

Understanding and Caring for the Person with Dementia

A Practical Guide for Caregivers



SIXTY PLUS SERVICES

 **Piedmont**
HEALTHCARE

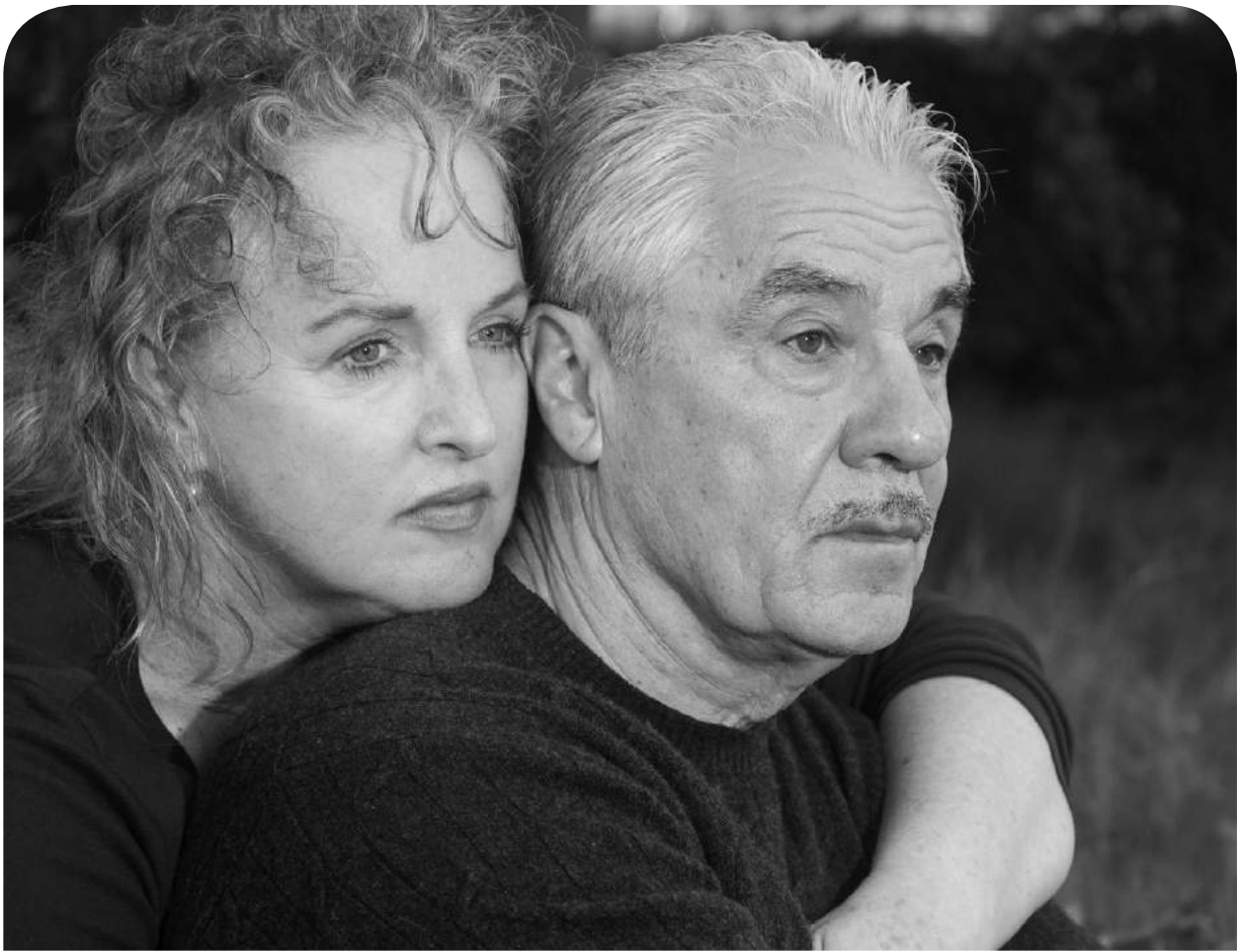
SIXTY PLUS SERVICES

Sixty Plus Services provides support, education and evaluation to enhance the well-being of older adults and their families. Piedmont Atlanta Hospital established this program in 1987 to address the unique needs of geriatric patients and their family caregivers. Piedmont continues to recognize the importance of providing comprehensive geriatric services and support for the community. Services include:

- Aging Information Helpline
- Caregiver Resources
- Comprehensive Geriatric Social Work
- Dementia Support, Education, and Evaluation Program
- Guidance Through the Insurance Maze
- Care Transitions

TABLE OF CONTENTS

Introduction.....	4
Disease Overview.....	5
Caregiving Tips and Techniques.....	10
Managing Daily Activities.....	13
Understanding and Managing Behaviors.....	20
How Dementia Impacts the Family.....	25
Caring for the Caregiver.....	28
Legal and Financial Issues.....	29
Hospitalization and Transition Back Home.....	32
End-of-Life Care.....	34
Spiritual Care.....	36
Acknowledgements.....	Inside Back Cover



INTRODUCTION

Understanding and Caring for the Person with Dementia: A Practical Guide for Caregivers is written primarily for family members caring for a loved one. It is also useful for training staff and volunteers who provide care in nursing homes, hospitals, adult day centers, assisted living facilities and private homes. The basic caregiving techniques are similar, regardless of the setting.

Information has been gathered from many sources, including current publications, websites, lectures and seminars, and real-life caregiving experiences. The guide is comprehensive and includes practical tips to help in the day-to-day care of the person with the disease.

The first chapter provides definitions and an overview of dementia. While most older adults with dementia have the Alzheimer's type, others have dementia from different causes. This chapter also describes the stages of dementia, along with suggestions for working with physicians.

Chapter 2 offers practical caregiving tips including suggestions for communicating with the person with dementia. Chapters 3 and 4 focus on daily activities and managing behavioral problems.

Chapter 5 addresses the impact of dementia on the family and provides information to help caregivers cope with the emotional issues they may face. Chapter 6 discusses the importance of caring for the caregiver.

Legal and financial issues are covered in Chapter 7. Chapter 8 explains what can happen during hospitalization, and the importance of having a good discharge plan back to the home.

The guide concludes with information about end-of-life care and spiritual care in Chapters 9 and 10.

DISEASE OVERVIEW

What Is Dementia?

Dementia is a syndrome characterized by a gradual onset and continuing decline in a previously alert person, resulting in impaired ability to perform daily activities. The decline most often affects memory and at least one of the following domains of cognitive function: language, perception, vision and space perception, calculation, judgment, abstraction and problem solving. Caring for someone with dementia requires flexibility, problem solving, some trial and error, and a great amount of creativity and patience.

Definitions

- **Cognition** – Refers to mental processes like thinking, understanding, remembering, judging and problem solving. “Cognitive decline” suggests an impairment in any of these processes.
- **Memory loss or forgetfulness** – Many people experience some mild memory problems or forgetfulness, having temporary difficulty recalling someone’s name or where an item was left. This often occurs with normal aging. The memory lapse is brief, and the information can usually be recalled. This kind of forgetfulness does not worsen over time and does not seriously interfere with daily functioning. The vast majority of older adults retain their ability to learn, remember and solve problems. Problems with memory can have many causes, including infection, reaction to medications, depression and vitamin deficiency. Profound memory loss is never a normal part of aging.

- **Mild cognitive impairment** – This is a distinct medical condition which causes problems learning new material, trouble recalling previously learned information and increased incidence of forgetfulness. People with mild cognitive impairment do not necessarily develop Alzheimer’s disease, but they are at increased risk for it.
- **Dementia** – This is an umbrella term referring to the loss of intellectual function and progressive cognitive decline. There are many different causes. Some dementias are reversible; most are not (see list below).
- **Senility** – An obsolete term used to describe mental weakness associated with old age. This term is no longer used and has no medical meaning.

Common Causes of Progressive Dementia

- **Alzheimer’s disease** – This is the most common cause of dementia. It is characterized by tangles and plaques in the brain. It cannot be diagnosed with certainty until autopsy, but the presentation of symptoms follow a typical pattern, leading to the diagnosis. Memory loss is the most common feature; behavioral changes cover a broad spectrum, from apathy and social withdrawal to paranoia, combativeness and extreme agitation.
- **Vascular dementia** – Also known as multi-infarct dementia, this disease is caused by the blockage or narrowing of the arteries, or stroke, which results in the interruption of blood flow to the brain. Usually the onset is abrupt, with a step-wise decline. History of stroke or Transient Ischemia Attack (TIA), a temporary decrease in blood supply to the brain, is common.

- **Parkinson's disease** – Many people with Parkinson's will never get dementia, but some will develop it in the later stages of the disease. The primary symptom of Parkinson's disease is impaired motor function.
- **Lewy Body dementia** – This condition is characterized by cognitive decline as well as motor impairments which resemble those present in Parkinson's disease. Lewy Body dementia is caused by widespread protein deposits in deteriorating nerve cells in the brain. Early symptoms tend to fluctuate, but the dementia progresses rapidly. Hallucinations, delusions and paranoia are common.
- **Frontotemporal dementia** – Also known as frontotemporal lobar degeneration, this diagnosis represents a group of diseases that affect the frontal and temporal lobes of the brain. Onset is often under age 65. Changes in mood and behavior are more pronounced than memory loss.
- **Aids dementia complex** – A rapidly progressing form of dementia which typically occurs after years of HIV infection.
- **Normal pressure hydrocephalus** – This is a type of “fluid on the brain” which can result in abnormal gait, incontinence and memory loss. However, if there is early diagnosis and treatment, these symptoms can be reversed.
- **Chronic Traumatic Encephalopathy (CTE)** – Associated with repeated head trauma, often due to athletic injuries, this type of dementia has only recently been identified as a distinct disease. Symptoms can include depression, memory loss, and aggression.
- **Alcohol related dementia** – Long term, excessive use of alcohol can affect the brain as a neurotoxin. Mental confusion and memory loss are the most pronounced symptoms.

