the question as if it had never been asked before. • Avoid a confrontation. • Speak softly and calmly.
Wandering	Walking aimlessly, becoming disoriented. May happen if the person wants to perform an important job like work or is searching for someone.	<ul style="list-style-type: none"> • Try to determine what situations or times of day prompt wandering. • Install locks or alarm bells. • Alert neighbors. • Have the person wear a name bracelet with your contact information. • Consider a medical alert bracelet or the Medic Alert® and Alzheimer's Association "Safe Return®" Program. <i>See "Resources for You" at the end of this guide.</i>
Sundowning	Becoming more confused, restless, or agitated late in the day or early evening. May be caused by decreased light at the end of the day; late-day tiredness may make the person less able to deal with stress. Also, Alzheimer's disease may cause changes in the person's biological clock.	<ul style="list-style-type: none"> • Increase daytime activities. • Discourage napping but allow for a rest period. • Eliminate caffeine and foods high in sugar. • Make evening a quiet time and keep bedtime around the same time every night. • Keep the environment free from hazards in case your loved one gets up at night.

Behavior	Definition and Cause	Options
Paranoia	People with Alzheimer’s disease may have difficulty interpreting the world around them. Because their memory of recent events is impaired, they may not recall explanations or people to whom they have been introduced. They cannot remember where they put things or follow conversations. As a result, they may become suspicious or accuse people of stealing because no other explanation makes sense to them.	<ul style="list-style-type: none"> • Do not take accusations personally. • Do not argue with your family member. • Reassure others that you do not suspect them. • Look for the missing items. • Try to distract or engage your family member in another activity. • Have extras of important items such as glasses or keys in case they are lost.
Hallucinations	Seeing or hearing things that are not there. These voices or sights are very real to the person experiencing them.	<ul style="list-style-type: none"> • Remain calm so your family member will not get more upset. • Reassure him or her that everything will be okay. • Try to distract him or her if possible. • Let the doctor know if your loved one begins to have hallucinations.

USING MEDICATIONS TO MANAGE BEHAVIORS

Sometimes medications may be necessary to help manage behaviors and symptoms such as anxiety, depression, sleep disturbances, and agitation. They should only be used if other interventions have been unsuccessful. Since each person responds differently to medication and because your family member may not be able to verbalize how he or she is feeling, it is important to monitor closely for any change that may be medication related. Observe for both positive and negative reactions. Ask the doctor what side effects you may expect and let him or her know if any occur.

Physicians will usually start with a low dose and gradually increase it after seeing what the effects are. If your family member’s doctor or a specialist prescribes a new medication, make sure he or she knows all of the medications your family member is taking. Also let any other doctor your family member sees know about the additional medication.

 **See also The Essentials: Safe Use of Medications.**

CHALLENGES WITH ACTIVITIES OF DAILY LIVING

In the earlier stages of the illness, your family member may need supervision and direction. As the disease progresses, he or she will become increasingly dependent upon others for both direction and hands-on assistance with Activities of Daily Living (ADLs) such as bathing, dressing, eating, and toileting. It is also important to remember that your family member may resist assistance with activities.

Recommendations for Grooming

Bathing: Protect your loved one's safety in the tub. Do not leave him or her unattended and make sure the water is the correct temperature. Follow previous routines where possible. Make the task simpler (e.g., lay out towels in advance, draw the bath water). If your family member refuses to bathe, it may be that it is too complex for him or her to complete. Your loved one may feel embarrassed to have help, be afraid of the water, or be fearful of getting in or out of the tub. If he or she resists bathing, focus on the steps one at a time rather than focusing on the need to bathe. You may want to start with a sponge bath, if getting in and out of the tub or shower is a problem. Sometimes your loved one may respond more favorably if an aide in a uniform assists rather than you.

Dressing: If your family member does not want to change clothes, do not argue. Try again later. Limit your loved one's choice of clothing to what is appropriate for the season. You may want to limit the choices to two each day and let your family member decide. If he or she wants to wear the same thing every day, consider buying two identical outfits. Lay out an outfit in the order your family member will put it on.

As the disease becomes more advanced, your family member will have increasing difficulty with things like buttons, zippers, and shoelaces. If buttons become too difficult, try Velcro. Look for clothes that are easy to put on and take off (e.g., pants with elastic waists and pullover tops where it does not make a difference which is the front and which is the back). You may even want to consider reversible clothes.

