SinceYouCare

A Series of Guides from MetLife in Cooperation with the National Alliance for Caregiving

Alzheimer's Disease - Caregiving Challenges

About the Subject

The number of older adults who will be alive in the decades ahead is staggering and unprecedented. Since advanced age is a primary risk factor for Alzheimer's disease, the possibility of millions developing it is a daunting prospect for families and societies. There are presently an estimated 4.5 million Americans with the disease. By 2050, as many as 16 million people may be affected.[1]

Since there is no cure for Alzheimer's as yet, providing humane and supportive care for people with the disease is where our efforts are focused. We all are aware of famous people - Ronald Reagan, Rita Hayworth, Sugar Ray Robinson - as well as family and friends with the disease. Alzheimer's affects entire families, not just the person with the illness. For every person with Alzheimer's, it is estimated there are 1-4 caregivers involved with helping.[2]

MetLife

Caregivers face many challenges as they search for information and make decisions about how best to provide care to their loved ones. To help meet their needs, MetLife offers SinceYouCare® — a series of guides which provide practical suggestions and useful tools on a variety of specific care-related products.

However, before we jump to the conclusion that any change in memory is indicative of disease and future disability, we need to know certain changes are common as we get older and related to the normal aging process. The difference between expected memory changes that come with age and the changes that occur with Alzheimer's disease is that the changes common to normal aging do not significantly interfere with a person's ability to function. They do require a certain level of acceptance, a sense of humor and some minor adaptations. Dementia, a name for the symptoms that accompany Alzheimer's disease, on the other hand, affects daily function in many ways, is sometimes not recognized by the person affected and is caused by an illness. It is not a normal part of aging.

Things You Need to Know

Memory Changes Associated with Age

During the past few decades, much has been learned about how our memories work. Many mid-life to older adults are working on word puzzles, attending classes, keeping up social contacts, reading, even doing mental gymnastics, all in hopes of keeping their aging brains functioning at maximum capacity. Considerable variability exists among people when it comes to memory. It can be expected that certain changes in memory may occur as we age. Learning new things may take longer. We may on occasion not be able to pull up a name or word that we are looking for or forget where we put our keys. We may not find it as easy to pay attention to more than one thing at a time. These changes need not cause great concern. It is also important to recognize that multiple factors may affect or appear to affect memory to a greater or lesser degree including stress, anxiety, grief, fatigue, diminished vision or hearing, medications and physical illnesses.

About Alzheimer's Disease

What is not normal is memory impairment, also known as dementia or cognitive impairment, caused by disease and illness. Dementia itself is not an illness but rather a symptom of an illness. Alzheimer's disease causes irreversible dementia which is a progressive, permanent loss of mental capabilities interfering with a person's work life, social interactions and daily activities. A number of conditions other than Alzheimer's can also cause dementia. Some of these conditions do not cause permanent dementia and can be reversed. Others like Alzheimer's disease cannot.

Reversible Causes of Dementia

- Thyroid dysfunction
- Vitamin B12 deficiency
- Depression
- Medication reactions

Non-Reversible Causes of Dementia

- Alzheimer's disease (AD) is the most common cause among older adults. One in ten Americans 65 and older and almost half of those 85 and over are affected.[3] It is a gradual degenerative brain disease affecting a person's personality, ability to manage daily activities and capacity to remember, think, use language appropriately and learn new things. It progresses at a variable rate but always on a downward slope.
- Vascular dementia or Multi-infarct dementia is caused by multiple small strokes. Although the behaviors of a person with vascular dementia may be the same as those for someone with Alzheimer's, its progression is somewhat different. The memory changes typically occur more in steps than a steady decline. The person may remain at the same level for some time before progressing further.

- Dementia related to illnesses such as:
    - Alcoholism
    - Parkinson's disease
    - AIDS as well as other less widely known conditions

Emotional Responses to Caregiving

Whatever the cause of the dementia, the emotional responses to the reality of becoming a caregiver for someone with progressive cognitive impairment are significant. It is important to understand that emotions influence our behavior and caregiving is an emotional, and at times isolating, experience. Emotions run the gamut from fear, anxiety, anger, sadness and resentment to understanding, empathy, acceptance and an appreciation of the opportunity to help someone you care about. Many of these emotions are present to a greater or lesser degree in most people touched by Alzheimer's caregiving.

Of equal importance are the emotions of individuals with the disease. They may feel embarrassed, fearful and uncertain. It is important to recognize their feelings. They want to remain respected, talked with and listened to, and not become invisible. How feelings manifest themselves in the caregiver and the person needing assistance is uniquely individual and changeable throughout the course of the disease and the caregiving journey.

No two caregiving situations are the same. Helping someone with AD is particularly difficult because Alzheimer's affects an individual's behavior, daily functioning and personality. Alzheimer's caregivers sometimes feel more burdened than caregivers of people with other chronic, debilitating diseases. The person with AD may appear well, acknowledge no problems and feel fine. Decreasing mental abilities are often well hidden from all but those closest to the person. It is, at times, a deceptive disease making acceptance that much harder.

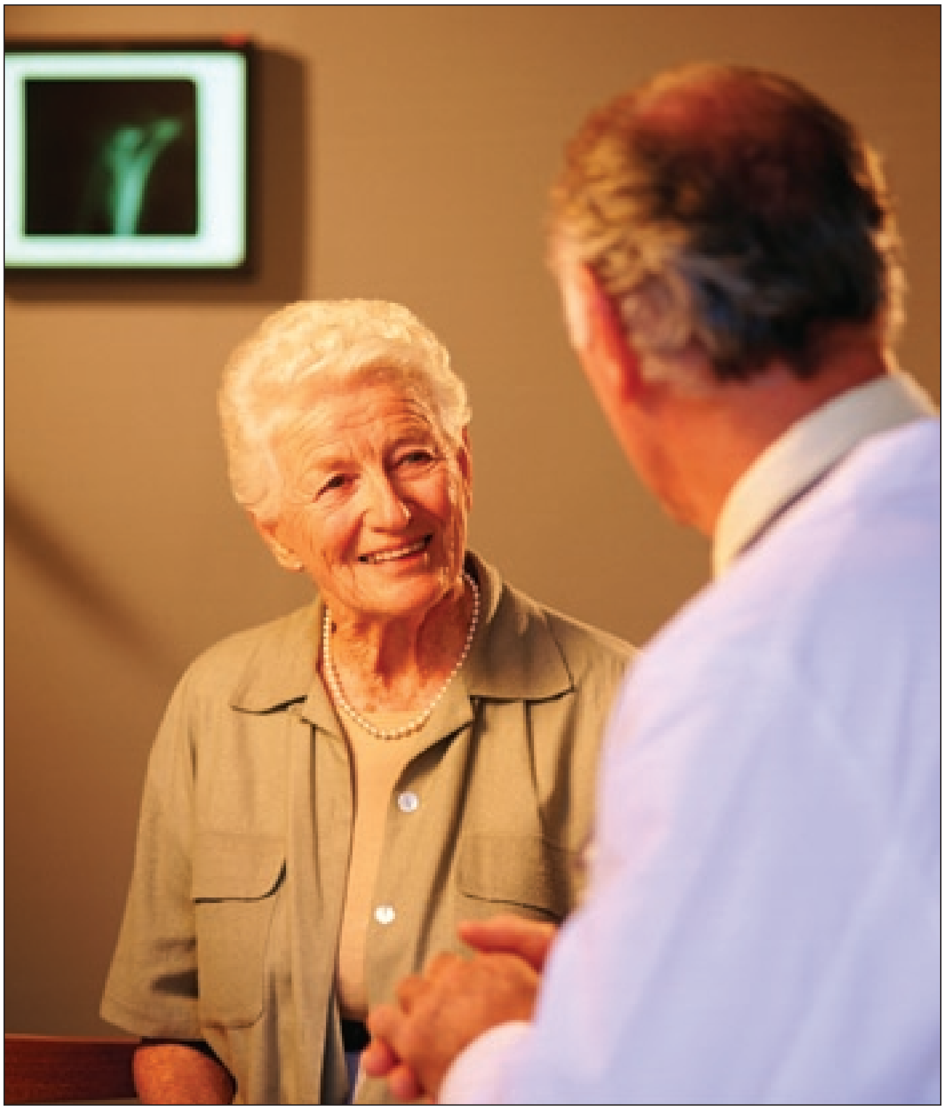
Unfortunately, there is no prescribed course to follow in this emotional Alzheimer's caregiving journey. Each situation is different just as we are each different from one another. What works for one person and family may not work for another. What works one day may not work the next. It is important to remember that as a caregiver you need not, nor should you try to, travel this road alone. There are professionals as well as fellow caregivers, informational resources, community services, friends, families, clergy and many others willing and able to help. To a certain extent, we all learn and grow as we go along. However, we can gain from those who have gone before us. They can tell us what has worked for them. They can provide understanding, guidance, information and support – all of which are vital to our maintaining emotional balance while developing our caregiving skills and gaining confidence in our ability to cope.