- **Mixed type dementia** – It's possible to have multiple causes of dementia at the same time. Brain autopsies of demented patients show that many have evidence of multiple causes, such as Alzheimer's, vascular dementia and Lewy Body dementia.

Diagnosis of Dementia

With so many causes of dementia, the first step is to have an evaluation and diagnosis by a physician. Basically, diagnosis of dementia is made by:

- The exclusion of other medical problems, and
- The presence of progressively worsening memory, judgment and cognitive deficits.

The diagnostic process usually includes a thorough medical and neurological evaluation. Internists will often assess and diagnose, but family caregivers may wish to have a specialist physician take on this role. Geriatric psychiatrists and neurologists commonly see many demented patients. In addition, the patient can be seen for extensive testing by a neuropsychologist who will then work with medical doctors to decide upon the most appropriate treatments.

Presently there is no laboratory test to diagnose Alzheimer's disease, but with other types of dementia existing tests are more conclusive. Frequently, family caregivers are questioned at length about the behavioral changes they have observed before the diagnosis is made.

Usually the diagnosing physician will give the news to the patient. This should be done in the presence of family members and take into account the stage of dementia of the patient as well as the individual's personality. The explanation of the disease should match

the person's current ability to understand new information. When presenting this information, simple and non-threatening language should be used, and the focus should be on the person's areas of competence, rather than deficits.

A dementia diagnosis can be very difficult for family caregivers. They may experience a sense of mourning and grief, similar to news of a death. But they need this information as soon as possible so that they can begin to plan for the future.

Routine follow-up with the person's physician is important for health maintenance and treatment supervision. The physician can help the patient and family adjust to changing behaviors and learn about what to anticipate as the disease progresses. Geriatric social workers at Sixty Plus can also provide education and support.

Stages of Dementia

The symptoms displayed with progressive dementia may vary in severity and order of appearance. There is a fluctuation of abilities for the person with dementia, often depending upon the time of day. Some days will seem much better, making family caregivers wonder if the diagnosis is correct – only to be followed by days in which the person is much worse.

Most people with dementia will generally decline over time, passing through the following stages:

- **Early/mild dementia** – In the beginning there is a slow functional decline resulting in problems with recent memory, judgment, reasoning, planning and minor problems in conversation. People in this stage are unable to organize or plan for

future events regarding household maintenance, cooking, money management, filling prescriptions and using the telephone. Getting lost, even in familiar places, is common. Families will notice that some bills aren't getting paid, and birthdays are forgotten. But the ability to perform the usual activities of daily living, like bathing, dressing, toileting and eating remains intact. Explanations of medical issues and treatments are not well comprehended. Social skills are still good, causing others to question whether there really is a problem. People at this stage respond to visual cues and can remember a series of actions.

- **Moderate dementia** – Memory, judgment, insight, reasoning and planning are very clearly impaired in this stage. The person will have trouble with familiar tasks. Grooming often declines, and using the bathroom independently is inconsistent. At this stage, the person is unable to comprehend his own safety needs. Falls become more frequent as the person doesn't recognize the risk of slippery floors or obstacles in the way. Strangers are welcomed into the home. Fraudulent telemarketers can easily take advantage of the person. Language problems increase, with word finding as well as understanding what others are saying. Suspiciousness and paranoid delusions may become frequent. There is no new learning at this stage. Social appropriateness declines, and the person may dress or apply make-up in odd or flamboyant ways. In addition, tactless comments to others can be frequent, because the person has lost his social "filters." As the person passes through this stage, generalized confusion becomes more obvious. Actions can be performed in response to physical cues, and the per-

son may repeat the action many times. Wandering away and getting lost becomes more common. There is minimal ability to use the telephone. It is dangerous for the person to live alone.

- **Severe dementia** – In this stage, people are totally dependent upon others. They usually have bowel and bladder incontinence. The ability to walk may be impaired, and there may be difficulty chewing and swallowing. Self feeding becomes very slow. People lose weight because their nutritional status declines. Weight loss leads to physical weakness and more frequent falls. They may become easily distressed with some tasks and may resist care. Showering can be frightening, so keeping the person clean becomes more challenging. People with severe dementia become less mobile which makes them more prone to pressure sores and infections.
- **End-stage dementia** – Eventually all body-systems will be affected. People in this stage no longer walk and speech becomes unintelligible. They are bedbound and resist swallowing food, which they will often pocket in their cheeks. At this juncture most family caregivers seek hospice care for their loved one.

Medications

While current medications cannot stop or reverse the disease process, some medications may slow or lessen the symptoms. Dementia medications fall into four broad general categories:

1. **Memory Enhancers:** Aricept, Namenda, Exelon (pill or patch) and Razadyne are commonly prescribed. These drugs influence certain brain neurotransmitters, like serotonin and dopamine. They are most effective the earlier they are prescribed in

the disease process.

2. **Antidepressants:** The basic functions of these medications is to lift the person's mood and to encourage greater focus on the surrounding environment.
3. **Antipsychotics:** These medications reverse or reduce psychotic behaviors like auditory and visual hallucinations, as well as delusions (fixed false beliefs). There are older antipsychotics, such as Haldol, and newer medications that are known as atypical antipsychotics, like Seroquel, Zyprexa, and Risperdal.
4. **Complementary or Alternative Treatments:** There are many nonprescription medications, herbs, and natural formulas that are marketed to improve memory and attention. Before trying any new therapies, consult your health care professional to learn about any potential risks or side effects with your current prescribed medications.
- **Ginkgo:** Supplements from this plant are linked to improving the blood flow to the brain. Studies have found that in some people, ginkgo may modestly boost memory and cognitive speed. Several studies have shown that ginkgo can help with memory problems caused by dementia, especially vascular dementia. Ginkgo is also a natural blood-thinner and therefore should be used with extreme caution with medical anti-coagulation therapy.
- **Ginseng:** Supplements are made from the root of the plant and have been called the "king of all herbs." Asian ginseng is widely used throughout the world to improve memory, boost immunity, build strength, and improve overall health. Let your health care professional know if you're taking it as it can cause changes in blood sugar and blood pressure.

- **St. John's Wort:** The extract of the fresh or dried tops of these yellow flowers is made into supplements which can help with depression or mild anxiety.
- **Valerian:** Supplements are made from the root of this plant. Valerian has been used as a safe alternative to prescribed medications for insomnia, restlessness, and other sleep problems.
- **Rosemary and Lavender:** Two wonderfully aromatic herbs with essential oils that are associated with enhanced mental focus and clarity.

General Considerations with Medications

- Medications are generally thought of as safe, as long as they are taken as prescribed by healthcare professionals. Someone with dementia may have lost the ability to correctly dose themselves; therefore, the caregiver needs to assume the responsibility of medication management. Much depends on the person's stage of dementia. A simple pill box may be all that is needed to ensure that someone with mild dementia gets the right medication at the right time, on the right day. However, if the person has more advanced dementia, he or she could potentially underdose or overdose on harmful drugs. Caregivers need to make sure that all medications are secured and unavailable to the person. They must ensure that all medications are taken correctly. All expired or discontinued medications should be safely discarded. You can call your local pharmacy to ask when and where to bring old medications. Please do not flush them down the toilets into our water system – they're not necessarily environmentally friendly.

- Become as knowledgeable as possible about the medications the person is taking. An informed caregiver is the doctor's best resource. Keep a current medication log for the healthcare team to review. This is especially important when a new medication or different dose of a current medication is started. Jot down any new or different behaviors you're observing.
- Ask questions. Whether it's the doctor, nurse, pharmacist or other healthcare professional, ask clarifying questions so you understand why the medication has been ordered, what positive effects you hope to see, and which negative side effects to watch for.

Basic Rules of Medications for Dementia

1. SAFETY FIRST
2. Start low (dose), go slow, but get there
3. Keep medications as simple as possible
4. Write out instructions clearly
5. Bring ALL medications to EACH doctor appointment
6. Use only one consistent pharmacy
7. Ask before you crush, dissolve, refrigerate, or store medications
8. SAFETY FIRST

And finally, a note about the cost of medications. Many medications are expensive, particularly for people with dementia who often take multiple prescriptions for their various symptoms. They may also have other chronic health problems for which they are taking medication. Make sure that the person you're caring for has prescription drug coverage through Medicare Part D or a similar insurance plan.

CAREGIVING TIPS & TECHNIQUES

Having a loved one with dementia can be overwhelming. The day-to-day problems often seem the most distressing. The disease slowly destroys the person's ability to think, remember events, concentrate, control impulses and make judgments about the activities of daily living. The loss of these abilities creates perplexing behavior which is difficult for others to understand.

The impact of the disease cannot be minimized. Due to the progressive loss of intellect and the resulting confusion about reality, the person with dementia may become increasingly fearful and insecure. This leads to withdrawal into still-familiar and comfortable settings and routines. Individuals with dementia become dependent on their caregivers as anchors and guides in a challenging world.