Eating Can Become a Greater Challenge

Some people with Alzheimer's want to eat all the time, while others are seldom interested. It is not uncommon for individuals with Alzheimer's to become malnourished — they may forget to eat, hide food, or throw it away. In the later stages of the illness, individuals may forget how to chew or swallow. They may have problems with choking.

Strategies to Help with Eating

- Establish a routine, avoid distractions, and limit the food choices at a meal if your loved one seems overwhelmed.
- Make sure your family member has good dental hygiene and that any dentures fit properly.
- Make sure your family member has plenty of fluids and try to accommodate his or her likes and dislikes in eating while maintaining proper nutrition.
- Your loved one may become messy with eating as the disease progresses. Buy plastic tablecloths and offer more finger foods, which are easier to eat.
- People with dementia may eat more slowly. Offer small portions or prepare a number of small meals instead of three larger ones.
- Keep healthy snacks where they can be seen. This may prevent hiding or hoarding food.
- As the disease progresses and your family member has more difficulty with chewing or swallowing, you may need to chop or purée foods. Discuss any concerns you have about your loved one's nutrition and ability to swallow or chew food with the doctor.

YOUR LOVED ONE'S ABILITY TO GET AROUND MAY CHANGE

Individuals with Alzheimer's may have increasing difficulty with mobility — getting up and down and walking. They will require supervision to prevent falls. Problems with walking gradually progress so many individuals will completely lose the ability to walk and become confined to a chair or bed.

Ways to Handle Mobility Issues

- Observe your family member and watch for signs that he or she can no longer do certain activities such as climbing up and down stairs safely.
- Make certain any items such as chairs or tables that he or she may grab onto are sturdy and will not tip over.
- Secure handrails. Consider a cane or walker only if your family member is able to learn to use it properly.
- Sometimes changes in gait or balance are related to medications or other conditions. Don't assume it is the Alzheimer's disease. Make your family member's doctor aware of any changes so that he or she can assess them.
- As your family member experiences problems with mobility, consider a physical therapist who can teach you ways to assist your family member with moving from bed to chair, walking, and positioning in bed so it is safe for your loved one and you will not injure yourself.

- Your family member may also have difficulty getting in or out of a car. It may be related to a combination of mobility and cognitive difficulties. A physical therapist can assist in evaluating the problem and teaching you ways to assist in helping your family member to get in and out of the care safely. You may also visit the National Center on Senior Transportation Web site sponsored by Easter Seals at <http://seniortransportation.easterseals.com>. Go to “For Older Adults and Caregivers” and click on the link “Easter Seals Transportation Solutions for Caregivers” which provides a tool kit that includes a video, an informational booklet, and a list of helpful products and resources related to transportation for those caring for family members with either physical or cognitive disabilities.
- If your family member becomes chair-bound, you may want to consider a specialized chair to help him or her maintain a sitting position and/or a seat that provides comfort. Make sure you provide protection to keep your family member from falling from the chair or trying to get up if he or she can’t walk.
- If your family member becomes bed-bound, you may want to consider a special mattress. Be sure to change his or her position frequently to prevent complications such as skin breakdown.

DEALING WITH INCONTINENCE

Incontinence, or the inability to control bladder or bowel function, may occur in the later stages of Alzheimer’s. The reasons include not being able to get to the bathroom quickly, not knowing or recognizing where the bathroom is, difficulty getting clothing off quickly enough, or being busy and forgetting to go. Also, the person may not remember the acceptable place or way to urinate or defecate.

Incontinence can also be caused by other physical illnesses and is sometimes treatable. If your family member becomes incontinent, let the doctor know. Do not assume it is caused by Alzheimer’s disease. It may be related to another condition such as a bladder infection, diabetes, or constipation.

Track When and How Often Episodes of Incontinence Occur

By doing a bit of detective work, you may find a key to managing toileting more successfully.

- **Consider time of day.** Do the episodes occur at particular times each day? Only at night? Do they occur after a particular activity? Does he or she want to go to the bathroom every few minutes?
- **Look for signals.** Does your family member give any indication that he or she needs to go to the bathroom? Is he or she pulling at clothes? Does he or she seem to be looking for the bathroom?

