RUSH UNIVERSITY
MEDICAL CENTER

The Rush Manual for Caregivers

Rush Alzheimer's Disease Center
Rush University Medical Center

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The Rush Manual for Caregivers

Sixth Edition
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Foreward

Loss of memory and other cognitive abilities have been recognized since antiquity. However, the modern age of Alzheimer's disease is less than 100 years old. In 1906, Dr. Alois Alzheimer described the case of a relatively young woman (in her 50s) who suffered from a rare form of progressive dementia. At the time of death, she underwent brain autopsy. Taking advantage of recent advances in neuropathology, Dr. Alzheimer described numerous neurofibrillary tangles and neuritic plaques in the woman's brain, which he presumed to be the cause of her progressive dementia. We now know that these are the same lesions found in the brains of older persons with dementia (or senility) and this too is Alzheimer's disease.

In 1906, when Dr. Alzheimer described his patient, life expectancy for the average American was less than 50 years. Remarkable medical advances over the past century have resulted in a marked increase in life expectancy so that a person born this year can reasonably expect to live to about age 80. Thus, greater numbers of persons are living to the age when Alzheimer's disease becomes common. There are currently an estimated four to five million Americans with the disease. That number is expected to triple over the next 50 years, making Alzheimer's disease among the most common – and most feared – chronic, age-related neurologic diseases.

The Rush Alzheimer's Disease Center (RADC) is dedicated to reducing disability due to Alzheimer's disease and other age-related neurologic conditions through clinical care, education and research. Since 1987, the RADC has been designated by the Illinois Department of Public Health as the Regional Alzheimer's Disease Assistance Center for Northern Illinois. In addition, the RADC has been designated since 1991 as an Alzheimer's Disease Core Research Center by the National Institute on Aging. The RADC's multidisciplinary clinical and educational staff is dedicated to creating an atmosphere that promotes the best possible care for people with these conditions.

Managing the care of someone with Alzheimer's disease requires patience, compassion and skills that go beyond the sophisticated therapies that characterize much of modern medical practice. The patient has a disease that frequently changes one's personality, robs a spouse of one's partner or a child of one's parent, and costs tens of thousands of dollars for care. An ongoing relationship between the RADC's staff and the patient's family is needed to ensure that the patient is kept in a stimulating and supportive environment if hospitalization, institutionalization and caregiver distress are to be avoided. While there are several pharmacologic options for treating the cognitive dysfunction and behavioral disturbances associated with Alzheimer's disease, there are many areas in which other types of intervention also can markedly improve the quality of life for both the patient and the family.

The way to improve the care of persons with Alzheimer's disease for future generations requires treatment and prevention strategies that will only come from the conduct of large, carefully designed longitudinal research studies. The RADC is at the forefront of such efforts. The National Institute on Aging has funded the Religious Orders Study since 1993 and the Memory and Aging Project since 2001. The RADC is nationally recognized for its clinical and basic-science research efforts that seek to understand the causes of Alzheimer's disease and other common neurologic diseases of aging. Our hope is that through our ongoing research efforts, we will learn how to improve the lives of people with these conditions and how to prevent these conditions from affecting our loved ones and future generations.

This sixth edition of The Rush Manual for Caregivers, reflects the vast experience of the RADC's dedicated team of physicians, psychologists, gerontologists, nurses and social workers who have evaluated thousands of patients over the past 20 years. We have learned much from our patients and caregivers and we will continue to learn from them in the years to come. This manual reflects the combined wisdom of both the RADC staff and the many people who have shared with us the joys and sorrows of taking care of someone with Alzheimer's disease.

David A. Bennett, M.D.
Director, Rush Alzheimer's Disease Center

What is Dementia?

Understanding Dementia

Many people are afraid to discuss changes they may be noticing in either their own or someone else's behavior. There can be confusion about whether such changes are due to normal aging or due to the onset of a disease. This chapter describes common symptoms of dementia; the evaluation that determines the cause and diagnosis; and explains different types of dementia.

What does dementia mean?

Dementia refers to a gradual decline in memory and other cognitive functions. It is a broad term describing a widespread problem in brain function. The symptoms of dementia interfere with an individual's daily activities. These symptoms can include, but are not limited to:

- Forgetting events, names, places.
- Repeating questions.
- Difficulty finding words or putting thoughts in conversation.
- Problems managing money or balancing a checkbook.
- Getting lost in familiar places.
- Trouble doing work or routine tasks.
- Personality changes.

There are many causes of dementia, Alzheimer's disease being the most common. It is important to look for the cause of dementia, so a diagnosis can be made and appropriate treatment started.

Is dementia a normal part of aging?

Contrary to popular thinking, dementia is not a normal part of aging. Most people over age 60 never show signs of cognitive decline. Although the likelihood of dementia increases with age, dementia affects only a minority of older people. It is true that as a person gets older, it takes longer to learn something new. However, once an older person has learned something new, it should be remembered as well as when the person was young. When there is a pattern of failing memory, it is considered abnormal and should be evaluated as a medical problem.

How is a diagnosis made?

Determining the cause of dementia requires a thorough evaluation. The evaluation may include blood tests and a brain scan. If some tests have been done previously, it may not be necessary to repeat them. The various components of a comprehensive evaluation are described below.

The history

Getting a complete medical history is the first step in the evaluation. This entails an interview with the individual and their spouse, relatives or close friends. Interview questions are designed to determine the onset of any cognitive or behavioral changes. It is important to know if there is a history of head injury, loss of consciousness, seizure, stroke, diabetes, thyroid disease or alcoholism. In addition, information about the person's education, work, and family history will be collected. Because medications can sometimes cause side effects such as confusion, names and dosages of all prescription and over-the-counter drugs will also be gathered.

Neurological examination

The purpose of a thorough neurological examination is to look for any physical findings that may account for cognitive and/or behavioral changes. Illnesses such as stroke, tumor, or Parkinson's disease may cause brain changes that mimic Alzheimer's disease. Brain functions that are typically tested include: memory, language, perception, orientation and motor skills.

Laboratory tests

At the discretion of the clinician, certain laboratory tests and brain scans may be indicated. These may include blood work such as a thyroid function test, vitamin B12 level, and RPR (a test for syphilis). Scans of the brain, such as a CT, MRI or SPECT may also be ordered.

Neuropsychological testing

Mental status is typically evaluated by a battery of standardized tests. A commonly used screening tool is the Mini Mental State Exam (MMSE), which involves a brief set of questions involving memory, orientation, perception, attention and language. The MMSE is scored between 0-30. The following categories provide a guideline for determining severity of cognitive decline.

MMSE Score	Stage
27-30	Normal
19-26	Early stage or mild impairment
11-18	Middle stage or moderate impairment
0-10	Late stage or severe impairment

Although the MMSE serves as a very useful screening tool and helps to monitor progression of cognitive decline, it has several limitations. For example, the MMSE score may be affected by education, language or culture. In addition, the MMSE is not sensitive to very early memory loss or very late stage disease.

There are many possible causes of dementia and many illnesses that can mimic Alzheimer's disease. Therefore, the physician's main task is to conduct a thorough examination and sort out the medical facts.

Periodic evaluations

It is usually a good idea for someone with dementia to be reevaluated at least once a year or whenever significant changes are noticed. These periodic evaluations will help to monitor the effect of treatment and the progression of the disease.

Genetic factors

Two types of Alzheimer's disease exist: early onset and late onset. In early onset Alzheimer's disease, symptoms first appear before age 60. Some early onset disease runs in families and often involves inherited gene mutations that are believed to be the cause of the disease. Early onset disease is rare, accounting for only 5-10 percent of cases. In these rare instances of a strong family history, genetic testing may be ordered.

Late onset Alzheimer's disease, the most common form of the disease, is thought to be less likely to run in families. At the present time, genetic testing is not a routine part of a dementia work-up. However, the role of genetics in the occurrence of late onset disease continues to be an area of study for many researchers.

Putting it all together

Although there is no definitive test for Alzheimer's disease, it is estimated that the diagnosis is 90 percent accurate by ruling out treatable or reversible causes of cognitive decline. Important illnesses to rule out include: depression, infection, thyroid disorder, stroke and hydrocephalus. The only definitive test for Alzheimer's disease is microscopic examination of brain tissue at autopsy.

Types of Dementia

Alzheimer's disease

Alzheimer's disease (pronounced Alts'-hi-merz), was first described by Dr. Alois Alzheimer in 1906. This disease accounts for approximately 70% of all dementia. Despite ongoing research efforts, the cause of Alzheimer's disease is still unknown. Suspected causes include a genetic predisposition, a slow virus, environmental toxins and inflammatory or immunologic changes. At the present time, there is no effective cure for Alzheimer's disease, although existing treatments aim to slow the progression of cognitive decline.

Typically, a person with the disease will show gradual and progressive decline in intellectual functions. Symptoms include short-term memory loss and impairment of language, judgment, orientation and other intellectual capacities. These symptoms usually worsen over a period of many years, causing a person to forget recent events or familiar tasks. Communication becomes difficult as the affected person struggles to find words, finish thoughts or follow directions. The disease may last 10 to 20 years with an average length of illness lasting approximately eight years from the time of diagnosis. However, the rate of progression can vary greatly from person to person. The disease eventually causes confusion, personality and behavior changes, and impaired judgment. Ultimately, the person with Alzheimer's disease becomes dependent on others for care.

The prevalence of dementia increases with age. One in 10 persons over age 65 and nearly half of those over age 85 have Alzheimer's disease. Most people with Alzheimer's disease are over age 65 but some individuals are diagnosed in their 40s and 50s. About 4.5 million people in the United States are now believed to have this disease. It is estimated that 14 million Americans will develop Alzheimer's disease by the year 2050. Caregivers are affected by this disease too. In a national survey, 19 million Americans said they have a family member with Alzheimer's disease, and 37 million said they knew someone with the disease. In the meantime, research efforts continue to focus on ways to delay the onset and slow the progression of this illness.

Related dementias

Other less common causes of dementia include: Dementia with Lewy Bodies, vascular dementia, Parkinson's disease, frontotemporal dementias, and Creutzfeldt-Jakob disease. Dementia with Lewy Bodies accounts for approximately 20% of dementia and presents clinically as a combination of dementia and Parkinsonian symptoms. Parkinsonian symptoms include slowed movements and muscle rigidity. Other symptoms of this disease may include hallucinations, difficulty walking, falls, sleep disturbances and fluctuating alertness. Visual-perceptual problems are also common and may lead to difficulty driving. Due to the complexity of symptoms, this disease may be challenging to diagnose and can be confused with Parkinson's disease. In fact, medications to treat Parkinson's disease may worsen the symptoms of Dementia with Lewy Bodies.

Vascular dementia accounts for approximately 10% of dementia. This diagnosis is reserved for cases where cognitive decline occurs subsequent to a stroke. Symptoms of stroke may include brief episodes of confusion, slurred speech, weakness and visual changes. These symptoms usually appear suddenly. Unlike Alzheimer's disease, vascular dementia may not cause progressive cognitive decline unless further strokes occur. Therefore, stroke prevention efforts such as controlling high blood pressure, cholesterol management and smoking cessation are very important. People may be instructed to take anti-clotting medications such as aspirin and to follow a heart healthy diet.

Parkinson's disease can also cause dementia. Approximately 20-30% of people with a primary diagnosis of Parkinson's disease develop dementia as the disease progresses. Drugs used to treat the motor difficulties associated with Parkinson's disease will not improve the memory symptoms.

Fronto-Temporal dementias (FTD) such as Pick's disease and Primary Progressive Aphasia are rare and are believed to account for only a small percentage of all dementia cases. Fronto-Temporal dementia presents with personality and behavioral changes before the onset of memory loss. This form of dementia typically occurs in mid-life rather than at an older age. Fronto-Temporal symptoms may include impulsive and/or disinhibited behaviors, loss of social awareness, poor judgement, loss of interest in grooming and language problems. Depression is also common in Fronto-Temporal dementia. Occasionally, this disease may be misdiagnosed as a psychiatric illness.

Primary Progressive Aphasia affects speech and language and begins with word-finding problems rather than memory loss. This form of dementia is extremely rare and can begin as early as age 40. People with Primary Progressive Aphasia are very aware of their deficits and can usually continue to live independently for many years. Although memory remains relatively intact, help with paying bills, writing checks and following directions may be needed as as a result of language deficits. Memory, personality and visual processing are not affected until late in the illness.

Creutzfeldt-Jakob disease is a rare form of dementia that has a sudden onset and is rapidly progressive. It is marked by rapid cognitive decline and involuntary muscle jerking that may look like a seizure. Unlike Alzheimer's disease, which can progress over a period of 10-20 years, the duration of Creutzfeldt-Jakob disease is one year or less. This disease typically affects individuals age 50-75.

Of note, it is common for Alzheimer's disease to coexist with any of the above mentioned dementias.

As answers are found to the mysteries of Alzheimer's disease, progress also will be made in clarifying the causes and potential treatments of these related disorders.

The Stages of Alzheimer's Disease

Symptoms get worse over time, but they vary greatly from person to person. Some people may appear to change very little over a period of many years, while others show a rapid decline within just a few years. The reasons for these differences are not yet understood.