Many people with dementia don't realize that they are forgetful. As a result, they may deny recent actions or behavior and become angry when confronted. In some people, the recognition of their losses leads to depression, especially in the earlier stages of dementia.

This behavior can be better understood with knowledge of the disease process. Often, it can be controlled through special care techniques. The use of simple communication tips will improve the quality of life for those with dementia and others around them.

Basic Principles for Understanding Dementia

- People with dementia function best in a calm environment with familiar, simplified routines of daily living and without the burden of making choices.

- Those affected by dementia are adults and therefore should be treated with respect and dignity, even if their behavior seems childlike.
- Not everyone with dementia will exhibit all of the symptoms associated with their particular disease, whether it's Alzheimer's, Lewy Body, vascular, frontotemporal or another type of dementia. Moreover, not every person will experience the disease the same way as others who have it. The course of the disease and the rate of decline will vary greatly from one person to another.
- People with dementia experience reality differently than unaffected people. Arguing will not change that reality. Constant corrections to try to bring the person back to reality won't work. People who have severe memory loss may become agitated if they feel they're always being told they're wrong. It's better for the caregiver to practice reminiscence. Remembering and discussing meaningful events of the past can promote closer communication and lift the person's self esteem.
- Many caregivers find it helpful to enter the reality of those with dementia, no matter how bizarre it may seem. For example, if the person with dementia insists his son is his father, the son can go along with the misperception and try to have a pleasant, reassuring conversation.
- Creativity and flexibility are necessary in the caring process. If one approach does not work, be ready to try another. Techniques can be recycled over time.
- The person with dementia becomes more dependent as the disease progresses, requiring increasing supervision. The caregiver needs to compensate more and more for the loss of skills.
- Each task and activity should be simplified as much as possible, broken down into

small steps. The person should be encouraged to take each task one step at a time, with steady reassurance and help from the caregiver.

- Most people with dementia are not stubborn, mean, suspicious or ungrateful on purpose, nor can they be taught to remember recent events or moral lessons. The disease causes the troublesome behavior; the person is not being intentionally difficult.
- Don't talk about the person as if he isn't there. Don't laugh at inappropriate behavior or speech.
- Even though dementia makes people forget and lose their capacity to understand what is being said, they still notice the emotional responses of those who are caring for them. They can be frightened and hurt by anger or impatience. Similarly, they respond well to calmness, reassurance and patience.
- Caregivers should set realistic expectations for themselves and for the person with dementia.

Ethical Lying

Although it may be hard for family members to actively lie to a loved one, ethical lying, also known as therapeutic lying, is an essential skill to develop. Dementia patients need to be kept safe, and they need to be closely monitored for all of their activities of daily living. This often requires being less than truthful in order to accomplish a task that needs to get done. In many circumstances, it's also kinder to ethically lie than to be completely honest. For example, reminding someone that a deceased loved one has died can continually make the person upset and sad.

Ethical lying can also help to ease difficult situations such as when the patient needs to stop driving. Having the car "disappear"

and suggesting the car may have been stolen can be a more compassionate way to handle what is almost always a devastating loss for the patient. This way, too, the caregiver stays on the side of the patient without becoming the one who is taking away the right to drive.

Communication Tips

- **Speak slowly and clearly.** Don't expect a quick response. Use short sentences and simple messages, and give the person time to process the information.
- **Present one idea at a time.** Don't try to give too much information in one sentence.
- **Understand that the person with dementia may say one word and mean another.** You may have to guess at the correct meaning, but try to clarify your guess with the person – you could be wrong.
- **Don't approach from behind and startle the person.**
- **Stand in front or in the direct line of the person's vision.** Touch his arm or shoulder gently to get or keep attention. Maintain eye contact.
- People with dementia can be sensitive to nonverbal communication. The tone of your voice and your facial expression are as important as the actual words. **Use a normal tone of voice in a calm manner.**
- **Use gestures and visual cues or aids to convey your messages.** Try using more than one of the senses to communicate, such as touching as well as talking. Do not use gestures that threaten the person.
- Whenever possible, **avoid questions that put the person on the spot**, such as quizzing about names of family members. Avoid "why" questions. Not knowing the answers embarrasses the person. Gently cueing with necessary information is usually more helpful and much kinder.

- It's extremely important to **avoid letting the person with dementia make important decisions that affect other people.** Matters that concern money, living arrangements, and hired help should never be decided by someone with dementia.
- Remember that the person with dementia is losing the ability to judge between safe and unsafe conditions. Evaluate each situation and **do not allow the person to be in a potentially dangerous situation.**
- **Create a safe home environment.** Remove all hazards and obtain equipment, alarms and other safeguards that will help the person.
- **Simplify everything** – the environment, tasks, conversation and routines. Eliminate distracting noises and activities as much as possible. Remember that change can be upsetting.
- **Encourage the person to be as independent as possible,** depending upon the stage of dementia. For example, the person may be able to dress alone if the clothes are laid out in the right order.
- **Use distraction.** A temporary change of subject often solves the problem and directs the person's attention away from the undesirable behavior. The person's forgetfulness may work in your favor.
- **Demonstrate by modeling correct methods** for those with more severe dementia. For example, show the motions of brushing teeth when it's time for this daily task. Or at mealtime, demonstrate eating motions.
- **Join in the person's specific reality.** Often, people with dementia are unable to live in the present. They feel safer talking about the past, and sometimes they believe they are living in the distant past. Go with wherever they are.
- **Don't accuse the person of lying.** Sometimes people with dementia will confabulate, meaning that they will fill in the gaps in their memories with fabrications that they believe are completely true. When you suspect that this is happening, relate to the underlying feeling that the person is expressing, whether it's happiness, fear, frustration, etc.
- **Don't be upset if the person makes unkind remarks** about you or is tactless and offensive. This can be very hard for caregivers, but it's important to try to step back and realize that dementia causes the person to misjudge situations and imagine things that aren't true.
- Similarly, the person may make offensive statements to strangers when out in public. It's helpful in these situations to discreetly **hand a card to the offended stranger** which states "Please forgive this gentleman. He has dementia and is not always in control of his behavior." People understand once they know about the dementia; chances are, they're also dealing with it in their own families.
- People with dementia lose the ability to keep track of time. This often makes them anxious. They might feel deserted when only a few minutes have elapsed, so **reassure as much as possible.**
- **Encourage the person to participate in activities which are pleasurable,** with little or no chance for frustration. Keep in mind, though, that people with dementia often have a short attention span. Problems in daily living may seem very challenging for family caregivers. The most common difficulties arise in the following areas.

MANAGING DAILY ACTIVITIES

The Home Environment

Because people with dementia are unable to make sound judgments and decisions about potential danger, it's essential to create a simple, safe and familiar environment for them. Make a thorough inspection of all areas of the home, including the surrounding yard and neighborhood, to identify possible hazards. Pay special attention to the proximity of busy streets and traffic patterns.

- Reduce clutter.
- Keep furniture in the same place; don't rearrange.
- Clear common pathways.
- Lower the thermostat on the water heater.
- Place gates or barriers at all stairways.
- Secure or remove potentially dangerous items. Many people with dementia live in homes that have guns. These must be removed for the safety of everyone.
- Hide a spare key outside the house.
- Use a very large key ring to identify keys easily.
- Supervise smoking.
- Place a lock at the bottom of the door, near the floor.
- Use night lights.
- Place locks on all the windows or use child-proof door knobs.
- Remove control knobs from the stove.
- If the person with dementia has a routine cocktail time, continue the routine but do not make real cocktails. Use the same glasses, ice, cherries etc., but use apple juice or ginger ale instead of spirits, or non-alcoholic beer or wine. Put the fake beverage into a real whiskey or wine bottle to complete the subterfuge. However, if the person has been a heavy drinker, the introduction of non-alcoholic beverages

should take place gradually, to wean the person off of the amount of alcohol they had been accustomed to drinking. It's best to take this step with advice from the person's physician. Sudden withdrawal of alcohol from a heavy drinker could result in serious health problems.

Bathing

It's common for persons with dementia to refuse to bathe. They may be afraid of the water coming hard and fast out of the showerhead, or they may resist the invasion of privacy that comes with bathing in front of a caregiver. Often they believe that they've showered already, so it's preposterous to think they have to shower again. Caregivers need to be especially creative to accomplish this task.

- Try to follow the person's previous routines. Consider the time of day and type of bathing that was preferred – showers, baths, sponge bathing, etc.
- Have everything ready before starting.
- Do one step at a time, talking through each step.
- Be calm and gentle; don't rush and hurry.
- Avoid discussing whether a bath is needed.
- Use only a few inches of water in a bath, or a fine, gentle warm spray in the shower.
- Always check the temperature of the water.
- Avoid bath oils or anything that may make the tub surface slippery.
- Use safety devices like grab bars, tub seats, and rubber mats. Using a seat and a hand-held shower attachment, to gently hose and rinse, can be less frightening for the person. Introduce the warm shower water gradually, starting at the feet and moving up the body.
- If the person seems unsteady, use an easily grabbed belt around the waist to quickly fend off a fall.
- Remove locks from the bathroom door.