Try These Approaches

- If the problem occurs at a particular time of day or following a particular activity (e.g., after breakfast), bring your family member to the bathroom at those times.
- If the incontinence occurs throughout the day without any warning, consider a toileting schedule. Take your family member to the bathroom every two to three hours.
- If incontinence seems related to inability to get to the bathroom quickly enough, consider a portable commode.
- If regular toileting or other techniques no longer work, there are many incontinence products that will make your caregiving tasks easier and provide dignity for your family member.
- If your family member has episodes at night, you may want to limit fluids in the evening, but make sure he or she has plenty of fluids throughout the day.
- Try to remain calm when accidents occur. Be reassuring, since the episode may be upsetting to your loved one.

Make a Plan

WHAT PLAN IS BEST FOR YOUR LOVED ONE AND FOR YOU?

Coming to terms with a family member's Alzheimer's disease is sobering. Although coping with the changes can be daunting, many caregivers say that it is also rewarding. The first step in dealing with your new reality is making a long-term care plan. Since Alzheimer's is a degenerative disease, the changes take place over time — you can adjust to each new phase and revise your plan when necessary.

 [See also the guides: *The Caregiving Journey and Navigating the Health Care System.*](#)

ESSENTIALS OF A LONG-TERM CARE PLAN

1. Determine Where Care Will Be Given

The possibilities include at home, in an adult day services center, in an assisted living community that specializes in caring for people with dementia, or in a nursing home that is accustomed to caring for people with Alzheimer's disease. Recognize that the setting may need to change as your loved one's care needs change.

 [See also *The MetLife Aging in Place Workbook.*](#)

2. Decide What Services Are Needed and Who Will Provide Them

If your loved one is in the early stages of Alzheimer's, he or she may primarily need support and supervision, which the family can provide. However, as the disease progresses, your family member will need increasing amounts of care and supervision.

You can start introducing outside sources of care on a gradual basis. Have some other caregivers — family, friends, and paid caregivers such as a companion — provide supervision. A home health aide can also assist with personal care for short periods of time. Their help will provide respite for you and allow your family member to become familiar with other caregivers over time. As taking care of your loved one becomes more time-consuming, you can add homemaking services and additional personal care services and/or companion services to meet his or her needs.

 [See also *The Essentials: Receiving Care at Home.*](#)

You may also want to consider an adult day services center. These centers are community-based, professionally staffed group programs that provide health oversight, supervision, and therapeutic activities for adults who are physically or cognitively impaired. Programs operate on either a partial or full-day basis and many specialize in caring for individuals with Alzheimer's disease or a similar disorder. This type of program can both benefit your family member and allow you to find time for yourself with the comfort of knowing your loved one is receiving care and supervision in a supportive group environment. They can be especially helpful if you are a working caregiver.

i [See also The Essentials: Adult Day Services.](#)

If your loved one's behavior changes or the Activities of Daily Living become too difficult for you to manage at home, you may want to consider a move to a residential setting such as an assisted living community or a nursing home depending upon the level of care required. Making these decisions is not always easy. It is helpful to explore the available options as early as possible so that you will be prepared as needs change.

i [See also The Essentials: Choosing a Nursing Home and Assisted Living Communities, and the tools: Assisted Living Checklist, Assisted Living Cost Calculator, and Nursing Home Assessment.](#)

3. Determine How Caregiving Costs Will Be Paid

Long-term care services are often financed through the individual's personal funds or assistance from family members.

- **Medicare** covers some nursing home and home care services on a limited basis if an individual meets Medicare's criteria for skilled care.
- **Medicaid** covers long-term care services for certain individuals with very limited income and assets.
- **Long-term care insurance** provides benefits for long-term care services. If your family member has such a policy, check to see what is covered. However, once an individual is already in need of long-term care services, he or she is not eligible to purchase a policy.

Some care options are less costly than others. For instance, adult day services can be a cost-effective alternative for many people living at home who require significant amounts of care or supervision.

4. Investigate Necessary Legal Documents

Discussing financial and legal matters with your loved one may be uncomfortable at first, but it is vital. Reassure your loved one that you will honor his or her wishes, even when he or she is no longer able to make them known. It is especially important when a family member has been diagnosed with Alzheimer's disease, because you may need to be the voice for your family member in the future and he or she may not have the capacity to execute these documents as the disease progresses.