Families often ask which stage of Alzheimer's disease their relative is in. Although we can identify and describe stages of the disease, it is important to remember that the disease develops differently in each person. Some people may appear to change very little over a period of many years, while others show a rapid decline within just a few years. The reasons for these differences are not yet understood.

Although each person progresses at a different rate, a description of general patterns of dementia may help determine suitable activities and resources.

Early stage/mild impairment

- Impairment of recent memory is usually the hallmark of the disease in this stage. People with early-stage dementia often write down reminders as a means of maintaining their independence as much as possible.
- The person may have difficulty performing calculations, integrating a lot of information, following multiple steps or directions and making complex decisions.
- The person may be unable to perform certain household tasks or job responsibilities. Decision-making, handling multiple duties and operating machinery may be too difficult to do well or safely.
- Problems develop in handling finances such as preparation of taxes, payment of bills or maintaining a checkbook.
- Although driving skills may become impaired, each case of driving safety needs to be assessed on an individual basis.
- The person with dementia may feel more comfortable in smaller groups and with well-known family and friends in familiar surroundings. The individual may be aware of their impaired memory and fearful of embarrassing themselves in social situations.

Although dementia imposes limitations, the person with early-stage symptoms is still able to enjoy many normal activities. Family members should emphasize the person's remaining abilities instead of focusing on the impairments.

Middle stage/moderate impairment

- The person often repeats questions.
- Difficulty with written and spoken language becomes more prominent. For example, trouble finding the right word in conversation may increase.
- Understanding concepts such as time and other abstractions may become more difficult.
- The person becomes unable to manage personal grooming and hygiene. At this point, you may need to take a more active role in assisting the individual to initiate and follow through on certain tasks such as bathing and brushing teeth.
- Getting lost or disoriented in familiar surroundings may occur.
- Losing things or hiding things may become problematic.
- In this stage, frustration or agitation may arise around certain situations. For example, when the person misplaces items such as keys, others may be blamed for "taking" the objects. Poor memory and misperceptions about the environment may lead to agitated behavior.

Late stage/severe impairment

- This stage is characterized by the inability to remember even the most basic things. Short-term and long-term memory are profoundly impaired.
- Language may be reduced to a few basic words.
- Incontinence (first of urine and then of bowel) usually occurs.
- The person ultimately becomes totally dependent and must be assisted with all tasks such as bathing, dressing and eating.
- Communication with the person must be carried out in very simple terms using short sentences, commands and gestures.
- Mobility may become unsteady or may be lost altogether.

Even in this late stage, a person with dementia is able to respond to emotions of happiness, anger and love. Although the words you use to express these emotions may not always be understood, you can communicate how you feel by nonverbal means such as touch and gestures.

Treatment of Alzheimer's Disease

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Until recently, nothing seemed to slow the cognitive decline of people with Alzheimer's disease. However, as researchers have learned more about the development of the disease, several promising treatments have been identified. Five drugs for the treament of Alzheimer's disease have been approved by the U.S. Food and Drug Administration (FDA) and many more are in development. Researchers are now optimistic that new treatments will be found to delay the onset of the disease and slow the mental deterioration it causes. Until new treatments are developed, learning how to cope with the effects of the disease will remain a major challenge for family and professional caregivers.

Acetylcholinesterase inhibitors

Cognitive impairment (memory loss, difficulty concentrating or difficulty using the correct words when speaking) is the main feature of dementia and the target of current drugs specifically designed for Alzheimer's disease. We know that low levels of a brain chemical known as acetylcholine is associated with the disease. Since acetylcholine is involved in memory and attention, drugs that increase the availability of this chemical in the brain are the focus of this type of treatment.

Thus far, four drugs in this class have received approval by the FDA for the treatment of Alzheimer's disease: tacrine (Cognex) and donepezil (Aricept), rivastigmine (Exelon) and galantamine (Reminyl). All of these drugs are known as acetylcholinesterase inhibitors. In other words, they inhibit the breakdown of acetylcholine so more of this chemical remains in the brain. Cognex was approved first but is no longer used because of its side-effects. Donepezil (Aricept) was approved in 1997 and once-a-day dosing makes it convenient to administer. Rivastigmine (Exelon) was approved in 2000 and galantamine (Reminyl) in 2001. Both of these drugs require twice-a-day dosing. In general, these medications are well tolerated but can cause side-effects such as diarrhea, nausea and weight loss. The potential benefits of these medications include a perceived improvement in memory, an increased ability to perform activities of daily living and reduced behavioral problems.

Although this type of medication may help stabilize cognitive impairment for an unknown period of time, they do nothing to alter the pathological progression of the disease. Further research is needed to determine the long-term effects of these medications.

NMDA - Receptor Antagonists

A new class of drug that prevents the over accumulation of glutamate in the brain was approved by the FDA in October 2003. Memantine (Namenda) is the first drug in this new class of medication to become available. It is indicated for moderate to severe Alzheimer's disease. It may be used alone or in combination with a cholinesterase inhibitor. This medication requires twice a day dosing and is generally well tolerated with very few reported side-effects. Possible side-effects to watch for include dizziness, headache and constipation.

Antioxidant therapy

Several lines of evidence indicate that oxidative stress plays a role in aging and, in particular, in neurodegenerative diseases such as Alzheimer's disease. Vitamin E belongs to a class of chemicals called antioxidants. These chemicals seem to protect cells from damage caused by oxygen and oxygen-breakdown products. A study of vitamin E given to people with Alzheimer's disease showed some benefits. The study participants who received a daily dose of 2000 IU of vitamin E fared better than a comparison group on several measures.

Ginkgo biloba has long been thought to enhance cognition and improve memory but lacks any evidence-based research to support its use. Although the mechanism of action remains uncertain, there is some evidence to support an antioxidant effect. Like all other medications, the decision to take ginkgo biloba should be discussed openly with one's health care provider. Ginkgo biloba can potentially interfere with other medicines and cause bleeding.

Anti-inflammatory agents

There is evidence to support that people who use non-steroidal anti-inflammatory agents (NSAIDs) for many years have a lower risk of developing Alzheimer's disease. However, preliminary findings from NSAID studies suggest that NSAID therapy does not significantly benefit a person once dementia has occurred. Rather, further studies aim to define the role of NSAIDS in the prevention of disease.

Hormone-replacement

There is controversey regarding whether or not there is a reduced risk for Alzheimer's in postmenopausal women treated with estrogen-replacement therapy compared with those who do not receive hormone therapy. Presently, postmenopausal women should not take estrogen solely on the basis that it may reduce Alzheimer Risk. No studies support the use of estrogen solely for the treatment of dementia once the person has the disease. Ongoing studies continue to explore the possible role of estrogen in the prevention of dementia.

Other potential treatments

At the present time, researchers are actively studying the role of cholesterol lowering drugs, high dose B complex vitamins and other alternative treatments for dementia. In addition, the role of a potential vaccine and the role of nerve growth factor is also being examined.

Participating in Research

Since Dr. Alzheimer first described the characteristics of the disease that today bears his name, we've struggled with its mysteries. Despite many scientific advances over the past decade, the cause and cure of the disease continues to elude us. The key to solving the puzzle lies in the research activities now being conducted throughout the world. The U.S. government, largely due to advocacy from family members, has greatly increased funding for Alzheimer's research. The federal government now funds 29 Alzheimer's disease centers, including the Rush Alzheimer's Disease Center.

Despite many scientific advances over the past decade, the cause and cure of the disease continues to elude us. The key to solving the puzzle lies in the research activities now being conducted throughout the world.

Research supports the building of knowledge and enables more and more pieces of the puzzle to be gathered. Once enough pieces are in place, it becomes easier to complete the picture. Alzheimer's research includes a variety of areas:

- Studying older adults who do not have dementia to compare normal aging with disease-related changes.
- Identifying risk factors, including the role of genetics.
- Detecting means of early diagnosis.
- Testing experimental medications that might prevent or slow the disease process or alleviate symptoms.
- Identifying why there is such great variability among people in regard to disease progression.
- Gathering information about the behavioral changes that may occur in the course of the disease.
- Exploring techniques that reduce the stress of caregiving.
- Examining the brain at autopsy for insights into the origins and progression of the disease.

Research studies offering the potential of direct, personal benefits are very appealing. For example, those taking part in trials of experimental drugs hope to be among the first to use an effective drug. Also, studies designed to help caregivers improve their coping skills may have immediate practical value. However, most research is focused on more basic questions concerning the nature of the disease. These studies may not offer any immediate benefits but may eventually lead to knowledge that has applications for others in the future.

Individuals agree to participate in research for several reasons. The key reason is that they want to help find the missing pieces of the puzzle. Many participants realize the picture will not be complete in their lifetime but perhaps future generations will benefit. Often participants say, "This may not help me personally, but it may prevent my children and grandchildren from facing this disease.”

Without human participation in research, it will take longer to understand this disease. The hope for the future lies in people’s generous agreement to participate in research studies. Most people are eager to accept this challenge in one way or another.

Participation in research may vary from an interview on just one occasion to a long-range commitment over a period of many years. All studies are strictly controlled and only people meeting certain criteria may be eligible to participate. There are usually numerous opportunities to participate in research so you will need to determine how much time and energy you can devote to the effort.

All research follows strict ethical guidelines. Individuals must be informed of each study’s goals, procedures and potential risks. Participation is always voluntary and an individual can withdraw at any time. Information obtained during the study and the participant’s name are always kept confidential.

The ultimate goal of Alzheimer’s research is to provide benefits to those with the disease and their families. It may take a long time to finally discover effective treatments or a cure. All of us involved in research, evaluation and treatment are interested in working with you to help solve this puzzle. Your participation in this combined effort is welcomed and greatly appreciated.

Communication

Bridging the Communication Gap

Dementia affects communication in many complex ways. Understanding these changes will help keep alive your relationship with the person with dementia. Learning new ways to communicate should also make your role more meaningful and less frustrating. You may find that the person's capacity to communicate fluctuates from day to day or with different people. The person's ability to communicate is affected by the following:

- Difficulty finding the right word when speaking and difficulty understanding the meaning of written and spoken words.
- Having a limited attention span, which makes it difficult to follow lengthy conversations or multiple step instructions.
- Losing train of thought when listening or talking.
- Difficulty remembering the steps in common activities, such as cooking a meal, paying bills or doing laundry.
- Difficulty filtering out background distractions that seem to compete for attention (radio, television, telephone calls, the conversations of others in the room).
- Getting frustrated if communication isn't working.
- Being hypersensitive to nonverbal aspects of communication such as gestures, touch, tone and volume of voice.
- Reverting back to a native language if English is a second language.

Making communication easier

No suggestions for improving communication work all the time with every person. Experiment with different methods of communication before settling on those that work best. Your methods will change as the disease progresses over time. Don't modify your way of communicating with the person unless you find that they can no longer understand you.

It's easy to slip into the habit of only communicating about tasks and the issues of day-to-day care. People with dementia, like all of us, have basic human needs: to feel safe, cared for and valued. Encourage a dialogue as long as possible. This helps the person with dementia maintain self-esteem long into the illness. Keep these suggestions in mind:

- Establish eye contact to get the person's attention first, before proceeding with what you have to say.
- Offer simple, step-by-step instructions.
- Ask questions that require a yes/no answer.
- Repeat instructions if necessary and allow more time for a response.

- If words alone don't convey what you want, try a different approach: show the person and use touch to gently guide them.
- Try using different words to convey what you want. Perhaps the appropriate word in the person's native language would work.
- If you find yourself becoming too frustrated, drop the effort as calmly as you can and return to it when you're in a better frame of mind.
- If verbal communication fails, try distracting the person. Instead, offer a pleasant activity like a snack or a ride around the neighborhood.
- Ignore angry outbursts if you can't think of a positive response.
- Be aware of your whole approach: tone and volume of voice, facial expression and body posture.
- Try not to correct or dispute "errors" in memory. Avoid saying "Don't you remember?" or "I told you…"
- Begin your conversation socially. Winning the person's trust first can often make a task much simpler.
- Your manner should be warm, affectionate and matter-of-fact.
- Allow sufficient time for a familiar activity and try not to rush it.
- Avoid criticizing mistakes. Instead say, "Let's try this way."
- Support each effort or attempt, even if the results aren't completely satisfactory. Say, "Thanks for helping."
- Be aware of how the person responds to you. These clues may give you important feedback that will help you detect a problem before it develops and allow you to adapt your communication.
- Be open to the person's comments and concerns even if these are difficult to hear.
- Sometimes "problematic behaviors" are a way of keeping control of daily life or expressing frustration. Let the person make some decisions and stay involved.

Keep communication a dialogue for as long as possible. The effort put into this should help the person with dementia retain self-esteem long into the illness.

The book, Understanding Difficult Behaviors, gives good advice about how to communicate with persons with dementia. The authors break their chapter on communication into seven parts: focusing on tone, topics of discussion, complexity of conversation and tasks. Below is their list of "things to do" with persons with dementia:

- Don’t argue with the person.
- Don’t order the person around.
- Don’t tell the person what he or she can’t do. State directions positively instead of negatively.
- Don’t be condescending.
- Don’t ask a lot of direct questions that rely on a good memory.
- Don’t talk about the person in front of them.

