



# Family Care Guide

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A GUIDE FOR FAMILIES CARING FOR  
SOMEONE WITH ALZHEIMER'S DISEASE  
OR A RELATED DEMENTIA

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Dear Caregiver:

This is the seventh edition of the Family Care Guide. The first edition was published in 1987 as part of an Administration on Aging Grant project. The intention then, as it is now, was to provide family caregivers with concise information on how to live and cope with Alzheimer's disease and other related illnesses. We want the Guide to be a quick reference book that provides stage-related information as you need it, when you need it.

Many of the strategies and techniques of care were originally contributed by active and former family caregivers. In a sense, the Guide was, and still is, a book of collective knowledge hard-gained by hundreds of caregivers providing thousands of hours of care. The information is also drawn from the latest literature on the various topics. This is a guide that is meant to be read in sections and probably not read from cover to cover in one sitting. We took this approach because we realize how demanding active caregiving can be.

There are more than 5 million persons with Alzheimer's disease in the United States today, and approximately 15 million family caregivers provide 17 billion hours of unpaid care in the community. On average, the person remains at home receiving care for five years. Time is a precious commodity for most caregivers.

In order to meet the demands of active caregiving for as long as possible, it is important that the caregiver(s) have regular predictable time off, time to replenish the soul, time for yourself or, time to socialize. Ask for help, if you need it. Consider using adult day health programs and volunteer or paid help in the home. Take care of yourselves as well as those in your care.

Since the first edition of this Guide, we have learned that many of the behavioral symptoms associated with Alzheimer's disease, and many of the related disorders, are treatable, if not outright avoidable. This Guide provides the reader with innovative practical approaches to care that can limit or prevent difficult symptoms. By no means are we implying that these techniques will arrest the progression of Alzheimer's disease, clearly they will not, but using them skillfully will limit many symptoms that were once thought to be an inevitable part of the disease process.

Because the ability to perceive emotion; to feel a range of emotions; to hold emotion; to respond to emotion; and to learn through emotional processing of information all remain intact late into Alzheimer's disease, maintaining positive emotion is a central concept in this Guide. The caregiver's goal is always to bring about a positive emotion in the person with Alzheimer's disease. Working from this perspective will allow you, the caregiver, to focus on the person that is still there, and not on what has been lost to the disease. Hopefully, this perspective will empower you with new skills that will reduce your stress and strengthen your relationship with the person with dementia.

Listed below are a few general guidelines that may help to maintain a positive emotion in the person with dementia and reduce caregiver stress.

- Never argue with the person, rather refocus the person's attention to something different or redirect his or her behavior to something new.
- Never assume the person will be able to change his or her behavior because of your instructions. New learning is often difficult for those with Alzheimer's disease.
- Establish a simple consistent daily routine.
- Understand that the person's behavior is caused by changes in the brain and may not always be intentional. To control behavior, the caregiver's approach or, the environment around the person must be adjusted to be more supportive.
- Don't dwell on what has been lost. Focus your attention on what the person can still do.
- Allow family and friends to help you. Don't become isolated. Communicate your needs, fears and problems with someone you trust. Join a caregiver support group.

## A Note on Terminology

Throughout the guide, you will see some of these common terms which are defined below:

**Alzheimer's disease**—References to "Alzheimer's disease" refer to Alzheimer's disease and related disorders. When something refers only to a particular disorder or disorders, it will be noted.

**Caregiver**—The term "caregiver" is used to describe family members, partners, or friends who care for a person with Alzheimer's disease or a related disorder as opposed to a professional individual paid to provide care.

**Dementia**—The term "dementia" refers to a group of cognitive symptoms including memory loss, disorientation, and language impairments that are often progressive in nature.

**Person**—The individual diagnosed with Alzheimer's disease or a related disorder.

Please note that throughout the text of this Guide, persons with Alzheimer's or dementia are referred to as male or female interchangeably.

## How to Use the Guide

This Guide is intended to be a handy reference for busy caregivers. Caregivers are encouraged to consult the Guide for ideas and suggestions as needed and to use any blank spaces at the end of each section, and in the margins, to jot down notes on approaches that have worked for them. Think of this guide as a tool that you customize based on your particular circumstance.

This is not the type of book that you should feel you need to read cover to cover. It is intended that you use the Table of Contents to identify a topic area when you need to use that information.

Suggestions in The Guide, from professional care providers and from family caregivers, have been compiled from the Habilitation Therapy model of care which I developed with Joanne Koenig Coste. Not all of these suggestions will be appropriate for every person with dementia, or appropriate for every stage of the person's illness. I hope that this information will aid you in understanding the needs of the person for whom you are caring, and that it will assist you in developing your own unique approaches to care. The "Guide" gives you strategies for care, and you must interpret and apply the strategy based on the situation, the needs of the person and your own capacity. The overall goal as a caregiver should be to promote and nurture a positive emotion in the person with Alzheimer's. You may modify any of the strategies in this guide to attain the goal of bringing about a positive emotion.

The Family Care Guide places control in the hands, mind and spirit of the caregiver. Use this guide wisely; it will help you to take control of this disease and your relationship with the person with dementia.

Paul Raia, Ph.D.  
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## Chapter 1

# INTRODUCTION

## What is Alzheimer's Disease?

Alzheimer's is a disease of the brain that is marked by a slow, progressive decline of cognitive functioning as brain cells are destroyed by plaques and tangles in the brain.

**Plaques** build up between nerve cells. They contain deposits of a protein fragment called beta-amyloid (BAY-tuh AM-uh-loyd).

**Tangles** form inside dying cells. Tangles are twisted fibers of another protein called tau (rhymes with "wow").

Although most people develop some plaques and tangles as they age, those with Alzheimer's tend to develop far more. Scientists believe that the damage from Alzheimer's disease begins in an area of the brain known as the hippocampus, which is responsible for recent memory and learning. In particular, the hippocampus controls the formation of new memories. This is why people with earlier stages of Alzheimer's disease experience the most trouble with recent memory and recall, yet usually have strong long-term memory.

Scientists are not absolutely sure what role plaques and tangles play in Alzheimer's disease. Most experts believe they somehow block communication among nerve cells and disrupt activities that cells need to survive.



### ***The difference between dementia and Alzheimer's disease***

**Dementia** is an umbrella term used to describe symptoms of memory loss and other changes in cognitive abilities severe enough to interfere with daily life.

Dementia is a condition that has many possible causes. **Alzheimer's disease** is the most common cause of dementia, accounting for 50 to 70 percent of all cases. Alzheimer's disease is also commonly referred to as a "type" of dementia. There are numerous other types of dementia.

These various types of dementia share many similar symptoms but they differ in the way they affect the brain, the order in which symptoms appear, the severity of individual symptoms, and how the disease progresses.

Other conditions that can cause dementia (or mimic Alzheimer's disease) include hydrocephalus, depression, brain tumors, nutritional deficiencies, alcoholism, infections, head injuries, and drug reactions. Some of these conditions may be treatable.

In addition to Alzheimer's disease, the following irreversible disorders can also cause memory loss, confusion and other symptoms associated with dementia:

- **Vascular dementia** is generally considered to be the second most common type of dementia. It refers to impairment caused by reduced blood flow to parts of the brain. Symptoms of vascular dementia can be similar to Alzheimer's disease. In some cases, the impairment associated with vascular dementia can occur in "steps" rather than in the slow, steady decline usually seen in Alzheimer's disease.
- **Dementia with Lewy bodies** often begins with wide variations in attention, alertness, judgment and rational thinking. Individuals affected by this illness often experience visual hallucinations as well as muscle rigidity, tremors, falls, and balance issues similar to those associated with Parkinson's disease.
- **Parkinson's disease** affects control of movement, resulting in tremors, stiffness, and impaired speech. Many individuals with Parkinson's also develop dementia in later stages of the disease.
- **Frontotemporal dementia or Pick's disease** is a disorder that may sometimes be hard to distinguish from Alzheimer's disease. Personality changes and disorientation often occur before memory loss. Symptoms often resemble depression. There are many different subtypes of frontotemporal dementia that feature different rates of progression and prominence of specific symptoms.
- **Huntington's disease** is an inherited, progressive disorder that causes irregular movements of the arms, legs, and facial muscles; personality changes; and a decline in the ability to think clearly. This disease can cause dementia, but varies in severity.
- **Creutzfeldt-Jakob disease (CJD)** is a rare, rapidly fatal disorder that impairs memory and coordination and causes behavior changes. Recently, "variant Creutzfeldt-Jakob disease" was identified as the human disorder believed to be caused by eating meat from cattle affected by "mad cow disease."
- **Normal pressure hydrocephalus (NPH)** is caused by a buildup of fluid in the brain. The cause of most cases is unknown. Symptoms include difficulty walking, memory loss and inability to control urine. NPH can sometimes be corrected with surgery to drain the excess brain fluid.
- **Physical injury to the brain** caused by a motor vehicle crash or other trauma can damage or destroy brain cells and in some cases cause symptoms of dementia such as behavioral changes, memory loss and other cognitive difficulties.

There are other forms of dementia. Doctors are discovering new subtypes all the time, so your loved one may have received a specific diagnosis that is not listed here. Some individuals may receive a dual diagnosis (e.g., Alzheimer's disease and dementia with Lewy Bodies).

### ***Younger-onset dementia***

Anyone diagnosed with Alzheimer's disease or a related dementia before the age of 65 is considered to have "younger-onset dementia." People who have younger-onset dementia essentially experience the same symptoms as older people with the disease. However, individuals with younger-onset dementia will face unique age-related issues. For instance, those under 65 may still be employed or have children living at home. Issues facing families include ensuring financial security; obtaining benefits; and helping children cope with the disease. Experts estimate that up to 5% of people with Alzheimer's disease are in their 30s, 40s, and 50s.

### ***Mild cognitive impairment (MCI)***

Sometimes a person may have problems with memory or another thinking skill that is serious enough to show up on tests, but not severe enough to interfere with daily life. Some doctors use the term mild cognitive impairment (MCI) to describe this situation.

Research has shown that individuals with MCI have an increased risk of progressing to Alzheimer's disease, especially when their main area of difficulty involves memory. But a diagnosis of MCI does not always mean the person will develop Alzheimer's.

## Symptoms of Alzheimer's Disease

The following are 10 warning signs which may indicate possible Alzheimer's disease:

### ***1. Memory loss that disrupts daily life.***

One of the most common signs of Alzheimer's is memory loss. This may include forgetting recently learned information, forgetting important dates or events, or asking for the same information over and over.

### ***2. Challenges in planning or solving problems.***

Some people may experience changes in their ability to develop and follow a plan or work with numbers. The person may have trouble following a familiar recipe, keeping track of monthly bills, or take much longer to do things than she did before.

### ***3. Difficulty completing familiar tasks at home, at work or at leisure.***

People with Alzheimer's often find it hard to complete daily tasks. Sometimes, people may have trouble driving to a familiar location, managing a budget at work or remembering the rules of a favorite game.

### ***4. Confusion with time or place.***

People with Alzheimer's can lose track of dates, seasons and the passage of time. The person may have trouble understanding something if it is not happening immediately. Sometimes she may forget where she is or how she got there.

### ***5. Trouble understanding visual images and spatial relationships.***

For some people, having vision problems is a sign of Alzheimer's. The person may have difficulty reading, judging distance and/or determining color or contrast. In terms of perception, she may pass a mirror and think someone else is in the room. She may not realize that she is the person in the mirror.

### ***6. New problems with words in speaking or writing.***

People with Alzheimer's may have trouble following or joining a conversation. The person may stop in the middle of a conversation and have no idea how to continue or she may repeat herself. She may struggle with vocabulary, have problems finding the right word, or call things by the wrong name (such as calling a "watch" a "hand-clock").

### ***7. Misplacing things and losing the ability to retrace steps.***

A person with Alzheimer's disease may put things in unusual places. She may lose things and be unable to go back over her steps to find them again. Sometimes, she may accuse others of stealing. This may occur more frequently over time.

### ***8. Decreased or poor judgment.***

People with Alzheimer's may experience changes in judgment or decision-making. For example, the person may use poor judgment when dealing with money, (such as giving large amounts to telemarketers). She may pay less attention to grooming or keeping clean.

### **9. *Withdrawal from work or social activities.***

A person with Alzheimer's may start to remove herself from hobbies, social activities, work projects or sports. She may have trouble keeping up with a favorite sports team or remembering how to complete a favorite hobby. She may also avoid being social because of the changes she has experienced.

### **10. *Changes in mood and personality.***

The mood and personality of a person with Alzheimer's can change. She can become confused, suspicious, depressed, fearful or anxious. She may be easily upset at home, at work, with friends or in places where she is out of her comfort zone.

\*Taken from *10 Warning Signs of Alzheimer's Disease*, Alzheimer's Association, 2009.

These warning signs are also the **symptoms** experienced by people diagnosed with Alzheimer's disease and related dementias. Not everyone will experience all of these symptoms, because every person is unique. It is possible to receive a diagnosis even if only a few symptoms have developed.

#### ***Normal age-related changes in memory***

It is normal to experience some changes in memory as we grow older. The majority of older adults experience some of the following normal changes in cognition:

- Forgetting names more frequently
- Experiencing difficulty switching from one subject to another
- Requiring more time and concentration to learn new information

Normal age-related symptoms of memory loss result from the brain's decreased capacity for quickly and efficiently retrieving information from long-term memory. It can take more time to recall information or learn new things. These memory changes may be bothersome, but they do not significantly affect daily functioning.

## Diagnosis of Alzheimer's Disease

There is no single type of doctor that specializes in diagnosing and treating Alzheimer's disease and related dementias. A primary care physician who suspects some type of dementia will likely refer to one of the following types of specialists:

- **Geriatrician**—Primary care physicians (MD) who specialize in conditions unique to older adults.
- **Geriatric Psychiatrist**—Physicians (MD) who specializes in mental and emotional issues among older adults. They may also diagnose conditions associated with dementia such as depression or anxiety.
- **Neurologist**—Physicians (MD) who specializes in diseases of the brain and nervous system and is qualified to perform extensive memory evaluations. Some, but not all neurologists, specialize in Alzheimer's.
- **Neuropsychologist**—Psychologists (PhD) with specialized training in testing the function of the brain by assessing cognitive abilities and determining strengths and weaknesses. Typically a referral from your doctor is needed in order to meet with this type of specialist.
- **Specialized diagnostic clinic**—Group practice with different kinds of specialists (usually including a neurologist, psychiatrist, psychologist, and social worker) who each perform part of the diagnosis.