Certain documents need to be executed by your loved one when he or she still has the capacity to understand the issues and make decisions. Consider discussing wills, living wills, estate planning, and powers of attorney for health and financial matters. In addition, locate health, life, and other insurance information as well as bank and investment information.

 [See also The Essentials: Legal Matters.](#)

GETTING HELP

Caring for a family member with Alzheimer's is a long, ever-changing journey, one during which you will need to enlist the assistance of others. You simply cannot do it all alone. It is helpful to start planning as early as possible when you discover your loved one has the illness. For you as well as for your family member, it is necessary to seek the help of others.

It may take several inquiries and time to find what you need, but there are people and programs to support you. Family, friends, neighbors, and others are often willing to assist, but you may have to ask for what you need. Keep a list of things that need to be done for your family member. If someone offers to help, you may look at that list and consider what activity might be appropriate for the person who offered to help. Be specific in asking for help from family and friends. For instance, ask your nephew to mow the lawn every couple of weeks or ask volunteers from your church to come and visit with your family member once a week so you can go grocery shopping.

FIND INFORMATION AND RESOURCES IN YOUR COMMUNITY

Numerous resources are available nationally and right in your community. Here are some places to begin learning more:

National and Regional Resources

- Contact your local Area Agency on Aging (www.n4a.org).
- Connect with the national Eldercare Locator at 1-800-677-1116 or www.eldercare.gov.
- Check with national organizations such as the Alzheimer's Association (www.alz.org) or the Alzheimer's Foundation of America (www.alzfdn.org).

Community Resources

These organizations also are good sources of information as well as services:

- Social service agencies
- Senior centers
- Caregiver support groups
- Adult day services centers
- Home health care agencies
- Long-term care facilities
- Hospitals

Helpful Professionals

- Your family physician
- Elder law attorney
- Financial advisor
- Professional geriatric care manager

 See *"Resources for You"* at the end of this guide.

ENLIST HELP SOON

Don't wait until your responsibilities seem overwhelming to enlist support. Begin to evaluate the resources in your community, including care at home, adult day services centers, and facility care, as soon as possible. This will help you to be prepared at various stages of your family member's illness.

HELPFUL HINTS

- **Become an educated caregiver — gradually.** Too much information at one time may overwhelm and immobilize you. However, when you're ready, be sure to ask questions and seek advice and assistance.
- **Do not sell your instincts or your own thoughts short.** You may be the best resource as to what is most helpful to your family member.
- **Focus on the positive.** Reinforce and use what your family member does well. Sometimes it is difficult to see the positives, but always remember small successes can bring a sense of satisfaction and joy to your family member. How he or she feels about an activity is more important than how well he or she completes the task.
- **Find small tasks that your loved one can complete.** Consider folding laundry or helping to set the table where your loved one can still feel like a contributing member of the family.
- **Be generous with reassurance.** Reassurance from you can make all the difference for your family member who is living in a constantly changing world of confusion, uncertainty, and often fear.
- **Continue to communicate with your family member.** Through each stage of his or her illness, treat your family member as an adult. Communicate constantly. Even if your family member does not seem to recognize you, the sound of your voice or your touch can be a source of comfort to him or her.
- **Help caregivers who may not know your family member as you do** to understand the kind of person he or she was before this illness—you are often your family member's voice to those around him or her. Educate others about what he or she likes and dislikes.
- **Be patient with yourself as well as with your family member.** Don't be afraid to experiment and try new things to best meet his or her needs.
- **Consider speaking with an elder law attorney as early as possible in your family member's illness.** If your family member understands what is going on and has the capacity to make decisions, he or she may want to provide you or someone else with the ability to make financial and/or health care decisions on his or her behalf at the point in time when your family member is no longer able to make these decisions.
- **Consider joining an online or in-person caregiver support group.** It is often helpful to be able to speak with others who are in a similar situation. Support groups can provide both emotional support and practical assistance.

 See *"Resources for You"* at the end of this guide.