A man with Alzheimer’s disease, quoted in the book *The Loss of Self*, seems to express the feelings of many people with dementia:

“No theory of medicine can explain what is happening to me. Every few months I sense that another piece of me is missing. My life . . . my self . . . are falling apart. I can only think half thoughts now. Someday I may wake up and not think at all . . . not know who I am. Most people expect to die someday, but whoever expected to lose their self first? I am hungry for the life that is being taken away from me. I am a human being. I still exist. I have a family. I hunger for friendship, happiness and the touch of a loved hand. What I ask for is that what is left of my life shall have some meaning. Give me something to die for! Help me to be strong and free until my self no longer exists.”

Helping the Person who is Aware of Memory Loss

Our own reluctance to approach people who have dementia and inquire about their feelings may be a roadblock to their acceptance of memory loss.

It was once commonly thought that people with Alzheimer's disease were unaware of their memory loss. We now know that some people with dementia show a great awareness of their disease, while others are completely unaware. There is little research to help us understand which individuals are aware of their symptoms and how we can help them cope with this awareness.

Some people may deny anything is wrong with their memory. Such denial may be their way of covering up or compensating for their cognitive deficits. On the other hand, some people simply forget that their memory is impaired. These people do not remember that they do not remember! Such a notion may be hard to grasp for those of us who take memory for granted.

Our own reluctance to approach people who have dementia and inquire about their feelings may be a roadblock to their acceptance of memory loss. If the person needs to talk about the changes they are noticing, take time to listen. Be as honest and sensitive as you can. Following are other ways you can help:

- Many people with dementia want to share what is happening to them, particularly when they notice problems doing once-familiar things, such as balancing the checkbook or preparing a meal. Take time to listen.
- Because of difficulties with word-finding, the person may need your patience as they try to put feelings into words. Help them find words, but don't force a conversation.
- Remember that as the person loses verbal language skills, they will rely on certain behaviors to communicate thoughts and feelings. It may be helpful to say out loud what the person may be experiencing. Ask "Are you frustrated right now?"
- Find out about support groups in your area for people diagnosed with Alzheimer's disease. The Alzheimer's Association has developed such specialized groups through its local chapters.
- Ask your local Alzheimer's Association chapter or a health care professional about books and articles written by people with dementia. Many videotapes also describe Alzheimer's disease from the perspective of someone with the disease. (See Selected Resources at the end of this Manual for selected books and videos)
- Your efforts to acknowledge and support the emotional needs of the person with dementia can go a long way towards maintaining their quality of life.

Changes in Marital Intimacy

Nearly every aspect of a relationship is affected by the diminished abilities of the impaired partner and the increased responsibilities of the well spouse.

> *"Psychological intimacy is the original glue of important relationships. It is an intangible, subtle, powerful motivator of sexual expression. When this form of intimacy is maintained, a long-term quieting of the inner self occurs. When it disappears, a multitude of sexual and nonsexual complaints may be created. Thus, the significance of psychological intimacy may be nothing less than an avenue to an emotionally rich life."*
>
> *Stephen B. Levine, M.D.*

Intimacy rests upon many interconnected abilities that are affected by dementia. These include the capacity to know what one thinks and feels and to share those emotions and ideas with another person, and the ability to understand verbal and nonverbal communication.

When a married person is affected by Alzheimer's disease, the couple faces enormous challenges. The diminished abilities of the partner with the disease and the increased responsibilities of the well spouse affect every aspect of the relationship. The expression of intimacy, particularly sexuality, is one of the main aspects of marriage that the disease often changes.

Coping with disease-related impairments in memory and behavior may be stressful for the person with dementia. Feelings such as fear, anxiety, depression, anger and low self-esteem are fairly common. They may cause the person to act dependent and cling to their spouse. Such reactions disrupt the marital relationship.

The well spouse may also feel distressed by the emotional and physical demands of caring for the one with dementia. As the need for care increases, there is often a blurring of roles between caregiver and intimate partner. The well spouse may feel alienated by the mate's chronic forgetfulness, repetitious questions and annoying behaviors. The marital commitment is bound to be tested.

Sexuality

A number of chronic diseases and certain medications have been identified as causes of sexual dysfunction. However, little is known about the impact of dementia on sexuality. Data from a few studies of people with Alzheimer's disease indicates that sexual dysfunction may be commonplace. In some cases, persons with dementia may be hypersexual: wanting sex often or more than normal. In other cases, persons with dementia may lose their desire for sexual activity. Also, spouses of persons with Alzheimer's disease may lose their desire to have sex.

Reasons for the loss of sexual functioning are not yet fully understood but a number of factors appear involved. For the impaired person, medications as well as structural changes in the brain and nervous system may account for sexual dysfunction. Also, impotence and decreased sexual desire can be rooted in emotional problems. The well spouse's desire for sex may diminish as the person with dementia begins to seem like a stranger. The spouse may avoid sexual relations when his partner forgets how to make love or immediately forgets when the lovemaking is over. Such incidents may cause the spouse to feel rejected or angry. On the other hand, the well spouse may feel ambivalent about engaging in sex for fear of "taking advantage" of his willing partner.

People with dementia occasionally are overly interested in sex. This hypersexuality may include frequent masturbation and attempts to seduce others. Some men who are impotent may crave sexual activity, resulting in frustration for themselves and their wives. Such behaviors are symptoms of the disease and seem related to brain damage, rather than maliciousness. Furthermore, such behaviors may signal the need for attention, reassurance and closeness instead of the need for sexual gratification. Touching, hugging and other forms of affection may help meet these other emotional needs. Medication is sometimes needed to curb this behavior.

When one or both partners in a marriage face any of these obstacles, mutually satisfying sexual activity may decrease as a priority in the relationship or may no longer be possible to achieve as a couple. However, most couples eventually learn to make the necessary accommodations.

Since sex is a private matter, there is usually a reluctance to discuss it with others. It may be helpful to seek the advice of a professional when problems arise. The person's physician should always be notified for possible medical intervention in cases of persistent sexual aggressiveness. The well spouse, in particular, may need accurate information, support and counseling to cope with the changes in the sexual aspect of marriage. Spouses of people with dementia have learned to adapt in the following ways:

- Exploring new sources of adult companionship or other pleasurable activities.
- Trying nonsexual forms of physical contact with their spouse such as massage, hugging, holding hands and dancing.
- Finding alternatives to sexual intercourse.
- Reflecting on the positive aspects of the past and present relationship.
- Enlisting the support of others to listen to feelings such as love and anger, compassion and guilt.

As your spouse's dementia has progressed, you may have already made many changes in your life. Coming to terms with the challenges to intimacy that the disease presents may be one of the toughest tests. Most spouses eventually meet this challenge. A special grace marks those who have learned to live with the disease and continue to find meaning in the marriage. The heartbreak of dementia may be offset by the fulfillment often experienced in striving "to love for better or worse, in sickness and in health."

Too often the changes in marital intimacy are not addressed, although they affect every couple coping with dementia to some degree. Discussion of these emotional issues with a confidante or within a support group is encouraged. Some books, articles and videotapes are available to help better understand these changes in marital intimacy. (See Selected Resources)

The Family Needs Care, Too

Care for the Caregiver

Maintain your sense of humor. Laughter is good medicine for the daily hassles you encounter.

Explore your religious beliefs with the help of your priest, minister or rabbi.

Alzheimer's disease has been compared to running a marathon, so you need to pace yourself. Eat right, exercise and get plenty of rest.

How do you balance your own needs with the needs of the person with dementia? There is often a strong temptation to do everything possible for someone under your care at the expense of your own physical and emotional health. However, if your own well-being is neglected, the quality of care you provide may be jeopardized. Therefore, it is essential for you to remain healthy by learning to cope with the stresses of caregiving.

Providing care to someone who is becoming increasingly dependent on you may require a change in your priorities. This may appear to be an overwhelming challenge, but if you have adjusted to past difficulties in your life, chances are you can succeed in this challenge, too. There are many ways of coping and no single strategy works for everyone. You might begin by learning as much as you can about the disease. Check out books and videos on the subject of dementia and attend educational seminars. If possible, check out Internet resources listed at the end of this manual. Share this information with family and friends so they will know how best to support you.

Find a physician or other healthcare professional who understands the disease and the impact it might have on you. Support groups made up of people facing similar challenges might also provide the guidance you need. The Alzheimer's Association offers groups of this kind. You may want to seek professional counseling as well.

As a caregiver, it is very important for you to have occasional breaks and to enjoy some leisure time. There are services available to care for your loved one while you take such breaks, including in-home care and/or adult day care, which can allow respite for you a few hours each week. This is important for your own physical and mental health. Other examples of ways to take care of yourself include pursuing hobbies, becoming active in your community or church, and meeting regularly with friends.

Realize from the beginning that you are in a difficult situation. It is likely that the disease will worsen in spite of your best efforts. Nevertheless, take pride in the care and comfort you can give. Your commitment and hard work enable another person to live with dignity.

Caregivers' Bill of Rights

Inasmuch as we, the caregivers, devote ourselves to the support of a loved one, we declare that we have basic inalienable rights. Furthermore, we recognize that we are not alone in our challenge to maintain a humane lifestyle for ourselves and our loved ones. Now therefore, we pledge our support to all who struggle with balancing the responsibilities of daily living. With this in mind, we mandate the following rights:

- The right to live our own life to retain our dignity and sense of self.
- The right to choose the plan of caring that accommodates our needs and the needs of those we care about.
- The right to be recognized as a vital and stabilizing source within our families.
- The right to be free of guilt, anguish and doubt, knowing that the decisions we make are appropriate for our own well-being and that of our loved one.
- The right to love ourselves enough to have the confidence to do the best that we are able.

If we as caregivers practice these rights, disabled people will be provided the best care that we are capable of giving.

"Caregivers' Bill of Rights" excerpted from Gwyther, L., "Clinician and Family: A Partnership for Support." *In Dementia Care: Patient, Family and Community* edited by N. Mace. Baltimore: The Johns Hopkins University Press, 1990.

Involving Family and Friends

Sharing information and coping strategies with relatives and friends gives them the satisfaction of being helpful as well as providing the caregiver and individual with Alzheimer's disease with much needed social support.

Caregivers of individuals recently diagnosed with Alzheimer's disease frequently ask when it is appropriate to share the news of the diagnosis with extended family members and friends. While there is no simple answer, this question raises some significant issues. Some individuals and their families feel that their privacy would be invaded or that friends would treat them differently if the diagnosis were known. Even more damaging is the belief that friends would avoid them if they were privy to this knowledge. A frank discussion of these concerns can reveal other possible outcomes.

Caregivers frequently acknowledge that relatives, friends and others already sense that something is wrong. If caregivers do not share what they know about the individual with Alzheimer's, then others are deprived of the opportunity to understand and make meaning of what they may see as strange behavior. A bewildered and upset response to the disease's symptoms lead uninformed people to limit contact with the individual. An honest statement of the problem can actually encourage people to be helpful to the individual with the disease and the caregiver. Some people may indeed retreat from contact, but those who remain loyal can then be advised on how to be helpful. This open communication in turn can reduce the isolation that some diagnosed individuals and caregivers experience. Sharing information and coping strategies with relatives and friends gives them the satisfaction of being helpful as well as providing the caregiver and person with dementia with much needed social support.

Although individuals with dementia have difficulty remembering recent events, they often retain their memory of the past. One way to interact well with someone who has problems with recent memory is to encourage the individual to reminisce about distant events and memories over which he or she still has mastery. Socializing with old friends and family members who shared in past life experiences can provide the individual with a comfort zone of mutual feelings. However, the person with Alzheimer's is often not able to initiate conversations or plan social occasions. He or she may be worried, fearful or embarrassed over the memory problems. Other people should take the initiative and assume responsibility for prompting memories of the past and arranging social engagements that may be satisfying to all involved.

It is helpful to prepare friends and relatives by letting them know just how important such interactions are to the person with memory problems. Ongoing encounters of this type are quite beneficial, and many caregivers report how much their relative still enjoys attending family reunions and meeting with old school friends, military buddies, club members and church members. In addition, the routines and rituals of everyday life can take on added significance. Going out to dinner, taking a walk, visiting a zoo or park, talking with neighbors and visiting old friends and relatives can be sources of enjoyment for people with memory problems.

Friends and relatives should be encouraged to give their time to both the caregiver and the person with dementia. Family members and friends can provide relief to a caregiver by spending time alone with the individual with dementia. Discomfort with the symptoms of dementia sometimes prevents friends and family members from volunteering their services. If the caregiver prepares family and friends for any troubling symptoms, they may learn how to cope with these difficulties and accept them as part of the disease. For example, explaining that it is best not to correct an error or memory lapse can provide direction to a helper unaccustomed to dealing with someone who has memory and language difficulties. Suggesting topics of conversation or activities to someone spending time with the person with dementia can be helpful. Interested friends and family members will also benefit from gaining greater knowledge of Alzheimer's disease and how best to care for those with the disease. The caregiver should share books and pamphlets about the disease with family and friends for ideas on how they can become involved.

Helping Children Cope

Children can be remarkably sensitive and creative in dealing with people with dementia.

Dementia in a parent, grandparent or great-grandparent will in some way affect a young child. Changes in the relationship between the older person and younger person are bound to take place. With honest communication and some coaching, you can help a child find satisfaction in the changing relationship.