There is no single test for Alzheimer's disease but experts estimate that a skilled physician can diagnose Alzheimer's disease with at least 90% accuracy. The only definitive (100%) diagnosis for Alzheimer's disease requires an autopsy to examine the brain tissue using a powerful microscope for evidence of the plaques and tangles that are hallmarks of the disease.

A diagnosis of Alzheimer's disease can be made after a complete medical, neurological and psychological examination is completed to rule out other possible causes of the person's symptom and assess the patterns of problems.

The diagnostic process may involve the following components:

- Review of personal and family medical history
- Evaluation of mood and cognitive skills
- Physical exam (including a blood test)
- Neurological exam including reflexes, coordination, eye movement, muscle strength and tone, speech and sensation
- Brain scan (CT, MRI or PET):
  - The MRI (magnetic resonance imaging) and CT (computed tomography) scans provide structural imaging about the shape, position or volume of brain tissue.
  - The PET (positron emission tomography) scan provides a functional image which reveals how well cells in various brain regions are working by showing how actively the cells use sugar or oxygen. This test can be rather expensive.
  - Currently, a standard medical workup for Alzheimer's disease often includes structural imaging with MRI or, less frequently, CT. These images are used primarily to detect tumors, evidence of small or large strokes, and damage from severe head trauma or a buildup of fluid. The MRI cannot detect Alzheimer's disease directly but is used to rule out other causes of cognitive impairment.
- Neuropsychological exam:
  - Neuropsychological tests are sometimes used to learn more specific information about an individual's cognitive strengths and weaknesses. Depending on the individual, a neuropsychologist may run one test or a number of tests.
  - Neuropsychological tests are not invasive. They involve interviewing the person and her caregiver, paper-and-pencil tests, and sometimes computerized tests.

Each of these tests is used to rule out the possibility of any reversible causes (for example, infection or medication issues). The components of the diagnostic process also help to inform a clinical diagnosis of Alzheimer's disease or related dementia.

### ***Why seek a diagnosis?***

- It is important to rule out a disease or condition that can cause symptoms that look like Alzheimer's disease but may be potentially treatable or even curable.
- The diagnosis will provide an explanation for symptoms and help the family and person begin to understand how to cope with the symptoms.
- An early diagnosis can help ensure appropriate treatment. We know that earlier treatment can be more effective.
- People may have the opportunity to participate in research that gives access to new treatments and increased support.
- An early diagnosis helps families get started with future planning and enables the person to be an active participant in that process.

## Risk Factors

Researchers have identified multiple risk factors that increase the likelihood of developing Alzheimer's disease. Some are risk factors that we cannot change, while there are others we may be able to influence.

***It is no one's fault if someone is diagnosed with Alzheimer's disease***

There are factors beyond one's control that influence the development of this disease. Even if a person takes every precaution to minimize risk factors within his control, it is still possible to develop Alzheimer's disease.

The most significant risk factors are those that we cannot control:

**Age** is the greatest known risk factor. Most individuals with Alzheimer's disease are 65 and older. The likelihood of developing Alzheimer's approximately doubles every five years after age 65. After age 85, the likelihood reaches nearly 50 percent.

**Family history and genetics** also play a significant role. Research has shown that those who have a parent, brother or sister with Alzheimer's disease run an increased risk of developing the disease. The risk increases if more than one family member has the illness.

Scientists have so far identified one gene (APoE) that increases the risk of Alzheimer's but does not guarantee that an individual will develop the disorder. Experts believe that the vast majority of cases are caused by a complex combination of genetic and non-genetic influences.



There are some risk factors that we may be able to influence:

1. There is a strong link between head injury with a loss of consciousness and future risk of Alzheimer's disease.
2. Heart health influences brain health. High blood pressure, high cholesterol, and diabetes are all risk factors for dementia.

## Progression of Alzheimer's Disease

Most types of dementia, particularly Alzheimer's disease, tend to show a slow progressive decline. One exception is vascular dementia, which can show a slow progression with periods of fast decline depending upon the occurrence of additional vascular damage.

The role a caregiver plays in the care and support of someone with Alzheimer's will depend on the changing needs of the person. The need for assistance will change over time as the disease progresses and each person with Alzheimer's will move through the disease in her own way. In addition, a person's need for assistance will vary from day to day. This means caregivers need to be flexible and sensitive to what the person needs help with at that moment. It is helpful for families to understand what changes are typical in the early, middle and later part of the disease. Knowing what to expect can help families plan ahead or better respond as changes occur.

### *Early-Stage Alzheimer's disease*

In the early part of the disease, some of the changes you may notice are:

- Trouble remembering conversations, recent events or the month or day of the week
- Losing things or misplacing things
- Repeating stories or questions
- Withdrawal from social activities or problems with initiating activity
- Greater difficulty performing complex tasks, such as paying bills or managing finances
- Driving ability is compromised
- Denial that something is wrong

***Sudden changes in a person with Alzheimer's disease or related dementias should always be referred to a physician to rule out if these changes are caused by:***

- Infection
- Dehydration
- Poor nutrition
- Lack of adequate rest
- Thyroid imbalance
- Medication side effects
- Depression
- Other health conditions

### ***Middle-Stage Alzheimer's disease***

Caregivers will need to become more involved in supervision or assistance with meals and eating, personal care, safety and other activities. In this stage of the disease a person may initially need only cues or prompts with an activity like dressing. As he moves through this stage more and more supervision and hands-on assistance will be needed. Ultimately, the person will require 24-hour supervision to ensure his health and safety.

Some of the changes you may notice are:

- Increased difficulty with speaking or understanding language
- Progression from needing reminders about personal care and other tasks to needing help with bathing, dressing, taking medication, and using the bathroom
- Changes in personality or emotions, such as: anger, agitation, paranoia, withdrawal, and depression
- Wandering or sundowning (restlessness or agitation in the late afternoon or evening)
- Changes in behavior, such as: shouting, pushing, slapping or other physical aggression
- Episodes of urinary incontinence if not reminded or scheduled to use the bathroom

### ***Later-Stage Alzheimer's disease***

At some point in the later part of the disease, a person will need full assistance with all personal care tasks, lose the ability to speak and walk and require 24-hour supervision. The challenges of assisting with bowel and bladder needs becomes more challenging as she moves from having episodes of incontinence to needing continual care in this area.

Some of the changes you may notice are:

- Limited or loss of ability to speak or respond with words although non-verbal communication (nodding, smiling, making sounds) may continue
- Lose ability to recognize people or things
- Lose ability to walk and need assistance to move or reposition
- Trouble with chewing or swallowing
- Incontinence of bowel and bladder
- Weight loss

The progression of Alzheimer's disease is highly variable. Although there are many common experiences, you can also expect to have your own unique experience as a caregiver. Rather than focusing on when to expect cognitive losses during the course of this disease, **try to focus on current strengths**. Even in the later stages, not all abilities are lost. For instance, the capacity for emotion and relationships remains intact throughout the course of the disease. As the disease progresses, caregivers should continue to foster positive emotions and capitalize on the strengths of the person with Alzheimer's disease.



## Chapter 2

# COMMUNICATION

Successful communication remains possible even though Alzheimer's disease eventually affects the person's ability to express herself and understand what is happening around her. **Keep in mind that speech, language and other communication difficulties vary from person to person and may vary from day to day, or even moment to moment.** Whatever the person's challenges are, it is important to take advantage of the abilities that remain and find ways of communicating despite the challenge of the disease.



As the person's ability to use speech declines, it may be difficult for others around her to adjust their communication style. Sometimes it is hard to accept the person's limitations, especially when she continues to look like the same person she once was.

If we were asked to define communication, we might describe it as talking to and listening to each other. It's equally important to realize that communication also includes how we relate to each other in non-verbal ways. The importance of tone of voice and body language cannot be over emphasized. Learning and practicing how we communicate with the person with dementia can help us to have more success in day-to-day living and decrease frustration and anxiety for everyone.

## Verbal Communication

Verbal communication includes "receptive" and "expressive" speech. The person with Alzheimer's disease will have difficulty taking in information (receptive) and making themselves understood (expressive). The ability to **receive** information includes **understanding and following directions, reading comprehension, and following conversations**. The ability to **express** oneself includes **finding the right words and organizing words logically**. The person with Alzheimer's disease often speaks less and/or relies on gestures.

The first steps to improved communication are to:

- Offer comfort and reassurance
- Begin where the person is coming from, rather than correcting him
- Always look for and acknowledge the emotion behind the words
- Supplement words with gestures, touch, smiles, nods, and eye contact
- Minimize distractions in the environment that may impede communication

Avoid these common problems:

- Trying to convince him to do something with logic or reasoning
- Arguing
- Pointing out that he has made a mistake
- Talking about him as if he weren't there

Helpful verbal communication strategies include:

- Use short simple words and sentences, speak slowly and clearly.
- Ask one question at a time.
- Patiently wait for a response but if the person is frustrated, offer a guess or suggestion.
- Repeat information or questions.
- Turn negatives into positives (Instead of saying "Don't do that," you might say "Come with me, I need your help with something").
- Make statements rather than requests.

### ***Tone of voice, body language and facial expression***

Your tone of voice, body language and facial expression are as important as what you say. The following are some helpful tips for communicating effectively through non-verbal communication:

- Use a calm and reassuring tone of voice.
- Be open and relaxed with your physical stance.
- Establish and make eye contact.
- Approach from the front and if possible, be at eye level.
- Use gestures such as pointing and modeling.
- Avoid sudden movements.
- Always remember humor, smiles and laughter go a long way.

### ***Asking questions or giving directions***

Asking questions or giving directions to a person with Alzheimer's can potentially cause frustration and upset--for you and the person. Maintaining a calm atmosphere can often be more important than communicating specific information. Do not argue or try to convince the person. For example, the person does not necessarily have to understand that he needs to take a bath or change his clothes, as long as he does so. If the person becomes upset or uncooperative, stop and try again later. Try to redirect his attention and distract him with another activity or thought.

- Do not ask questions that rely on memory.
- Ask one question or give one direction at a time.  
*Example: "It's time to sit at the table" instead of "It's time to sit at the table and eat dinner."*
- Ask questions that require only one choice at a time.  
*Example: "Do you want coffee?" instead of "Do you want coffee or tea?"*
- Demonstrate what you mean and use gestures.
- Allow ample time for the individual to respond or act.
- Provide frequent reassurance and praise.
- Use positive statements.  
*Example: "Let's go this way" rather than "Don't go that way."*

### ***Responding to the Person with Alzheimer's disease***

If the person with Alzheimer's is trying to talk to you and becomes frustrated with her inability to be understood, empathize with her. Validating her feelings will lessen her frustration. Always be patient and non-critical. If the person cannot find the word, suggest a word, provide a verbal cue, or if she can, ask her to try writing it down.

Some other strategies for responding to the person with Alzheimer's disease are:

- Ask a question that helps her find a different way of communicating the same information.  
*Example: If she is having trouble describing something, try asking, "Would you show me where it is?"*
- Don't hesitate to use small fibs or "therapeutic fiblets" to keep the situation manageable.  
*Example: If he does not like going to the doctor, simply tell him that you are doing errands to get him to leave the house.*
- Focus on a piece of information that will make things okay for the person.  
*Example: If she gets upset about your going out, emphasize that a favorite person is coming over to spend time with her.*
- Eliminate details from your response that will not help the person, or may cause anxiety, fear, or defensiveness.  
*Example: When he asks why he needs to go to the day program, remind him of all of the help he gives the staff and other participants there and do NOT explain all of the benefits of the day program.*

If the person with Alzheimer's asks the same question over and over, remember that she probably cannot remember the answer (or even that she asked the question before.) Repeat your answer once or twice and then try to change the subject or redirect her attention with an activity. Reassure her that everything is fine, that you are there, and that she is not alone.

Don't laugh *at* the person who is having difficulty, but if the person can laugh at themselves or be lighthearted as you struggle together to understand each other, there is an opportunity to use humor to diffuse difficult situations.

It is helpful to just listen. Your interest conveys respect and concern. If the person makes up stories, don't argue or disagree. It may be helpful to change the subject or respond to the part of the story that is accurate. Even if she mumbles or rambles, try to listen without comment. Do not discourage communication by criticizing her speech.



### *Handling complaints or insults*

Not always, but at times, the person with dementia who is anxious or frustrated may express himself with complaints and hurtful remarks. If that is something you experience, try to listen for the emotion behind the words. The following tips may help caregivers who experience this:

- Do not take such comments personally and don't argue.
- Respond sympathetically to the underlying feeling being expressed; for example, "I'm sorry that you're upset".
- Remain calm with your tone of voice and body language.
- Leave the room and take a break if necessary and try again later.

Always remember not to respond directly to the remark but rather change the subject or redirect the person to another activity.

### Providing Cues in the Environment

As long as the person continues to understand written words, signs and labels can be useful reminders of what things are and how they are used.

- Label household items and rooms with words or pictures.
- Use simple signs with large clear print to prompt memory, such as "Turn off the stove".
- Prominently display a large easy-to-read clock. Digital clocks may be easier to read than conventional ones.
- Display a bulletin board or blackboard with the day, date, and season printed clearly.
- Provide the person with a wristwatch if he is able to read one.
- Use a calendar with large print and cross off each day.
- Display pictures of family and friends with their names under the pictures.



## Chapter 3

# DAILY LIVING

Giving daily care and assistance to a person with Alzheimer's or another dementia can be challenging for a number of reasons. As the disease progresses and symptoms change, you will need to take on more responsibilities for hands-on care. The person may become more confused, need more time to do things, and may even be resistant to help. Understandably, this can be frustrating for the caregiver and the person with dementia. At some point, the person will require 24-hour supervision and assistance with all care tasks. The following section provides guidance for how to best approach daily care to lessen disagreements and to support the person to participate as much as he can with daily activities.



## Bathing

Bathing can be one of the most difficult tasks for a caregiver to accomplish. Many persons with Alzheimer's disease have a fear of water. A bath can be scary and confusing for a person who does not fully comprehend what is happening.

### ***Make bathing less stressful for you both:***

- Think about the best time and routine for bathing. It may reduce anxiety if you follow the same routine each time.
- Avoid discussion of the need for a bath or shower. Take a matter of fact approach: "It is time to take a bath now."
- Do not schedule a bath or shower at times that are already stressful for you or the person. If possible, when you have an appointment together, try to take care of showering the day before or earlier in the day. That way you will not be rushing her to get ready.
- Pick a time when you are least likely to be interrupted. Leaving a confused or frail person alone in the tub or shower can be frightening and dangerous.
- Organize all the bath items you need (in order of use) before starting the bath or shower.
- Allow the person to do as much for himself as possible.
- If he becomes frightened, distract him with conversation.