Monitor and Adapt

STAY FLEXIBLE AND ADAPT AS NEEDED

Caring for a loved one with Alzheimer's is a long, ever-changing journey, and the course of the disease varies from person to person. What works one month may need to be changed the next month. Going forward, it will be important to evaluate the situation periodically and consider whether adjustments are needed.

COMMUNICATION IS KEY

If you are the primary caregiver, it will be vital to communicate proposed changes with your loved one and other members of the care team (i.e., your family and any paid caregivers). But beyond the day-to-day communication about practical matters such as medication adjustments, it will be important for you to share your feelings and concerns with someone you trust and let people know when you need help.

- **Know and communicate your limitations as a caregiver.** A family member, parent, or significant other may want you to be the only caregiver. However, they must understand that this is not always possible, and that you may need to enlist the services of others from outside the home. Setting limits may be difficult at first, but once you do, you may find that family members worry less, knowing that you are taking care of yourself. Also, by effectively communicating your limits, you will take much of the guesswork out of planning and problem solving.
- **Ask for assistance from others.** Other family members, neighbors, friends, and community support groups may be willing to help, but they will not know you need help unless you ask. Do not be afraid to make specific requests when someone offers to help. Include everything from help with housekeeping to respite care.

 **See also the tools [Personal Health Information, Emergency Information for Family Caregivers, and Important Information for Caregiving.](#)**

TAKE CARE OF YOURSELF

As a caregiver, your well-being is vital. As you probably have discovered, the person with Alzheimer's is not the only person affected by this illness. It is easy for caregivers to become isolated. Be sure to take care of your own health. Have regular follow-up with your physician and follow-up with needed lab work and preventive testing such as mammograms.

Nurture Yourself, Too

- Keep your other relationships going — see your friends or talk with them by phone or e-mail.
- Continue your spiritual/religious connections.
- Pay attention to your mental and physical health. Exercise. Eat properly. Get adequate rest.
- Find time for yourself. In a small way every day, do something that gives you pleasure — listen to music, look at the birds, read a magazine, see a funny movie, or garden.
- Try to maintain a sense of humor — it eases tension and is good for your health.

Taking time for yourself will ultimately benefit both you and your loved one.

Resources for You

Alzheimer's Association

www.alz.org / 1-800-272-3900

This is a not-for-profit national organization that provides information and supportive services to families and individuals dealing with Alzheimer's disease. The organization offers print and online educational materials and caregiver guidance. Its help line is available 24 hours a day, seven days a week. In addition, it provides information about local chapters that can assist families in finding support groups and other services in their communities. The Web site also includes an "online community" which connects caregivers with other caregivers from all across the country.

The Alzheimer's Disease Education and Referral (ADEAR) Center

www.alzheimers.org

This is a service of the National Institute on Aging, which is a part of the Federal Government's National Institutes of Health. The Center provides information to patients, families, and professionals about Alzheimer's disease and services available to assist them. They may be called at 1-800-438-4380 from 8:30 a.m. – 5:00 p.m. EST.

The Alzheimer's Foundation of America (AFA)

www.alzfdn.org

The AFA is a not-for-profit organization whose mission is "To provide optimal care and services to individuals confronting dementia, and to their caregivers and families — through member organizations dedicated to improving quality of life." Its Web site includes information about brain health, Alzheimer's disease, and other forms of dementia as well as tips for caregivers. The AFA toll-free hotline 1-866-AFA-8484 (1-866-232-8484) is staffed by certified social workers and other professionals knowledgeable about Alzheimer's disease and other similar disorders. It is available to assist with questions caregivers may have as well as to provide information about local resources to assist individuals with Alzheimer's disease and their families. The hotline is open Monday through Friday 9 a.m. – 5 p.m. EST.

The Alzheimer's Store

www.thealzheimersstore.com

The Alzheimer's Store provides unique products and information for those caring for someone with Alzheimer's disease or other similar disorders. Categories of products and information include wandering, falls, caregiving, incontinence, alarms, books, videos, etc.

American Bar Association Commission on Law and Aging

www.abanet.org/aging

The Commission on Law and Aging seeks to support and maintain the quality of life issues amongst elders. The Commission functions within the American Bar Association. The site provides a very helpful resource guide for consumers, *Law and Aging Resource Guide*, which contains information on a variety of topics including health care decision-making tools as well as state-specific contact numbers and resources for legal assistance for older adults.