The Importance of Seeking a Diagnosis

Why

Individuals with cognitive impairment and their families are encouraged to seek medical assistance to find the underlying cause as soon as they suspect there may be a problem. The reasons to determine the cause of the dementia are:

- Some forms of dementia are reversible and can be successfully treated particularly if identified early.
- It is possible to have more than one condition causing significant cognitive impairment such as depression and Alzheimer's. Treating the depression can reduce the degree of impairment.
- New medications may help delay the progression of the symptoms of Alzheimer's disease and perhaps improve function if begun early in the course of the disease. While not helpful to everyone,



medications including Aricept, Exelon, Reminyl and Namenda are designed to improve or delay progression of cognitive impairment. There are also experimental drug trials taking place throughout the country for which some may qualify.[4]

- Knowing what the problem is is the first step toward planning for needed care and identifying resources that may help both you and your family member.

Where

- **Primary Care Physician** – This is usually the best place to start. Often it is family or a friend who is most concerned about the person. The individual affected may sense there is something wrong but may be reluctant or unable to recognize the degree of the impairment. It is important that your family member's physician be made aware of concerns you and/or your family member may have. Some other health care professionals who can help with diagnosing the problem include geriatricians, neurologists, psychiatrists and psychologists. You might want to speak with your family member's primary physician about seeing a specialist for an evaluation. The primary physician should be able to identify a resource for you and make any necessary referrals.
- **Geriatric or Memory Assessment/Evaluation Centers** – These centers are now available in many communities. They are often associated with a hospital or university medical center. You may find out about such centers in your area by asking your primary physician or contacting your local hospital, Area Agency on Aging or Visiting Nurse Association. A referral from a primary care physician may be required to obtain an assessment. It is also possible for someone to contact a center directly to get information about the process for making an appointment and to determine what information may be needed before setting up an appointment, e.g. referral information from the primary physician. In addition to diagnosing the problem, these centers can assist in developing a plan of action. The plan should include suggestions for things needing your immediate attention, guidance

for obtaining community services and medical follow up and help in finding education and support for you and your family member.

How to Prepare and What to Expect

- Before any evaluation visit to a physician or assessment center, it is helpful for the caregiver and the person, if able, to make a list of the behaviors or reasons that cause them to be concerned about significant memory impairment. The list, as well as details such as the length of time you have been concerned and how quickly the changes occurred, can help the physician determine how to proceed with diagnosing the problem.
- Geriatric or Memory Evaluation Centers perform comprehensive assessments by collecting medical, social and psychological information about the person from the primary care physician, other professionals involved in the person's care, the family and the person. The basic evaluation team usually includes a nurse, social worker and physician. Sometimes psychiatrists, nutritionists, pharmacists and other professionals are available to participate in the evaluation as needed. Psychological testing, laboratory and other diagnostic procedures may be recommended to help make a diagnosis.

Changes that Occur with Alzheimer's Disease

Often in the beginning stages of AD, the changes in a person's ability to function are not easily seen. It can be difficult to recognize these changes until they obviously interfere with daily functioning. Many people think that forgetfulness and repeating the same questions or stories are the only things to consider when deciding whether or not memory changes need professional evaluation. Memory impairment caused by Alzheimer's results in other difficulties as well.

Changes may be observed in:

- Communication – A person may have trouble finding names for words, be vague about things, may not initiate conversations or may withdraw from them.
- Understanding and Learning – The individual may have difficulty following directions and learning new things. He or she may frequently repeat things, ask the same question multiple times, focus conversation on the past rather than the present and not understand subtle humor or abstract ideas.
- Judgment and Orientation – He or she may frequently leave pots on the stove and burn them, may not recognize dangerous situations, may wander, or may get lost going to or from previously familiar locations.
- Performing Previously Routine Activities - He or she may no longer be able to pay bills, balance the checkbook, write checks, shop, cook or take medications as prescribed.

To help people understand and anticipate what to expect, Alzheimer's disease is often described as having certain stages, although the stages are not precise. These stages describe the progression of AD in general terms, but each person with the disease experiences it differently. Trying to determine when a person has gone from one stage to another is not always possible or practical. Each stage presents different problems and new challenges for the caregiver. The early stages are marked by forgetfulness and personality changes such as irritability, anxiety, depression. In the early stages the individual may not need to have much physical assistance, but he or she may begin to exhibit errors in judgment and have difficulty managing new tasks as well as more complicated tasks such as finances. As the disease moves through later stages, the physical needs of the person increase, behaviors may become more difficult to manage, and higher levels of care are needed. The prospect of being a caregiver for someone with Alzheimer's disease may be overwhelming. To think of the disease in stages may help the caregiver to focus on one set of needs at a time.

Dealing with Changing Behaviors and Abilities

The many changes that accompany Alzheimer's disease pose challenges for the caregiver throughout the course of the illness. Effective techniques for helping a person with dementia often require a caregiver to alter his or her response to the person's behavior, to make adjustments in the person's environment or do both. The caregiver must be able to adapt to emotional and behavioral changes as well as physical changes in his or her family member.

The discussion below looks at some of the key issues that cause concern for caregivers. While suggestions are provided in this guide, it is important to remember that sometimes there is no right or wrong answer, that each family's experience is unique, and that the best approach to a specific circumstance is often found by a period of trial and error.

Be patient with yourself as a caregiver. Caregiving is a process and you learn as time goes on. With an illness like Alzheimer's disease, where needs change over time, the caregiver must be especially flexible. Understand that despite your best efforts there may be times when nothing seems to work. Don't be afraid to ask for assistance from the doctor or other health care professionals at these times.