***Make bathing safer by using:***

- Plastic containers rather than glass
- Rubber bath mat and grab bars in the tub. Make sure the bars are installed properly.
- Sturdy chair or stool in the bath or shower that eliminates some of the problems involved in getting the person into and out of the tub or shower. It will also help to prevent falls. Bath chairs are available from drug stores and other suppliers of durable medical equipment.
- Hand-held showerhead which can be easier for you and less threatening to the person.

***Daily bathing is not always necessary.***

It can even be damaging to fragile skin. Washing the person's face, hands, and genital area may be all that is needed. A sponge bath can be an effective alternative to a shower or bath.

***Hygiene tips:***

- Use moisturizing soap. Avoid bubble bath and bath oil because they can make the tub or shower slippery and contribute to urinary tract infections.
- Be certain the genital area is clean to avoid infections. If the person needs assistance, be matter-of-fact and calm. Sometimes using a washcloth and a hand-over-his hand approach can be less threatening and more comfortable.
- Dry the skin thoroughly. Use a lotion for dry skin after the bath, and check the condition of the skin for any changes, including bruises, discoloration, or breaks in the skin. If you note any changes, be sure to arrange for the person to be seen by a medical professional. See section on Pressure Sores later in this chapter for more information.

**Grooming**

Good grooming helps to maintain the person's sense of self-esteem. Encourage the person with Alzheimer's to groom himself for as long as he can. Be prepared to guide and assist him as needed. Give step-by-step instructions, allowing him to finish one step at a time.

- Keep fingernails and toenails clean and cut short. Hand massage and manicures may be good grooming treats and very relaxing to the person.
- For men, encourage daily shaving with an electric razor. Use a pre-shave softener to help reduce pulling and razor burn.
- For women, continue a normal or modified makeup routine if practical.
- Short hair is usually easier to manage than long hair. Continue to visit the barber shop/beauty salon regularly. Some hairdressers will make home visits. To reduce waiting and confusion, ask for the first or last appointment of the day.

## Dressing

With increased memory loss, the steps involved in getting dressed become more difficult for the person to handle by herself. Allow the person to dress herself as long as she is able to do so, regardless of how long the process takes. Give step-by-step instructions, allowing her to finish one step before continuing on to the next.

- Lay out clothes in the order they will be put on. If necessary, hand each item of clothing one at a time to the person.
- Describe what you are doing as you do it. For instance, tell the person, "It's time to get dressed. Here is your shirt."
- Provide comfortable and loose fitting clothing.
- Involve the person by encouraging her to make clothing choices, but limit choices to two things.
- Keep only seasonal clothes in the closet or keep the closet locked and put out one outfit at a time.
- If the person insists on wearing the same clothing day after day, try buying several duplicate sets of the same clothes and rotating them.

*If shoelaces, zippers, buttons and buckles are difficult, instead consider using:*

- Slip-on shoes (ones that won't slip off easily)
- Elastic shoelaces
- Sneakers with Velcro® closings
- Pants with elastic waist bands
- Clothing that closes in the front (bras with front closure, etc.)
- Velcro® tape or large zipper pulls.

If the person wears dentures, you may need to supervise the cleaning process and see that they fit properly. Poorly fitting dentures make it difficult to eat and digest food.

## Oral Hygiene

Poor oral hygiene can lead to infection, gum disease, or toothaches. Demonstrating the steps of brushing can be a simple way to help the person brush her own teeth. Allow her to imitate you, one step at a time. Sometimes if you start the motion, her lifelong habit may take over. Try guiding the hand that is holding the toothbrush until she takes over on her own. Brushing your teeth at the same time as the person may help encourage her.

Other suggestions for good oral hygiene:

- Dispense toothpaste as needed rather than leaving the tube out.
- Try using a long-handled or angled brush if you are doing the brushing.
- Be aware of medications that cause dryness of the mouth. Frequent mouth rinses can help dry mouth, but avoid commercial rinses that contain alcohol, which contributes to dryness.
- Continue routine dental appointments as long as possible.

## Using the Bathroom

As memory loss progresses, a person with Alzheimer's loses the ability to use the toilet without assistance. Initially, encourage the person to be as independent as possible. If assistance is needed, do not provide more help than is necessary. Start with verbal cues and gestures before helping with clothing, positioning, wiping, and readjusting clothing.

### ***Remind him where the bathroom is.***

- Verbally tell him or point to it; lead him there if necessary.
- Clearly mark the bathroom with a sign or a picture of a toilet; or paint the bathroom door a bright color.
- Make a "trail" to the bathroom with wide fluorescent tape or carpeting.

### ***Learn the signs that the bathroom is needed so you can prompt him to use the bathroom.***

- Be aware that restlessness or pulling at clothes may indicate a need to use the toilet.
- Learn the words or statements that the person uses to state his need to use the bathroom.

***Ensure safety.***

- Remove the lock from the bathroom door
- Use an elevated toilet seat and/or try grab bars that can help prevent falls and make it easier for the person to use the toilet independently
- Consider bringing the toilet closer to where the person spends most of his day or getting a portable commode or urinal

***Some other considerations include:***

- If necessary, stimulate urination by running water or giving liquids to drink.
- If the person is no longer able to properly wipe himself, provide assistance because of the risk of infection. Remember to wash the person's hands and your own after contact.
- Encourage fluids during the day; they are necessary for good health. Do not limit fluids during the day. Limiting fluids in the evening can reduce the need to use the bathroom at night.

***Constipation***

Forgetfulness, poor diet, inadequate fluids, lack of exercise, and certain medicines may contribute to constipation. The following are signs of constipation to watch for: abdominal pain or bloating, headaches, restlessness or increase in agitation, frequent trips to the bathroom, and straining. Remember, however, that it is not necessary to have a bowel movement every day.

To prevent constipation, the person's daily diet should include plenty of liquids and foods containing fiber and roughage (such as prunes, figs, and prune juice; whole grain breads, cereals, and pasta; and fresh fruit and vegetables). Daily exercise also helps prevent constipation. If you suspect medication may be causing or contributing to the person's constipation, speak with his doctor about an assessment and treatment. Sometimes an accumulation of hardened feces in the rectum or lower colon can cause a blockage called impaction. This is a serious medical condition. If this is a suspected problem, the person should be seen by his doctor. Also, consult with the doctor about any use of a stool softener or agents that add bulk to the stool to prevent bowel problems.

Using the bathroom is easier when clothing is easy to manage. Avoid belts. Use pants with elastic waists such as sweatpants, which are comfortable, non-binding, and easy to take on and off.

## ***Incontinence***

Incontinence refers to the loss of bladder or bowel control. Stress incontinence may follow laughter, coughing, lifting or any sudden exertion. Incontinence is a symptom that is invariably part of the progression of Alzheimer's disease and can evoke feelings of anger, shame, and helplessness--for both the person with Alzheimer's and her caregiver.

Do not try to reduce incontinence by limiting daytime fluids which can lead to dehydration, constipation, or irritation of the bladder.

***Incontinence may be a correctable medical problem; a medical evaluation is the first step in dealing with it.*** It can be caused by factors not related to Alzheimer's disease, notably urinary tract infections and constipation. Prostatic enlargement in elderly men can cause a problem with fully emptying the bladder, with resulting "overflow." Some medications may predispose the person to incontinence.

If the doctor has determined there is no medical cause for incontinence, it may be that the person with Alzheimer's is unable to express discomfort or the need to urinate. Or, the incontinence may result from the person's inability to find the bathroom or undress quickly enough. Refer to the section on Using the Toilet earlier in this chapter for more information.

Steps that can help manage incontinence:

- Establish a regular toileting routine every 2-3 hours (upon rising, before and after meals, and at bedtime). If necessary, distract the person from toileting at other times.
- Praise independence and regular use of the bathroom; do not punish or shame for episodes of incontinence.
- Keep the genital area clean and dry to avoid infections and discomfort. "Baby wipes" are effective for this purpose.
- Keep track of bowel movements in order to learn the person's patterns, if there are any. This will help to avoid accidents.

***If the onset of incontinence is sudden or is accompanied by a change in behavior, fever, chills, or a strong odor to the urine, consult your physician.***

To minimize clean-up:

- Use adult sanitary briefs, adult "diapers," or other incontinence products if needed.
- Don't forget to request a senior citizen's discount (if the person is eligible) when purchasing incontinence supplies.
- For the bed, use plastic sheets or disposable bed pads.
- On chairs, use washable chair cushions or towels over plastic cushions.



## Pressure Sores (“bedsores” or decubitus ulcers)

A person who is not able to walk independently and spends most of his day in bed, a chair or wheelchair may develop pressure sores or “bedsores.” Pressure sores first appear as reddened spots over bony areas and develop into open sores. The most common areas for pressure sores are the base of the spine, shoulder blades, and heels. The problem is more likely to occur if the person stays in the same position too long, is very thin or has another health condition, such as diabetes.

Pressure sores are more difficult to cure than to prevent. Preventive measures:

- Good nutrition
- Exercise that promotes circulation
- Use of protective aids such as soft cushions, waterbeds, lambskin, or an “egg-crate” foam mattress pad
- Loose clothing made of soft fabric reduces friction and pressure on the person’s skin

If the person with Alzheimer’s is confined to a chair for long periods, help her stand and, if possible, walk at least every 2 hours. If the person is bedridden and unable to turn herself, change her position every 2 hours. Turn her from side to side and use pillows for support. Check daily for redness of the skin (particularly ears, shoulders, lower back, hips, and heels).

## Nutrition

A balanced diet is essential for good health. It helps avoid dehydration, constipation, malnutrition, or other illnesses, and promotes a sense of well being.

- Be sure the person eats a balanced diet and drinks at least 6 cups of liquid daily. It is important that the foods offered meet any medical requirements, especially if the person is on a low fat, low salt, diabetic, gluten-free, or other restricted diet.
- Rather than argue with the person about foods that she should avoid for health reasons, it is better not to have tempting but unhealthful foods in the house. Or store them in an inaccessible place so that you can control how often they’re eaten.
- If weight gain is a problem, try serving smaller portions or small frequent meals. Substitute nutritious snacks for high-calorie “junk food” or increase the person’s level of exercise.
- If the person is losing weight, consult a medical professional. There may be problems with absorption of food, or other medical problems. Eating problems may stem from treatable causes such as poorly fitting dentures or a sensitive tooth. If the person is eating poorly and is otherwise in good health, a nutritional supplement may be needed.

## Mealtime

Although most persons with Alzheimer's do not need special diets, the person may develop eating problems that make it difficult to make sure she is receiving proper nutrition. Dehydration is also a danger for the person who loses her sense of thirst or simply forgets to drink. There are many strategies to improve nutrition and hydration.

### *Keep a calm routine.*

- Try to maintain a routine and a relaxing atmosphere at mealtime.
- Serve meals at regular times and at the same table.
- Encourage the person to sit in the same place at the table.
- Serve foods the person knows and enjoys; new foods may confuse her.
- Allow the person enough time to eat.

### *Engage the person.*

- A person who has been accustomed to cooking may enjoy helping with meal preparation.
- Depending on her level of functioning, appropriate tasks may include stirring food, setting the table, folding napkins, wiping the table, or washing the dishes. Colorful, aromatic, and flavorful food may enhance the person's appetite.
- If restlessness makes it difficult for the person to stay seated for an entire meal, smaller, more frequent meals or serving finger foods that will allow the person to eat while moving around might work better.

### *Reduce clean-up.*

- Use a plastic tablecloth.
- An apron helps protect clothes from spills.
- Buy a "collar" that fits over the edge of the plate that will help keep food on the plate and make using a fork easier.
- To avoid spills, do not fill glasses or cups to the top.
- Avoid clear glass or plastic that may be difficult to see and try using a spill-proof cup or mug with a large handle.

***Keep it simple.***

- Serve one food at a time
- Demonstrate how to use utensils if needed
- Consider using a bowl instead of a plate
- Provide a spoon only
- Serve finger foods (e.g., sandwiches or cut-up vegetables) to avoid the need for utensils

***Make it safe.***

- Encourage the person to eat slowly and chew one mouthful at a time.
- For easy swallowing, have the person sit with her head slightly forward, not backward.
- Remember soft, thick food is less likely to cause choking than pieces of food that are slippery or require a lot of chewing.
- Do not feed a person who is drowsy or agitated or who is lying down.
- Keep her sitting up for 20 minutes after eating when possible. If a person lies down too quickly, food just swallowed may come back into the throat and cause choking.

***Tips for Dining Out***

- Try to go out at times when restaurants are the least busy; try making a reservation to avoid having to wait in line.
- When making the reservation, let the manager know that you will need a table near the restroom.
- Avoid very noisy restaurants and try to dine with a small number of people rather than a large group.
- When dining, spend some time talking about familiar past events. This will help the person with Alzheimer's contribute to the conversation.
- Allow her to sit quietly if it is more comfortable for her to not join the conversation.

***Suggestions for finger foods:***

Finger foods can help to save your energy and give the person with Alzheimer's more independence. Some examples: chicken nuggets; fish sticks; grilled cheese sandwiches (cut up); French fries; raw vegetable sticks; English muffins or toast; hard boiled eggs (quartered); fried vegetable sticks; cheese sticks; pork or beef (cut in small pieces). Always watch for signs of choking.

Medications, including over-the-counter drugs, may affect the sleep-wake cycle. Consult a doctor or pharmacist if you suspect the person's medication may be contributing to a problem with sleeping.

## Sleeping

Changes frequently occur in the sleeping patterns of a person with Alzheimer's disease. Sleeplessness at night is common. Some strategies to improve sleep include:

- Maintain a consistent and soothing bedtime routine and a regular wake-up time.
- Help her to avoid naps if the person has trouble sleeping at night.
- Encourage daily exercise.
- Evaluate any physical or emotional problems that may be contributing to sleep difficulties, such as pain or depression.
- Avoid fluids after dinner, particularly those with caffeine.
- Have the person use the toilet before going to bed.
- Use a nightlight in the bedroom if that seems to help.

Keep a normal bedtime routine as much as possible, for as long as possible. Eventually it may become necessary to allow the person to sleep wherever he is comfortable, perhaps on a couch or in a comfortable chair.

## Exercise

Exercise aids sleep, relieves tension and restlessness, regulates appetite, helps digestion, and improves strength, coordination, and flexibility. If the person already has an exercise routine, continue it as long as possible. If he does not have a routine, attempt some type of daily exercise. Consult a medical professional if he has physical or medical problems that may limit his ability to exercise.