Adults tend to protect children from painful realities, such as dementia. But children are naturally curious and should be given clear and age-appropriate information about the disease. Their questions should be answered simply and honestly. They need to be reassured that they did not cause the disease. They also need opportunities to freely express their feelings of sadness and anger, and they should be given specific suggestions on how they can be helpful. Children cope well if they have a proper understanding of what is happening in their lives.

If a child lives in the same household as the person with dementia, special steps must be taken to ensure the child's welfare. Although a child may want to share in the care of the person, there must be time for the usual activities of childhood such as friends, play and school. A child should not be allowed or expected to provide care at the expense of normal childhood development. Nor should a child have to compete for the attention of his parents, who may be wrapped up in providing care and attending to other responsibilities. Efforts must be made to preserve the integrity of the entire family by balancing everyone's needs, particularly the needs of a child in the midst of a busy household.

Children can be remarkably sensitive and creative in dealing with people with dementia. Both generations may be able to share a number of enjoyable activities such as playing games, taking trips to a park or strolls in the neighborhood, doing simple arts and crafts, playing music, singing, reviewing photo albums or reading aloud story books.

Older children, especially teenagers, may have difficulty accepting how the person with dementia has changed. They may avoid contact. They are also more easily embarrassed than younger children who tend to take the changes in stride. Address the older child's concerns and don't force the child to spend time with the person.

Children usually do not talk about their negative feelings, but instead act them out. A problem at school or with peers may be a sign that a child is experiencing emotional distress. Such problems must be taken seriously. It may be necessary to involve a professional counselor from school or a social service agency.

Several books have been written to help children understand dementia. These books are tailored to particular age groups, from preschoolers to adolescents. A list can be found in the last chapter, Selected Resources.

Acknowledging Spiritual Needs

In a poem entitled "Love," writer May Sarton compares love to a spider's web that is fragile and easily broken. The final lines in the poem read:

Spiders are patient weavers.
They never give up.
And who knows
What keeps them at it?
Hunger, no doubt,
And hope.

Caregivers are people who know hunger and hope. The question of what keeps caregivers at the task of continuing to offer care is at the heart of this chapter. All people have spiritual needs. Even if you do not belong to a church or identify with a particular religion or even profess faith in God, you probably have a need to find meaning in your life. People search for ultimate meaning, for a relationship to something bigger than themselves. The following story from Rabbi Lawrence Kushner's book, Honey from the Rock: Visions of Jewish Mystical Renewal, captures the essence of the word "spirituality."

"One day I visited my daughter's first-grade class. There was a teacher and her assistant and myself. And 18 souls who had been present for but six winters. The air hung with a November chill. The children were playing in four or five groups. Then the mist outside turned imperceptibly into snowflakes. 'Look! It's snowing outside!' one shouted. 'Winter is here!' And the groups crumbled as their members ran to the windows . . . 'Quick Daddy! Help me on with my coat. We're going outside!' And I stood at the window watching the snow fall on my little girl."

In this story, a father finds a world bigger than himself in the delight and wonder he shares with his daughter and her classmates. Once people know this profound sense of connection, they hunger for and seek its repetition throughout life. Following such an experience, there remains a hope that no matter how often the fragile thread of connection is broken, it can be recreated. For the caregiver of the person with Alzheimer's, the threads of hunger and hope may remain. You may hope for a cure for Alzheimer's, hope that you will have the strength to continue in your role as caregiver and hope that you will be able to continue to respond to the person with patience and love. You may hunger for the past, for a sense of meaning, for the experience of being nurtured yourself. Hunger and hope, together with other motivators, may enable you to carry on in the midst of great demands.

Ernest Becker in his book, Escape from Evil, defines spirituality as “an expression of the will to live, the burning desire of the creature to count, to make a difference on the planet because he has lived, has emerged on it and has worked, suffered and died.” This desire to make a difference, to count, may serve as a source of strength and motivation for caregivers. It is not unusual to hear caregivers say, “I may not be able to change the world, but I can affect what goes on in my little corner of it.”

Spiritual Needs of Caregivers

When you can view your caring as an opportunity rather than a burden, the stresses of providing care may diminish. The spiritual need for peace and harmony is enhanced when people have enough inner-strength to help them care freely. If you provide care primarily out of a sense of duty or obligation, the burdens and stresses can seem great. The commitment to caring for the person with Alzheimer’s must be made again and again. Each time the decision is made, you must assess both the needs of the person with Alzheimer’s and your own internal resources. Do you have sufficient inner-strength to offer care with a minimum amount of distress?

One of the chief aspects of spiritual well-being is self-knowledge. All people need to be recognized, appreciated and loved. All people need social interaction. When you assume the role of caregiver, those needs do not disappear. Self-knowledge will enable you to be aware of how much recognition, appreciation, love and social interaction you need or can expect from others.

It is wise to remember that people who choose to be caregivers do so with a complex set of motivations. Some of these motivations are viewed as admirable and altruistic. Love, loyalty, duty, self-sacrifice, familial and/or religious obligation are often among the motivators. Low self-esteem, financial need, rigidity, fear, habit and self-punishment may also be among the motivators. Positive and negative motivations can be present at the same time. Self-knowledge that leads to an awareness of your own needs, values, limitations and complex motivations may be the first step in enabling you to see these factors as opportunities for continued growth.

Caring for people with Alzheimer's elicits a wide range of feelings in the caregiver. The acknowledgment of those feelings is an activity of the spiritual life.

Caring for someone with Alzheimer's elicits a wide range of feelings in the caregiver. The acknowledgment of those feelings is an activity of the spiritual life. Particular feelings that arise again and again are helplessness, anger, aloneness, joy and delight, sorrow and loss.

The "Why did this happen?" question is one that Alzheimer's raises over and over. To acknowledge the randomness of the universe and one's helplessness is to begin to find the strength and capacity to cope. The serenity prayer of Alcoholics Anonymous expresses this request for strength:

> *God, grant me the serenity to accept the things I cannot change,*
> *and the courage to change the things I can, and wisdom*
> *to know the difference.*

The "WHY?" question is an appropriate one and needs to be asked. But, there comes a point when the question no longer serves the questioner, and a decision must be made to abandon the cycle of blame, helplessness and self-pity that it generates. Energy can then be redirected to problem solving and coping. The decision to live with certain mysteries in life is a spiritual one that will likely lead to harmony and peace.

Spiritual Needs of People with Dementia

The seeds of spirituality are sown in childhood. Long before children have words to describe feelings, they know what it is like to be loved or the loneliness of not having someone care for them. These feelings are stored in the long-term memory and can be tapped even in late stages of dementia. Many people with dementia are also able to respond to religious or spiritual symbols and rituals from their childhood. Old memories may be stirred up by participating in religious activities. You can help the person tap into their spirituality in these ways:

- Take a walk in the woods together and appreciate nature's wonders.
- Listen to moving music or favorite religious hymns.

- Read familiar Scripture passages or prayers.
- Enjoy objects of beauty or religious significance.

In addition to tapping into remembered faith, it is important that caregivers be attentive to the issues of grief and loss that confront the person with dementia. The person might mourn over not being able to perform certain tasks independently. Acknowledge the person's feelings of sadness and loss while focusing on remaining abilities. Caregivers contribute to the spiritual well-being of the person when they promote empowerment and respect.

Everyone has a need to be heard. It is important that you listen to the concerns of the person with Alzheimer's and allow them to express anger, even anger at God. Frequently, caregivers and the people they care for try to protect one another from the pain each feels. The result is further isolation. The sharing of an experience that is a source of spiritual nourishment can break down isolation. Read together significant spiritual passages from the Bible for their religious meaning or literary references that convey profound feelings about the human condition.

Commitment to Replenishment

Caring for a person with Alzheimer's means that you must give much of yourself. Acknowledge that you also need to be cared for. Allow others to help you run errands and to give you emotional support. Remember that to gracefully receive care from others is a skill that requires practice. It requires commitment to reach out and ask for help. It requires commitment to accept the offers made by friends and family.

Just as the needs of the person with Alzheimer's change as the disease progresses, so will your needs. Know yourself, acknowledge your feelings, and commit to finding and using sources of replenishment every day. The spider is a patient weaver. May you be patient and gentle with yourself as you assume the challenges ahead.

Know yourself, acknowledge your feelings, and commit to finding and using sources of replenishment every day.

Taking Charge of Legal Matters

The individual must understand the nature of the document they are signing, who it affects and to whom authority has been given.

As the person with Alzheimer's disease lose more and more of their mental capacity, they become less able to make decisions about personal care and the management of personal property. This is where legal tools such as wills, trusts and durable powers of attorney become crucial. Who will make decisions for the person when they can no longer take care of themselves? What are the person's wishes regarding care in the terminal stages of the illness? These are questions that should be addressed early on in Alzheimer's disease, when the person still has the capacity to make decisions.

Planning ahead

Planning ahead for incapacity allows the person with Alzheimer's disease and the family to make choices and decisions. It is important to understand the concept of legal capacity before examining specific options for the management of a person's health, personal care and property. To be considered competent or capable, an individual should have the capacity to understand, to reason and deliberate, and to have a relatively stable set of values. The individual must understand the nature of the document before signing, who it affects, and to whom authority has been given.

The question of an individual's ability to make decisions is complex. It is not an "all-or-nothing" phenomenon. A person who has early-stage dementia and is mildly confused may still be capable of making choices and expressing preferences about healthcare. They may be able to execute a will, but may not be able to make decisions that require a higher level of cognitive ability, such as deciding about the management of property via a living trust. A thorough medical evaluation should provide an accurate impression of the person's capacity for decision-making. Then the medical findings should be discussed with a lawyer.

Living will

The living will is a signed, dated and witnessed declaration in which the person states in advance their wishes regarding care during the terminal stages of an illness. It provides guidance to family members and healthcare providers regarding the use of artificial, life-sustaining procedures such as cardiac resuscitation, tube feeding, the use of antibiotics or dialysis, and the person's wishes regarding transfer to a hospital.

Because the decisions involved in completing a living will are complicated and require knowledge of medical procedures, the person with dementia must be operating at a high level of cognitive ability to complete this document. A person who has early-stage dementia should be able to manage these decisions.

Living wills are only effective if their existence is known. Therefore, the person's physician should agree to honor the expressed wishes in the living will and should have a copy of it on file. Copies should also be available at home in case emergency medical attention is required, and a copy should accompany the person to a nursing home or hospital upon admission.

Durable Power of Attorney for Health Care

A durable power of attorney for health care has advantages over a living will in that it is more flexible and valid throughout the United States. With a durable power of attorney, the person designates a trusted family member or friend to make decisions in the event they are unable to make those judgments independently. The document empowers the designated individual to make selected health care decisions on the person's behalf, including decisions about life and death. The individual receiving this authority is known as the "agent." A power of attorney can only be assigned before the person's incapacity. In cases of Alzheimer's disease, this means in the early or middle stages of the disease. The durable power of attorney can be amended or revoked by the person at any time and in any manner, while they still have the capacity to do so.

In Illinois, the durable power of attorney for health care may specify a date on which it becomes effective. On the other hand, it may state that it is only effective if the agent certifies that the principal (the person giving the authority to another) is no longer able to make decisions. In this case, it goes into effect only when disability strikes. This ensures that the person with a disability such as Alzheimer's disease remains autonomous for as long as possible. The authority of the health care agent may extend beyond the principal's death to matters involving anatomical gifts, autopsy or disposition of the principal's remains.

As with the living will, durable power of attorney for health care forms should be included with the person's medical records, and copies should be available at home in the event they are requested by a health care provider.

Illinois Surrogate Health Care Act

The Illinois Surrogate Health Care Act permits family members or close friends to make decisions about medical treatments on behalf of the person who lacks the ability to make decisions. The act applies when the person has not completed a durable power of attorney for health care or a living will and lacks the capacity to make decisions on their own behalf.

If a durable power of attorney for health care or a living will have not been completed, the law designates a surrogate decision-maker in the following order of priority. Once identified, the surrogate decision-maker is authorized to make decisions regarding medical treatment for the person with Alzheimer's disease.

- court-appointed guardian of the person
- spouse
- adult daughter or son
- parent
- brother or sister
- adult grandchild
- close adult friend (as established by affidavit)
- court-appointed guardian of the estate

Durable Power of Attorney for Property

A durable power of attorney for property instructs an agent to manage the person's property such as income or assets. As in the durable power of attorney for health care, the person designates a trusted family member or friend to make decisions in the event they are unable to make those judgments independently. Some legal planners caution against using this mechanism as the sole means of property management for people with considerable assets.

If a living will or durable power of attorney were not drawn up while the person with Alzheimer's was still capable of comprehensive decision-making, the only legal recourse may be guardianship, which involves the court appointment of a person to the property and personal care of the person with Alzheimer's. The discretion of the guardian is partly restricted, and any decisions, such as consent or refusal of major medical procedures, require a court ruling. It may be useful to petition for guardianship on behalf of the moderately to severely demented person if they have not put into place any of the other legal tools discussed above.

Guardianship not only protects the person from abuse and neglect but also protects from financial exploitation or poor health care decisions.