Communicating Effectively

When an individual has Alzheimer's disease or a similar condition it is important to keep in mind important considerations to promote the most effective communication possible regardless of the cause of the dementia or the degree of impairment.

- Patience and understanding are required.
- Individuals with visual or hearing deficits will have greater difficulty with communication and may require other adaptations to improve interactions.
- Always treat the person with respect and as an adult even though the behavior may seem child-like or his or her ability to communicate appears very limited.
- Non-verbal communication conveys our feelings in a way words do not. People with dementia are able to understand or sense the feelings of others longer than they retain their ability to understand the meaning of words. Therefore, they are extremely sensitive to non-verbal communication such as body language, tone of voice, eye contact or physical touch. They may, however, misinterpret the non-verbal communication and respond inappropriately. The old adage, "it's not what you say, it's how you say it," is the golden rule for communicating with memory impaired individuals.

When Using Words Try To

- Face your family member when you speak.
- Limit distractions so that he or she can pay more attention to what you are saying.
- Speak slowly and distinctly. Use short, simple, familiar words and sentences.
- Ask one question at a time. Limit choices and open-ended questions.
- Use simple explanations. Break activities down into steps.
- Avoid using pronouns like they, it, she and he. Pronouns may add to a person's confusion.
- Use positive statements instead of negative ones.

- Patiently repeat answers or information to frequently asked questions. Try to act as if each time the question is asked is the first time.
- Use gestures or demonstration to show the person what your words are saying.
- Use a calm, relaxed tone of voice as much as possible.
- If your loved one is able to read write things down as reminders or post signs.

Try to Avoid

- Using logic or lengthy reasoning.
- Arguing with your family member or raising your voice.
- Using the word "don't". Try using "do" as much as possible.
- Saying things like "You're repeating yourself." or "Don't you remember?"
- Asking questions that require factual answers.
- Using abstract ideas or concepts.
- Talking about your family member as if she or he were not present.

Focus on feelings, not facts.

When you do not understand what your family member is saying, ask a few questions. If that does not help, try to discern the meaning or the feelings behind the words or behavior. If she or he seems happy, smile; if upset, try to comfort or distract. Figuring out what he or she is trying to communicate may seem like a puzzle. The more you know about him or her, the more time you are with him or her, the easier it becomes to understand. The greater the impairment, the greater is the challenge to comprehend.

Non-verbal communication

- Be aware of your feelings and attitudes. They can be conveyed in your tone.
- Try to act unhurried even when you are.
- Maintain eye contact during interactions.

Since the communication skills of people with dementia diminish, certain gestures or body language of the caregiver and others might be interpreted differently by the person than intended. While smiling, laughing, appropriate hugging, hand holding and other human touch are important, some individuals may see these expressions of concern and reassurance as something else. Likewise, other gestures such as raised eyebrows, hands on hips, facial expressions that caregivers may not even realize they are doing, can be seen as anger, questioning or disapproval. As a caregiver it is important for you to remember that non-verbal communication can have unintended effects on your loved one – positive or negative. Through experience you will sense how your body language is seen by the family member to whom you are providing care. Be patient with yourself as you gradually gain that understanding.

Promoting Safety and Independence

When someone has Alzheimer's disease, environments need to be adapted according to the person's degree of impairment to help him or her function as safely and independently as possible with daily activities. There are important considerations to keep in mind when caring for a loved one with dementia.

Assuring Safety

Do not expect your family member to take responsibility for his or her own safety. You will need to anticipate potential hazards and adjust the environment to minimize or eliminate them prior to a problem occurring. Potential sources of danger are numerous. They may include:

- activities such as smoking, cooking and using power equipment and hot water
- structures such as stairs, ladders and swimming pools
- items like matches, cleaning products, poisonous substances, medication and razor blades.

It is best to lock up items that are potentially harmful. Later in the illness, your loved one may be unable to tell the difference between what can and cannot be eaten. General home safety precautions are recommended especially for someone with dementia. These include:

- night lights
- grab bars in bathroom
- limited use of scatter rugs
- adequate lighting throughout the house
- lower hot water temperature to prevent burns.

Promoting Activity in a Safe Environment

Physical environments affect behaviors and can be set up to promote as much independence and activity as possible for an individual with dementia. Keep in mind these important principles when making adjustments in the home:

- Structure - Keep things in the same place. Do not rearrange furniture or other items even if you think it would look better. Familiarity and predictability are more important than décor.
- Simplicity - Remove clutter with your family member's permission. Keep things simple and organized.
- Safety - Shadows and darkness increase confusion. Glare on floors may appear as a wet spot or dark colored rugs may be perceived as a hole and therefore limit a person's willingness to walk in those areas. In later stages of the disease, it may be necessary to install locks on doors above eye level, remove knobs or disconnect stoves to prevent harm to your family member.
- Security - Environments should provide a sense of security to the person. If there is something your loved one really wants to keep as is, as long as it is not dangerous, try to go along with the request.

Safety and Driving

One of the key issues caregivers deal with when a family member has Alzheimer's disease or another condition that causes dementia is the person's ability to drive. When a person's driving becomes unsafe because of progressive cognitive impairment, the loss of a car can be a particularly distressing experience for the caregiver as well as the driver. Driving is a complex activity that requires quick decision making and reactions. Many of the skills needed to drive safely are impacted by the progression of Alzheimer's disease. As stated previously, a person with AD is frequently unable to realistically evaluate his or her own abilities and this includes driving. Therefore, it falls to the caregiver or family member to monitor the person's driving to assure continued safety on the road.

If your family member is driving, it is important to observe his or her driving over a period of time to accurately assess his or her skills. Keeping a written list of observations and the dates as they occur is helpful in determining when he or she should no longer drive. Listed below are some of the reasons for concern:

- Forgetting how to find familiar places
- Disregarding traffic lights or signs
- Driving too fast or too slowly
- Getting angry or confused while driving
- Having 'near misses', traffic accidents, fender benders
- Making poor decisions or responding too slowly in driving situations.

When your observations cause you increasing concern, share the list of examples with other family members, health care professionals and where possible the family member about whom you are concerned. Keep in mind both the safety of others and the preservation of your loved one's self-respect. If you can involve your family member in the decision to stop driving, it will help to preserve his or her dignity. Explore with him or her other options for transportation. Reassure your family member that you will make sure that a ride will be available if he or she needs to go somewhere.

Look to others for assistance if you have concerns about your family member's willingness to give up driving. Often the doctor is more effective than a family member in persuading an individual to no longer drive. Sometimes if the doctor writes a letter or a prescription that says "No Driving" it can be used as a reminder for your family member when he or she wants to drive. Other professionals such as your family member's attorney or car insurance agent can also be helpful in reinforcing the message.

You may also need to experiment with ways to distract your family member from wanting to drive, e.g. indicating someone else should drive because you're taking a new route or suggesting he or she deserves a chance to sit back and enjoy the scenery while someone else drives. Experiment to see what might work for you.

Taking away his or her access to the keys or disabling or selling the car are last resorts when other means have failed, and your family member insists on driving when it is no longer safe for him or her to do so. There is no precise formula for making or implementing this decision. It is never easy. However, because of the safety concerns for both your loved one and others, the issue of driving is one that must be addressed.[5]

Challenging Behaviors[6]

Alterations in behavior are often the most upsetting and difficult aspects of Alzheimer's caregiving especially for family members. The behaviors are not willful or spiteful. They are part of the illness and may occur because a person is attempting to convey a need or feeling. The behavior is the problem, not the person. The challenge for caregivers is to determine the meaning or cause of the behavior and then find ways of preventing it or reducing its impact.