Encourage exercise that the person enjoys. This can give him a feeling of satisfaction. Some types of exercise to consider are:

- Walking is easy and safe. It also provides a change of pace and a chance to get out of the house.
- Dancing is not only good exercise but can be relaxing and fun.
- Playing with pets and children can be a pleasurable way to get some exercise.

You can ask your doctor to write a prescription for a physical therapist to come to your home to set up an exercise program for the person. You may find books and videos on exercises for people with physical limitations helpful.

## Shopping

Shopping can be a good activity for a person with Alzheimer's disease, if care is taken to anticipate and avoid potential mishaps. Window shopping is a form of exercise and can be a good leisure activity. Grocery shopping involves exercise and helps the person feel useful. To make shopping more enjoyable for both you and the person with Alzheimer's disease:

- Try to shop when stores are least busy and consider explaining in private to regular merchants that the person has Alzheimer's (and what that means).
- Keep the person busy by giving him things to hold, asking him to push the cart, and asking him to check off a list of items.
- Before leaving the store, check for items in the person's pockets, or be sure he wears clothes without pockets.
- In a difficult situation, distract the person or move with him to another location to avoid embarrassment for everyone involved.

*Any type of movement can provide exercise and provide a sense of accomplishment:*

- Sweeping the floor
- Raking leaves
- Tossing a ball
- Riding a stationary bicycle
- Rocking in a rocking chair
- Exercises can be done sitting in a chair while listening to music.

## Activities

Creating an atmosphere of quiet activity in the home promotes the feeling that the person with Alzheimer's disease continues to be an important member of the household. Restlessness decreases, and life is more enjoyable for everyone. Some activities, such as cooking, may help the person feel a part of what is happening around her. Other examples include gardening, raking leaves, and doing simple household chores. Helping with these types of tasks gives the person the opportunity to contribute to the household. Tasks that do not require much supervision can give the caregiver a break.

Some guidelines to consider when planning activities for the day include:

- Remember that the person's ability to perform a certain task may vary from day to day or moment to moment.
- Offer activities that provide an opportunity for self-expression including dancing, singing, playing a musical instrument, drawing or coloring, painting, or working with non-toxic clay.
- Try to include some form of exercise in each day's activities such as walking, throwing a ball, or playing with a pet.
- Consider other potentially entertaining activities such as car rides, excursions to zoo/garden/pet shop/art museum, listening to music, playing cards/table games or simple puzzles, or watching sports.
- Try activities that involve reminiscence that helps promote a feeling of well being by sorting or looking at old photographs, looking at picture books, or listening to music from earlier years.

Keep in mind that the person with Alzheimer's is likely to have a short attention span. She may have little creative capacity and may not be able to initiate activities. You may need to provide things for her to do. Activities that call for making choices or decisions may cause her stress. You'll need to be creative and willing to experiment with new approaches. Refer to Appendix 1 for a list of fifty specific activity suggestions.

## Chapter 4

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# UNDERSTANDING BEHAVIORS

Alzheimer's disease and other dementias not only affect memory but can cause the person to act in different and unpredictable ways. The person can become easily confused, anxious or even angry. He may accuse you or someone else of stealing their things or say he wants to go home when he is in his own house. He may refuse your help or push you away when you try to assist him or even strike out.



Understandably, these behaviors are upsetting to a family caregiver. It is not easy to try to help someone who is angry or difficult. It is important to remember that these behaviors are caused by the disease and are not something that can be controlled by the person you care for. It is often helpful to try to understand why the behavior is happening and to make changes in the home environment or how you provide care. The following section mentions things that can help you to make changes that may prevent or resolve difficult behaviors and make caregiving easier.

Consider using techniques that can decrease your frustration and stress while at the same time providing relief and reassurance to the person with Alzheimer's:

### **1. Keep it simple.**

Schedule daily routines for tasks that require his cooperation, such as baths and medication, at different times of the day.

### **2. "Redirect" instead of contradicting.**

For example, if the person keeps telling you that he needs to go home for dinner, rather than telling him that he is home, ask him what he would like to have for dinner.

### **3. Use "therapeutic fiblets."**

A fiblet responds to the emotion they are expressing rather than the person's specific words. For example: the person becomes increasingly anxious looking for a deceased loved one. You can tell him that you have not seen that person yet, but when you do, you'll make sure they stop by to say hello.

## Losing and Hiding Things

The person with Alzheimer's may not remember where to find an item, where she placed it last, or even that she had it. She may put things in unusual places. Sometimes she may accuse others of stealing. This may occur more frequently over time.

**If the memory-impaired person insists on searching for missing items**, his anxiety may have more to do with a general sense that "something is missing" (his memory), than with the need to find a specific item. Reassurance or redirection may help reduce anxiety.

There are steps you can take to help reduce the frustration and anxiety associated with lost items:

- Label drawers and cabinets where you keep everyday articles with large printed signs.
- Limit the number of hiding places by locking rooms, closets, and drawers that are not regularly used.
- If necessary, important or valuable items such as medications can be kept out of sight or locked up.
- Designate special storage places for items such as keys, eyeglasses, hearing aids and batteries, dentures, and other essentials. Keep spares whenever practical.
- Learn the person's hiding places. Try old favorite hiding places for gifts, etc.
- Check trash baskets before you empty them.

## Shadowing or Clinging

Following the caregiver from room to room ("shadowing or clinging") may give the person with Alzheimer's a needed sense of security but can be difficult for family members. This behavior may result from the anxiety caused by a scary or overwhelming situation, from a feeling of helplessness, or from simply not knowing what else to do.

Tips to consider trying:

- Reduce confusion, noise, and clutter in the household environment.
- If physical contact helps the person, try substituting a pet, doll, or stuffed animal.
- Provide a useful diverting activity while you are busy with something else.
- If constant attention is needed, schedule regular "breaks" for yourself.



## Pacing

For some people, pacing seems to be triggered by certain circumstances, such as a noisy or confusing environment. For others, it becomes part of their everyday behavior and is related to changes in the brain.

Always try to discover and, whenever possible, remove the reason for pacing. Reasons may include:

- Response to changes in the environment
- Boredom
- Emotional reactions such as anger, anxiety, frustration, fear, or confusion
- Need for exercise
- Constipation
- Pain or discomfort
- Too much sleep
- Hunger or thirst
- Need to use the bathroom
- Depression

If the person's pacing is related to changes in the brain and therefore unavoidable, rather than trying to prevent it there are things you can do to **keep the person safe**:

- Provide the person with supportive, non-skid shoes.
- Set up a secure area in which he can pace without danger of tripping or getting lost.
- Watch his feet and legs for swelling, blisters, bruises, and redness; provide treatment for any problems that arise.
- See that he is dressed in loose comfortable clothing.
- Try to provide frequent rest periods.
- Offer frequent snacks and fluids since calories are burned when pacing.

## Anger

Anger displayed toward you is often not meant for you. It can reflect a misunderstanding of a situation, or the person's justifiable frustration with her disabilities. The person with Alzheimer's may become very demanding of you at times. Keep in mind that inappropriate or annoying behavior is usually not intentional; these changes result from physical changes in the brain. Try not to let your own anger show. Often the person simply doesn't remember what is expected of him.

**Irritability and belligerence can be signs of physical pain, illness, or fatigue that the person is unable to express or describe. Ask him directly if he is in pain.**

Different approaches may work at different times:

- A calm, predictable, safe environment should be maintained.
- If you simplify a task, he may be able to do it instead of demanding that you do it.
- A doll or stuffed animal may be effective in calming or soothing him.
- Pets can have a calming and soothing effect on the person with Alzheimer's. If keeping a dog or cat is not feasible, try animals that don't require as much care, such as birds or goldfish.
- Sometimes simply ignoring specific demands and redirecting them to another activity or focus is the best approach.

Irritability and belligerence may be the person's defense against negative feelings about himself. A warm, accepting, positive approach on your part and simple courtesies such as "please" and "thank you" indicate that you accept him as he is.

It can happen that a person with Alzheimer's becomes violent. **As a safety precaution, remove any weapons from the home and keep emergency telephone numbers easily accessible.** If he does become violent:

- Call for assistance if necessary to protect yourself and the person.
- If you are in danger, protect yourself until help arrives.
- Isolate the person if he is in danger of harming himself or others and remove anything that might be used as a weapon.
- AVOID chemical or physical restraints. They may only serve to increase agitation and injury.

## Catastrophic Reactions

A situation that overwhelms the person with Alzheimer's disease can lead to a reaction that is out of proportion to the situation. New places, loud noises, new people, large groups, or uncertainty about a task may lead to an excessive emotional reaction such as weeping, shouting, or striking out.

Whenever possible, it is best to avoid stressful situations that may trigger catastrophic reactions. Learning which situations may cause the person to have this reaction can take time. If such a reaction does occur, make note of it so you can steer clear of these triggers in the future. Be aware that a catastrophic reaction may be the result of late afternoon confusion, (see section in this Chapter on Late Afternoon Confusion).

**Sometimes the simplest solution is removing the person from the distressing situation. Below are some other ideas for preventing and managing a catastrophic reaction.**

### *Prevention:*

- Try to avoid sudden moves that can frighten a person with Alzheimer's.
- Reduce the confusion around him.
- If a task is becoming too difficult for the person, simplify it or redirect him to another activity.
- Do not force participation in an activity if he is resisting.
- Do not ask him to make decisions if he is already upset.

### *Management:*

- Stay calm and do not overreact. Your nervousness or anxiety can heighten the tension in an already tense situation.
- Cautiously distract his attention with an activity that he can easily do and enjoys.
- Even very angry people can respond to reassurance. A calm statement like, "I know that you are upset and I want to help you," may defuse the situation. Hold and touch when appropriate.

Forgetfulness can be a benefit in these situations because a person with Alzheimer's may quickly forget the episode.

## Hallucinations and Delusions

Alzheimer's disease sometimes causes a person to see or hear things that are not there (hallucinations) or believe things that are not true (delusions). It is not uncommon for the person to be suspicious (paranoid) of caregivers or others.

Misinterpretations by the person with Alzheimer's can seem like hallucinations to you:

- Changes in perception may cause the person with Alzheimer's to misinterpret her environment and appear to be hallucinating.
- Inadequate lighting and noises can be misinterpreted by the person.
- Whispering or laughing in front of the person may be misinterpreted by her.

### *Discuss it with the doctor*

- Paranoia is a treatable condition so let the person's doctor know if she is acting suspicious of you.
- Do not assume that hallucinations or delusions are an inevitable consequence of Alzheimer's disease. Medications and other illnesses can cause hallucinations or delusions.
- Have her hearing and eyesight checked. Check that her glasses or hearing aid are the correct strength and fit comfortably. Be sure she wears them.

### **If a delusion/hallucination does not seem to frighten or bother the person, ignoring it may be the best approach.**

- If the person appears to be hallucinating, leave her alone or approach her slowly to avoid scaring her.
- Avoid arguing or trying to explain that what she is thinking, seeing, or hearing is not real. Reassure her but do not argue with her. Hallucinations look or sound very real to the person who is experiencing them.
- Try to interpret what the delusion/hallucination may mean for her; or respond to the emotion being expressed. For example you might say, "It sounds as if you are frightened."

## Late Afternoon Confusion

For unknown reasons, an increase in confusion in the late afternoon or early evening, sometimes coupled with restlessness, is a common symptom of Alzheimer's disease. This phenomenon is also known as "**sundowning**." While you can't necessarily prevent this from happening, there are things you can do that can help make this time of day less stressful. You may have to try more than one of these techniques to find the one that works for the person on that particular day. It also helps to decrease your expectations of the person during this time of the day.

### **Simple tasks and calm activities can help manage late afternoon confusion.**

- Engage the person in a physical activity or simple chore before the time when she would typically become anxious.
- Stay nearby while she's doing the task so that you can reassure her.
- Repetitive activities such as peeling potatoes, washing tabletops or raking leaves, which can redirect frustration, can offer a "failure-free" alternative.
- Encourage a nap after lunch, if it does not interfere with sleeping at night.
- Make "quiet time" with soft music after lunch part of your routine.
- Have an early dinner or late afternoon snack.

Good lighting can sometimes assist in reducing confusion. Reducing noise and excess stimulation, such as activities in which the person is not involved can help. Telling her the time, where she is, and what is going on can also help decrease confusion and anxiety.

## Aggression

Aggressive behaviors can be verbal (shouting, yelling, cursing) or physical (pushing, hitting, kicking). These may occur suddenly or in the midst of a frustrating situation. It is important to try and understand what is causing the person to lash out with their words or physical behavior, to prevent the behavior from reoccurring.

### **Here are some things that will help to understand and respond to aggressive behavior:**

- Try to identify the immediate cause (Were you rushing him? Pulling at him? Was it too noisy? Did I approach him from behind?).
- **Don't get upset.** Be calm and reassuring.
- **Focus on their feelings.** Acknowledge they are angry or upset and be reassuring
- If he is safe and you are alright, give them some time to calm down before trying another activity.

## Sexuality and Alzheimer's Disease

Sexual desire may increase or decrease after the onset of Alzheimer's disease. At some point, a spouse or partner will need to adjust her expectations in a sexual relationship with a person with Alzheimer's disease.

Inappropriate sexually-oriented behavior can be embarrassing and difficult to manage. Keep in mind that many persons with Alzheimer's have little physical contact. Appropriate physical contact conveys reassurance and caring. By increasing appropriate physical contact you can decrease inappropriate behavior.

Although it can be very hard to discuss, let family, friends and others that the person with Alzheimer's regularly interacts with know that this behavior is a result of the disease. This will allow you to use your energy towards caring for the person rather than worrying about the reactions of others.

### ***Behaviors that seem sexual in nature may be the person's way of communicating something else.***

- If she exposes herself, she may need to use the bathroom. Have a plan for various toileting situations while traveling or attending social activities outside the home.
- If she tries to disrobe, it may mean that she is tired and wants to go to bed.
- If sexually explicit language occurs, stay calm and redirect the person rather than correct her.

### ***Indiscreet self-fondling, touching others, and suggestive fidgeting should be discouraged gently and discreetly.***

- Try redirecting the person's attention.
- Try loosely fitting clothing with elastic waistbands which are more comfortable and discourage fidgeting.
- Try fitting a multi-pocket apron over her clothing. Snaps, buttons, or "safe" pocket-sized household items placed in the apron will provide a distraction.

### ***Sexual aggression is treatable.***

- A frank discussion with the person's physician is necessary if he is sexually aggressive.
- Never leave a child alone with a person who has a history of sexually aggressive behavior.