- Don't leave hair dryers, electric razors, etc., within reach.
- Check for skin rashes and sores while bathing the person.
- Showering with the person may be a solution. Wear bathing suits if appropriate.
- If the person has always washed hair in the shower, try to keep up this routine. For women who have always gone to a salon for shampoos, try to maintain these outings for as long as possible. If it becomes too difficult to go to the salon, arrange for a hairdresser to come to the home.
- Use body lotion on dry skin. This can be a very relaxing experience for the person with dementia, sort of like getting a massage.
- To avoid agitation, if the person adamantly refuses to bathe, wait and try again later. One good bath or shower per week is usually fine; just make sure to monitor the skin for problems, especially if the person is incontinent.

Oral Hygiene

Tooth brushing is often avoided by people with dementia. They resist doing it, and they don't want anyone to try to do it for them. One solution is to use toothettes for effective oral hygiene of teeth and gums. Use with a diluted hydrogen peroxide solution. If the person fights this, stop for a while and try to resume later. If the person consistently refuses to cooperate with oral care, fresh fruit, such as apples, can aid in cleaning teeth. Mouthwashes in small amounts may also be helpful.

Regular dental examinations are as important for the person with dementia as they are for anyone. Consider going to a dentist who specializes in treating those with memory loss. Sixty Plus Services can recommend such practices.

Meals and Nutrition

It can be hard to make sure that someone with dementia is eating a well-balanced diet. The disease makes people unable to recognize the sensations of hunger and thirst. What is a favorite food one day may be avoided the next. People will rarely say that they are hungry; yet if food is put in front of them, they'll eat every bite. Sometimes sweet foods are craved, and the demented person will only want candies or cookies. At other times inappropriate items may be eaten, such as soap or other household items. Monitoring what the person eats and drinks can be time consuming, but it's one of the most important aspects of caregiving. Proper nutrition reduces the risk of constipation, dehydration, and vitamin deficiency. These conditions contribute to increased confusion and a decline in physical functioning, so they must be avoided as much as possible.

Consulting with a nutritionist can be helpful in planning balanced, creative meals. The nutritionist can often make suggestions, such as adjusting the thickness and consistency of liquids to be served.

Evaluation by a speech pathologist is indicated when the person begins to have trouble swallowing.

- Avoid trying to convince the person that a meal has been eaten.
- For those with more advanced dementia, use simple, one-step instructions, such as "Pick up the fork," "Put the food on it," and "Raise the fork to your mouth."
- Limit the number of food choices the person has to make.
- Put only one utensil and only one food in front of the person at a time.
- Serving finger foods is easier and less messy.

- Encourage the person to sit up in a comfortable position.
- If the person has trouble chewing or has poor fitting dentures, grind or cut the food into very small pieces. Serve foods with a soft consistency, such as applesauce, cottage cheese or eggs.
- Beware of the temperature of food that's served; demented people lose the ability to sense hot or cold and could burn their mouths.
- Fill glasses only half-full, but encourage frequent fluid intake.
- Remind the person to eat slowly.
- Suggest frequently that each bite be chewed thoroughly.
- You may need to remind the person to swallow the food.
- Try to serve favorite foods for a greater incentive to eat.
- Avoid placing condiments on the table until requested as they may be used inappropriately.
- To reduce confusion, use a plain plate with no design.
- Use a bendable straw if the person has trouble drinking.
- For someone who has trouble using regular utensils, experiment with adaptive devices like curved spoons, sectioned plates and non-skid surfaces.
- Secure all items that look like food such as dog biscuits, flower bulbs, artificial flowers, etc., so that they aren't eaten by mistake.
- If the person only wants to eat sweet foods, sprinkle vegetables, meat, fish and other savory items with sugar or sugar substitute.

Dressing and Grooming

The self-esteem of the person with dementia is still very important. Past grooming habits should be considered as caregivers help their loved ones get ready for the day. Try

to maintain hairstyles, beards, and make-up the way that the person liked to appear before dementia developed. Social customs should also be respected.

- Encourage maximum dressing and grooming independence for as long as possible.
- Don't rush or hurry the task.
- To reduce choice, remove clothes that are seldom worn from the closet.
- Use simple garments with large zipper pulls, few buttons or Velcro fasteners.
- Use cardigan sweaters instead of pullovers. Sweat suits can simplify dressing.
- Be sure clothes are not too long or full as they may become a tripping hazard.
- Lay clothes out in the order in which they should be put on.
- If necessary, use constant repetition to remind the person of the next step.
- Use nonskid shoes, such as washable rubber-soled shoes with Velcro fasteners, or slip-on shoes.

Toileting and Incontinence

Dementia will eventually cause the person to become incontinent. The ability to recognize or respond to the body's urges is lost. People also forget where the bathroom is located, even if they've been in the same house for years. They also forget what to do when they can find the bathroom.

Family members and other caregivers may feel awkward or embarrassed when assisting with toileting. This is normal, and it usually subsides over time.

A matter-of-fact, calm, and reassuring manner with the person with dementia is the best approach.

- Post a colorful sign on the bathroom door to help the person identify the room.
- Set a regular schedule for using the bathroom.

- Monitor mealtimes and foods consumed so that you can predict when it's time to use the bathroom.
- Watch for restless behavior, which may be a signal that the person needs to use the bathroom.
- Respect the person's privacy as much as possible.
- Assist with removing or adjusting clothing as necessary.
- Help the person get in the right position, if needed.
- Give cues if the person doesn't know what to do.
- Talk through each step.
- If you take the person to a public restroom, go together – don't let the person enter the restroom alone. If you're a female caregiver with a demented gentleman, use the ladies room and if necessary hand out cards to startled strangers stating that the person has dementia. Do the opposite if you're a man caring for a woman. Many places now have "gender-free" handicapped bathrooms, so use them as well.

When a confused person suddenly loses bowel or bladder control, this should be evaluated by a physician. Possible causes may be a urinary tract or other infection, dehydration, side effects of medications, prostate problems or another medical condition.

Suggestions for Incontinence

- Avoid using laxatives but encourage a high-fiber diet.
- Restrict fluid intake two hours before bedtime.
- Use incontinence aids such as disposable briefs and pads for beds and chairs, or condom catheters for men at night.
- Dress the person in manageable clothing and consider eliminating underwear.

- Be sure to clean the person properly, using a wash cloth or baby wipes to avoid skin irritations.

Exercise and Leisure Activities

Walking provides good exercise and may relieve tension and stress in people with dementia. It may also help to increase the person's appetite. Simple exercises that encourage a range of motion in the arms and upper body can help maintain optimal muscle functioning.

The confused person has a short attention span and may become easily frustrated when faced with multiple-step tasks or activities. Keep things simple. Gardening, painting with water colors or finger paints, drawing, or coloring with chalk or crayons are good ways for confused people to express themselves. Large, colored wooden beads or blocks strung on to rope can be another good activity.

Research shows that activities done in the past can still resonate with an older person who has advancing dementia. Retired business executives may like to sit at a desk with a phone (better to have it disconnected), with files filled with paper. An old keyboard and computer screen may be interesting to the demented person who was internet-savvy. Older women who spent years as homemakers may enjoy baby dolls in cribs, or domestic activities like folding laundry or sweeping.

Musical activities are usually very successful with individuals with dementia, whether they are making the music themselves or just listening. Music can help them to recall pleasurable moments from the past. They frequently remember the words to songs learned in childhood. Dance music from their youth

might encourage them to jitterbug, waltz or twist around the room. Many people even in advanced dementia can still sit at a piano to play a favorite hymn. Quiet, familiar music in the background is often soothing and calming.

Books, newspapers, and magazine articles can serve as cues for reminiscence and a great springboard for family conversation in which the demented person may still participate. Certain television programs can be of great interest, whether they're classic movies, historical shows, or even cartoons. Animal programs are often much beloved by those with dementia.

- Rocking chairs can be calming, but make sure they don't cause the person to become unsteady or fall as they get up.
- Encourage dancing.
- Have the person participate in household chores, such as folding towels, raking leaves, or sorting objects.
- Some TV shows can be upsetting to someone with dementia, particularly violent, suspenseful, or horror shows. Remember that the person can no longer sort out what's real and what's fiction. News stories can also be alarming, so caregivers need to closely scrutinize what's being watched.
- Leaf through family photo albums to encourage past memories.
- Keep activities on an adult level, though children's toys can be usefully adapted in the later stages of dementia.
- Family members can team up with the person to play familiar games – cards, bingo, board games, etc.
- Having a special place in the garden for digging and working with plants and flowers can be very enjoyable for both the person with dementia and the caregiver.
- “Therapeutic biographies” use home videos that focus on old photographs that are mean-

ingful to the person with dementia. Family members provide commentary about the people and places in the photos. The videos can then be shown over and over to the person with dementia.

- Many people regularly attend adult day programs specifically for those with dementia. Although it's common for them to resist initially, they eventually like the new routine and social activities. This also provides a consistent time for caregivers to get a break.
- Some people will hallucinate and imagine that deceased family members are visiting them. They will have forgotten that these loved ones have died. The hallucinations usually are quite comforting and pleasurable for the person with dementia and actually improve the quality of life. To encourage this experience, it's helpful to make life-size photos of the deceased and hang them in the person's bedroom.

Sleeping

Sleep disturbances are common and may be responses to dreams, inadequate exercise, strenuous activity, dozing during the day, confusing night with day, or getting lost at night on the way to the bathroom.

- Give the person a snack and play some quiet music.
- Try a backrub for a relaxing effect.
- Make sure the person uses the bathroom before going to bed.
- Put reflective tape around the bathroom door.
- Use blackout shades.
- See that the person gets sufficient exercise during the day – but not too much.
- If nothing else works, try medication recommended by the physician.