Your family member will not display all the behaviors you read about here, but will most likely have a few you find hard to live with or about which you are deeply concerned. No two people with AD are alike in their behavior and no two caregivers react in the same way. How you deal with a given situation may differ from another caregiver. You will find many suggestions for handling behaviors and multiple resources available to help. At any one time, limit yourself to a few informational resources you trust.

General guidance for coping with behaviors:

- Do not take the behavior personally.
- See if you can figure out the cause or meaning of the behavior or what triggers it.
- You may need to change your behavior or the environment to accommodate behavior your loved one cannot change.
- Ask for help and support from others
- Consult a physician when behavior management suggestions do not work. Medication may be needed.
- Discuss sudden changes in behavior with the physician. They may be caused by medications or other treatable conditions such as infection, discomfort, pain or physical illnesses.

Agitation

Individuals with Alzheimer's disease may experience anxiety and worry. They may pace, be restless, irritable and/or agitated. They may not be able to tell the caregiver what is wrong. Some of these feelings may come from changes in the brain. Others may relate to such things as uncertainty about what is going on, not knowing what they are expected to do, losing or misplacing an important item. They may be worried about people from the past or looking for a familiar place. These feelings may be also be impacted by things such as changes in caregiving arrangements or living environment, the mood of others around them, the presence of visitors in the home, fatigue, too much noise or too many people or activities all at once, travel and physical or medical causes.

Suggestions for Preventing or Handling Agitation

- Maintain routines and rituals. Try where possible to avoid disruptions to the daily routines.
- Provide a stable living environment.
- Have familiar objects in the home to give a sense of security.
- Allow your family member to do as much as possible for himself or herself.
- Listen to your family member's anger and frustration with his or her limitations.
- Distract or redirect him or her to another activity or place when agitation begins.
- Reassure your loved one that everything is okay.
- You may need to slow yourself down.
- Reduce noise.
- Limit attendance at large gatherings.
- Do not challenge or confront your family member when he or she is agitated.
- Respond in a caring manner. Use a calm tone of voice.
- Move at your family member's pace in any activity. If he or she becomes restless or agitated stop the activity.

Repetitive actions or speech

Individuals with Alzheimer's and other similar disorders may engage in repetitive actions or speech. An individual may fold a towel over and over again, may pace back and forth, or ask the same question repeatedly. This may upset or annoy others but usually the person appears untroubled by the repetition. Repetitive behavior may be caused by boredom, wanting attention or anxiety about what is going on around them. People with Alzheimer's disease lose the ability to keep themselves occupied. They may resist suggestions from others because they may not understand them. Activities they used to enjoy may now be too complicated or difficult. They may continue with the same activity over and over because they have trouble switching to a new one. There is not a single answer to addressing these issues.

You will need to learn from experience what works for you. Those listed below are possibilities.

Suggestions for Preventing or Handling Repetitive Actions or Speech

- Consider music or exercise as a distraction.
- Rather than suggest an activity start one and encourage your family member to join. Make it a simple adult activity, one which your loved one will enjoy and will be able to do.
- Ignore the behavior or question. Touch gently on arm or hand. Respond to the underlying emotion
- Avoid any confrontations such as "You asked that 10 times already." Try to answer a question as if it had not been asked before.
- Reassure your loved one. Speak in a soft calm manner.

Wandering

Wandering is not unusual for people with dementia. It can, however, be a serious problem both at home and in other settings. A person may walk aimlessly, or with purpose, and then become lost. He or she may leave a familiar setting, become disoriented and go into an inappropriate or unsafe place. The person when lost may try to hide this fact from others. Wandering may be due to a variety of things including lack of sufficient exercise, wanting to perform an important job like going to work or child care, searching for a specific person, place or thing. A person may be calm when wandering or appear anxious and agitated.

Suggestions for Preventing or Handling Wandering

- Because there are different reasons that people may wander and there are different kinds of wandering, finding the cause may be helpful in managing the problem. Try to determine if the wandering occurs at a particular time of day, if certain situations seem to prompt it, if your loved one appears calm or agitated when wandering. Always be alert to how he or she responds to your attempts to intervene. You may need to change your approach based on experience and the particular situation.
- Establish a daily routine and structure including music, walking and/or household tasks the person can perform.
- Identify and implement safety measures to prevent your family member from leaving home undetected. Install locks that are difficult to open and not familiar to him or her. Check other ways of leaving the home such as large windows. Make certain they are not easily opened.
- Install audible bells/alarms to let you know if your loved one is leaving the house.
- Inform neighbors and others nearby of the situation and ask to be notified if your family member is outside alone.
- Make certain your loved one wears a bracelet with his or her name, your phone number, and an indication that he or she is memory impaired. This will help anyone who may find your family member to understand the concern and assist in getting him or her home.
- You may want to consider registering your family member with the Alzheimer's Association *Safe Return* program, a national system for locating, identifying and returning individuals who wander and become lost, or with another similar program.[7]

To access information about the *Safe Return* program or to enroll go to http://www.alz.org/Services/SafeReturn.asp.

"Sundowning"/Sleep

When someone becomes more confused, restless or agitated late in the day or early evening, this is known as sundowning. A person may also experience episodes of sleeplessness or awakening in the middle of the night, getting dressed and thinking it is time to go out. These behaviors may be caused by decreased light at end of day, late day tiredness making the person less able to deal with stress or changes in the person's biological clock caused by AD, resulting in a confusion of day and night.

Suggestions for Handling Sundowning

- During the day, increase activities. Discourage napping but allow for a rest period.
- Eliminate caffeine and foods high in sugar especially late in the day.
- Increase lighting. Close curtains before sunset. Use nightlights and a light in the bathroom.
- Make evening a quiet time. Keep bedtime about the same time every night.
- Keep the environment free from hazards in the event that your loved one gets up at night. If there are stairs and he or she might fall consider a gate. Follow other previously discussed home safety and wandering precautions.

Paranoia

People with Alzheimer's disease often have difficulty interpreting the world around them. Their memory of recent events is impaired. They do not recall explanations that were given to them a short time earlier or people they have been introduced to. They can't remember where they put things. They can't follow conversations. As a result, they may become suspicious or paranoid. For instance, they can't remember that the new person in the home is a care provider. They may think that person has stolen something that they cannot find and accuse him or her. They may also accuse family members if they have misplaced something. No other explanation seems to make sense to them. How they view a situation is very real to them. These accusations are not behaviors that individuals with dementia can control. They are part of the illness.

Suggestions for Handling Paranoia

- Do not take accusations personally.
- If others in the home such as friends who may be visiting, housekeepers and care providers are accused, reassure them that you do not suspect them and explain that this is part of your loved one's illness.
- Do not argue with your family member.
- Help to look for a missing item and then try to distract or engage your family member in another activity if possible.
- If money is "missing," give a small amount for your family member to keep in his or her pocket or bag.
- Try to find his or her favorite places for putting "lost" items so you can recover them when accusations are made.
- Have extras of important items such as keys and glasses in case they are lost.
- Don't keep a large amount of cash around the house and keep valuable items such as jewelry in a safe or not easily accessible place.