## Depression and Alzheimer's Disease

Many persons with Alzheimer's, especially when in the early stages, are understandably depressed. Loss of independence and feelings of failure can also lead to depression or withdrawal. Reassurance and support will help. For many people, treating the depression that accompanies Alzheimer's disease can provide **a better quality of life** for the person and his caregivers. Depression can be successfully managed with medications and non-drug therapies such as counseling.

If you are concerned about depression, the first step is to pursue a thorough evaluation by a professional, possibly one skilled in geriatric psychiatry. ***For those with Alzheimer's disease, treating depression can improve the person's sense of well-being, quality of life, and functioning – even in the presence of ongoing decline in memory and thinking.***

### ***Some of the common signs of depression:***

- Withdrawal/isolation
- Decreased ability to concentrate
- Signs of apathy, either verbal or non-verbal
- Restlessness or agitation
- Change in appetite
- Change in sleep patterns
- Sudden onset of problems with activities of daily living, especially dressing or grooming
- Reemergence of prior symptoms of depression

### ***Strategies for dealing with depression:***

- Encourage exercise.
- Avoid alcohol, which is a chemical depressant.
- Avoid giving false hope or patronizing pep talks.
- Encourage the person to talk about or otherwise express his feelings.
- Do not force him to interact with others, but encourage him to be as socially active as possible.
- Encourage participation in simple activities that provided enjoyment in the past, or in a non-demanding task or "job".
- Notice whether certain activities or people trigger moments of sadness or an improvement in his mood and direct him away (or toward) accordingly.

**Do not ignore references to suicide.** Consult a mental health professional for advice on how to handle references to or threats of suicide.





## Chapter 5

# SAFETY ISSUES

Changes in judgment and orientation that occur with the progression of Alzheimer's disease can present risks to the person you are caring for and those around him. Addressing these risks often involves difficult decisions about limiting a person's independence and increasing supervision and services. The information in this section will guide you as you make these decisions. You may need to consult your physician, elder law attorney, the Alzheimer's Association or other family or health care providers for individualized advice.



## Wandering

Wandering away from home and becoming lost is an all-too-common behavior associated with Alzheimer's disease. In fact, more than 60 percent of people with Alzheimer's will wander at some point. For caregivers, it is an emotionally wrenching experience. For the person with Alzheimer's, it can be life-threatening. A person with Alzheimer's who wanders may not realize when she is lost. She may wander into dangerous areas; wandering also puts her at increased risk of exhaustion, dehydration, and exposure.

**One of the most important things you can do is enroll the person with the MedicAlert® + Alzheimer's Association Safe Return® program.** This is a 24-hour nationwide emergency response service. If a person with Alzheimer's wanders away from home or a facility, a community support network, including the Alzheimer's Association MA/NH Chapter, police and hospitals, is activated to help find the person who wandered. The program provides identification jewelry for the person and also for the caregiver. There are modest fees associated with this program, but help is available for those who cannot afford it. For information on enrollment or assistance in paying for the program, please call the Alzheimer's Association's 24/7 Helpline at 800.272.3900 or visit [www.alz.org/manh](http://www.alz.org/manh).

It is impossible to predict if or when a person with Alzheimer's disease will wander, but sometimes the person will provide clues or behavioral signs that indicate he may be at heightened risk of wandering. The clues include:

- Tries, or wants to "go home" even when at home  
*Try redirection. Instead of telling him that he is home, for example, tell him that it's a long trip home, and that he may want to take some food with him. Redirect him from the exit door into the kitchen or dining area. Calmly switch his focus from leaving to eating.*
- Tries, or wants to "go to work" or other former obligations  
*Try using fiblets. Instead of telling him that he's been retired for 10 years, reassure him that he doesn't have to go to work today because he's "on vacation."*
- Is restless or paces  
*Offering exercise and other meaningful activities throughout the day may help control wandering behavior caused by restlessness.*
- Is nervous or anxious  
*Reducing noise levels or other distractions can reduce agitation and help avoid a sudden attempt to leave.*

Once a person shows signs of wandering behavior, it can help to look more closely at the circumstances surrounding the behavior such as:

### **1. What triggers it?**

Is there a certain time of day when the wandering behavior is more common? Or does the person commonly exhibit a particular clue before attempting to wander?

### **2. Is there something new in the person's life?**

Has there been a recent move or a new medication that could be increasing confusion?

### **3. Is the person hallucinating?**

Offer reassurance, provide a distraction or use redirection. For more on hallucinations see Chapter 5: Understanding Behaviors.

### **4. Is there a pattern to the person's wandering?**

Does she usually take the same route? Can this route be incorporated into periodic walks?

As Alzheimer's disease progresses, the person will need more and more supervision from caregivers to prevent wandering and meet other needs. In addition to close supervision, the following ideas can also reduce the risk of wandering:

- Place a slide or dead bolt out of the normal line of vision, about six inches from the top or bottom of doors that lead outside.
- Use child-safe doorknob covers that fit over the knob so that only the cover turns, not the knob.
- Attach a bell or an electronic device that buzzes or chimes to exit doors (as merchants do to alert them to customers entering or leaving).
- Keep items that can be misinterpreted by the person as cues to leave, such as hats, coats, umbrellas, purses, away from exit doors and out of sight.
- Try placing a simple black doormat in front of the exit door. This may appear to the person as a "hole" that he should avoid. Keep in mind that if the mat is left in place over time, the person may ignore it.
- At night, disguise exit doors with a full curtain or screen, or drape a foot-square cloth over the area around the knob.
- Try putting traffic "stop sign" on the inside of the exit doors.

One of the most effective strategies for reducing the risk of wandering is a routine. During the day, that routine should include meaningful activity and enough physical exercise that will both distract a person from wanting to wander and provide an outlet for energy. That activity coupled with a regular bedtime routine will help to reduce the risk of nighttime wandering.

**In the event that your loved one wanders, here are the steps to take to help ensure a safe return:**

- Inform the local police and call Medic Alert® + Alzheimer's Association Safe Return® program at 888.572.8566 whether or not the person is enrolled in the program.
- Alert neighbors to call you if they see the person outdoors unsupervised and keep a list of neighbors' phone numbers handy.
- Note the places where the person may have wandered in the past or has recently talked about visiting.
- Keep several copies of a recent clear photo on hand.
- Keep an article of clothing with the person's scent on it in a plastic bag.

## Driving

Even in its earliest stages, Alzheimer's disease shortens attention span and affects judgment, reaction time and visual-spatial abilities. Driving demands these very abilities: good judgment, quick reaction time, and split-second decision making. There is no argument that **at some point, a person with Alzheimer's disease will be unable to drive safely.**

Driving is an issue that needs to be addressed sensitively – but early – in the disease process. Often the person with Alzheimer's disease recognizes that she is losing her ability to drive safely and voluntarily stops driving. Others continue to drive because of a fear of losing the sense of independence and competence that comes with driving. Some people, because of the disease, just cannot recognize the danger posed to herself and others.

***There are steps you can take to support the person with Alzheimer's make the decision to voluntarily stop driving.***

- Offer to drive. Get backup driving help from family members or volunteers.
- Learn about alternative transportation resources by contacting 1-800-AGE-INFO (see PLANNING AHEAD).
- Learn about home delivery services that reduce the need to go out to stores.
- At the time of diagnosis, have the doctor ask if the person still drives. In explaining the diagnosis, the doctor can gently point out the problem. Often families need to talk to the doctor prior to the appointment to make sure that she brings up the issue.

***If the person with Alzheimer's agrees that she should no longer drive, she may still need reinforcement that she made this decision.***

- Remind the person that her doctor said she should no longer drive.
- Ask the doctor to write a note or prescription that specifically says she is not to drive.
- Have someone else she trusts reinforce the no-driving message.
- Ask your family's attorney or insurance agent to reinforce the message by explaining the potential for liability.

***A person with Alzheimer's may be strongly resistant to giving up the keys.***

- Be careful not to overwhelm the person with demands that he stop driving at a time when he may still be reeling, emotionally, from news of his diagnosis.
- Do not let yourself become the focus of his anger at the idea that he needs to stop driving.
- Involve his doctor in a family conference to discuss the issue and strategize approaches.
- Be honest with the person. Tell him that he has a problem with his memory and that it is not safe for him to drive.
- Have his driving skills assessed through a driving evaluation program. Contact the Alzheimer's Association's 24/7 Helpline at 800.272.3900 or at [www.alz.org/manh](http://www.alz.org/manh) for more information about these programs.
- Be firm, but avoid arguments about driving. Focus on other activities that the person with Alzheimer's can enjoy and still do successfully.

A person with Alzheimer's who still drives will sometimes claim that he "doesn't drive very far from home," "drives slowly," or uses only familiar routes. While these claims appear reassuring, most crashes occur at lower speeds, at intersections, and near home.

Some caregivers will approach the issue by acting as a "co-pilot" for the person with Alzheimer's who still drives. This is a risky and unreliable fix, since it cannot repair the central problem of the driver's progressively declining memory, reaction time, visual-spatial ability, and judgment.

**Sometimes the resistance comes from other people.**

It is important that all of the person's caregivers agree on the need for the person to stop driving and a common approach to addressing the issue. If others in the life of the person with Alzheimer's do not agree that he should give up the keys, ask them these questions:

Would you be comfortable with your child or grandchild riding in the car the person was driving?

Would you be comfortable with your young child or grandchild stepping out into a pedestrian crosswalk in front of the car the person was driving?

A note of caution about technological devices in cars: satellite-based Global Positioning System (GPS) navigation devices come installed in some cars and can be purchased for others. These require that the driver be ready and able to use them. A person with Alzheimer's who is lost is unlikely to be able to successfully use this device. These devices will not prevent unsafe driving.

As the disease progresses, there are additional steps you may need to consider taking.

- Eliminate visual cues  
*Seeing the car is a visual cue to use it. Remove it, garage it, or park it out of sight with a neighbor or friend. Car keys are another visual cue. Keep the car locked and control access to the keys.*
- Disable the car  
*Have a mechanic install a "kill switch" that, in the off position, will prevent the car from starting. Some stores sell car batteries with an "off" switch. If necessary, disconnect the battery, distributor cap, or starter wire to make the car inoperable.*

## Financial Safety

The person with Alzheimer's disease generally loses her ability to handle money or a checkbook before she loses the feeling that she needs money. To protect financial health, it is vital that families complete legal and financial planning very early in the disease process. (See Planning Ahead.) To avoid arguments revolving around money, consider arrangements that reduce the person's direct involvement in handling checks or money.

- Remove all credit cards from the person's wallet or purse so that they will not be lost or misused.
- Fill the person's wallet with photographs, a small amount of money, identification cards, and other items. This will allow her to feel as though she still has her "valuables."
- If she wants to pay the cashier in a store, hand her the correct change.
- Arrange for direct deposit for pension or Social Security checks.
- Consider utilizing money management services available through agencies in order to reduce the person's direct involvement in handling checks or money.

## Smoking and Drinking

Drinking alcoholic beverages may increase confusion and may be dangerous for persons who are taking medications. Smoking can be especially dangerous for a person with Alzheimer's who may forget that a cigarette or pipe is lit and may leave it unattended or hide it where it could start a fire. If the person with Alzheimer's engages in these behaviors, you should:

- Consult the person's pharmacist or physician as alcohol interacts with certain medications.
- Consider substituting non-alcoholic beverages such as a non-alcoholic beer or sparkling grape juice.
- If the person's physician is comfortable with moderate drinking and smoking, maintain control by mixing the drink yourself and giving out cigarettes one at a time.
- Reduce the risk for a fire by supervising the person while he smokes and by keeping matches, lighters, and cigarettes in your possession.

## Absence of the Caregiver – Going Out Alone

In the early stages of Alzheimer's disease, a person can sometimes safely go out alone. First, however, her safety should be considered. Ask yourself if she can reach her destination and return safely. Awareness of her surroundings will decline over time, so her abilities should be continually re-evaluated. To help ensure the person's safety if she is going out alone:

- Enroll her in the MedicAlert® + Alzheimer's Association Safe Return® program as explained in the beginning of this chapter.
- Tell the local police and neighbors that the person has Alzheimer's disease and is at risk for wandering.
- Make sure she carries personal identification.
- Give her a card with her address, telephone number, directions to her house, and instructions on what to do if she gets lost.
- Observe the person frequently to evaluate her ability to cross streets and follow other safety rules.

## Absence of the Caregiver – Staying Home Alone

Persons in the early-to-middle stages of Alzheimer's disease can sometimes be safely left alone. First however his safety should be considered. Ask yourself if he gets agitated or nervous when left alone in a room for even a short period, or attempts to look for you by leaving the house. His ability to stay home alone will decline over time, so you will need to constantly re-evaluate. Appropriate precautions can minimize the anxiety and safety risks caused by a brief or extended absence of a familiar caregiver.

If person is to be home alone, some recommendations to follow are:

- Even if you are leaving for only a short period, say good-bye and tell the person the approximate time you will return.
- Leave a note in sight indicating where you are going and when you will return.
- Leave a photo album of family members easily accessible to provide reassurance.
- Enlist the support of neighbors so they'll be ready and willing to help if needed.
- Enroll him in the MedicAlert® + Alzheimer's Association Safe Return® program as explained in the beginning of the chapter.
- Let the local police know that the person has Alzheimer's disease.
- Be sure safety hazards are removed or reduced from the home (see the section on Household Safety at the end of this Chapter).



## Medications

Persons with Alzheimer's disease are vulnerable to overmedication and to reactions from drug combinations. The person's behavior should be closely monitored for any changes that may indicate negative effects of medication.

### *Preventing medication errors*

- Establish a routine for taking medications that encourage cooperation and accuracy.
- If he is capable of understanding, tell the person, in simple terms, what the medication is and why it is being given.
- Keep a written record of all current medications with name, dosage, and starting date.
- Medication boxes that separate pills by the day and time to be taken can be a useful memory aid for the caregiver and for persons with early stage Alzheimer's. Automated medication dispensing options may be available at your pharmacy.

### *Safety and swallowing*

- If necessary, put a lock on the medicine cabinet or use a locked drawer to prevent the person from taking the medications without supervision.
- If you are not sure what or how much the person has taken, call the poison control center for advice at 1-800-222-1222 or take the person to a hospital emergency room.
- Be certain that pills have been swallowed. Pills can be hidden in the cheek and under the tongue.
- If the person is unable to swallow pills, ask your pharmacist if you can crush and mix them with a small amount of food or liquid. Some medications come in liquid form; ask your doctor or pharmacist.

***Consult a doctor or other medical professional before giving over-the-counter medication.***

Over-the-counter medicine, vitamins and supplements can interact negatively with prescription medications. Pharmacists are a good source of information about medications and their effects.