Eldercare Locator

www.eldercare.gov / 1-800-677-1116

The Eldercare Locator, a public service of the Administration on Aging (AOA), U.S. Department of Health and Human Services provides older individuals and family caregivers with information on state and community resources in their local area.

Family Caregiver Alliance (FCA)

www.caregiver.org

The Family Caregiver Alliance provides information, education, services, research, and advocacy for the nation's caregivers. Based in California, it is a resource for national, state, and local levels of support. FCA produces informational fact sheets including one on Alzheimer's disease and one entitled, *A Caregiver's Guide to Understanding Dementia Behaviors*. These and other publications are available online or they may be ordered from FCA. The site also has online support groups available to caregivers. Call 1-800-445-8106 Monday through Friday, 9 a.m. – 5 p.m. PST.

Foundation for Health and Aging (The American Geriatric Society)

www.healthinaging.org

The Foundation for Health and Aging (FHA) is a national, nonprofit organization established in 1999 by The American Geriatrics Society (www.americangeriatrics.org) to advocate on behalf of older adults and their special health care needs. The FHA Web site contains a comprehensive online guide, *ElderCare at Home*, which addresses physical and mental/social problems, problems in managing care, and contains specific chapters on dementia. The site also offers a "What to Ask" series with questions to ask health care providers about various care issues.

Medic Alert® and Alzheimer's Association "Safe Return®" Program

www.alz.org/safetycenter/we_can_help_safety_medicalert_safereturn.asp

This program is a 24-hour nationwide emergency response service for individuals with Alzheimer's disease or a similar disorder who wander or have a medical emergency. The Web site provides information about the program and provides the ability to enroll online. You can also call the 24-hour hotline for the Alzheimer's Association at 800-272-3900 with questions.

Medline Plus

www.nlm.nih.gov/medlineplus

Medline Plus is an online connection to the National Library of Medicine, part of the National Institutes of Health. The site contains reliable information about a large variety of diseases, conditions, current trends in medicine, with links to other resources.

National Academy of Elder Law Attorneys (NAELA)

www.naela.org

This Web site is for attorneys who deal with the many issues facing older adults and the disabled. NAELA attorneys can assist their clients with estate planning, long-term care issues, powers-of-attorney, wills, and trusts. Within the site is a search field to find an elder law attorney in your area. There is also a very helpful question-and-answer section that will assist in the search for an elder law attorney: www.naela.com/public/index.htm. You may reach NAELA by phone at 520-881-4005.

The National Adult Day Services Association (NADSA)

www.nadsa.org

This is the membership organization which serves as the leading voice for the diverse Adult Day Services community. Their Web site includes a national directory and guide to choosing an adult day services center. Call 1-877-745-1440 for more information.

The National Alliance for Caregiving (NAC)

www.caregiving.org

The National Alliance for Caregiving Web site contains research on caregiving as well as practical assistance for caregivers. This site also currently includes a link to an educational Web site for caregivers which is co-sponsored by the National Alliance for Caregiving, the National Family Caregivers Association, and Eisai Inc. This Web site provides assistance and information for family caregivers on a variety of issues related to caregiving as well as resources for locating needed services. The Web site can be accessed directly at www.familycaregiving101.org.

National Association of Area Agencies on Aging (n4a)

www.n4a.org

The National Association of Area Agencies on Aging (n4a) is the umbrella organization for our nation's 629 area agencies on aging and a champion for the 246 Title VI Native American aging programs. The Web site allows you to search for your local area agency on aging. Area Agencies on Aging were established under the Older Americans Act (OAA) in 1973 to respond to the needs of Americans 60 and over in every local community. They provide a range of options that allow older adults to choose the home and community-based services and living arrangements that suit them best to help them remain in their homes and communities as long as possible.

The National Family Caregivers Association (NFCA)

www.nfcacares.org

The NFCA is committed to support, educate, and speak up for family caregivers. It provides a number of practical tip sheets and checklists for caregivers which can be accessed at www.thefamilycaregiver.org/ed/tips.cfm. Topics include caregiver tips for talking on the phone, improving doctor/caregiver communication, when your loved one is hospitalized, and communicating effectively with health care professionals.

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