Hallucinations

Most commonly, hallucinations are when someone sees or hears things that are not there. While not experienced by others, these voices or sights are very real to the person experiencing them. Occasionally, a person may also feel, smell or taste things that are not there. Hallucinations are a symptom that may be caused by many things including drugs and certain diseases. By themselves in an older person they are not necessarily a sign of dementia. However, they can occur when a person has Alzheimer's disease or another form of dementia. If they occur remain calm so you will not further upset your family member. Reassure him or her that everything will be okay. Try to distract him or her if possible. If your loved one experiences hallucinations you should let the doctor know. There are medications that can be used to help with these symptoms.

Medications - Additional Help with Behaviors

Sometimes medications are needed to manage behaviors when non-drug attempts have not been completely successful. They should only be used when other interventions are not successful in addressing the problems. Medications are available to treat behavioral and other symptoms that may occur from time to time throughout the illness. These symptoms include anxiety, depression, sleep disturbances and agitation.

Since each person responds differently to medications, it is important to monitor the person closely to observe for both positive and negative reactions to the drugs. Ask the physician what side effects might occur and what improvements in behavior you can anticipate seeing. Let the physician know what you observe and be sure to report any side effects you notice. Physicians usually prescribe a low dose to start and gradually increase after seeing what effects the drug has.

Medications can be prescribed by primary care physicians, geriatricians or psychiatrists. However, one physician needs to coordinate medication administration to reduce the possibility of a person receiving too much or too little and to increase the likelihood that the desired results from the medication will be achieved. If a doctor is prescribing a new medication always make certain he or she is aware of any other medications your family member is taking.

Problems with Activities of Daily Living[8]

Just as Alzheimer's disease results in problems with memory, behavior and judgment, it also impacts an individual's ability to perform routine daily activities. In the earlier stages of the illness the individual may need supervision and direction. As the disease progresses he or she will become increasingly dependent upon others for both direction and hands on assistance. In addition, it is important to remember that some individuals may resist assistance with activities such as bathing and dressing. As with behavioral difficulties, it is important to understand that the disease process will impact not only your family member's ability to perform these activities but his or her perception of these activities as well. Some of the important areas of concern are listed below.

Bathing is a personal task that requires a number of steps and is typically considered a private activity. If your loved one refuses to bathe it may be that it has become too difficult or complex for him or her to complete. He or she may be embarrassed to have you assist or frightened of getting in the tub or shower.

Suggestions for Handling Bathing

- Try to follow previous routines where possible. If your family member usually bathed after breakfast try starting at that time. Once a time of day is set try to stick to it.
- Try to let your loved one do as much as he or she is able.
- Try to make the task simpler e.g. lay out towels in advance, draw the bath water.
- Provide simple directions in steps.
- If your family member resists getting in or out of the shower or tub you may want to start with a sponge bath.
- Rather than focusing on the need to bathe, focus on the steps one at a time.
- Sometimes your loved one may respond more favorably if an aide in a uniform assists rather than you.
- Protect your loved one's safety in the tub. Do not leave him or her unattended. Make sure the bath water is the correct temperature. Your family member may not be able to distinguish this. It is important to take steps to prevent slipping or falls. Do not use soaps or bath oils that will make the tub slippery. Use a bathmat that will not slip when getting out of the tub. As your family member needs more assistance you may need to get grab bars to help him or her get in or out of the tub or a chair seat for the shower.

Dressing may become an increasingly confusing activity for your loved one. Again, it is important to maintain as much independence as possible if your loved one is able to participate in the task. Finding ways to simplify the task and accommodate your loved one's preferences are important.

Suggestions for Handling Dressing

- If your family member does not want to change clothes do not argue. Try again later.
- Your family member may not be able to understand what is appropriate clothing for the season. Have only those clothes that are appropriate available for him or her to choose from at any given time of year.
- If your family member wants to select an outfit, give only two choices of clothing. Show the clothes to your family member and let him or her choose which of the two to wear. When the decision making becomes too difficult, you will need to choose the clothes.
- Lay out an outfit in the order that your family member will put it on.
- If your family member wants to wear the same thing every day, consider buying two identical items.
- As the disease becomes more advanced your family member

will have increasing difficulty with things like buttons, zippers and shoelaces.

- Try to find clothes that are easy to put on and take off, e.g pants with elastic waists and pull over tops where it does not make a difference which is the front and which is the back. You might even consider reversible clothes. Buy socks that are easy to get on and off and try slip on shoes so there is no worry about laces.

Eating poses a number of potential challenges. Maintaining proper nutrition is important to everyone's health and requires attention when caring for an individual with Alzheimer's disease or another similar disorder. Some people want to eat all the time and others are seldom interested. It is not uncommon for individuals with Alzheimer's to become malnourished as they may forget to eat, may hide food, or may throw it away. Finding spoiled food in cabinets, the refrigerator, or sitting on counters are signals that someone is not managing alone. In the later stages of the illness individuals may forget how to chew or swallow. They may have problems with choking.

Suggestions for Handling Eating

- As with other activities, try to establish a routine at mealtime. You will be able to learn whether your family member eats better if alone at the table or with others present.
- Make certain he or she has good dental hygiene and that dentures fit properly.
- Avoid distractions such as the television at meal times.
- Your family member may have likes and dislikes. Try to accommodate them where possible and still maintain proper nutrition. If he or she will only eat one or two foods you may need to use nutritional supplements.
- Your loved one may become more messy with eating as the disease progresses. Try to accommodate changes in his or her ability to eat. Buy plastic table cloths and offer more finger foods which are easier to eat.
- If he or she has another illness such as diabetes make certain foods that should not be eaten are not accessible to him or her.
- Sometimes too many types of food on the plate can be confusing. Limit the choices of food at any given meal.
- People with dementia may eat more slowly. Offer small portions or have a number of small meals each day instead of three larger ones.
- Keep healthy snacks where they can be seen. This may prevent hiding or hoarding food.
- Make certain that your family member is getting enough fluids in addition to food.
- As your family member has more difficulty with chewing and swallowing you may need to chop or puree foods. Discuss any concerns you may have about his or her nutrition, ability to swallow, and problems with choking with the physician.

Mobility will become more limited as Alzheimer's disease progresses. Individuals may have increasing difficulty with getting up and down and walking. They may have changes in their posture and in their gait. They will require supervision to prevent falls. Problems with walking gradually progress to the point where many individuals will completely lose the ability to do so and will become confined to a chair or in some instances to bed.

Suggestions for Handling Mobility Problems

- Problems with gait and balance can be related to medications or other causes as well as to progression of the disease. Don't assume it is the Alzheimer's. Any changes in this area should be reported to the physician so that he or she can assess the problem. Providing the doctor with details of the problem will help his or her evaluation. Your loved one may have a problem that is treatable.

- Observe your family member and watch for signs that he or she can no longer do certain activities such as climbing up and down stairs safely.
- As previously discussed, it is important to have an environment that promotes independence and minimizes the risk of falls. Follow the general recommendations discussed in the safety section of this guide and refer to the enclosed *Home Safety* checklist.
- If your family member is unsteady have him or her hold your arm when walking.
- Make certain any items such as chairs or tables that he or she may grab on to are sturdy and will not tip over.
- Make sure any handrails are secure. Consider a cane or walker only if your family member is able to safely learn how to use it properly.
- While many people gradually lose the ability to walk, if your family member has a sudden inability to walk you should let the doctor know right away.
- If your loved one becomes chair-bound you may want to consider a specialized chair which will help him or her maintain a sitting position and/or a seat that provides for comfort when sitting for long periods of time. You will want to have some protection to prevent your loved one from falling out of the chair or trying to get up when he or she is unable to stand.
- If your family member is bed-bound it is important to make certain that his or her position is changed frequently to prevent complications such as skin breakdown. You may also need to consider a special mattress.
- As your loved one experiences problems with mobility consider consulting a physical therapist. A therapist can teach you ways to assist your family member with moving from bed to chair, walking and positioning in the bed so that it is safe for your loved one and you will not injure yourself.