## Household Safety

Persons with Alzheimer's disease are vulnerable to a number of dangers in and around the home. Taking the time to make the home as safe as possible is important to preventing injury since it is not always possible to be in the same room with the person every minute of every day. An intercom system, or child monitor, allows you to hear the person when you are not in the same room.

***The home can contain some serious threats to safety which should be removed or locked up including:***

- Firearms
- Sharp objects such as knives, meat forks, scissors, and other pointed utensils
- Garbage disposals should be disconnected both to avoid injury and to prevent it becoming clogged with food or other household items.

### ***Ways to reduce trip and fall hazards***

A person with Alzheimer's disease may be prone to falling due to stooped posture, shuffling gait, stiffness, loss of motor coordination, or misjudging distances.

- Maintain good lighting.
- Keep walkways clear avoiding scatter rugs, small pieces of furniture and exposed extension cords.
- Keep remaining furniture in its usual place and pad or cover the sharp corners.
- Don't wax the floors to the point of being slippery.
- Consider safety locks on windows.
- Make stairs safer:
  - Try a gate to prevent access to stairs.
  - Lock attic and basement doors to prevent access to those stairs and areas.
  - Keep stairways well lit.
  - Consider painting the top and bottom stairs a different color from the others.
  - Apply non-skid strips on steps.
- Place sturdy grab bars or handrails near the bed, toilet, bath, and on stairways and hallway walls.
- Evaluate the outside of the house and surrounding areas for the need for rails and fences.
- Eliminate objects that are on wheels and could be misused by the person for support when walking.

### ***Ways to reduce poisoning and choking hazards***

Changes in judgment can place a person with Alzheimer's at risk for eating and/or choking on unsafe substances.

- Keep poisons, all medications and hazardous substances, such as bleach and furniture polish, out of reach or in a locked cabinet.
- Remove poisonous plants. Common examples include coleus, philodendron, and poinsettia.
- Limit the number of small items within reach and put knick-knacks away.
- Avoid the use of "look-alike" objects, such as fruit-shaped magnets on the refrigerator.

### ***Ways to reduce fire and burn hazards***

Impaired memory and judgment can present risk for fire and burns especially while cooking.

- Be sure to have fire extinguishers and working smoke detectors in the house, and have them checked regularly.
- Help prevent kitchen fires by removing the knobs from the stove, disconnecting appliances, or restricting access to the kitchen when not in use. Try shutting off the circuit. This includes microwave as well as conventional ovens.
- Set hot water temperature no higher than 120 degrees Fahrenheit to avoid scalding.

### ***Prevent getting locked in or out***

People with Alzheimer's disease have a tendency to lose things such as keys or accidentally lock themselves into a room or a caregiver out of the house.

- Use non-locking doors inside the house, or remove existing locks. Be sure that you have keys for doors that lock.
- Hide a spare key outside the house in case the person locks you out.
- Give a set of keys to one or more trusted neighbors, friends, or family members.

### ***Being able to respond appropriately and summon help quickly in the event of an emergency is essential.***

- Have a working knowledge of first aid procedures, such as the Heimlich maneuver (a technique for dislodging food caught in the throat). Information and courses are usually available from your local library, Red Cross chapter, or hospital.
- Keep a list of emergency numbers, including the poison control center and the Safe Return program, by every telephone.
- Keep on hand an emergency reference list of medications, physicians, and phone numbers of back-up people.



## Chapter 6

# PLANNING AHEAD

The Family Care Guide discusses many ways to help you support and care for a person with Alzheimer's disease. You should be armed with knowledge about the disease, communication skills, safety issues, behavior management, and assistance with daily living that will help make caregiving more manageable and improve quality of life for you and the person with Alzheimer's disease. No one can or should provide care



on their own. It is important to have a knowledgeable medical team behind you and to seek assistance in legal and financial planning and providing daily care. This section will provide general guidance in these areas, but for provider referrals in your geographic location and for your specific needs, please call our 24/7 Helpline at 800.272.3900.

## Partnering with Your Doctor

Choosing a primary care doctor and developing a working relationship with her is one of the most important steps to managing Alzheimer's disease.

A good primary care physician can:

- Ensure that other chronic medical conditions and acute illnesses are treated so that the person with Alzheimer's can function to the best of his ability.
- Help to coordinate referrals and recommendations of specialists that can include neurologists, psychiatrists, and neuropsychologists.
- Oversee prescription and over-the-counter medications to minimize side-effects and avoid interactions.

**To find a primary care physician** who can best support someone with a diagnosis of Alzheimer's disease:

- Ask friends and family to recommend someone they trust. The friends that you make through Alzheimer's support groups or education events may be able to recommend primary care physicians who are familiar with Alzheimer's disease.
- Most hospitals and Alzheimer's diagnostic clinics should be able to refer you to primary care physicians and/or geriatricians with an understanding of the disease.
- Most health insurance companies have websites and/or referral lines that can refer you to physicians in your area who are accepting new patients.
- Once you receive several referrals, call the physicians' offices and ask to speak with a staff member who can provide details about the doctor's credentials and expertise. Ask how many patients are in the age range of your loved one and if the physician has experience with Alzheimer's disease.

***Include the person with Alzheimer's in conversations with the doctor but do not talk about her in front of the physician.***

If you find this impossible, communicate your concerns and observations with the doctor prior to the appointment by phone, letter, fax or email.

***Always check with the primary care physician before adding or stopping any medication.***

This includes all prescriptions, over-the-counter drugs, and vitamin/herbal supplements.

To prepare for a doctor's visit:

- Make a list of questions.
- Take a family member or friend with you.
- Write down changes in memory and thinking that you or others have noticed since last visit.
- Bring a list of ALL medications including prescriptions, over-the counter medications, and vitamins/herbal supplements.
- Ask for a longer appointment if you have a lot of questions.

At the doctor's appointment:

- Be honest and open about how you are doing.
- Ask questions especially if you do not understand the doctor.
- Discuss treatment options and opportunities for clinical trials.
- Write down or tape record information from the doctor.

Call the doctor immediately if the person with Alzheimer's experiences any of the following symptoms:

- Sudden change in mental status or mood
- Blackouts, fainting spells, or falls
- Sudden inability to speak or move part of body
- Fever
- Sudden incontinence

## Legal and Financial Planning

As Alzheimer's disease progresses, the person's ability to deal with medical, financial and legal matters will be affected. The sooner you begin making legal and financial plans, the more the person will be able to participate in decisions that affect his future. If possible, you can have conversations with the person about his thoughts regarding long-term care and the kind of medical treatment he wants. *Five Wishes*, available from the website [www.agingwithdignity.org](http://www.agingwithdignity.org) can be a useful tool for generating these discussions.

It is never too early to start planning ahead. Taking steps now can prevent undue stress later, minimize potential negative financial and legal consequences, and ensure that the wishes of the person are honored in the future by putting several important documents in place. An elder law attorney can help you to draw up the following documents:

1. Durable Power of Attorney—Names person to take care of financial matters if you are unable to do so.
2. Health Care Proxy (in Massachusetts)/Durable Power of Attorney for Health Care (in New Hampshire)—Names a person to make medical decisions for you if you are unable to do so.
3. Will—Describes financial estate and itemizes distribution in the event of your death
4. Living Will (Optional)—States your preferences for critical medical procedures, if you are unable to make decisions. State laws vary.
5. CPR directive (Optional)—Tells emergency personnel that you do not want to be resuscitated. Talk to your doctor if you are interested in a CPR directive. State laws vary.

Some other things to consider when planning ahead and to discuss with an elder law attorney or financial advisor are:

- Get valid signatures on legal documents while the person is still able and competent to sign.
- Learn about benefit programs that provide income support or help pay for services, such as Social Security Disability and Medicaid, for which you or the person may be eligible.
- Investigate long term care insurance. It is an option that is suitable for some individuals and may be worth investigating. Carefully examine specific policies, looking for benefit limitations, pre-existing condition exclusions, provisions for inflation, etc. Most companies will not insure an individual with an Alzheimer's diagnosis.

**Medicare and most private health insurance programs pay for very limited services provided in the home or in a nursing home.**

Only Medicaid (which is NOT the same as Medicare) and a few private insurance policies pay for extensive skilled nursing home care. Medicaid regulations are complex and change often. Seek knowledgeable help and advice from the Alzheimer's Association MA/NH Chapter, a social worker or case manager, or a lawyer or financial advisor who is familiar with Medicaid regulations.

***The Alzheimer's Association, MA/NH Chapter offers a free program on legal and financial planning.***

The program is presented by elder law attorneys who volunteer their time. It is held in various locations throughout the region. For a full listing of our educational programs, please visit our website [www.alz.org/manh](http://www.alz.org/manh) or call our 24/7 Helpline at 800.272.3900.

- Locate the following documents and keep them in a safe yet accessible place:
  - Insurance policies (health, life, etc.)
  - Will
  - Bank books
  - Automobile titles and property deeds
  - Tax records
  - Safe deposit box keys
  - Social Security card
  - Medicare card and other insurance cards
  - Cemetery plot deed.



## Available Community Resources

There are a wide range of support services available for people with Alzheimer's disease and their care-partners, some of which are appropriate at any stage of the disease process and others which are appropriate at a specific stage of the disease. Services are provided by a number of different kinds of agencies. The cost for some of these services may be covered by health insurance policies or be subsidized through government programs, many of which have eligibility guidelines based on the person's age, residence, and income and assets. Other services can be paid for privately (out-of-pocket).

For advice and information at any stage of Alzheimer's disease, the Alzheimer's Association offers a 24/7 Helpline and individualized Care Consultation at no cost.

- 24/7 Helpline (1.800.272.3900)—Advice and information available from trained staff and volunteers from the Alzheimer's Association 24 hours a day 7 days a week. The Massachusetts/New Hampshire Chapter provides follow-up calls to those who would like them.
- Care Consultation—In-depth, person-to-person assessment, education and support provided by appointment through the Alzheimer's Association, Massachusetts/New Hampshire Chapter.
- Education—Programs offered at various locations throughout Massachusetts and New Hampshire on a variety of topics related to Alzheimer's disease and caregiving. A listing of programs is available on our website, [www.alz.org/manh](http://www.alz.org/manh), or by calling the 24/7 Helpline.

In the Appendix 1, you will find a detailed Table of Community Resources that explains what they are and how to locate them.

For in-depth and ongoing assistance with planning services, there are private geriatric care managers. Geriatric care managers have diverse experience, education and backgrounds. Many geriatric care managers are nurses or social workers. They provide individualized and ongoing assessment of needs and coordination of services for a fee.

The system of community services can be confusing and overwhelming. You should not hesitate to ask for help. Assistance in navigating the system is available from the Alzheimer's Association's 24/7 Helpline at 800.272.3900 or [www.alz.org/manh](http://www.alz.org/manh). In Massachusetts, you can also call 800-AGE-INFO (800-243-4636). In New Hampshire, you can also call Service Link (866-634-9412).

## Socialization

Throughout the disease process, it is very important that the person with Alzheimer's disease be engaged in routine activities that provide meaning and socialization. Providing this level of mental engagement can be very difficult for one caregiver to manage. There are several ways to enhance opportunities for meaningful activity and socialization including:

- Involvement of family and friends
- Volunteers from community and religious organizations
- Activities at local Senior Centers/Councils on Aging—Local agencies located in all towns that provide information, programs, and services for senior citizens. The type of programs and services varies widely by town. Senior centers do not provide supervision for people with Alzheimer's disease and would require that someone accompany him.
- Social or adult day health care—More structured programs for people who need more supervision and direction than offered at a senior center. The cost of these programs might be subsidized if certain eligibility guidelines are met.
- Private pay companions—Available through home care agencies. Caregivers can also hire companions independently.

## Transportation

Available transportation services can vary by town, so a good place to start is with your local Council on Aging for referral information. For Massachusetts residents, you may also contact your local Aging Service Access Point (ASAP) for additional information. For New Hampshire residents, contact your local Service Link center. Call our 24/7 Helpline to obtain the contact information for these service agencies in your town and state.

For referrals to any of the services described in this guide and consumer advice on how to select services, call the 24/7 Helpline at 800. 272.3900.

## In-Home Services

At some point in the disease process, caregivers will probably need some assistance in their homes to help with personal care, meal preparation, and household tasks to meet care needs and to provide respite. Services can include Meals on Wheels, home health aides, and homemaking. Some of these services are subsidized by the state, and others are paid for privately. A good place to start exploring in-home services are:

- **Aging Services Access Points (ASAPs - Massachusetts)**—Regional agencies that cover the entire state of Massachusetts to provide information and referral, programs and services to people 60 and over and anyone with a diagnosis of Alzheimer’s disease and related disorders. There are financial, age, and need requirements to be eligible for some services. To find the Aging Service Access Point for your city or town, call 800-AGE-INFO (800-243-4636).
- **Service Link** – A network of resource centers across the state of New Hampshire that provide information and resource referrals to older adults, adults with chronic illnesses and care partners. The toll-free number for service link is (866) 634-9412.

### ***Successful introduction of services to a person with Alzheimer's disease***

Once the decision has been made to bring services into the home or to involve the person with Alzheimer's in a day program, it is important to think about how to introduce the change. Expect that there will be an adjustment period – for you and for the person.

- **Be persistent.** Often the person with Alzheimer's is resistant to change because it confuses and frightens her. Over time, she will become accustomed to substitute caregivers in the home or at an adult day program.
- **Establish a consistent routine.** This will help the person adjust to new situations or environments.
- **Try to introduce only one service at a time.** Too much change at once can be overwhelming.
- **Ask for help.** Staff members of the various service agencies are accustomed to dealing with the challenge of reluctance, so don't be afraid to ask them for help.

### ***Tips for working successfully with in-home help***

- Start with someone familiar.  
*Try leaving the person alone with a familiar relative or friend a few times before introducing him to a stranger. This can help him get used to spending time with people other than you.*
- Stay the first time.  
*Staying with the person the first time the home-care worker comes can help reduce anxiety.*
- Give instructions.  
*Find out if the home-care worker has training or experience working with persons with Alzheimer's. This will give you an idea of how much instruction you will have to give.*
- Touch base.  
*Be present when the worker arrives and be home before the worker is scheduled to leave.*
- Tell the worker about the person's routine.  
*Provide a written or verbal description of the daily schedule along with helpful tips to the worker when he or she arrives.*
- Point out safety issues.  
*If the person cannot be left alone, or needs to be supervised when eating, be sure that the worker understands this.*

### ***Tips for introducing the person to an adult day program***

- Go for a visit.  
*Visit the program yourself first. Then schedule a visit together during a time when there is an activity that the person would enjoy.*
- Consider what schedule would work best.  
*For some persons with Alzheimer's, it may be best to start with a few short days and gradually increase the schedule as he becomes more comfortable going. For others, it may be better to attend several days in a row so that the environment and people become more familiar more quickly.*
- Be gentle, but firm.  
*The person may be resistant to going, but typically once he attends for a few days he will usually look forward to it. Reinforce any positive experiences he has while there.*
- Consult the staff.  
*You will likely learn that the person is developing friendships and enjoying activities more than he is reporting to you. Remember, adult day programs would be empty if their clients couldn't adjust.*

### ***Residential Care May Become Necessary at Some Point in Care***

Residential care can be provided in two settings, assisted living facilities and nursing homes. It is highly recommended that you choose an assisted living facility or nursing home with a special care or Alzheimer's care unit that is secure with specially trained staff. You can obtain a consumer guide on how to select the best place for your loved one from the 24/7 Helpline.