People with dementia and their families are encouraged to put into place the appropriate legal tools as early in the disease as possible—while the person still has the ability to make good decisions.

Trusts

A revocable living trust is a legal means of giving a designated person or institution, known as the "trustee," the right to manage all or a portion of a person's assets, including property and income. Trusts of this kind are set up for people with substantial assets. They should be established in the early stages of Alzheimer's disease, when the person's cognitive abilities are still intact. A trustee can take control immediately or only under certain conditions, such as when the person becomes disabled and loses the ability to make decisions. Terms of the trust can be amended or revoked at any time.

Wills

A will is the traditional means of planning for the distribution of assets after one's death. A will contains a bequest plan, which designates how property will be divided. Since making a will does not require a high level of cognitive ability, it can be completed in the early or middle stages of Alzheimer's disease. The will is only valid, however, if the person possesses the following abilities when executing the will:

- Awareness of making a will.
- Knowledge of the extent of property to be bequeathed.

- Ability to formulate a reasonable plan for the distribution of the property.
- Ability to understand the relationship between oneself and the recipients of one's belongings.

Persons with dementia and their families are strongly encouraged to put into place the appropriate legal tools as early in the disease as possible, while the person still has the ability to make important decisions. Planning for the future will clarify everyone's legal and financial roles and responsibilities.

Safety Concerns

Tips for Traveling

When traveling, try to follow the routine that is followed at home. And be sure to allow plenty of time for everything.

Traveling long distances with a person in the early stage of dementia may still be quite enjoyable. As dementia advances, however, traveling may become unpredictable as the person becomes more confused. Plan ahead for a trip by gathering important documents: insurance cards, passports, your physician's phone number, refills on medications and a copy of medical records in case the person with dementia needs to see a physician while away. It might be a good idea to pack these items in carry-on bags so they will not get lost en route. Remember to bring sufficient resources in case you must change your plans suddenly and return home. Also, you may want to bring along a brief letter from your physician to the airline or hotel to expedite a change in plans.

When traveling, try to follow the routine that is followed at home if possible. And be sure to allow plenty of time for each activity. Plan for rest periods throughout the day. For example, if you're taking a tour by bus, you may want to remain in the bus on occasion so the person can take a nap instead of visiting all the sights.

The person who is at risk of wandering may also do so in an unfamiliar place. Make sure the person wears an identity bracelet or necklace, provided by "The Safe Return" program through the Alzheimer's Association. Put a card with the name and address of the hotel where you are staying in the person's pocket. In addition, you may want to carry a recent photo of the person in case they get lost.

Traveling may also make the person more anxious, thus bringing along an anti-anxiety medicine may be necessary. You might want to pack items the person enjoys looking at or holding to provide comfort and reduce nervous energy. Toileting is an issue that requires some forethought when you are traveling. If you are driving, stop at rest-area toilets every couple of hours. Make sure a full change of clothing is readily available. In hotel rooms, be sure to keep the path to the toilet well-lighted and leave the bathroom light on at night.

A few more travel tips to keep in mind: If you are traveling by car, never leave the person with dementia alone in the car. Try to bring along a relative or friend to share in the driving. And if you are traveling by plane, you may want to notify the airline ahead of time, so you can ask for any assistance.

The Dangers of Driving

Does the person you are caring for have problems driving a car? This section addresses what caregivers can do when the person with dementia should no longer be on the road. Driving a car safely requires a complex set of skills and abilities. These include good judgment, orientation, perception, memory, coordination, alertness, and the ability to make quick decisions. Most of these abilities are affected to some degree by dementia.

A person with dementia may appear to be driving safely but may have lost the ability to respond appropriately or react quickly enough to an unexpected problem on the road. For most people, driving becomes routine and automatic. Even when there are severe memory problems, people with dementia may be able to follow their habitual way of driving. But if the person is not able to change quickly from a habitual response to a new response when the situation demands it, that person should not be driving. To continue to do so may have grave consequences for that person and the general public.

A person with dementia may appear to be driving safely but may have lost the ability to respond appropriately or react quickly enough to an unexpected problem on the road.

It is not always easy to know when driving should be terminated. Drivers who have very mild cognitive problems may be able to continue driving for a time with certain limitations. These limitations may include driving only short distances from home, not driving on expressways or during rush hours, not driving at night or only driving with a companion.

The American Medical Association's guidelines on driving state that "once the presence of dementia is established and it is demonstrated that the person is at risk of making errors in judgment likely to affect the ability to drive safely, an individual should not drive again."

Most people with dementia voluntarily decide to stop driving when they feel they are not as sharp as they used to be. However, there are many people with dementia who are unaware of their deficits and continue to drive beyond the point when they are safe on the road. Family members need to monitor how the person is doing when driving. They might watch for unaccounted periods of time when the person is driving and might be lost. They might check the car for unexplained bumps or dents. Family members might try riding with the person to personally assess how they are driving. Family members have the responsibility to intervene if they feel the person is not able to make good decisions behind the wheel.

How you can help the person to stop driving?

When the person's driving causes concern, try discussing this with them if possible. In an understanding and helpful way, the person should be made aware of the potential dangers of continuing to drive. Alternatives should be suggested to help maintain the person's independence and mobility. Some possibilities include asking family or friends to drive or using a taxi service or public transportation.

Sometimes a person will refuse to give up driving. If this happens, here are some suggestions:

- Have the person's physician tell them to stop driving. Physicians are usually willing to write the order "Do not drive" on a prescription pad. This can be shown to the person when a reminder is needed. A formal letter can also be written.
- Arrange for a formal evaluation at a driver evaluation program under the direction of an expert on driving performance. The evaluation, which can cost from $125 to $500, includes a "behind-the-wheel" test as well as other tests of driving skills. A written report describes their driving performance and a recommendation is made as to whether driving should continue or discontinue. Such a report may persuade a person to stop driving if they are deemed unsafe. Call a staff member at the Rush Alzheimer's Disease Center at (312) 942-4463 for a list of driver evaluation programs in the local area.
- Make the automobile unavailable to the person. This can be accomplished in a number of ways. The car can be parked some distance from the house, the car keys can be conveniently "lost," or the car itself may be disabled by a variety of means such as disconnecting the battery or removing the distributor cap. The latter is a simple procedure that can be easily reversed when others need the car. Ask a service station attendant to demonstrate how this can be done.

Restricting or stopping driving may become an added burden if the person's spouse does not drive. If this is the case, the spouse may consider taking driving lessons. Also, people with dementia who become too impaired to take public transportation may qualify for special services provided for the disabled. An application for these special transportation services can be obtained from your local transit authority. In most areas, disabled people are picked up in a van and may be escorted by the caregiver. A nominal fee is charged for this service.

In Chicago, call (312) 521-1154 for information about CTA Special Services. Transportation services are also available in suburban Cook County for disabled seniors. For this information, call the Suburban Area Agency on Aging, (708) 383-0258. Local governments may also sponsor special transportation services.

In some states, the department of motor vehicles may investigate and suspend a license if it receives written notice from a physician that a person's medical condition prevents safe driving. If an impaired person continues to drive in Illinois, the Medical Review Board of the Department of Motor Vehicles in Springfield should be notified by calling (217) 782-7246. The person may be ordered for testing or their license may be revoked outright.

If a person has been told by a physician not to drive and continues to do so, the caregiver may be found negligent if that person has an accident or injures someone. This could lead to serious consequences. In many respects, you face a dilemma when determining a person's ability to drive. Concern for depriving the person of independence needs to be weighed against the potential risks of unsafe driving. Please consult your physician when such decisions need to be made.

Creating a Safe Home

If the person wanders, put tape or a piece of fabric across the door frame at eye level to keep them from wandering outdoors.

Install safety gates at the tops of stairways so the person won't fall down the stairs.

Secure all doors and windows; special locks may be necessary.

The environments in which we live or our everyday surroundings are made up of a rich variety of things we see, hear, smell, taste and touch. Though many of us may not pay much attention to our surroundings, we can usually identify things that we find uncomfortable or distressing and take action to correct any situations that cause us discomfort. To block out a noisy street, we can shut the window. If it's chilly, we might put on a sweater. But for the person with dementia, these solutions are not so simple.

Dementia changes a person's ability to understand, interpret and respond to what is happening in the environment. The person may easily be confused by what goes on around them. As a caregiver, one of your most important responsibilities is to monitor the home environment. Start by paying careful attention to how the person responds to the sounds and sights of their surroundings.

Controlling noise and activity

Noise and activity can confuse and trouble the person with dementia. They may become overwhelmed by noise or not be able to track where sounds are coming from and think what's happening on television is actually taking place in the room. Similarly, when they hear someone talking loudly, they may think they are being scolded. The individual may feel threatened and become tearful or aggressive. Loud noises such as from a hammer or blender can cause stress and confusion. Even certain music may be disturbing to the person. Try as much as possible to limit confusing noise in the environment. Shut off the radio and television when they aren't in use. If noisy activities must take place in the home, see that the person is away during that time. When entertaining guests, limit the numbers of people coming and going at one time to keep commotion to a minimum.

Handling problems with visual stimuli

Just as noises can overwhelm and confuse the person, so can visual stimuli. Patterns on drapes, floor coverings or clothing may look three-dimensional to the person with dementia. They may try to pick up the "pieces" or trip on a patterned floor. Seeing one's face in a mirror might confuse them and they might also mistake their image for that of another person. Rearranged furniture in a room or the addition of holiday decorations can also be troubling.

The key is to keep the environment consistent. Minimize clutter in the person's surroundings. This will help them get around more safely. If mirrors are troublesome, cover or remove them. To prevent slips or falls, remove area rugs or tack them down. If you're installing floor covering, choose a simple pattern not a busy one. Night-lights in the hallways will help the person see at night. An excellent book that is full of practical advice about home safety is *Homes That Help: Advice From Caregivers for Creating a Supportive Home*. See "Selected Resources" at the end of this Manual.

Lock up anything that could be dangerous to the person such as tools, firearms, kitchen knives, cleaning fluids, even medicines.

In the bathroom, put nonskid mats in the bathtub or shower and install "grab bars" near the tub, shower or toilet.

Providing Daily Care

Keeping Active

Persons with dementia need to be active and have meaningful things to do. "Activity" refers to the doing or interaction between the individual and their environment, defined in its broadest terms to include physical, social, and cultural environments. Activities are the tasks that give purpose, meaning, and definition to one's daily life. Working in a kitchen or a yard, reading a book, listening to music, singing a song, watching television, or visiting with a neighbor are activities. Activities also include things related to taking care of oneself, such as bathing, grooming, and eating. Most of these activities are tasks that a person does routinely throughout life and can be done without much thought. Such activities are integral parts one one's day and contribute to feelings of control and mastery.

A person with dementia usually has difficulty deciding what to do each day. The day may appear like a vast space of unstructured time. This may evoke feelings of worry and fear. The apathy and tendency to withdraw from others sometimes displayed by persons with dementia may be related to difficulty with planning and initiating activities and tasks. The person with dementia is not being lazy or unproductive, but may need someone to give structure and direction to their day. Jitka Zgola, an occupational therapist specializing in Alzheimer's disease writes:

"We do things to define ourselves as individuals, to exert control over our environment, and to develop and secure meaningful relationships with others. Alzheimer's disease gradually erodes a person's ability to engage in many of the activities that fulfill these basic psychosocial needs. It then becomes the responsibility of the [caregiver] to offer the [person] alternatives that enable him or her to continue with meaningful activities."

Activity ideas

There are general types of activities that persons need to be involved in each day. A good variety of activities can be both stimulating for the person with dementia and can be a diversion or help to the caregiver. A balance between household and leisure activities will include social, physical, cognitive and spiritual activities.

Household activities

Washing dishes, sorting mail, clipping coupons, sorting socks, folding laundry, sweeping the floor, polishing shoes, raking leaves, weeding in the garden, watering plants, rolling dough, snapping green beans, sorting recycling materials, sorting cards, are fairly simple work activities that can be done independently or with some assistance. When the person with dementia engages in these activities, it is important to dignify the work and be thankful for their assistance.

Music activities

Music has universal appeal. Listening to a specific song may or may not be familiar to the individual, but it may be enjoyable because of its rhythmic quality and its ability to trigger emotions and memories. Musical activities might include playing records or tapes, singing old familiar songs, dancing, reminiscing about the music and past events, or playing musical games like "Name that Tune." Listening to a favorite musical or opera and discussing the story and the composers can be enjoyed alone or together. Consider attending a concert or an afternoon matinee of a musical production. Such activities might also be useful for a visitor unsure about what to do or talk about during a visit.

Pets

There is something magical about the presence of a dog, a cat, or a bird which seems to bring people to life. Pets can offer opportunities for a person with dementia to still enjoy some responsibilities. Being with an animal also increases socialization, decreases anxiety, and provides a nice diversion from the frustration of memory loss. Activities that incorporate the use of such animals can be basic pet care like grooming, feeding, and exercise.

Gardening

Staying connected to nature is an important way to be productive and care for other living things. Working with plants indoors or in an outdoor garden can spur memories of past summer days and enjoyable times spent outside. Planting herbs, flowers, and vegetables can help support remaining talents and provide an ongoing project. Watering the plants each day, discussing their progress, and reminiscing about past gardening experiences make the days fuller and more meaningful.