Incontinence

Incontinence, the inability to control bladder or bowel function, may occur in the later stages of AD. Incontinence can be related to a number of factors including not being able to get to the bathroom quickly, not knowing or recognizing where the bathroom is located, having difficulty getting clothing off quickly enough or being busy and forgetting to go. The person may not remember the acceptable place or way to urinate or defecate. Incontinence can also be caused by other physical illnesses and is sometimes treatable.

Suggestions for Handling Incontinence

- If your family member starts to be incontinent try to track when and how often episodes of incontinence occur. Do they occur at particular times each day? Are they only at night? Do they occur after a particular activity? Does your family member give any indication that he or she needs to go to the bathroom before the episode? Is he or she pulling at clothes? Does he or she seem to be looking for the bathroom? Does he or she seem to have difficulty getting there on time? Does he or she want to go to the bathroom every few minutes? Tracking the episodes and your family member's behavior may give you clues has to how to address the problem. It may also help the doctor to assess the problem. If your family member begins to become incontinent it is important to let the doctor know. Do not assume it is related to Alzheimer's disease. While it may be, it may also be related to a medical problem such as a bladder infection, diabetes or constipation. Whether it is bladder or bowel incontinence the first step is evaluating the problem.
- If the problem is occurring at a particular time of day or following a particular activity e.g. after breakfast try to bring your

family member to the bathroom at those times.

- If the incontinence occurs throughout the day without any warning from your family member consider a toileting schedule. Take your family member to the bathroom every 2-3 hours.
- If incontinence seems related to inability to get to the bathroom quickly enough, you may consider a portable commode. This might be especially helpful if your loved one needs to go up and down stairs to use the bathroom or if the problem occurs at night.
- If your family member is restless or pulls at clothing, it may indicate the need to go to the bathroom. Bring him or her at those times when you seem to be receiving a signal.
- If regular toileting or other techniques no longer work, there are many incontinence products that will make your caregiving tasks easier and provide dignity for your family member.
- Try to remain calm when accidents occur. Be reassuring since the episode may be upsetting to your loved one.
- When assisting your family member after an episode of incontinence, check his or her skin to make certain there are no rashes or evidence of skin breakdown related to the incontinence.
- If your family member has episodes of incontinence at night you may want to consider limiting fluids in the evening. It is important, however, that your family member receive plenty of fluids throughout the day.

Getting Help

Caring for a family member with Alzheimer's disease is a long, ever changing journey, one during which you will need to enlist the assistance of others. You cannot do it alone. It is helpful to start planning as early as possible in the illness. For you as well as for your family member, it is necessary to seek the help of others. It may take several inquiries and time to find what you need but there are people and programs to support you. Family, friends, neighbors and others are often willing to assist but you may have to ask for what you need. Keep a list of things that need to be done for your family member. If someone offers to help, you may look at that list and consider what activity might be appropriate for the person who offered to help.

To get information and find out about resources in your community, contact your local Area Agency on Aging, call the national Eldercare Locator or check with national organizations (see *Resources to Get You Started*). Most communities have senior centers, long-term care facilities, hospitals or home care agencies that are good sources of information. Legal and financial advice, caregiver support groups, respite services, adult day centers, home health care agencies, physicians, social service agencies and care managers can give you guidance or assistance. Included at the end of this guide is a tool (see *Asking for Help*) to aid you in assessing your situation, then deciding what help to look for and where you might find it. Don't wait until your responsibilities seem overwhelming to enlist supports. Begin to evaluate the resources in your community, including care at home, adult day centers and facility care, as soon as possible. This will help you to be prepared at various stages of your family member's illness. You can start enlisting outside sources of care on a gradual basis by introducing some other caregivers, both paid and informal, including friends and other family members for short periods of time. This will give you some relief and help your loved one to become familiar with other caregivers over time.

You may also want to consider an adult day center which typically offers a range of activities and an array of services in a community setting on either a full day or partial day basis. These centers often specialize in caring for individuals with Alzheimer's disease and similar disorders. A program such as this can both benefit your loved one and provide you with some needed time for yourself.

Taking Care of Yourself

As a caregiver, your well-being is vital. As you probably have discovered, the person with Alzheimer's disease is not the only person affected by this illness. It is easy for caregivers to become isolated. Keep your other relationships going – see your friends or talk with them by phone or email. Continue your spiritual/ religious connections. Pay attention to your mental and physical health. Exercise. Eat properly. Get adequate rest. Find time for yourself. In a small way every day, do something that gives you pleasure – listen to music; look at the birds; read a magazine; see a funny movie; or garden. A sense of humor eases tension and is good for your health. Nurture yours and be kind to yourself.

When you can, schedule recreation and relaxation for yourself away from the situation. Even if you are not ready to begin regular ongoing services to assist you in caring for your loved one, consider looking into respite programs that might be available in your community even if only for a few hours per week. Check with your local Area Agency on Aging or Senior Center. They will likely be aware of programs in your community. Taking this time for yourself will ultimately benefit both you and your loved one.

Helpful Hints

- Become an educated caregiver – *gradually* - too much information at one time may overwhelm and immobilize. There are a variety of sources to help you learn including professionals, other caregivers, the internet and your own ongoing experience. Do not be afraid to ask questions, to seek their advice and assistance. Most importantly, do not sell your instincts or your own thoughts short. You may be the best resource as to what is most helpful to your family member.

- Focus on the positive – reinforce and use what your family member does well. Sometimes it is difficult to see the positives but always remember very small successes can bring a sense of satisfaction and joy to your family member. How he or she feels about an activity is more important than how well he or she completed the task.
- Reassurance from you can make all the difference for your family member who is living in a constantly changing world of confusion, uncertainty and often fear. Continue to communicate with your family member through each stage of his or her illness, always treating him or her as an adult. Even if your family member does not seem to recognize you, the sound of your voice or your touch can be a source comfort to him or her.
- Keep in mind that you are often your family member's voice to those around him or her. Help those caregivers who may not know your family member as you do to understand the kind of person he or she was before this illness. You will need to educate them as best you can as to what he or she likes and doesn't like. The knowledge you can give to others will help them to provide the kind of care that will most benefit your loved one.

- Be patient with yourself as well as with your family member. Don't be afraid to experiment and to try new things to best meet his or her needs.
- Consider speaking with an elder law attorney as early as possible in your family member's illness. If your family member understands what is going on and has the capacity to make decisions, he or she may want to provide you or someone else with the ability to make financial and/or health care decisions on his or her behalf at the point in time when he or she is no longer able to make these decisions.
- Consider joining a caregiver support group. It is often helpful to be able to speak with others who are in a similar situation. Support groups can provide both emotional support and practical assistance.