- Assisted living facilities offer a combination of housing, meals, and personal care services. The level of nursing and medical care varies, but these facilities are generally not designed for people with serious medical conditions. The payment source for Alzheimer's Care Units is private pay.
- Nursing homes provide 24-hour skilled nursing care to people with qualifying medical needs. Medicaid (or MassHealth) will pay for nursing home care once income and asset guidelines are met.



## Chapter 7

# TAKING CARE OF YOURSELF

Taking care of a family member who is suffering from Alzheimer's disease can be emotionally and physically exhausting. Often caregivers forget or put off taking care of their own physical and emotional health. It is important to pay attention to your needs as the caregiver; otherwise your own health may be put at risk, and the person's care may suffer. You should see your primary care physician or other health care provider if you recognize any of the following symptoms in yourself:



- Mood swings
- Unusual irritability
- Inability to fall asleep or stay asleep
- Difficulty concentrating
- Digestive problems
- Unfamiliar aches and pains
- Increased desire for use of drugs or alcohol
- Frequent bouts of crying, a sense of failure or hopelessness
- Lack of interest in family or normal activities

Keep in mind that research shows that many caregivers die before the person for whom they provide care. So though it may seem difficult to make the time, caring for you, the caregiver, is critical.

## Caring for the Caregiver

Caregiving can leave you with little time and energy to care for yourself, but you cannot care for someone else if your own physical, emotional, and social needs are not met. Here are some important considerations for taking care of yourself.

### *Get some exercise*

- Start a routine, or keep up your pre-caregiving exercise routine.
- Ask a friend, neighbor, or family member to stay with the person while you go for a walk.
- Consider taking a group exercise class.
- Remember that a wide range of exercise can be beneficial including walking, dancing, biking, bowling, dancing and gardening.

### *Maintain outside interests and activities*

- Get out of the house for a period of time each day.
- Don't isolate yourself. **Keep in touch with friends.** You may have to call them. People may hesitate to call, not wanting to intrude or interrupt at a bad time.
- Keep your appointments with your physician, dentist, counselor, etc.

### *Ensure adequate rest*

- Have someone sleep over occasionally who is willing to take over providing care, so that you can get **an uninterrupted night's sleep.**
- When the person rests, try to rest yourself or do something special for yourself.
- Take advantage of respite services in your community.



### *Give yourself an “emotional break”*

- Try to avoid feeling guilty. Remember that caring for yourself is equally good for him for as it is for you.
- Try to keep realistic expectations for yourself, the person, and others.
- Pace yourself. Do what is most important, and then do more if you have the energy. If not, stop.
- If you are trying out a new caregiving strategy, do not expect to do it perfectly right away.
- Know when stresses are becoming too much to bear and what you need to get your strength and objectively back.
- Allow yourself to the time grieve the losses that accompany Alzheimer’s disease.
- Take time occasionally to remind yourself of the value of what you are doing.
- Don’t lose your sense of humor. If you can laugh, even alone, do it.

### *Get help*

- Give friends and relatives concrete ideas on what you need help with.
- Remember that you should not do all of the care yourself.
- Fully explore what is available and make use of community resources.
- Consider counseling. Depression is commonly associated with caregiving, and it can be treated.
- Try a support group.

## Support Groups

It is sometimes difficult for caregivers to believe that support groups can be of value to them. For someone who already feels too busy, attending a meeting can seem like just another burden. The benefits of joining a group, however, are often enormous. The goal of support groups is to aid caregivers in managing behaviors and in understanding and coping with the daily challenges of caregiving. Mutual support and guidance, as well as educational information, are offered. The Alzheimer’s Association is committed to the support and promotion of caregiver support groups, based on the belief substantiated by research that they can be of significant and continuing benefit to caregivers.

There are many different kinds of support groups. Some are small and intimate; others are more formal, with speakers and presentations. Try different groups until you find one that meets your needs. Contact the Alzheimer’s Association’s 24/7 Helpline at 800.272.3900 or at [www.alz.org/manh](http://www.alz.org/manh) for more information and a list of groups.

## Supporting Children and Teens

It is important that we recognize the impact of caregiving on all the generations that are touched by Alzheimer's disease. Children learn how to care by watching and role modeling the adult caregivers. The key to supporting children and teens through the various stages of care required for the person with Alzheimer's disease is to provide reassurance through a positive emotional response.

### *Talk to the child or the teen.*

- Teach children about Alzheimer's disease; about how the disease changes behavior; and what to expect as the disease progresses.
- Discuss potential behavior by the person with Alzheimer's that a child or teen may find embarrassing, so the child knows the behavior is not willful.
- Explain that because of the disease they cannot expect the behavior of the person to be the same today as it was yesterday, and it may be different tomorrow.

### *Encourage questions and sharing.*

- Encourage children to ask questions, but be careful to provide only as much information as you feel they are able to handle.
- Encourage children to "tell someone" about their loved one with Alzheimer's disease and how the caregiving experience has impacted their lives and family.

### *Offer support and education.*

- Contact the child's guidance counselor at school and let him know how caregiving issues at home may be impacting the child's behavior or study habits.
- Give children as well as the person with Alzheimer's all the reassurance, affection, and security they need.
- Contact the Alzheimer's Association's 24/7 Helpline at 800.272.3900 or at [www.alz.org/manh](http://www.alz.org/manh). The website contains helpful information and videos especially geared towards children and teens.

### *Let them be involved.*

- Allow children to share in caregiving responsibilities that are age-appropriate.
- Remember that the quality of time that a child enjoys with a person with Alzheimer's disease is far more important than the quantity of time. A shared project, lasting no more than an hour, will enable the child to remain a child and not assume the role of an adult caregiver.

## Talking to Family and Friends

There is no right way to tell others that someone has a diagnosis of Alzheimer's disease, and everyone has their own methods. Most people prefer to tell those closest to them first, and these family members and friends may be able to help you tell others in your social circle. Sometimes a face-to-face conversation is best, and other times a telephone call, e-mail, or letter will suffice. Whatever method you chose, it is important to include the following information:

- Basic information about Alzheimer's disease and where to find more information
- How Alzheimer's disease is currently affecting the person, such as what symptoms she is experiencing
- What things the person is still able to do and enjoy
- Specific ways that others can be helpful

It is important not to be ashamed about a diagnosis of Alzheimer's disease. Public awareness and understanding about Alzheimer's disease is improving in our society, but some people still hold onto false stereotypes about it. If family and friends react negatively to the news, it is important to remember that their reaction is based on lack of education and understanding. The Alzheimer's Association MA/NH Chapter can provide materials that you can share with them. You should not take anyone's negative reaction personally. While some people may drift away, **friends, neighbors and relatives can be excellent sources of support** if they understand what is involved in caring for a person with Alzheimer's.

### *Educate supportive people*

- Tell friends and family about the person's condition. Explain that the person may act in ways that are different and confusing. Although outwardly the person may look fine, she has a brain disease.
- Recommend that friends and relatives learn more about Alzheimer's disease (share this Guide or direct them to the Alzheimer's Association MA/NH Chapter website at [www.alz.org/manh](http://www.alz.org/manh)). Invite them to accompany you to a support group meeting.

### ***Tips for a successful family meeting:***

- Allow everyone equal time to share their opinions and observations on the issue and what each individual can contribute to its solution.
- Limit the conversation to the issues decided upon beforehand and do not bring up old family disagreements.
- Show respect to one other and keep a sense of humor.
- Take notes on what is agreed upon at the meeting—how, by whom, and when things will be done.
- Make a plan for following up with one another and keeping lines of communication open such as a group email so that everyone gets the same information at the same time.

### ***Help them help you***

- Suggest specific tasks for friends and relatives to do, such as grocery shopping or other errands.
- Some friends and relatives will handle visits with the person better than others will. For those who have difficulty, suggest other ways for them to assist you.
- Remind friends and relatives that the person is an adult. Do not talk about the person with Alzheimer's in their presence as though she were not there. A person with Alzheimer's, like all human beings, needs to be related to in a way that helps maintain her dignity and self-esteem.

### ***Help visits to be successful***

- Encourage children to visit. Children will typically relate to who the person is now. They can often communicate well with someone who has a limited ability to express herself verbally.
- Prepare the visitor for problems with communication. Teach friends and relatives what you have learned about ways to communicate with the person.
- Suggest that people visit one at a time to avoid overstimulating and confusing the person. Suggest that visitors stay for only a short time.
- Encourage them to plan activities for their visit, such as having a snack, going for a walk, or doing a simple activity like looking at a photo album.

### ***Keep lines of communication open***

- Talk over problems as they arise to avoid misunderstandings.
- Family stresses have a way of surfacing during this time. For example, adult children may disagree about what is the best approach to caring for a parent with Alzheimer's; a spouse may refuse help because he doesn't want to burden his extended family; one family member may refuse to get involved at all.
- Try setting up a family conference to air problems, divide tasks, and make decisions together. You and each family member should have a clear understanding of the disease and how caring for the person affects you and other family members.

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# APPENDIX 1:

## 50 activities to do with a person who has Alzheimer's disease

1. Clip coupons.
2. Make a Valentine collage.
3. Rake leaves.
4. Play favorite songs and sing together.
5. Use the carpet sweeper or broom.
6. Take a ride.
7. Bake cookies.
8. Dye eggs.
9. Read the daily paper out loud.
10. Match a basket of socks.
11. Ask someone with a baby or young child to visit.
12. Take a walk.
13. Reminisce about the first day of school.
14. Plant seeds indoors or outdoors.
15. String Cheerios® to hang outside for birds.
16. Look at family photos.
17. Toss a ball.
18. Sweep the patio.
19. Color pictures.
20. Have an afternoon tea.
21. Weed the flower bed.
22. Make cream cheese mints:  
2 lbs powdered sugar, 8 oz cream cheese,  
2 drops peppermint extract. Knead  
together and press dough into molds. Chill.
23. Remember great inventions.
24. Sing favorite hymns or recite prayers.
25. Make holiday cards.
26. Play Pictionary® or other suitable games.
27. Dance and/or listen to music.
28. Sort playing cards by their color.
29. Write a letter to a family member or have  
the person dictate a letter to you.
30. Pop popcorn.
31. Read from journals or magazines.
32. Give a manicure.
33. Make paper carnations out of facial tissue.
34. Invite a neighbor or friend who has a calm  
pet to visit.
35. Cut pictures out of greeting cards or  
magazines.
36. Make homemade applesauce or cranberry  
sauce.
37. Wash silverware and put it away.
38. Put a simple puzzle together.
39. Bake homemade bread.
40. Sort objects such as beads and buttons  
by color or shape.
41. Read classic short stories.
42. Use colored paper, string, and paste for  
jewelry.
43. Put bird feed out and watch the birds.
44. Sing holiday songs.
45. Say "Tell me more" when the person  
starts talking about a memory.
46. Clean out a pumpkin. Bake seeds.
47. Roll yarn into a ball.
48. Work in a garden or create a small indoor  
garden in a box.
49. Listen to recordings of family and friends.
50. Look at art books or travel books, and  
engage in conversation about what the  
person sees.





## APPENDIX 2:

### Table of Community Resources

	What they are and how to locate them
<p><b>Adult Day Programs</b></p>	<p><b>There are three types of Adult Day programs:</b></p> <p><b>Social Day Care:</b> Structured, supervised activities with no medical component and generally open 2-5 days per week. Payment is generally private pay; or through an ASAP or Service Link on a sliding scale for those who qualify. (See below for information on ASAPs). In New Hampshire, there are programs called Day Away Programs designed for people with early-stage Alzheimer’s Disease.</p> <p><b>Standard Adult Day Health Programs:</b> Structured, supervised day programs for adults who require medical supervision or rehabilitation services. Payment sources include Medicaid; through an ASAP (on a sliding scale for those who qualify) or Service Link; private insurance; the Department of Veterans Affairs (VA); and private pay.</p> <p><b>Specialized Alzheimer’s Day Programs:</b> Specialize in serving individuals with Alzheimer’s and related dementias. These programs have trained staff as well as appropriate activities, low client-to-staff ratios, and a safe environment for people who may wander. Payment sources for these programs are generally the same as for standard Adult Day Health programs.</p> <p>For information about and referrals to adult day programs in your area, contact the Alzheimer’s Association’s 24/7 on line with Helpline at 800.272.3900 or at <a href="http://www.alz.org/MANH">www.alz.org/MANH</a>.</p>

**Aging Services  
Access Points  
(ASAP) /  
Service Link  
and  
Area Agencies  
on Aging  
(AAA)**

In **Massachusetts**, ASAPs and AAAs are a network of agencies that operate a wide range of services for older adults and their family caregivers. There is an ASAP/AAA that provides services in every community in Massachusetts.

**ASAPs provide:** information and referral to home and community services; case management; homemaker services; chore and personal care (home health aide) services; **respite** services (in-home as well as adult day programs); **home-delivered meals**; family caregiver support services; and protective services.

**Payment:** Many services are provided on a sliding scale for people age 60+ who financially qualify as well as for individuals under age 60 with a documented diagnosis of Alzheimer's or a related dementia who financially qualify. Some services request a voluntary donation only.

**For information** or to be directed to the ASAP that serves your community contact 800-AGE-INFO (1-800-243-4636) or visit their website at [www.800ageinfo.com](http://www.800ageinfo.com).

In **New Hampshire**, the ServiceLink and Disability Resource Center assists older adults and their family caregivers in finding local and state resources. ServiceLink can direct families to opportunities for services to be subsidized. The toll-free number for ServiceLink is (866) 634-9412. The website is [www.servicelink.org](http://www.servicelink.org).

## Assisted Living

Assisted living offers a **combination of housing, meals and personal care services**. They do not provide medical or nursing services. They are not designed for people who need serious medical care. Assisted living is intended for adults who need some help with activities such as housecleaning, meals, bathing, dressing, and/or medication reminders.