Children

Staying in touch with children of all ages keeps a bridge between the generations and can often stimulate conversation and memories. Both children and older adults increase their self-esteem, develop mutual respect, and form deeper bonds if they can enjoy their time together. Consider playing simple board games or reading stories or books together. Consider visiting relatives with small children and having young mothers visit with their babies. Walks in the park and school yards provide exercise and trigger conversations about children. Consider attending school or church programs involving young people.

Outings

Early in the disease, outings that were fun in the past should be continued. Consider such outings even as the disease progresses and modify them as needed. Trips can include walks at the zoo, botanical gardens, forest preserves or shopping malls. A swimming pool during a slow time offers great sensory stimulation. You may want to consider using a business card for such public outings that states, “My companion has Alzheimer’s disease. Thanks for your consideration.” This information can be shared with store clerks and restaurant staff and can make outings more comfortable for all involved. Outings should be carefully planned based on length of the activity, time of day, and destination that allows for maximum success.

Physical fitness

Staying physically active is a key component of well-being. Not only does exercise provide physical benefits but it can also improve one’s mood. A daily walking routine is one of the simplest and most beneficial physical activities. If the person with dementia walks alone, then an ongoing assessment of safety is crucial. It is a challenge to allow the person with dementia to be independent while at the same time planning for safety. Consider making “Sit and Be Fit” a regular part of a daily routine. This is a TV program that emphasizes range of motion and low-impact aerobic exercise. There are also exercise videos specifically tailored to the exercise requirements of older adults. As in any exercise program, a standard routine should be followed to ensure proper warm-up and cool-down. Exercise should always be followed by a drink of water or juice to ensure proper hydration.

Adapting activities

All activities can be designed to meet the abilities and needs of the person with dementia. Whether the person is participating fully or is a passive observer, each activity can be adjusted to meet one's specific needs. The idea of "grading" an activity to suit one's abilities at different stages of dementia is suggested by Zgola in the book, *Key Elements of Dementia Care*. An example of modifying or "grading" an activity such as baking cookies can be seen at several levels:

1 Independent-organizer-doer (e.g., decides on ingredients, shops, bakes).

2. Independent-doer (e.g., makes cookies, once the recipe and ingredients are prepared).

3. Doer-of-a-specific-task (e.g., measures, mixes and pours, depending on ability).

4. Doer-of-a-modified-task (e.g., does a specific step with help or supervision).

5. Observer-monitor (e.g., listens for the oven timer to go off).

6. Observer-advisor (e.g., tells of own experience).

7. Observer-critic (e.g., tastes cookies).

8. Observer (e.g., watches or listens).

Regardless of the activities that are chosen to fill one's day, a caregiver must take the lead and choose things that are most enjoyable for all concerned. Whether an activity can be done alone by someone with dementia or must be carried out with others, the main point is to maximize opportunities for success and enjoyment.

Ensuring Personal Hygiene

The person with dementia may eventually need assistance with bathing, grooming and dressing. Since these are usually private activities, the person may refuse help. With a calm, matter-of-fact approach you can usually get cooperation. Bathing the person can be one of the caregiver's most difficult challenges. Many people with dementia develop fear about bathing. To reduce fear about a bath or a shower, consider these tips:

- Start by organizing all the items you need for the bath; use moisturizing soap and avoid bubble bath or bath oils because they can make the tub slippery and may cause urinary tract infections.
- Keep the bathroom warm and well lighted.
- Avoid discussion about the need for a bath or shower. Be matter-of-fact: "It is time for a bath now."
- If the person is embarrassed about being bathed, try covering them with clothing or a towel and then using a sponge or washcloth to bathe underneath the covering.
- If the person is frightened, distract her with conversation.
- Bathing is not necessary every day; two to three times a week may be sufficient.
- Washing the face, hands and genital area may be all that is necessary.
- It may be easier to wash a person's hair in the sink, especially if they usually bathe in the tub. You can buy a hose attachment for the sink.
- Try to adhere to the person's lifelong bathing habits. For example, if the person always took a bath before bed or a shower just after breakfast, try to follow this routine.
- Despite your best efforts, someone else, such as a friend or relative, may be more effective in helping with the bathing. A paid professional person from a home care agency may work well, too.

After a bath, pat the person's skin with a towel and dry off completely. To prevent rashes or infections, make sure the person is dry between folds of skin. Apply a thin layer of cornstarch under folds of skin. Cornstarch is more absorbent than baby powder. If incontinence is an issue, apply a protective ointment to protect the skin.

Oral hygiene

Good oral hygiene is essential for the person with dementia. When regularly practiced, it prevents dental problems and promotes good nutrition. The following tips may be helpful:

- You may need to demonstrate the brushing motion for cleaning teeth or dentures, step by step. You may want to brush your teeth at the same time the person is brushing theirs.
- Supervise denture cleaning and rinse their mouth after each meal if dentures are worn.
- If you must brush the person's teeth, try a long-handled or angled toothbrush, or one that is electric.

Dressing

A person with dementia often takes more time to dress than in the past. It can be difficult for the person to organize things and make decisions. The person may inappropriately layer clothes or select the wrong clothing for the season. They may wear clashing colors or forget to put on some item of clothing. Allow the person to dress on their own for as long as possible:

- Lay clothes out in the order a person should put them on such as underclothes first and then a skirt and sweater.
- If necessary, hand the person each item of clothing or give step-by-step instructions as needed.
- Eliminate a large selection of clothes. Keep only seasonal clothes in the closet or dresser and reduce the number of clothing choices.
- You may want to keep the closet locked and put out one outfit at a time.
- A person may try to wear the same clothing every day. If so, buy three or four sets of the same clothes and rotate them.
- Clothing should be loose-fitting and comfortable. Women should avoid girdles, control-top pantyhose, knee-high nylons, garters, high heels, constricting socks and binding bras. Short cotton socks and loose cotton underwear are best.
- If shoelaces, zippers, buttons and buckles become difficult to manage, try Velcro tape or large zipper pulls for clothing; slip-on shoes that won't slide off or sports shoes; sneakers with Velcro closures and pants with elastic waistbands.

Follow these safety measures:

Never leave a confused or frail person alone in the tub.

Always check the water temperature before the person gets in the tub.

Use plastic containers rather than glass.

Use a rubber bath mat and install safety bars in the tub.

A sturdy "shower chair" in the tub or shower will support a person who is unsteady. It could prevent falls. Special chairs are available from drug stores and medical supply stores.

Personal grooming

Grooming is another important daily activity that should be encouraged for as long as possible. Encourage a woman to wear makeup if she has always worn it. Stick to powder and lipstick only and avoid eye makeup. Encourage a man to shave and help him as needed. Use an electric razor to ensure safety. It's a good idea to continue taking the person to the barber or beauty shop or it may be possible to arrange for the barber or beautician to come to your home. Always keep the person's nails clean and trimmed.

Promoting Mobility and Exercise

Problems with mobility may occur in the middle to late stages of Alzheimer's disease. People with dementia who are able to walk and move independently tend to maintain a positive outlook and a good quality of life. As control of their life decreases because of the disease, their ability to walk encourages self-confidence. The body needs to move to maintain use of muscles and joints and promote good cardiovascular functioning, weight control, healthy sleep habits and healthy skin. Getting outside every day for a walk should be part of the daily routine. An exercise routine is also encouraged.

The person with Alzheimer's disease may have some problems that limit their mobility and ability to exercise. These include poor endurance, poor coordination, sore feet, an acute illness and confinement to bed. You can encourage mobility by suggesting simple activities around the home such as sweeping and dusting. Try to make the exercise fun by counting repetitions. Have the person wear a radio with earphones to prevent them from being distracted by noises in the room. Suggest the person use a stationary bike to exercise. Balls or balloons can be used for stretching. Be sure the person is safe when they exercise.

Dealing with immobility

If the person cannot move on their own, you can move their body joints with "range of motion" exercises. Move each joint six to eight times. A physical therapist, nurse or occupational therapist should demonstrate this method for you. If these exercises are not done correctly, joints can be damaged. Helping the immobile person to move is very important because it slows the breakdown of skin and contracture of arms, hands and legs.

Here, too, are suggestions to help the bedridden person be more comfortable:

- To reduce pressure sores, use specialized seat cushions and bed mattresses.
- Make sure to reposition the person at least every two hours.
- When the person is seated, give them a lap-board to rest the arms and help support the upper body.
- A wedge-shaped cushion for the chair that is high in the front and slants to the back of the chair will help the person sit up straight and prevent them from sliding out of the chair.

Have the person hold an object, such as a washcloth, while being moved. They will be less likely to grab onto you or the furniture.

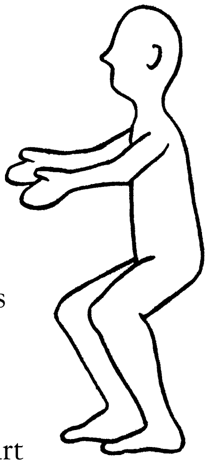
If the person is weak on one side, lean toward their stronger side so they can help you with the repositioning.

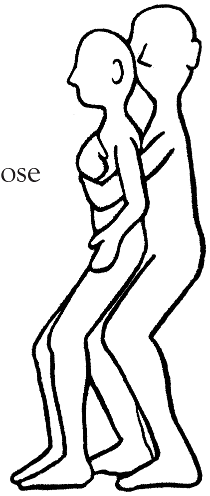
When lifting the person, slide them to the edge of the chair or the bed. Use a transfer belt that is wrapped around their waist. Face the person, put your hands under the belt on either side of the waist, bend your knees and then pull up. Use your thigh muscles to raise the person from a seated into a standing position.

When the problem is too much mobility

Sometimes a person with dementia walks or paces for hours. Pacing may actually help to ease tension. However, if the person is too active, they may be losing weight and will need to be closely monitored. Make sure the person has sturdy, comfortable walking shoes. Frequent snacks or meals served "on the move" may reduce the possibility of excessive weight loss.

Although it should only be implemented as a last resort, a restraining device may have to be used if the person is unsafe to oneself or others. A restraint can be a vest-like garment that is tied to a chair. Such equipment can be purchased at medical supply stores. Ask a health care professional to demonstrate how to use the restraints to ensure they are used safely and correctly; misuse may result in serious injury.





Body mechanics

You must always be aware of your own strength when assisting the person. An injured back, for example, will greatly limit your ability to provide care. To avoid injury when lifting someone, try to use your body wisely. Practice "body mechanics," the principles of which are described below:

- When lifting, bend at the knees and then straighten your thigh muscles; keep your back straight and do not bend at the waist.
- Hold the person to be lifted as close to you as possible to avoid reaching away from your body.
- Keep a wide base of support by placing one foot in front of the other or spacing your feet comfortably apart.
- Use little steps to move the person from one seat to another; do not twist your body.

A physical therapist, nurse or occupational therapist can demonstrate these techniques for you. Ask your physician for a referral to one of these professionals.

Adapted with permission from Hellen, C. Alzheimer's Disease: Activity - Focused Care. Stoneham, MA: Andover Medical Publishers, Inc., 1998.

Dealing with Incontinence

A "commode chair" might be useful to the person, particularly at night. The chair is a portable toilet equipped with a removable bedpan.

If the incontinent person is male, consider having him sit down to urinate rather than stand. This may be effective if he is agitated or unsteady on his feet.

Loss of bowel and bladder control or "incontinence" may occur as Alzheimer's disease progresses into the late stage. Bowel incontinence is a separate problem from bladder incontinence, and a less common one. One can occur without the other. Whenever incontinence occurs, the person may either be unaware of the problem or, at the other extreme, very upset by it.

Bladder incontinence

Bladder or urine incontinence may occur in a number of ways: leaking or dribbling of urine, emptying of the bladder at once, soiled undergarments or bed linens. In any case, if urine incontinence is a problem, a physician should be consulted. There may be a treatable cause of the incontinence such as a urinary tract infection, enlarged prostate gland, dehydration, uncontrolled diabetes, and use of water pills or excessive amounts of caffeine. The physician will want to know several things about the incontinence, such as:

- Does the person leak urine when they laugh, cough or lift something?
- Does the person urinate frequently and can they get to the bathroom on time?
- Are they urinating in improper places?
- Is the person taking diuretics, antihistamines, antidepressants or sedatives?
- Is this a regular or occasional problem?

First of all, you may need to remind the person to go to the toilet every two to three hours in an effort to minimize or prevent incontinence. It is important to keep the person's clothing comfortable, and easy to remove. Jogging suits, for example, are simple to put on and take off. Keeping a diary of the person's toilet and fluid intake habits may help manage the incontinence. Does the person urinate first thing in the morning or right after drinking caffeinated fluids? Use this information to develop a schedule.

Make sure the person drinks at least six 8-ounce glasses of fluid each day. Don't greatly restrict fluids unless a fluid-restricted diet has been recommended. If incontinence occurs at night, you may want to limit fluids after 6 p.m. or 7 p.m. Before bedtime, fresh fruit rather than fluids can quench the thirst.