Driving

Driving is a complex task that requires the ability to make and execute split-second decisions. Dementia affects a person's ability to process many different pieces of information at the same time. Driving and dementia don't mix.

Some states have strict laws, requiring doctors to contact the Department of Motor Vehicles whenever someone is diagnosed with dementia. This is not the case in Georgia. Generally in this state it falls to families to ensure that someone stops driving.

Very often families refuse to stop the person from driving because they know it will cause much distress. Driving is equated with independence, and it is terribly hard to give up. In addition, more responsibility falls on the family when someone can't drive. This means time taken from work to get to a doctor's appointment, help with grocery shopping, pick up medications, etc.

Nevertheless, when someone has dementia, driving creates too much risk. People get lost, even in neighborhoods where they've lived for many years. They can go missing, driving miles and miles away until the police find them while their families are terrified back home. And in the worst case scenarios, demented drivers cause accidents in which they injure or kill themselves or others.

Poor driving: warning signs

- Getting lost in familiar areas
- Not observing traffic signs
- Making slow or poor decisions in traffic
- Driving either too slow or too fast
- Getting angry or confused while driving
- Swerving into wrong lanes

- Having a history of car accidents, from fender-benders to more serious incidents
- Confusing the gas and brake pedals
- Hitting curbs
- Incorrect signaling
- Riding the brake
- Poor judgment about distance, particularly making left turns

When caregivers need to take away the car keys, it needs to be done as sensitively, but firmly, as possible. Most individuals with dementia don't understand why they can't drive. They're likely to become furious. They need reassurance that they won't be left isolated and that other forms of transportation will be available to them. It can be helpful for the family to "blame" a health care professional for the decision so that they don't have to be the bad guys; some doctors will work with the family and be willing to take the responsibility for insisting that the person stop driving.

It's usually best to completely remove the person's car once they get a diagnosis of dementia. If it is kept at the home, at the very least the vehicle should be permanently disabled. All car keys need to disappear.

Doctor-Recommended Driving Assessment Programs

If you feel that your loved one is still driving well, in spite of the dementia, err on the side of caution and get confirmation by a professional. A hospital-based driving assessment program is the best source for this type of evaluation. A doctor's order is needed to begin the process. The assessment is performed by an occupational therapist with special expertise in driving rehabilitation. In-office tests are administered to gauge the

person's reaction time, hearing, vision, and recall; if these tests are passed, then the person is taken out for a driving test in a specially equipped car. The person is then told whether he is safe to drive under all circumstances, safe to drive with specified restrictions, or not safe to drive at all. This test can be partially billed to Medicare, but usually results in a substantial self-paid charge. Call the Sixty Plus Helpline if you would like more information about local driving assessment programs. Even if someone with early dementia passes a driving assessment, continued driving will have to be very closely monitored, as the dementia progresses.

UNDERSTANDING & MANAGING BEHAVIORS

As dementia progresses, the affected person continues to become more dependent upon family caregivers. The ability to express one's needs is more and more impaired, causing much frustration and confusion. This may result in behaviors that seem intentionally difficult or mean-spirited. But the person with dementia has no control of them, and in fact they are a normal part of the dementia process. Not everyone with dementia has such difficult behaviors, but they are extremely common nevertheless.

All behavior has a purpose. It just may not be easily identified. Sudden behavior changes are often triggered by things that can be controlled.

Triggers for Difficult Behaviors

- **Fatigue** – People with dementia tire easily because it takes intense concentration to make sense of their world. They are using many coping skills to adapt to the illness and sort out everyday tasks.
 - Provide rest time in the morning and afternoon, either a nap or just a quiet period. This should be done in an easy chair or sofa, rather than the bed, so that they recognize it as a rest time and not the beginning of another day.
 - Avoid foods and drinks with caffeine.
 - Provide rest periods before and after a social activity or trip. Don't try to accomplish too much in one day. Plan in advance a place and time where the person can rest during a prolonged gathering or special occasion.

- Identify the time when the person functions best. Use this time for appointments or social engagements.
- Try to make all activities, including those done at home, short in duration.

- **Change** – Adjusting to change in any form is overwhelming to the person with dementia. It causes confusion and agitation due to the fear of a new, unfamiliar situation. Minimize change as much as possible.

- Do the same activities at the same time and place. The timing is not as important as the sequence of activities.
- Decline offers from others for special events that will be too disruptive.
- Be careful during holidays. Keep decorations simple so as not to change the look of the home. Long gatherings and crowds of people can produce frustration and anxiety. Simple festivities are better tolerated.
- During an outing, keep it short. If the person becomes restless and wants to go home, try to comply.
- Traveling with a person who has dementia can be very challenging. Think hard about whether it's worthwhile to include the person.
- Arranging for respite care while caregivers leave town may be a much better option. Airports, the confinement of airplanes, time changes, crowds, and different food all contribute to an escalation of confusion and stressful situations for everyone.
- Special occasions like weddings and graduations require extra planning. If you decide to include your person with dementia, it's usually best to make sure that a designated caregiver is there at all times, perhaps someone

who is hired for the event. Otherwise family members may not enjoy themselves and be free to celebrate.

- During a hospital stay, expect increased confusion and agitation. Try to arrange for someone familiar to stay with the person. Educate the hospital staff about behavior management strategies that help to reduce agitation in your loved one.
 - Have continuity in caregivers. Allow plenty of time for the person to become acquainted and build trust with any newcomer.
- **Illness** – The mental abilities of a person with dementia decrease with discomfort or acute illness. A sudden change in behavior or increase in confusion that does not go away with rest should be reported to the physician for evaluation. It could be the presenting symptom of an acute illness, rather than the natural progression of the dementia. A change in behavior may be the only signal of a physical problem such as pain, urinary tract infection, flu, medication reaction or serious constipation.
 - Make sure the person’s diet contains adequate fiber. The risk of constipation increases as the person becomes less active.
 - Urinary tract infections are common causes of agitation. Does the urine smell strong? Has the person been drinking adequate amounts of fluid? Is there sudden incontinence?
 - Have the physician or pharmacist review medication frequently, including all over-the-counter medications.
 - Avoid alcohol. Many people with dementia overreact to alcohol.
 - If the person unintentionally loses more than six pounds in six months,

this is a cause for concern and should be evaluated by the doctor. A consultation with a nutritionist may also be helpful.

- **Pain** – People with advancing dementia typically have trouble identifying and communicating pain and discomfort. Look for body language that could signal signs of pain, like facial grimace, change in posture or gait, falling, knees drawn up, rubbing or holding a body part, clenched fists, moaning, pacing or fidgeting, decline in interest in usual activities, combativeness and agitation, and problems with sleep.

Pain may be caused by an acute illness or a chronic condition that results in ongoing discomfort. Caregivers need to closely observe to try to figure out the cause of the pain. Sometimes less obvious causes, like ingrown toenails or toothache, can be the culprit. Severe pain is often treated with narcotic medications which are effective, but often accompanied by troublesome side effects. Constipation is common, as are sluggishness, dizziness, and an increased risk for falling. Consult closely with the doctor regarding any pain medication.

Hard-To-Manage Behaviors

Because people with dementia lose their ability to receive and interpret information, they will often display bizarre behavior which puzzles and frustrates their caregivers. Frequently they will “perseverate,” meaning that they will get stuck on a subject and ask about it constantly. Or they might become agitated, feeling anxious, restless, and easily provoked, all at the same time.

- **Repeated Questions** – Very often the questions asked are not really about the problem. Try to identify what the person is really worried about and offer reassurance.
 - Write the answer on an index card and have the person carry it around. When the person asks again, point to the card.
 - To avoid repetitive questions, don't announce anything more than 24 hours in advance.

- **Hiding and Hoarding** – Hiding things often represents a concern about theft. When the person can't find things, it might be assumed that they've been stolen. This can be a very frustrating aspect of dementia.
 - Remove valuables from easy access. Pack away larger items.
 - Place seldom used jewelry in a safety deposit box, or have a jeweler replace valuable stones with imitations.
 - Get to know the hiding places routinely used – typically under a mattress, in the pages of a book, under pillows, in food containers, in plastic bags, and in the freezer.
 - Lock closets, cupboards, and unused rooms.
 - Keep duplicates of important items such as glasses, important keys, and hearing aid batteries in a place that the person can't get to.
 - Check wastebaskets before emptying.

- **Sundowning** – Later in the day, as the sun goes down, many people with dementia become restless, more wakeful, and at times very agitated. Family caregivers frequently remark about this behavior and how especially difficult it is. As everyone else is getting ready to go to bed, the person with dementia is more active than ever.
 - Arrange the person's daily schedules so that few major activities take place in the evening. Try to create a calm, quiet and very predictable evening schedule.
 - Eliminate caffeine and alcohol later in the day.
 - Allow the person to pace. If possible, take an evening stroll which may help to tire the person.
 - If necessary, consider medication. It's essential for family caregivers to get their sleep at night, so the person with dementia must sleep, too.