To find out about nearby support groups you can contact your local senior center, an adult day center in your community, your local Area Agency on Aging or a national association such as the Alzheimer's Association or the Alzheimer's Foundation of America. See *Resources to Get You Started* for additional information.

Resources to Get You Started

Books and Publications

Alzheimer's Early Stages: First Steps for Family, Friends, and Caregivers
This book contains information on Alzheimer's risk factors and treatment as well as a chapter called "Voices of Experience" which provides reflections from family members. It provides families with help and hope as they struggle to come to terms with the changes in roles and responsibilities they assume when a family member is diagnosed with Alzheimer's disease.
Kuhn, D., (2003-second edition), Hunter House, $15.95, ISBN: 0897933974.

The Caregiver Helpbook: Powerful Tools for Caregiving
This book seeks to provide guidance and support tools for caregivers in the realms of personal stress, communication, boundaries, seeking help, dealing with the emotions of anger, guilt, etc. It contains several chapters specific to dementia. Schmall, V.L. PhD, Cleland, M. R.N., Sturdevant, M. RN, M.S.W., L.C.S.W. (2000). Legacy Health System; 1st Edition, $22.00, ISBN: 0967915546. It can be ordered directly from: Legacy Caregiver Services, The Caregiver Helpbook, 1015 NW 22nd Avenue, Portland, OR 97210 for $22.00 or on-line at www.legacyhealth.org, click "Health Information," then "Legacy Caregiver Services."

Creating Moments of Joy... for the Person with Alzheimer's or Dementia
This book provides a straight forward, practical approach to the many issues facing the caregiver and the individual with dementia. Brackey, J. (2004), Purdue University Press, 3rd Revised Ed., $16.97, ISBN: 155753360.

How To Care for Aging Parents
This book is a useful starting point for those finding themselves in a caregiver's role for parents or any other older relative. It provides information on health care issues, caregiver concerns, community and facility based services as well as an extensive listing of helpful agencies and organizations, with contact information to assist caregivers. Morris, Virginia, Workman Publishing Company; Rev&Expand edition (October, 2004), $18.95, ISBN: 0761134263.

Learning To Speak Alzheimer's: A Groundbreaking Approach for Everyone Dealing with the Disease
This guide for families presents an approach to caring for people with Alzheimer's disease with a focus on communicating with the family member who suffers from Alzheimer's disease and assisting the individual to use the skills that he or she still has. The goal is to promote as much dignity and independence as possible for the person. The book offers many practical tips to caregivers and includes listings of support organizations and home health care products.
Coste, Joanne Koenig, (2003), Houghton Mifflin, $24.00, ISBN: 0618221255.

The Loss of Self: A Family Resource for the Care of Alzheimer's Disease and Related Disorders
A book for family members or professionals involved with the care of someone with dementia. It provides information about causes, treatments, medications, as well as the personal and emotional challenges faced by caregivers. Cohen Ph.D., D., Eisdorfer Ph.D., C. (2002), W. W. Norton & Company, Revised and Updated Ed., $16.95, ISBN: 0393323331.

Shattered Lives: Finding Hope in the Midst of Alzheimer's and Other Related Dementia
This book gives practical guidance to those dealing with the many facets of caring for someone with dementia. It speaks to the many emotional challenges and coping strategies that develop in response to these challenges.
Childress, E., ErkenBrack, P. (2000). Dorrance Publishing Co., $14.00, ISBN: 0805948120.

The 36-Hour Day: A Family Guide to Caring for Persons With Alzheimer Disease, Related Dementing Illnesses, and Memory Loss in Later Life
This book provides valuable information for families coping with Alzheimer's and other dementing disorders. It gives factual information from the physical and psychological standpoints of the disorders to the impact they have on the caregivers involved. Legal, financial, and caretaking tools and suggestions are provided.
Mace, N.L., Rabins, P.V., (2001). Warner Books, Revised Ed., $7.99, ISBN: 0446610410.

Internet Sites

Administration on Aging (AOA)
AOA is maintained by the U.S. Department of Health and Human Services and provides resources, news and developments and information for older adults. AOA funds the Eldercare Locator, a service that gives information to callers about state and community resources that provide assistance to older persons and their caregivers. The AOA's home page may be accessed at: www.aoa.gov. The Eldercare Locator may be accessed at: www.eldercare.gov, or by calling 1-800-677-1116, M-F, 9 a.m.- 8 p.m. EST.

National Association of Agencies on Aging (N4A)
N4A is the national organization of Area Agencies on Aging throughout the United States, which provides information and services for older adults and their caregivers. The website can be accessed at www.n4a.org.

Alzheimer's Association
This is a not-for-profit national organization that provides information and supportive services to families and individuals dealing with Alzheimer's disease. The organization offers print and on-line educational materials, caregiver guidance and access to information about the *Safe Return* program. They may be called at 1-800-272-3900, 24 hours a day, 7 days a week. In addition, the help line provides information about local chapters that can assist families in finding support groups and other services in their communities. The Association web site, www.alz.org, also includes an "online community" which connects caregivers with other caregivers from all across the country.

The Alzheimer's Disease Education and Referral (ADEAR) Center
This is a service of the National Institute on Aging, which is a part of the Federal Government's National Institutes of Health. The Center provides information to patients, families and professionals about Alzheimer's disease and services. They may be called at 1-800-438-4380 from 8:30 a.m. to 5:00 p.m. EST or access the web site at: www.alzheimers.org.

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

The Alzheimer's Foundation of America (AFA)
The AFA is a national organization which offers information about brain health, Alzheimer's disease and other forms of dementia as well as tips for caregivers. The AFA has a toll-free hotline 1-866-AFA-8484 (1-866-232-8484) which is staffed by certified social workers and other

professionals knowledgeable about Alzheimer's disease and other similar disorders. It is available to assist with questions caregivers may have as well as to provide information about local resources to assist individuals with Alzheimer's disease and their families. The hotline is open Monday through Friday 9:00 a.m. to 5:00 p.m. EST. The AFA web site can be accessed at www.alzfdn.org.

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

The American Geriatric Society Foundation for Health and Aging (FHA)
The FHA is a national non-profit organization established in 1999 by The American Geriatrics Society to advocate on behalf of older adults and their special health care needs. The website contains a comprehensive on-line guide entitled *ElderCare at Home*. The guide addresses physical problems, mental/social problems, problems in managing care and contains specific chapters on dementia. The site also contains a *What to Ask* series with questions to ask healthcare providers about various care issues. www.healthinaging.org/ - A hard copy of the guide can also be ordered for $19.95 by calling 1-800-334-1429 x 2529.

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

Medline Plus
Medline Plus is an online connection to the National Library of Medicine, part of the National Institutes of Health. The site contains reliable information about a large variety of diseases, conditions and current trends in medicine with links to other resources. Access it at: www.nlm.nih.gov/medlineplus.

MetLife Mature Market Institute (MMI)
The Metlife Mature Market Institute offers a series of *Since You Care* guides similar to this one on a variety of caregiving issues. Other guides in the series include: *Legal Matters, Community Services, Adult Day Centers, Choosing an Assisted Living Facility, Understanding Home Care Agency Options and Making the Nursing Home Choice.* These guides can be downloaded on line at www.maturemarketinstitute.com.