Assisted living residences can be freestanding or may be combined with other levels of care such as nursing homes or independent living units. Increasingly, assisted living residences are being designed to meet the special needs of individuals with Alzheimer's disease or related dementias.

For most residences the **source of payment** is private pay or long-term care insurance. In MA, some people may be eligible for assistance through the Group Adult Foster Care (GAFC) program, which pays for the service component only. To be eligible for **GAFC**, the person must qualify financially for Medicaid and must also demonstrate that he needs daily assistance with activities such as dressing, bathing, eating, daily hygiene, and ambulation. GAFC is not currently available in NH.

The **Massachusetts** Office of Elder Affairs certifies assisted living residences, and offers the **Assisted Living Ombudsman Program** to provide advocacy, information and complaint resolution to consumers. The Department of Health and Human Services, Health Facilities Administration oversees Assisted Living Licensure. [www.dhhs.nh.gov/oos/bhfa](http://www.dhhs.nh.gov/oos/bhfa), 603.271.9499.

In **New Hampshire**, the Department of Health and Human Services, Health Facilities Administration oversees Assisted Living Licensure and offers the Longterm Care Ombudsman program as a resource.

(continued next page)

## Assisted Living

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***For more information***

Contact the Massachusetts Assisted Living Facilities Association (MASS ALFA) at 781-622-5999 or at [www.massalfa.org](http://www.massalfa.org).

In Massachusetts, for information about GAFC or the Ombudsman program, contact 800-AGE-INFO (1-800-243-4636) or visit their website at [www.800ageinfo.com](http://www.800ageinfo.com).

Contact the New Hampshire Department of Health and Human Services, Health Facilities Administration at 603-271-9499 or at [www.dhhs.nh.gov/oos./bhfa](http://www.dhhs.nh.gov/oos./bhfa).

To reach the New Hampshire office of the Long-Term Care Ombudsman contact 603.271.4375 or 800.442.5640 or [www.dhhs.state.nh.us](http://www.dhhs.state.nh.us).

For information on Alzheimer-friendly assisted living residences, contact the Alzheimer's Association's 24/7 Helpline at 800.272.3900 or at [www.alz.org/manh](http://www.alz.org/manh).

<h2>Benefits Programs</h2>	<p>There are a number of different benefit programs that can provide <b>income support or financial assistance</b> for medical care. These programs have varying eligibility requirements and application processes. Contact the phone numbers and websites listed below for more information on specific benefit programs.</p> <p>In <b>New Hampshire</b>, contact Service Link for resource information at 866-634-9412.</p> <p>In <b>Massachusetts</b>, contact 800-AGE-INFO (1-800-243-4636) or visit their website at <a href="http://www.800ageinfo.com">www.800ageinfo.com</a>.</p> <ul style="list-style-type: none"> <li>• Medicare 1-800-MEDICARE (1-800-633-4227) <a href="http://www.medicare.gov">www.medicare.gov</a></li> <li>• Social Security 1-800-772-1213 <a href="http://www.ssa.gov">www.ssa.gov</a> Can also provide information about <b>Social Security Disability</b> benefits and <b>Supplemental Security Income (SSI)</b></li> <li>• <b>Medicaid</b> (also called <b>MassHealth</b> in Massachusetts) 1-800-841-2900 Customer Service Center 1-888-665-9993 MassHealth Enrollment Center <a href="http://www.mass.gov/elders">www.mass.gov/elders</a> Can also assist with <b>GAFC</b> (see Assisted Living)</li> <li>• Veterans Massachusetts Department of Veterans' Services 617-210-5480 <a href="http://www.mass.gov/veterans">www.mass.gov/veterans</a></li> </ul> <p>U.S. Department of Veterans Affairs 1-800-827-1000 Benefits questions 1-855-260-3274 National Caregiver Support Line <a href="http://www.va.gov">www.va.gov</a></p>
<h2>Bill Paying Services</h2>	<p>These services typically provide <b>basic money management tasks</b> such as sorting mail, paying bills, and balancing checkbooks. They generally do not offer legal or financial planning.</p> <p><b>Payment</b> for these services is typically private pay, although a no-or-low-fee service is available through the local ASAP for those who qualify. Contact your local ASAP about their Money Management Program or for private pay referrals.</p>

<p>Care Consultation Alzheimer's Association, MA/NH Chapter</p>	<p>The Alzheimer's Association, MA/NH Chapter offers an in-depth, personalized service for individuals and families who are facing the many decisions and challenges associated with Alzheimer's disease and related dementias. The goal is for each family to <b>develop a better understanding of the disease, make a plan to secure needed care, and develop strategies</b> for the best possible symptom management and communication. Consultations are provided in person and by phone. Consultants are also available to answer questions by email. This is a free service. Contact us at our 24/7 Helpline at 800.272.3900 or at <a href="http://www.alz.org/MANH">www.alz.org/MANH</a>.</p>
<p>Case Management / Care Management</p>	<p>Many agencies provide case management (sometimes called care management) services which help families <b>access and coordinate services</b>. Some case management services are provided at little or no charge through your local ASAP for those who qualify. Case management can also be purchased on a sliding scale or fee-for-service basis from many agencies and individual practitioners. For information and referrals, contact your local ASAP or the Alzheimer's Association's 24/7 Helpline at 800.272.3900 or at <a href="http://www.alz.org/MANH">www.alz.org/MANH</a>.</p>
<p>Councils on Aging (COA) and Senior Centers</p>	<p>The mission of these municipally appointed agencies is to <b>link older adults with community resources</b> by developing and/or coordinating services, community education and advocacy. The services and programs offered vary by community. Some cities and towns have a senior center in addition to a COA. To find your local COA/ Senior Center in Massachusetts, contact 800-AGE-INFO (1-800-243-4636) or visit their website at <a href="http://www.800ageinfo.com">www.800ageinfo.com</a>, or contact your local ASAP. In New Hampshire, contact ServiceLink at (866) 634-9412 or <a href="http://www.servicelink.org">www.servicelink.org</a>.</p>

<p><b>Crisis Intervention</b></p>	<p><b>Behavioral health emergency services, crisis assessment, intervention and stabilization services</b>, available 24 hours per day/7 days per week/365 days per year. To find the Emergency Service Program (ESP) that serves your area call 1-877-382-1609 or visit <a href="http://www.masspartnership.com">www.masspartnership.com</a>.</p> <p>ASAPs also operate <b>Adult Protective Services</b> program. Contact your local ASAP if you believe an older adult is at risk for abuse or neglect. You can also call the <b>Elder Abuse Hotline</b> in Massachusetts at 1-800-922-2275.</p> <p>In New Hampshire, contact the <b>Bureau of Elderly &amp; Adult Services</b> at 603-271-9203.</p>
<p><b>Diagnostic Centers</b></p>	<p>Provide comprehensive assessments needed to determine what is causing the changes you are observing, as well as a care and treatment plan for the person. For a list of diagnostic centers in your area, contact the Alzheimer’s Association’s 24/7 Helpline at 800.272.3900 or at <a href="http://www.alz.org/MANH">www.alz.org/MANH</a>.</p>
<p><b>Driver Evaluation Programs</b></p>	<p>Evaluate the skills of an individual relative to their ability to continue or resume driving. A good program includes provisions for counseling and periodic re-testing, and includes a road test along with other evaluation measures. Insurance often pays for part of the testing with the remainder of the cost paid out-of-pocket. Contact the Alzheimer’s Association’s 24/7 Helpline at 800.272.3900 or at <a href="http://www.alz.org/MANH">www.alz.org/MANH</a> for more information and referrals to programs in your area.</p>
<p><b>Durable Medical Equipment</b></p>	<p>Durable equipment (<b>wheelchairs, commodes, canes, crutches, walkers, hospital beds</b>, etc.) is available from a variety of sources. Insurance pays for some equipment; the ASAP may be able to help with the cost of some equipment for people who qualify; and the COA may have an equipment “loan” program. Call your local ASAP or COA for more information.</p>

<p><b>Friends and Family</b></p>	<p>Family and friends are often overlooked as resources because a caregiver doesn't want to burden them. In most cases, family and friends do want to help but don't know how and believe that if they were needed, they would be asked. Caregivers need all the help they can get and need to <b>learn to ask for and accept help</b>. Contact the Alzheimer's Association's 24/7 Helpline at 800.272.3900 or at <a href="http://www.alz.org/MANH">www.alz.org/MANH</a> for tips on asking for help.</p>
<p><b>Hospice Care and Palliative Care</b></p>	<p><b>Hospice</b> care provides support and care in the home (and in institutional settings) to terminally ill individuals and their families. <b>Palliative</b> care extends the principles of hospice care to individuals that could benefit from receiving this type of care earlier in their illness or disease process. Palliative care often segues into hospice care as the illness progresses.</p> <p>The range of services provided varies from agency to agency and insurance typically covers much, but not always all, of the services available through hospice and palliative care.</p> <p><b>For more information</b> and referrals, contact the Alzheimer's Association's 24/7 Helpline at 800.272.3900 or at <a href="http://www.alz.org/MANH">www.alz.org/MANH</a>, or the Hospice and Palliative Care Federation of Massachusetts at 800-962-2973 or at <a href="http://www.hospicefed.org">www.hospicefed.org</a>, and the Hospice and Palliative Care Organization of New Hampshire at 603-415-4298.</p>
<p><b>In-Home Care</b></p>	<p>Is a generic term that includes a wide variety of services such as nurses ("visiting nurses"); aides to help with personal care or provide companionship and supervision; grocery and meal delivery services ("meals on wheels"); or help with housework and laundry. Some of these services are covered by insurance or are subsidized by the state, others are paid for privately. There are varying eligibility guidelines for insurance-covered or state-subsidized services. Contact your local ASAP for information about and referrals to private pay services and to find out if you and/or the person with Alzheimer's qualify for state-subsidized services.</p>



## Legal Services and Financial Planning

**Legal aid** clinics provide free legal advice for older adults. They are geared to lower-income older adults and generally focus on housing problems, benefits eligibility (including Medicare and Medicaid), and nursing home issues. For more information or to find the legal services office in your area, call the **Massachusetts Senior Legal Helpline** at 1-866-778-0939 or the **New Hampshire Senior Citizens Law Project Advice Line** at 888-353-9944 or 603-624-6000 or at [SCLP@nhla.org](mailto:SCLP@nhla.org).

**Other legal services** which caregivers may need include preparation of documents such as health care proxies, durable powers of attorney, and wills. These documents must be executed while the person is mentally competent. If the person is not competent, the family may have to go to court to seek a guardianship. Families should also consult an attorney or financial planner to avoid financial hardship for the person's spouse. These services are generally private pay.

For assistance locating a knowledgeable elder law attorney and/or financial planners, contact the Alzheimer's Association's 24/7 Helpline at 800.272.3900 or at [www.alz.org/MANH](http://www.alz.org/MANH).

<p><b>Nursing Homes (Skilled Nursing Facilities)</b></p>	<p>Nursing homes provide <b>24-hour skilled nursing care</b> to people with qualifying medical needs. Some nursing homes have Alzheimer's Special Care Units that are specifically designed to meet the needs of individuals with Alzheimer's disease or related dementias. For information about these facilities, contact the Alzheimer's Association's 24/7 Helpline at 800.272.3900 or at <a href="http://www.alz.org/MANH">www.alz.org/MANH</a>. For information on nursing homes contact the Massachusetts Senior Care Association at 1-800-CARE-FOR (1-800-227-3367) or at <a href="http://www.massseniorcare.org">www.massseniorcare.org</a>.</p> <p>The Massachusetts Office of Elder Affairs oversees the <b>Long Term Care Ombudsman Program</b> which advocates for residents of nursing homes. Ombudsmen offer a way for residents and their loved ones to voice their complaints and have their concerns addressed so that residents can live their lives with dignity and respect. To connect with the Ombudsman serving your area, contact 800-AGE-INFO (1-800-243-4636) or visit <a href="http://www.800ageinfo.com">www.800ageinfo.com</a>, or contact your local ASAP.</p> <p>In New Hampshire, the Office of Long-Term Care Ombudsman receives, investigates, and resolves complaints or problems concerning residents of long-term care facilities. Contact the Office of the Long Term Care Ombudsman at (800) 442-5640 in NH or (603) 271-4375 outside of NH, or at <a href="http://www.dhhs.state.nh.us">www.dhhs.state.nh.us</a>.</p>
<p><b>Religious Affiliated Service Agencies</b></p>	<p>Groups such as Jewish Family Services, Catholic Social Services, and Pastoral Counseling Services serve people of all religions and offer a variety of support and in-home services. Your place of worship may also be a source of information and referral or may have other programs that could be of help.</p>

<p><b>Respite Care (Relief for the Family Caregiver)</b></p>	<p>The purpose of respite care is to <b>temporarily relieve those caring for older adults who require 24-hour care</b>. Respite care may be provided in the home, through an adult day program, or at a nursing home or assisted living. Contact your local ASAP for information and referrals about these services or to find out if you qualify for respite services through the ASAP or Service Link.</p>
<p><b>Safe Return (program for people who may wander)</b></p>	<p><b>MedicAlert® + Alzheimer’s Association Safe Return® program</b> is a 24-hour nationwide emergency response service. If a person with Alzheimer’s wanders away from home or a facility, or is found in the community lost and confused, the emergency response line can be called at 1-800-625-3780.</p> <p>The <b>initial fee</b> includes ID jewelry with information specific to the person with Alzheimer’s and a checklist of steps for a safe return, in addition to the 24-hour emergency response service. There is an annual fee after the first year. <b>Assistance</b> paying for the fee is available for those who qualify from the Alzheimer’s Association MA/NH Chapter or from your local ASAP. Contact your local ASAP or the Alzheimer’s Association’s 24/7 Helpline at 800.272.3900 or at <a href="http://www.alz.org/MANH">www.alz.org/MANH</a>.</p>
<p><b>Support Groups and Educational Programs</b></p>	<p>The Alzheimer’s Association offers many support groups and educational programs for persons with Alzheimer’s and their family members and caregivers. Other agencies, such as COAs and ASAPs offer this type of support as well. For a complete list of groups and programs in your area contact the Alzheimer’s Association’s 24/7 Helpline at 800.272.3900 or at <a href="http://www.alz.org/MANH">www.alz.org/MANH</a>, or contact your local COA, ASAP, or Service Link.</p>
<p><b>Transportation</b></p>	<p>Some older adults qualify for free or low cost transportation for medically necessary trips. Contact your local COA or ASAP or Service Link for information about and referrals to transportation services in your area.</p>







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