- **Suspiciousness and Paranoia** – Dementia frequently results in a general feeling of insecurity. The world becomes a frightening place for the affected person, and so it's hard to trust anyone. Family members are often accused of dreadful things, potentially causing much shock and distress.
 - No matter how hurtful the person's behavior is, try not to argue or reason.
 - Don't confront or try to teach a lesson about the bad behavior.
 - Learn to respond calmly, not defensively. Remember that it's the disease talking, not your loved one.
 - If the suspicion centers on a missing item, offer to help find it.
 - Try not to whisper in front of the person.
 - Most people who are very suspicious are also very afraid, though they won't be able to verbalize their fear. Offer reassurance. Let them know that you understand they feel badly, and that you're there to help them and keep them safe.

- **Wandering** – This is a common and potentially dangerous behavior. The demented person who is physically agile can leave home quickly and get lost before anyone knows there’s a problem.

- If the person is becoming agitated or restless, try to distract to a more absorbing activity.
- Provide a safe area for wandering, such as a fenced-in yard.
- Obtain a Safe Return bracelet from the Alzheimer’s Association. This device, which cannot be removed once the person is wearing it, will alert police that the person has dementia and is away from home.
- Camouflage the home. Put posters on doors to discourage the person from going outside. Put a black mat in front of every door – people with advancing dementia avoid any area that looks like a black hole. Contact the Alzheimer’s Store, www.alzstore.com, for other clever suggestions to keep the person free from wandering.
- Use childproof doorknobs.
- Place locks on doors at the very top or at the very bottom. People with dementia will rarely look up or down to unlock a door.

- **Delusions and Hallucinations** – Delusions are fixed or persistent beliefs that in fact are not true, but to the person with dementia, they’re completely true. Hallucinations are anything experienced with the five senses that are not real. Most hallucinations are visual, but they can also be auditory, such as when someone is hearing voices, or olfactory, imagining a strong smell that doesn’t really exist. Delusions and hallucinations are both very common in people who have dementia.

In most cases, these behaviors can be effectively managed by reassuring and humoring the person with dementia. However, if the delusions or hallucinations become frightening and threatening, it’s best to consult with the physician about possible medications to keep them under control. Antipsychotic medication may be prescribed. These drugs are very strong and need to be monitored closely so that they don’t cause too much drowsiness, or unsteadiness leading to falls. Some antipsychotic medications have more serious side effects, like diabetes, another important consideration.

- Don’t try to argue or convince the person that the delusion or hallucination isn’t real. Accept what is being said. Correcting the person will only lead to greater agitation.
- If the delusion or hallucination is scary, reassure the person that you’re there to help. You’ll keep them safe.
- Reduce clutter and shadows. Have the person’s hearing and vision evaluated.
- You may be able to identify the specific cause of the delusion. For example, many demented people become frightened by mirrors. They don’t recognize themselves and presume that a stranger is in the house. Cover mirrors if you realize this is happening. Similarly, TV shows can be threatening. Keep them turned off when the person is awake.
- Some delusions and hallucinations are harmless or even pleasurable. If the person enjoys them, join in and discuss what’s happening.

- **Catastrophic Reactions** – Sometimes people with dementia have an intense emotional reaction to a minor problem. This can catch caregivers off guard – they may not be able to identify what triggers the behavior. Anything can cause a catastrophic reaction: illness, injury, constipation, a new caregiver, or even a time change. The person may cry inconsolably, shout, swear or become combative. Catastrophic reactions do not usually respond well to medication. The person needs gentle reassurance and calming attention from family members during these difficult moments.
- **Sexually Inappropriate Behavior** – It's quite common for people with dementia to become uninhibited. This is often the case with things that they say, blurting out comments that may be offensive to others. But demented people can also become sexually uninhibited and try to touch others around them. Lack of impulse control and the desire for soothing contact contribute to this behavior. This can create major problems within families and in social situations.

If you realize that your loved one is displaying overt sexual language or behavior, try to remain calm and analytical. You may be able to identify triggers and avoid future problems.
- Try to distract and redirect the person's attention.
- Be alert for any groin rash. Sometimes what appears to be self-stimulation is in fact a skin problem.
- Be sensible and practical with family members or friends who may be receiving unwanted attention. Help them understand that dementia is causing the behavior, but also let them know that it's OK if they choose not to be around the person.
- In public situations, discreetly hand out cards to offended strangers, explaining that the person has dementia.
- **Possible Need for Hospitalization** – Most of the time family caregivers are able to handle challenging behaviors with their own calm responses. Sometimes, too, the demented person will need medication, especially if agitation or paranoia becomes too intense. But extremely troublesome behavior may be best treated in a hospital environment, where the person can be closely observed and medicated until stabilized. This type of hospitalization, which is quite common, usually lasts from one to two weeks. Contact Sixty Plus for further information about hospital admissions for those who have difficult dementia behaviors.

HOW DEMENTIA IMPACTS THE FAMILY

The diagnosis of dementia can be confusing to family members, many of whom may not understand just what this diagnosis means. Some families will deny what's happening and insist that the person is not that bad; others might feel overwhelmed with sadness, grief, and fear. But as the affected person's dementia progresses, usually one or two family members emerge as the primary caregivers. It may be the person's spouse, or a sibling or a child who has the most available time. Someone has to take charge and make sure that the person is getting whatever is needed. In the process, life for the family is disrupted until a new equilibrium can be established.

Dementia changes relationships within a family. It affects how family caregivers use their time. It can also significantly impact their finances.

To cope with this disease, family members must recognize and accept their feelings and develop new ways of relating to the person with dementia. Sometimes dementia will splinter families, causing resentment because not enough of the caregiving responsibility is being shared. But most of the time families rise to the occasion. They may even find that this disease can bring them closer together.

Family caregivers often careen between strong emotional responses. It's important to acknowledge all that you might be feeling.

Denial

It's not unusual for families to refuse to believe a doctor's diagnosis of dementia. The often fluctuating nature of dementia, where

the person seems much more lucid on some days, contributes to the feeling that things aren't so bad. But prolonged denial interferes with appropriate planning. It can prevent accurate understanding of the symptoms associated with the disease.

Anger, Resentment, and Guilt

Feelings of anger and resentment can have many different causes: the loss of dreams for the future, feeling trapped in a long-term caregiving role, having to perform unpleasant daily tasks, dealing with frightening dementia behaviors. Many caregivers feel overwhelmed and find that their resentment significantly affects their sleep and general health. Moreover, not all caregivers have had a good, loving history with the person who has dementia; this can make caregiving extra hard. If it's your responsibility to take care of a parent who abused you, or a spouse who mistreated you, deep-seated anger is a very normal response.

Caregivers often feel guilty. If they lose their temper and snap at the demented person, they'll often berate themselves relentlessly. If the person becomes ill, or wanders away from the home while the caregiver is busy, the guilt can be enormous. They can feel that they've let their loved one down and that they're failing at their job.

Social Isolation

There can be so much for caregivers to do every day that they lose touch with their old lives. There's no longer time to spend with friends. There are no more vacations. Meanwhile, many friends slip away. They don't understand dementia and feel awkward visiting. And if the person with dementia has difficult behaviors in public, even trips to the store or local restaurants become much less frequent.

Embarrassment and Shame

Although dementia is a medical disease, like arthritis or cancer, many families still associate it with mental illness. The demented person doesn't look sick; he just acts in a strange and unpredictable way that can cause much embarrassment for the family. To complicate matters, not everyone in public recognizes dementia for what it is. They may be offended by the person's behavior. However, as the incidence of dementia increases, more and more families are learning about this disease first hand. It can help to diminish the feelings of embarrassment if you realize that just about everyone knows somebody with dementia.

Grief

When someone dies, the custom is for families to publicly grieve at a funeral or memorial service in which the person is eulogized and honored. The family gets much emotional support and sustenance from their close friends and community. But when someone develops dementia, there is no formal grieving process. Families have to endure the loss of the person they knew and loved all on their own. Often called "the long good-bye," the process of watching your family member decline with dementia is draining, and can last for years. It can cause much suffering for caregivers, who can feel very isolated with their sadness.

Financial Fears

Dementia can be an expensive disease. Caregivers may need to leave paid employment to stay home with the patient. Patients themselves may still be in the workforce when they're diagnosed, another loss of income. In addition, paying for care can cost a lot, whether it's adult day programs, hiring help

in the home, or using a long term care facility. Care may extend over a period of many years. Public assistance programs tend to be available only to the most indigent families. Some patients may be eligible for veterans' benefits which can help pay for care, but most middle class families will need to incur care costs themselves.

Depression and Anxiety

Lack of control over the progression of dementia can make caregivers feel helpless and hopeless. Depression is a natural reaction to any catastrophic disease, and it's extremely common for family caregivers. Anxiety is closely connected to depression, but the symptoms are different. Whereas depression results in feelings of great sadness, sluggishness and exhaustion, anxiety tends to make you feel tense, restless and irritable. Anxiety can cause many physical symptoms, such as chest pain, heart palpitations and other body aches. Both depression and anxiety affect sleep patterns and appetite. Many people suffer from anxiety and depression at the same time. The good news is that there are excellent medications available to treat these conditions. They're non-addictive and very effective, making caregivers feel much better about their ability to cope.

Caregiver Role Changes

Finding yourself in a completely different family role can be so strange and disruptive that it leaves you feeling bewildered, lost and sometimes, incompetent. The wife who never managed the checkbook suddenly has to take on all the family finances when her husband becomes demented. The husband who has never had to cook has to plan and prepare all meals, for the first time in a long marriage. The son who is caring for his mother has to

assist her in the bathroom, and help her get dressed. These role changes are especially perplexing. It's not what anyone is used to, nor what you anticipated would happen. Give yourself time to adjust and let yourself off the hook if things aren't done perfectly. Not only is the demented person experiencing a profound life change, but you are as well.