National Academy of Elder Law Attorneys (NAELA)
This is the web site for attorneys that deal with the many issues facing older adults and the disabled. NAELA attorneys can assist their clients with estate planning, long-term care issues, power-of-attorney, wills and trusts. Within the site is a search field to find an elder law attorney in your area. There is also a very helpful question and answer section that will assist in the search for an elder law attorney. Access the main site at www.naela.org and the specific question and answer site at www.naela.com/public/index.htm. If you do not have access to a computer you may reach NAELA by phone at 520-881-4005 or via mail at NAELA 1604 N. Country Club Road, Tucson, AZ 85716-3102

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

The National Family Caregivers Association (NFCA)
The NFCA is committed to support, educate and speak up for family caregivers. It provides a number of practical tip sheets and checklists for caregivers which can be accessed at http://www.thefamilycaregiver.org/ed/tips.cfm. Topics include caregiver tips for talking on the phone, improving doctor caregiver communication, when your loved one is hospitalized, and communicating effectively with healthcare professionals. The main website for the National Family Caregiver's Association is www.nfcacares.org.

Useful Tools

- *Asking for Help* - This tool is intended to help you identify and locate needed services.
- *Home Safety Checklist* - This tool is a checklist for needed safety measures in the home.

Endnotes

[1] Alzheimer's Association, www.alz.org.

[2] Alzheimer's Foundation of America, www.alzfdn.org.

[3] Ibid.

[4] MedlinePlus; www.nlm.nih.gov/medlineplus/alzheimersdisease.html#clinicaltrials.

[5] Adapted from *"Fact Sheet: About Driving"* The Alzheimer's Association, 2004, www.alz.org.

[6] Mace, Nancy L. and Rabins, Peter V., *The 36-Hour Day*, Baltimore, The Johns Hopkins University Press, 1999. www.alz.org or 1-888-572-8566. (*Challenging Behaviors* section partially adapted from this book.)

[7] Alzheimer's Association, www.alz.org or 1-888-572-8566.

[8] Mace, Nancy L. and Rabins, Peter V., *The 36-Hour Day*, Baltimore, The Johns Hopkins University Press, 1999. www.alz.org or 1-888-572-8566. (*Problems with Activities of Daily Living* section partially adapted from this book.)

About the Authors of Since You Care®

Since You Care guides are prepared by the MetLife Mature Market Institute in cooperation with the National Alliance for Caregiving and MetLife's Nurse Care Managers.

MetLife Mature Market Institute® is the company's information and policy resource center on issues related to aging, retirement, long-term care and the mature market.

MetLife Nurse Care Managers are available to MetLife's long-term care customers and their caregivers, on a daily basis, to help identify and resolve caregiving questions and concerns through counseling and referral.

National Alliance for Caregiving is a non-profit coalition of 38 national organizations that focuses on issues of family caregiving.

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This booklet offers general advice, however, it is not a substitute for consultation with an appropriate professional. Please see a health care professional, attorney, or other appropriate professional when determining how the information and recommendations discussed in this booklet apply to your specific situation.

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SinceYouCare

Home Safety Checklist

General Safety

____ Remove clutter, unnecessary furniture; multiple items may increase confusion

____ Keep walk areas clear of potential hazards

____ Repair uneven floors, steps, loose rails

____ Remove small rugs or secure them to floor

____ Use smoke detectors and carbon monoxide sensors

____ Make sure electrical wires, phone lines or oxygen tubing cannot be tripped on

____ Use night lights in bathrooms, hallways, bedrooms

____ Install grab bars in bathroom; use non-slip mats in tub or shower

____ Keep hot water temperature at 120 degrees or less to avoid burns

____ Have list of emergency numbers near telephone

____ Be sure light bulbs have adequate voltage to see

Alzheimer’s Specific Safety

____ Use safety latches or locks on cabinets

____ Hide or lock up knives and other sharp objects, cleaning products, poisonous substances, matches, medications, firearms

____ Put appliances such as toasters, coffee pots, hair dryers, electric razors out of sight

____ Remove locks from interior doors particularly bathroom doors

____ Check content of refrigerator often; discard spoiled food; place food to be eaten in front

____ Discard poisonous houseplants, decorative fruits or other edible-looking objects

____ Disconnect, remove knobs or install automatic shut-off switch on stove

____ Keep small and large ladders, power equipment, tools out of reach

____ Install locks on outside doors and windows above or below eye level

____ Do not leave person home alone if unable to respond to an emergency

Asking for Help

Deciding What You Need

What kind of help do we need?

____ Accurate information about Alzheimer’s disease, other health or medical conditions
____ Someone to talk with about the situation
____ Professional guidance and advice about treatment/care
____ Supervision, companionship, activities for my family member
____ A ‘break for myself’ – to go for a walk, see a movie, be alone
____ Finding services and programs for people with Alzheimer’s near us
____ Grocery shopping, meal preparation
____ Housekeeping chores, laundry, home maintenance
____ Transportation to appointments, shopping, religious services
____ Assistance for my family member with bathing, grooming, dressing, eating, toileting
____ Legal, financial advice to plan for our present situation and the future
____ Ideas & suggestions for Alzheimer’s caregiving, including planning activities for my family member
____ Emotional support for both my family member and myself

What can we afford?

____ Will our medical, long-term care or other insurances pay for any help? What kinds of services will be covered? What are the eligibility requirements?
____ How much of our own money can we spend for help?
____ Are there any sources for financial assistance? Are we eligible?
____ Can we find help that does not cost money?

When do I need the help?

____ How often? Now and then, once a week, every day?
____ Which day(s), what time of day, how many hours?
____ Should we have in-home assistance? Use an adult day center? Consider other living arrangements?

Who can help me?

____What and how much can I realistically do myself?
____Do we have family members or friends willing and able to help? What specific things can they help with?

Notes: ____

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Finding Needed Help

- National organizations provide free information to callers about Alzheimer's disease and other conditions as well as assistance in locating help near where you live. Contact them on line or by calling toll free.

- Community Resources - Each community differs in the availability, type and operation of services.

☐ *Informal Assistance* –Family, friends, neighbors, religious communities and volunteer organizations can help with companionship, shopping and other chores.

☐ *Information & Referral to Resources (I&R)* – Senior centers, community mental health services, Agencies on Aging, Employee Assistance Programs and physicians can help identify local resources.

☐ *Support Groups* – offer emotional support, information and practical advice from other caregivers - in-person & internet groups, early stage Alzheimer's support groups for those with the disease. Adult day centers, long-term care facilities and other places offer these groups.

☐ *Care Managers* (sometimes called Geriatric Care Managers) – are professionally trained individuals that can help locate, obtain and coordinate services, plan for care or assist in a crisis.

☐ *Legal & Financial Advice* – Attorneys help with signing documents such as wills, powers of attorney, designation of health care agents and living wills and assist with financial planning.

☐ *Adult Day Centers* – offer activities, meals, socialization, supervision, health monitoring for family member during the day. Some programs are available evenings and weekends. Caregivers can obtain information and guidance as the disease progresses.

☐ *Home Care, Respite* –Home health agencies, companion and homemaker organizations provide companionship, supervision, personal care, nursing care and therapies in the home. Overnight respite can be provided in the home or a residential setting such an assisted living facility or a nursing home.

☐ *Hospice Care* – available for those with end stage Alzheimer's disease either at home or in a facility.

Notes: ______________________________

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Adapted in part from Community Care Options Fact Sheet, National Family Caregiver Alliance, www.caregiver.org.