If the person is confused, using the bathroom will be a challenge. There are ways you can help minimize the confusion, such as marking the bathroom door with a colorful sign that reads, "TOILET." The bathroom should be safe and comfortable; the person may get agitated if the lighting is too bright, or the temperature is too warm or too cold. The toilet seat should be stable and at a good height. Raised toilet seats are available at medical supply stores. Public restrooms may present special problems for the person with dementia. If possible, try to assist the person when using a public bathroom.

Many products for incontinence are available in drug stores and medical supply stores. These products include adult disposable diapers, bed protectors and waterproof mattress covers.

The person may be confused by the roll of toilet paper. You may need to give them the proper amount of paper and help them use it correctly.

Care of the incontinent person's skin is crucial. After each episode of incontinence, wash the person's skin with soap and water, dry with a towel and swab with lotions or ointments. This will prevent breakdown of the skin.

Addressing Nutritional Needs

A person with Alzheimer's disease may have rigid likes and dislikes, often preferring familiar foods cooked in familiar ways. New foods may be confusing.

In the early stage of Alzheimer's disease, eating habits usually do not change unless the person lives alone. In this case, there is a chance that meals are skipped or forgotten. There is also the risk of burning foods left cooking on the stove and starting a house fire. These are signs that the person probably should not be living alone any longer. In the meantime, foods may have to be purchased that are easy to prepare. Reminding the person by phone to eat may be sufficient. On the other hand, someone may have to prepare the meals. You may be able to arrange home-delivered meals through a local social service agency or catering service.

It is not unusual for a person with Alzheimer's disease to have a change in eating patterns in the middle and late stages. The person may no longer be aware of a mealtime schedule. Food may be either of increased interest, or of little or no interest. The person may forget how to cook and eat only a limited variety of foods. Whatever the case may be, a person with Alzheimer's disease may not be getting proper nutrition. Here are some suggestions for improving eating habits.

Mealtime at home

- Provide a quiet environment and regular routine to prevent confusion. Avoid over-stimulation with television, noise and too many people. You may want to play soft, relaxing music during mealtime.
- Try offering just one food at a time instead of filling the plate and table with too many things, which may be distracting.
- If the person is on a sugar-restricted (diabetic) or salt-restricted diet, try to keep certain foods out of reach such as ketchup, vinegar, oil, salt and pepper. A locksmith can put a lock on the refrigerator door if necessary. Putting masking tape near the top and/or bottom of the door may be enough of a hindrance. Childproof locks can secure cabinets.
- If a person has dentures, make sure they are tight-fitting. Loose dentures may cause choking or pain, making it difficult to eat. It may be best to leave loose dentures out until the person can be refitted for new dentures.
- A person may eat with their fingers. Offer finger food such as cheese, small sandwiches, kabobs, fried chicken, fresh fruits or vegetables. Sandwiches made with pita bread are easy to handle.

- Have the person wear a bib to prevent soiling their clothing. You may want to use a plastic or cloth cape that can be purchased at a wholesale outlet for beauty supplies.

Utensils

- Make sure the dish and placemat are different colors so they are more visible. To keep dishes from sliding, try putting a wet washcloth or suction cups underneath the dishes. Suction cups are available at medical supply houses. You may also want to try skid-resistant placemats.
- A bowl is usually easier to manage than a plate. However, a "plate guard" can keep food from being pushed off a plate. You can also use a "scoop dish" that can be purchased at medical supply stores.
- Travel mugs or spill-proof cups are useful for drinking soups and beverages.
- To help the person "catch on" to the motion of eating, place the fork or spoon in their hand, and help them guide the utensil to the mouth. Visual and verbal cues are often helpful, such as saying, "Put the spoon in your mouth" and then demonstrating this action.
- If hand coordination is a problem, try using utensils with large handles. You can purchase these or use foam rubber to build up the handles of your spoons, forks and knives.

Dining at a restaurant

- To avoid anxiety while waiting to be served, choose quiet, well-lighted restaurants where service is fast but friendly.
- Consider carrying printed cards to hand waiters that read: "My companion has Alzheimer's disease and cannot always understand you. Your understanding and patience will be appreciated."

Weight loss

As Alzheimer's disease progresses, weight loss is sometimes a problem. The person with the disease may have a loss of appetite or difficulty chewing or swallowing. Most often, increased pacing and activity without appropriate food intake causes weight loss. Following are ways you can help increase the person's appetite and the amount of food they eat:

A person who has forgotten what they have just eaten may ask for more food right after a meal. When this happens, offer nutritious snacks. If weight gain is a problem, try celery, carrots, fresh fruit or other low-calorie snacks.

- Encourage the person to eat high-calorie, nutritious foods. Offer high-calorie snacks such as protein milk shakes. You can purchase high-protein drinks and powders at any drugstore. Put pureed food in instant breakfast or high protein drinks. Let the person drink the food instead.
- Offer a multivitamin once a day.
- Double portions of breakfast food as the person will often eat breakfast, since it is the first meal of the day.
- Don't skimp on fats. Use extra cooking oil, margarine, butter and mayonnaise in cooking and preparing food.
- Consult your physician if the person has significant weight loss, such as 10 pounds in a month.

Problems with swallowing

As Alzheimer's disease progresses to the late stage, the person may no longer have the coordination to chew and swallow correctly, which can lead to poor nutrition and weight loss. If there is choking with each bite of food, there is a risk that the food could go into the lungs and cause pneumonia. These suggestions may ease problems with swallowing:

- Make sure that food is cut up in small pieces and is soft enough to eat.
- Ground or pureed foods may ensure safe swallowing. You can grind or puree most foods in a blender or a baby food grinder.
- Offer other soft foods such as ice cream, milk shakes, yogurt, cream soups, applesauce, Jello or custard.
- Thin liquids are most difficult to swallow. Remember these tips:
  Do not have the person use a straw. Instead, have them drink small sips from a cup.
  Milk may not be a good choice; it tends to get caught in the throat.

- Cold drinks are easier to swallow than hot drinks.
- A product called "Thick-It" is available in most drugstores. It can be added to liquids to thicken their consistency.

- Don't hurry the person. Each mouthful should be chewed and swallowed before the person takes another bite.
- Don't feed a person who is drowsy or lying down. The person should be in an upright, sitting position during the meal, and for at least 20 minutes after the meal.
- When swallowing, have the person keep their neck forward and chin down.
- A book called *The Non-Chew Cookbook* is available from Wilson Publishing Co., P.O. Box 2190, Glenwood Springs, Colo., 81602; order by calling (303) 945-5600.

Recommendations may vary for each person. Try not to lose hope. Some people may go through phases of having a poor appetite and then resume better eating habits. Try to make mealtime a social, enjoyable activity.

Managing Health and Understanding Behaviors

Understanding Behavior as a Form of Communication

With any person the way we act and behave is really a form of communication. It tells those around us what we are thinking and what we are feeling. Along with what people say, their behavior and actions are an important indicator of their thoughts and moods.

People with Alzheimer's disease begin to have more trouble expressing themselves verbally. They are not always able to tell us what they are feeling and thinking. For this reason, the behaviors they exhibit really become an important way for them to communicate with those around them. Looking closely at their behaviors becomes our chance to better understand what the person might be feeling.

This might take a change in attitude on the part of the caregiver. Years ago it was thought that the behaviors exhibited by the person with Alzheimer's disease were an unfortunate and inevitable part of the disease process. It was thought that the best course of action was to try and stop the behavior without really looking at what might be causing the person to act in such a way.

We now undestand that to best meet the needs of the person with Alzheimer's disease it is more important to look at all behaviors, both positive and negative, and ask what might the person be feeling to respond in such a way. If the behavior they are exhibiting seems positive we want to encourage that to continue. If the behavior they are exhibiting is negative and unpleasant for the person we want to learn why that might be happening and think of ways to reduce it from happening again.

When looking at the behaviors that someone is exhibiting a person takes on the role of an investigator. One must ask such questions as what might the person be feeling and why would they be feeling that way? Are there any factors that might be influencing the person? Some of these factors include emotional and physical well-being, environmental factors, and the approaches of others.

Emotional Well-Being

Our emotional well-being greatly influences how we act. When we are feeling down, overwhelmed or scared we will show it through our behavior. People with Alzheimer's disease often feel this way. Their self-esteem is often lowered because of the confusion and uncertainty they are experiencing. They can also become stressed easily if there is a change in routine. If more people are over to visit or if they are going out to a new location they can become more agitated or anxious. At times they might become scared or frightened.

Behaviors are a a form of communication. They tell the caregiver what the person with Alzheimer's might be thinking and feeling.

Physical Well-being

Another factor that can influence how we act is our physical well-being. People with Alzheimer's disease are not always able to tell others when they are feeling uncomfortable or in pain. As family members we have to be very observant for any of the following physical problems:

- negative reaction to medication
- pain
- impaired sleep
- infections
- dehydration and malnutrition
- constipation
- poor vision and hearing

Environmental Factors

Sometimes the environment can be confusing or overwhelming for anyone. This can especially be true for a person who is confused. Finding their way from one room to the other can be stressful and difficult. This is true even in a home where they have lived many years. Noise around them might be more then they can tolerate, such as TV, radio, and other's talking or laughing. You might need to look around your home and see if there is anything that could be adding to the stress of the person.

Approaches from Others

The final area of stress that can influence the person's behavior is the approach of others around them. If unrealistic expectations or demands are placed on the person it will probably add to their levels of anxiety. At times it can be difficult to remember that the person might not be able to do all the tasks that they had done before. It is not always easy to accept the fluctuation with this disease, where one day their abilities can greatly differ from another day. As caregivers we must keep in mind that this disease can make even simple activities difficult for the person to perform.

Also, sometimes a person's verbal response can add to the anxiety of the person with Alzheimer's disease. People with dementia are not always able to understand words said to them but they are very good at picking up on the mood of the person. If their caregiver shows that they are angry, frustrated or annoyed the person with AD often becomes aware of this. The most successful caregivers find ways to keep these emotions from the person. This is not always easy since these are often common emotions for a caregiver. It takes practice to see what response is the most helpful for the person with AD. As caregivers we can not be too hard on ourselves when we make mistakes.

By looking at what might be causing a person to be acting in such a way we will be able to have a better understanding of what the person with AD might be feeling. When we have a better understanding of what they might be feeling we get better at meeting their needs. For any caregiver the goal is to help the person with Alzheimer's disease to feel safe and comfortable.

Common Medications

During the course of Alzheimer's disease, the person with dementia may need medication for two possible reasons: to treat problems that occur as the disease progresses or to treat other medical conditions not related to dementia. Remember that medication is anything taken by mouth, inhaled, put on the skin, or taken rectally, which is prescribed by a health care professional or bought over the counter. Vitamins, alcohol or dietary supplements should be considered medications.

Medication Administration

To ensure that medication works effectively, ask your health care professional about the purpose of the medicine, the possible side effects and how long it takes for the medication to begin working. Be aware that all medications can cause side effects; therefore, report any new symptoms that occur when the person with dementia takes a new medicine. Be sure to report the names of the medications that the person is taking, including all over-the-counter medicines. If the person with dementia is unable to take pills, many medications come in another form, such as capsule or liquid. Some pills can be crushed and sprinkled on food such as applesauce or yogurt. However, others should not be crushed since their protective coatings allow the drug to be absorbed in the intestine rather than the stomach. Do not stop medications on your own and do not give any medicine prescribed for you to someone else.

People in the early stage of dementia can often participate in the administration of their own medication with the aid of reminders such as daily phone calls or pill boxes. However, as confusion and forgetfulness increase, you will need to assume more responsibility for supervising medication administration. Administering medication is easier if you give simple instructions. Store all medications in a safe place using a locked container if necessary. Pill containers with compartments for days of the week can be purchased at most pharmacies. The pill box can help you remember when to give a medication.

Avoid scenes or arguments when you give medications. If medication is refused, don't argue but rather try again in a short time—the person may forget they refused it before.

Try not to skip doses of medicine and do not give double doses of medicine to try to catch up.

Treating behavior changes with medications

As the disease progresses, the person with dementia may develop agitation, restlessness and sleeplessness. Before treating these behaviors with medication, try to determine if the behaviors are triggered by underlying factors such as a need to go to the toilet, pain, alcohol use, medication, caffeine (found in cola, coffee, tea and chocolate) or cigarettes. Some behaviors may be due to physical discomfort, an upsetting environment or changes in the usual routine. It is usually better to try managing behaviors first without medications and if unsuccessful, a trial of medication should then be considered.

The person with dementia may experience anxiety, restlessness and depression. The following section describes some of the classes of medications that may be prescribed. The general purposes, types, and possible side effects are noted. Be sure to report any changes you notice in the person with dementia if any of the drugs are prescribed. Do not assume that the side effects listed are normal or inevitable. It often takes several weeks for the medication to produce the desired effect. To evaluate how the medicine is working, communicate often with your health care provider.

Anti-Anxiety/benzodiazepines

Purposes: This class of drugs is mainly used to alleviate anxiety, restless and mild agitation. These drugs can also be used at night as sleep aids when anxiety is at the root of the sleep disorder.

Types: The most commonly used anti-anxiety agents are: Ativan (lorazepam), Xanax (alprazolam) and Valium (diazepam).

Possible side effects: Drowsiness, dizziness, unsteadiness, and lethargy. These drugs can increase confusion, and the risk for falls. These medications can cause a paradoxical reaction, that is, instead of producing a calming effect, the person may become more agitated. This is a rare reaction, although it is necessary to be aware of this possibility.