Planning and Decision Making

Making decisions is a continuous process, beginning with the realization that your loved one is becoming increasingly forgetful, and not ending until after the death of the person with dementia. There is so much to do: getting the correct diagnosis and treatment; making sure the person is kept safe, with an optimal quality of life; attending to all of the daily chores and caregiving activities that never seem to end; and making decisions about future plans, for yourself as well as your loved one.

Family caregivers need to attend to legal matters early in the course of the disease. Advance directives for both health care and finances need to be completed. Legal guardianship may be necessary. Gifts of assets and trusts may need to take place. An elder law attorney can be an excellent resource at this juncture. It can also be helpful to work with a geriatric social worker who can lead you to the most appropriate community resources. Call the Sixty Plus Helpline for more information.

CARING FOR THE CAREGIVER

Caring for a person with dementia is a stressful and demanding job which usually happens quickly, with little or no preparation for family members. To manage most effectively, the realities of the disease must be accepted. But it's also necessary to acknowledge the risk that caregivers themselves will face.

If the primary caregiver is not functioning well enough, the person with dementia won't be functioning well, either. Everything hinges on the health and stability of the primary caregiver. There are many reports in medical literature about the acute emotional and physical strain that caregivers suffer. In many cases, they die first, before the demented person passes away.

Managing someone with dementia is beyond the resources of a single, unassisted family member. It's crucial to get help.

Where and how to get that help will differ from family to family. Large families with more available relatives may share in giving the primary caregiver regular breaks. Some families will pay for hired help in the home or make use of adult day programs for the affected person. Others will take their loved ones for respite care stays in local assisted living facilities. Still others will decide that caring for the person at home is no longer viable and seek a good long term care placement in a convenient location.

Remember that there is no perfect caregiver, anywhere. What works for one family won't work for another. You have to find your own way to leave the caregiving to others so that you can be replenished. Whatever you decide, make sure it happens often enough.

Most caregivers require steady, predictable breaks, at least once per week, lasting several hours at a time.

Try to maintain your friendships. Try to get out of town. Try to read your favorite books and magazines. Get a massage. Go to a museum. Get your nails done. Go fishing. Exercise. Take a long, warm bath while you listen to your favorite music. Meditate.

You must also maintain your own health care with regular visits to your doctor. Report any symptoms of anxiety or depression, sleeplessness, or appetite changes. You might benefit from seeing a psychotherapist or counselor who specializes in caregiver stress.

It helps tremendously to attend support groups. Sixty Plus offers local groups specifically for family caregivers of those with dementia. These groups are free and available in the daytime or evening. They're comprised of spouses, children, siblings, and close friends who want the camaraderie of others who understand what it's like and who don't need lots of explanations. Support group participants will find a safe place for their tears and frustration and even find themselves laughing about the strange world of dementia. There's also a lot of practical information and advice that's disseminated at each meeting.

Many excellent websites are available for caregivers. A few to try are www.caregiver.org, www.alz.org, www.thealzheimerspouse.com and www.wellspouse.org.

Whatever you decide to do, and wherever you go for help, remember that you're not alone. Millions of families are dealing with this disease, and there are many services for you and your loved one, in every community.

LEGAL & FINANCIAL ISSUES

If the person with dementia has not already signed advance directives – documents that allow for trusted family members or friends to be surrogate decision makers – this should be done as quickly as possible. However, the person with dementia still needs to have some lucidity in order for the documents to be valid. For someone with severe dementia, it's too late. It's best to get this done very early in the disease process because it's hard to predict how quickly the dementia will progress.

Similarly, there needs to be close attention paid to the financial status of the person with dementia. A clear understanding of the costs incurred for dementia care will help families plan for the future.

Legal Documents

Most of the following documents are necessary when caring for someone with dementia. This information is specific to Georgia, but every state has similar documents. Keep the originals and make as many copies as needed for other family members and health care providers.

- **Georgia Advance Directive for Health Care** – This document, revised in 2007, combines a living will and the Power of Attorney for Health Care. It allows the person to appoint a health care agent, a trusted individual who will make surrogate health care decisions assuming that the person is no longer capable of making decisions. It also asks the person to record treatment preferences, as well as who should be appointed guardian should one ever be needed. This document does not need to be notarized. It requires the signature of two witnesses

who are not family members. This document is available in the Sixty Plus office at Piedmont Atlanta Hospital and also on our website.

- **Durable Power of Attorney for Finances** – The affected person needs to have a designated surrogate who can take over financial matters, from paying monthly bills to managing investments. Just like the advance directive for health care, the DPOA for finances decrees that the agent named cannot force decisions upon the person as long as he remains mentally capable. However, when he no longer has mental capacity, the DPOA for finances is activated. This document is available from the bank used by the person with dementia; sometimes, however, family attorneys will be responsible for making sure this is signed.
- **Guardianship** – If there are no advance directives signed before someone becomes significantly demented, the only way to gain decision making authority for health care and finances is through guardianship. This is a legal arrangement which appoints both a guardian of person and conservator of finances, and requires court supervision. There is a substantial filing fee for guardianship. The person seeking guardianship must submit a petition to the probate court in the demented person's county of residence. A court appointed mental health professional will then evaluate the person to determine competency. Guardianship can be very time consuming; guardians must justify to the court how the demented person's money is being spent. It is, however, a necessary step when no powers-of-attorney exist, and especially when there is family disagreement about care plans.

- **Do Not Resuscitate/Allow Natural Death Orders (DNR/AND)** – This is a directive ordered and signed by a physician for those patients who do not want to have cardiopulmonary resuscitation (CPR) administered if there is a heart attack. Hospitals and nursing homes are accustomed to these orders and will honor them, but it is always best to specifically discuss this issue with staff members well in advance of any medical emergency, usually when the patient is first admitted. Assisted living facilities and personal care homes may have a different approach to DNR/AND orders. Please make sure that you discuss this issue in advance of moving your family member into one of these facilities. Many families are clear that they do not want CPR and would prefer for their person to die naturally. Whenever a demented person moves into this facility, this issue should always be discussed. Many families are very clear that they want CPR to be withheld.

Many people being cared for at home also want DNR/AND orders. They can obtain a DNR/AND order signed by the primary care physician and display it prominently in the home. You can get a copy of the order by searching on the internet “Georgia DNR order,” print it, and bring it to the doctor. Everyone caring for the dementia patient needs to know about this order and feel comfortable with complying with it. If the patient collapses, 911 should be called but it should also be stated very clearly during the call that the patient has a signed DNR/AND order. When the paramedics arrive, they need to be shown the order immediately or else they will attempt resuscitation. Once shown the order, they will examine the patient to determine if death has occurred.

For many family caregivers, having DNR/AND orders makes a lot of sense. However, it’s essential to carefully think through how you, or others in the home who are providing care, may respond in the moment when the patient collapses. It can be very hard not to call 911 and want immediate resuscitation. Please discuss this with everyone involved in the patient’s care. Keep in mind that if the patient is in the end-of-life phase of dementia and already on hospice care, the hospice nurse should be called, not 911.

Georgia now has another medical order that enables very sick patients to designate the treatments they want and to ensure that these choices are honored by health care professionals. The POLST – Physician Orders for Life-Sustaining Treatment – has recently been introduced in Georgia, though it is well established in other states. It provides choices for code status, such as whether to do CPR, as well as what types of medical interventions, antibiotic use, and artificially administered nutrition and hydration the patient may want. The order should be printed on pink paper, and like the DNR/AND, be displayed prominently in the patient’s home. Please note that because the POLST is new to Georgia, many medical professionals – even paramedic EMT services – are not familiar with it. Therefore, if you are caring for someone who does not want to be resuscitated, it is best to not rely only on the POLST form to indicate the patient’s wishes but to also have a DNR/AND order. For more information about the POLST, go to www.gapolst.org.

Paying for Care

- **Home Care** – If you decide to hire extra help in the home to care for the patient, there’s a good chance this will be an out-

of-pocket expense. Unless the demented person has long term care insurance with a home care provision, and unless he or she has a low enough income to qualify for certain Medicaid programs, all home care is paid for privately. Medicare and supplemental health insurance plans don't cover the cost of ongoing home help. If you hire workers from a private duty agency, you'll want to request Certified Nursing Assistants who are experienced in dementia care. The current hourly cost for CNAs in Georgia ranges from \$18 to \$25 per hour, and usually there is a four hour minimum shift. It's possible to find independent workers who are not associated with an agency who will charge less per hour, but then it is your responsibility to handle their taxes and withholdings. In addition, hiring independent workers requires that you complete thorough background checks and talk to references to ensure that the person is trustworthy.

- **Adult Day Programs** – There are many adult day programs which offer both half day and full day care specifically for people with dementia. This is a good option for someone living at home with family members who need to go to work every day or who need consistent breaks from caregiving. Adult day care provides socialization and appropriate structured activities for patients who tend to enjoy them very much. Some programs offer transportation and a meal. Costs begin at about \$50 for a half day program and upwards for longer days. Some programs offer sliding fees based on the person's income, and some long term care insurance policies will cover day care.
- **Residential (long term) Care** – Residential care can be found at assisted living com-

munities, personal care homes, or nursing homes. Sometimes a person with dementia who is not too advanced in the disease will be able to live successfully in "regular" assisted living, as long as wandering is not a problem. But for more demented patients who want to live in an assisted living community, it is necessary to be in the locked dementia unit, which most communities have. It is more expensive to live in dementia units. Please note that assisted living and personal care homes are only paid for privately in Georgia, with just one small exception for those who have a low income.*Nursing homes generally take patients who are more advanced in dementia, and who are likely to have other health problems as well. Nursing homes are paid for privately, or for those who qualify, Medicaid will pay. Medicare never pays for long term care.

Before making a permanent decision about any residential facility, visit many places and talk to other families who use them. Recent state inspection reports on nursing homes are available from www.medicare.gov. You can also consult with the clinical social workers at Sixty Plus, who are familiar with various facilities, their costs, and programming.

**The Community Care Services Program provides assistance to older adults in declining health who want to remain in their homes rather than move into long term care. There is an income cap and CCSP participants must qualify for Medicaid. CCSP can also help some participants with the costs of personal care homes, which are similar to small assisted living communities.*

HOSPITALIZATION & TRANSITION BACK HOME

An inpatient stay in an acute care hospital can be a turning point in the lives of frail older adults. Their physical and mental health may seem to decline after hospitalization. This is particularly true for patients with dementia.

Most patients are not followed by their primary care physicians when hospitalized. It is usually a “hospitalist” doctor who takes over, and then at discharge the patient is transferred back to the primary care doctor. Although it may seem distressing to realize that the primary care doctor is not the one in charge, this new arrangement is actually very beneficial considering the complex nature of acute medical care. Hospitalist physicians coordinate and manage all aspects of the hospital stay; they don’t have private outside practices, and so all of their time and attention is focused on hospitalized patients. They are specialists in this regard. They know all other departments in the hospital well and thus they can network promptly and efficiently on their patients’ behalf.

However, anyone with dementia is still going to have a challenging time when hospitalized, no matter who is in charge of the medical care. Feeling sick and being in an unfamiliar environment will exacerbate confusion. Family caregivers are often shocked by the swift decline in mental functioning that occurs during a hospital stay. Therefore, it becomes more important than ever to be organized and proactive.

Points to Remember

- Try to think of yourself as an advocate for a holistic approach to your patient’s needs.

Hospitals are very busy places where things happen quickly. Not all doctors, nurses, or other health care providers may know that your family members has dementia. Their focus instead will be on the acute medical problem that caused the hospitalization. You may need to inform them of the patient’s dementia. This piece of information could help to determine the course of treatment.

- It’s very helpful to the hospital staff to have the patient’s family designate one primary contact person; this may well be the primary caregiver. This will help the communication flow and let everyone know, hospital staff and other family members alike, that there is one “information keeper” who knows everything that’s going on. You may be asked to have a password in order for hospital staff to share information.
- Be prepared to stay in the hospital, close to the patient, night and day. If you or other family members cannot be there, you’ll probably need to hire someone to make sure that your loved one is not trying to get out of bed or pulling out IVs.
- Understand that a major focus of the hospitalization will be on developing the best discharge arrangement for the patient. Hospital staff will begin conversations about discharge plans very shortly after the patient is admitted.
- In a notebook, record what transpires during the hospitalization: who is treating your loved one, his/her response to treatments, sleep cycles, appetite, etc. This information forms a crucial part of the patient’s ongoing health history.

- Be meticulous about discharge medications. Have a list of every prescription your patient should be taking. Make sure that the discharge nurse reviews it with you so that dosing instructions are clear. Discuss any over-the-counter medications you give to your patient, to make sure everything “mixes” well.
- Have a clear understanding of services that are supposed to be offered in the home after discharge. Very often a visiting nurse or physical therapist will be ordered to work with the patient for several weeks. You’ll need to know which agency will be providing these services, their phone number, and when they’re supposed to start.
- Similarly, know what medical equipment you’ll need to have at home. Medicare covers the cost of many types of equipment. Find out what equipment is being recommended and the name of the medical supply company involved. Find out when the equipment will be delivered. And remember to bring home any equipment which has been given to you for future use.
- Promptly schedule follow-up appointments with your patient’s primary care physician and specialist physicians.
- Watch out for “red flag” symptoms when the patient returns home. For example, are there signs of a worsening medical condition, like greater lethargy, declining appetite, more confusion or worsening balance? If so, contact the doctor ASAP.

END-OF-LIFE CARE

For many people with dementia, physical health will decline gradually but steadily, resulting in further cognitive problems, weight loss, immobility and eventually an inability to swallow. When someone reaches this point, the family must determine whether to seek tube feeding, to keep the person alive. Often, families will choose to decline extraordinary measures to prolong the person's life, and instead allow nature to take its course.

Hospice care is available to those with life-limiting neurological diseases, including dementia. However, the person must be given a prognosis of six months or less to live. There are other specific medical criteria which need to be present in order to qualify for hospice care.

A physician must order a hospice evaluation when it appears that the person is approaching the end of life. Usually the family will decide which hospice program they wish to use. After the hospice receives the physician order, a nurse will evaluate the person to make sure that he or she meets the eligibility criteria for hospice admission.

When families seek hospice care, it is understood that no further lifesaving interventions will be made. The demented person no longer goes to doctors' appointments, and if there is an emergency, the person is not rushed to a hospital emergency room. Instead, the hospice nurse is called. The emphasis at all times is on the patient's comfort and quality of life.

Most people receive hospice care wherever they live – either in the family home, or assisted

living facility, or nursing home where they permanently reside. The hospice team consists of a nurse, social worker, dietitian, physical therapist, clergy, and very often volunteer staff as well. They visit frequently and remain available to the dying person and to the family, as often as needed.

Some hospice programs offer in-patient care, where those who are “actively” dying can spend their final weeks or days. Insurance coverage for in-patient hospice care is often limited, so it's important to check with the insurance company about the exact extent of coverage. Medicare, for example, will cover all home-based hospice services, but not necessarily all of an in-patient hospice stay.

Hospice care in the home does not pay for ongoing custodial and personal care; family members or hired workers perform these tasks. Hospice team member visits are brief and episodic. Their intention is to monitor the person's rate of decline and to ensure that maximum comfort and quality of life are being provided. They work very closely with family caregivers, providing education, understanding, and support. They are available 24 hours per day.

Very often those who are receiving hospice care will live longer than expected, exceeding the six month mark of life expectancy. This is not a problem; patients in this situation can be re-certified for hospice care by the doctor, as long as hospice criteria continue to be met.

You may hear the term palliative care in reference to frail patients who are clearly in physical decline. These patients have little or no hope for recovery. Sometimes they

are said to have a syndrome called “failure to thrive.” More and more hospitals and out-patient programs are developing palliative care approaches which, like hospice care, focus on the person’s comfort. People with advanced dementia are eligible for palliative care before they become eligible for the more structured approach of hospice care.

Remember that those with dementia often succumb to another disease later in life, such as cancer, lung disease or heart disease. But if death is not caused by another terminal illness, end-stage dementia will cause the person to die. The staff at Sixty Plus Services can recommend resources for learning more, as well as grief support groups that family members may wish to attend.

Please call us if you are uncertain whether your loved one is ready for end-of-life care. We can help you figure out if the time is right.

SPIRITUAL CARE

People with dementia continue to need spiritual care, especially if spirituality has been an important part of their lives. As dementia progresses, spiritual experiences for both the patient and the family caregivers can be especially meaningful.

Even those who are severely demented will remember prayers, songs, and rituals from childhood. It can be comforting and reassuring when family caregivers recite passages from the Bible, Torah or Koran, or sing holiday carols. If the patient is not part of a formal religion, spiritual time can be preserved through music, nature, and other experiences that are meaningful to the individual.

Although it may no longer be possible for the person with dementia to attend worship services, devotional time can still be observed by tuning into TV or radio programs.

Alternatively, the family may want to set aside regular quiet time for prayer and meditation, perhaps at a point during the day when the person is usually more subdued and peaceful. Clergy can visit, and Eucharistic ministers can be called upon to serve the person at home.

Many faith traditions are now actively reaching out to members of their congregations who are demented, and to family caregivers as well. Elder care ministries are being recognized as an essential part of organized religion, to respond to the overwhelming need for spiritual support as so many families contend with dementia. If you are part of a religious community where this has not yet been developed, you may want to ask your spiritual leaders to address this specific need. And please try to find regular time for your own spirituality. Faith can help you to cope with the daily challenges of caregiving.



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SIXTY PLUS SERVICES

Sixty Plus Services would like to thank the Georgia Chapter of the Alzheimer's Association, Jewish Family Services, and the Visiting Nurse Health System for their contributions to the first editions of this guide, in 1985 and 1996. Since then, the guide has been updated every three years by the Sixty Plus staff, to reflect current knowledge and best practice information. We are also grateful to the patients and families with whom we work. It is because of their support and interest that we can continue to offer our services to the Piedmont Healthcare community. For information, call the Sixty Plus Services **AGING HELPLINE** at **404.605.3867**.

The programs and support provided to older adults and their families through Sixty Plus Services are made possible by the generosity of our donors. The Sixty Plus Services program operates with no private insurance support. All donations are used exclusively for our work with older adults and their caregivers. Piedmont Healthcare is a 501(c)(3), not-for-profit institution. Private gifts to Piedmont Healthcare Sixty Plus Services are tax deductible. For more information or to make a gift, visit **donate.piedmont.org** or call **404.605.2130**.

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