Anti-Psychotics

Purposes: Anti-Psychotics may be effective in reducing paranoia, hallucinations, delusions, agitation, and aggressive behavior.

Types: Atypical anti-psychotics include Risperdal (risperidone), Zyprexa (olanzapine), Seroquel (quetiapine), Geodon (ziprasidone) and Abilify (aripiprazole). Older anti-psychotics such as Haldol are used less frequently because of their side-effects and should only be used with extreme caution and close monitoring.

Possible side effects: The side effects of anti-pyschotics include drowsiness, dry mouth, dizziness, constipation, increased confusion, muscle stiffness, and a shuffling gait.

Antidepressants

Purposes: Symptoms of depression are quite common and may respond to treatment at any stage of dementia.

Types: There are several types of drugs used in the treatment of depression. One class of anti-depressant frequently prescribed for persons with dementia are known as SSRIs (serotonin reuptake inhibitors). These include: Prozac (fluoxetine), Zoloft (sertraline), Paxil (paroxetine), and Lexapro (escitalopram). Most antidepressants usually require up to four weeks before any positive effects can be detected.

Possible side effects: Common side effects of SSRIs include nausea, diarrhea, abdominal cramps, anorexia, tremor, insomnia and dry mouth.

It is usually better to try managing problem behaviors first without drugs and if various techniques are not successful, a trial of medication should then be considered.

Hypnotics

Purposes: Insomnia or sleep disturbances can occur in dementia. Many people with dementia experience insomnia at some point in their illness. Some can have a problem falling asleep but then will be able to have several hours of sustained sleep. Others will fall asleep but awaken after a few hours and be unable to fall asleep again. Still others will fall asleep and wake up several times throughout the night. Depending upon the kind of insomnia, different medications can be used. Good sleep habits should also be maintained and excessive napping during the day should be discouraged. Keeping an active routine is the most important way to prevent sleep disorders. Traditional sleeping medications are intended for short term use and should not be used for ongoing management of a sleep disturbance.

Types: Some of the drugs available for sleep disorders are Ambien (zolpidem tartrate), Noctec (chloral hydrate) and Restoril (temazepam). Since sleeping pills may adversely affect cognition, it may be preferable to use an anti-psychotic medication such as Seroquel or an anti-anxiety drug such as Ativan for sleep disorders.

Possible side effects: Common side-effects include lightheadedness, dizziness, poor balance, and increased confusion.

Anticonvulsants

Purposes: Persons with severe aggressive behaviors that do not respond to anti-psychotics may benefit from drugs which are normally used to control seizures.

Types: The most commonly used anticonvulsants for this purpose are Depakote (valproic acid) and Trileptal (Oxcarbazepine).

Possible side effects: Side effects include skin rash, tremor, involuntary movements, muscle stiffness, gait problems, dizziness, drowsiness, double vision, and slurred speech. In addition, Depakote may cause bone marrow depression and blood levels must be monitored.

Of note, it is often challenging to find the right drug and dose that will be effective in treating behavior changes. Medications prescribed for behavior changes should be re-evaluated periodically since they may not be needed through all stages of the illness.

Facts about Basic Medical Problems

As Alzheimer's disease progresses, the person may have difficulty with walking and other motor abilities.

Caring for the person with Alzheimer's at home requires basic medical knowledge and good common sense. As the disease progresses, some other medical problems might arise. These complications may lead to behavioral problems, which can be alleviated if the underlying problem is addressed first.

Flu and pneumonia

Adults need to be immunized and protected from serious diseases such as influenza, pneumonia, diphtheria and tetanus. Influenza, or flu, is a highly contagious disease, and complications of the flu such as pneumonia, weight loss, and dehydration are more likely to occur among older persons with dementia. The flu vaccine is advised for all adults aged 65 years and older. A yearly shot is advised every fall since different strains of the flu virus are active each season. Side effects of flu shots are mild for most people, but the benefits far exceed the risks since the flu can magnify symptoms of dementia for weeks. Equally important is a pneumonia vaccine to protect against the bacteria that causes diseases such as meningitis, bacteremia, and bacterial pneumonia. Everyone 50 years of age and older should get a pneumonia shot. Again, side effects of the shot are minimal and pale in comparison to the risks of getting pneumonia. This vaccine is considered effective for about five years. The flu and pneumonia shots can be given at the same time without increasing side effects. Medicare pays for the cost of both shots.

Fever

A fever may indicate an infectious disease, dehydration, heat exhaustion or constipation. The person may not be able to inform you that she is not feeling well or has a fever. If you suspect a fever, it is best to use an oral, battery-operated thermometer. A mercury-filled, glass thermometer can easily break in the person's mouth and cause injury. Report any fever of more than 100 degrees to your health care provider immediately.

Falls

As Alzheimer's disease progresses, the person may have difficulty with walking and other motor abilities. Perception, balance and coordination may be affected. The person in the late stage of the disease may begin to walk slower, shuffle, lean to one side or become hesitant in climbing stairs. Arm and leg rigidity may develop along with tremors. The person may become unsteady on their feet and be at risk for falls. Some people become apprehensive if the floor surface they are walking on changes from tile to carpeting. They may "freeze" in place and have difficulty moving again. They may also have trouble changing positions from standing to sitting or vice versa. Some people have trouble getting into cars or crossing a threshold from one room to another. They may not be able to make judgments about the space or objects around them and may bump into furniture or people in their path. Others may seem oblivious to clear dangers in their way. For example, they might walk into the street without noticing passing traffic.

It is important not to restrain the person because you fear they may fall. Staying mobile is important for exercise. But you will want to keep your home free of obstacles. For example, throw rugs should be eliminated or tacked down.

Consider installing railings in a long hall, which may aid in walking. Grab bars placed at strategic spots in the bathroom near the toilet will help with balance. Chairs with arms help in sitting down and getting up again. Make sure the person wears sturdy walking shoes, preferably without shoelaces.

Choking

People with late-stage dementia are prone to choking and swallowing problems. This results from a complex set of problems involving the gag reflex and swallowing. Some people have difficulty eating certain kinds of food, such as lettuce, meat and fish. If this is the case, solid foods should be softened or pureed into a consistency that is easily consumed.

The person with dementia may resort to "pouching," in which food is partially chewed and tucked in the cheeks. They may forget they are eating and may choke on the food in their mouth. Make sure to closely monitor the person's eating. You may need to remind them to swallow and chew. You may even need to remove the food from their mouth so they won't choke. Don't interfere with a person who is choking unless they can no longer talk, cough or breathe; then you must offer help immediately.

The Heimlich maneuver forces out the food caught in the throat. Whether the person is seated or standing, stand behind them and overlap your two hands in the middle of their belly right below the ribs. Pull hard and quickly up toward you. If the person is lying down, turn them face up, put your hands in the middle of the belly, and push down and toward their head. This should cause the lodged piece of food to fly out of the mouth. Ask a nurse or other health care professional to demonstrate the Heimlich maneuver.

Constipation

The person with dementia may become constipated due to changes in eating patterns, medications, decreased activity, and decreased fluid intake. Although it is normal not to have daily bowel movements, any significant change in the usual bowel pattern may mean the person is constipated. Untreated constipation can result in hard feces impacted in the bowels. Removal of this blockage may require medical attention. Encourage the person to drink at least six glasses of fluid a day. This can include water, decaffeinated coffee, tea, soup, Jello, ice cream or hot cereals. Also, encourage walking and stand-up/sit-down exercises. Such activities help stimulate the bowels to move on a regular basis. Provide foods that include roughage, such as whole-grain breads and cereals, raw fruits and vegetables, stewed prunes, fruit juices and bran. If necessary, give Metamucil or some other fiber supplement. If the problem persists, consult your health care provider.

Diarrhea

Diarrhea can have many causes, including an infection, impaction in the bowels, overeating, eating the wrong foods or side effects of medications. To manage the diarrhea, make sure the person drinks at least eight glasses of clear fluids a day, such as broth, ginger ale, or tea. A bowl of Jello may also count as a glass of fluid. Solid foods should be avoided. When the diarrhea begins to subside, the person may try a diet of dry toast, bananas and rice. Remember to not scold the person if they have an accident. A sign that reads “TOILET” or a picture of a toilet on the bathroom door will help the person find the bathroom and perhaps prevent accidents from happening. Over-the-counter medications such as Imodium or Kaopectate may help relieve the diarrhea, but if it continues for more than 48 hours, notify your health care provider.

Careful attention to dental hygiene needs to be an integral part of daily care.

Dental problems

The person with dementia cannot always tell you if they are feeling dental pain. For example, with a toothache, they may respond to the pain by becoming either agitated or subdued. An annual exam by the dentist is important to detect any problems such as tooth decay, infection, or ill-fitting dentures. Careful attention to dental hygiene needs to be an integral part of daily care. Dental hygiene should include a thorough brushing of teeth. In the early stage of Alzheimer's, this may be part of one's daily routine. However, as the disease progresses, the person may need reminders and assistance.

Myoclonus

Myoclonus is a brief spasm or muscular contraction in the arms, legs or the entire body. These movements appear similar to seizures but are relatively mild in nature. Consciousness is not lost, but the person must be watched to prevent them from striking a limb or their head on an object. Medications that are used to treat seizures often are not useful for myoclonus. Notify your physician about this problem.

Skin problems

The skin is the body's first line of defense against disease. If the skin becomes broken due to cuts, abrasions or pressure sores, infection can result. The person with dementia cannot always communicate effectively about a skin problem. Therefore, you should give particular attention to skin care.

Bedridden people in particular are at risk for breakdown of the skin or pressure sores. To avoid these skin problems, pay special attention to the bony areas of the body such as the heels, hips, shoulders, spine, elbows, knees and ankles. Wash the skin with mild soap and water and apply moisturizing creams every day, gently massaging the cream into the skin. The person who is bed-bound should be turned at least every two hours during the day and bony areas of the body should be massaged during each turn. Use an alternating pressure mattress, egg crate mattress or wheelchair pad for additional precaution against pressure sores. These items are available through a medical supply store.

Foot care

Another important consideration is foot care. Feet need to be examined for open cuts, pressure sores, corns and calluses. Toenails should be cut on a regular basis. Daily foot care, which consists of soaking feet in warm water and washing with mild soap, may help prevent foot problems. Application of skin cream may also be useful. A podiatrist should be consulted about persistent foot problems.

Another important consideration is foot care. The person’s feet need to be examined for open cuts, pressure sores, corns and callouses.

Dehydration

Dehydration refers to excessive loss of water from the body. It can be due to vomiting, diarrhea, diabetes, certain medications or decreased fluid intake. Symptoms of dehydration include a rapid pulse rate, dry mouth, dizziness or hallucinations. To prevent dehydration, remind the person to drink at least six glasses of liquid daily. This amount should be increased during hot weather, especially if the person is outside for any prolonged period of time or if the home lacks air conditioning. Be sure to report instances of vomiting and diarrhea since dehydration can easily result from these problems.

Other problems

Of course, people with Alzheimer’s disease are not immune to other chronic medical problems such as hypertension, arthritis, diabetes, glaucoma or cancer. Common acute problems such as urinary tract infections and pneumonia are often accompanied by increased confusion and/or behavior changes. Any sudden change in a person’s congitive or functional abilities warrants an evaluation to rule out a medical problem. Make sure the person gets an examination by a health care provider at least annually, or anytime there is a sudden change.

Easing a Trip to the Emergency Room

A trip to the emergency room is stressful for most people, but for the person with dementia it can be especially challenging. People with dementia do best in an environment that is calm and predictable, and an emergency room is anything but that. The loud noises, strangers and frenetic activity typical of most emergency rooms can all increase anxiety in the person with dementia.

What can a caregiver do to make the experience less threatening while meeting urgent medical needs? Here are six suggestions to help maintain control and ease stress in an emergency situation:

1. Prepare a list of all the information you will need in advance and keep it handy. Include the person's name, nickname, address, insurance information (including policy numbers and pre-authorization phone numbers) and physicians' names and phone numbers. Also bring copies of advance directives, such as durable powers of attorney, to ease decision-making. A current list of medications and dosages is also helpful.
2. Call a friend or family member to meet you in the emergency room. While you are completing forms and answering questions, someone else can focus on your family member and help him or her feel safe.
3. Be prepared to explain the medical symptoms and events several times. You may even want to take notes so you can quickly repeat the information to different staff members. If you can provide a record of the past few days, it may help with the diagnosis and treatment of the condition. For instance, if your family member has been running an elevated fever or has been vomiting, it is helpful to have an accurate account of these symptoms.
4. Inform staff about the person's dementia, especially in relation to his or her communication needs. Provide tips on how best to ask questions and make the person feel safe. Tell the staff to make eye contact and talk slowly and calmly. Remember to keep the tips simple and to the point. Emergency room staff persons often have little or no training in Alzheimer's disease, so you may be their first and only teacher.

5. The next challenge is to wait. After the initial flurry of activity, you may spend hours waiting for test results, further examinations, doctor consultations and a final decision on whether or not to admit the person to the hospital. Having a snack can be an excellent way to pass the time and keep up strength during the waiting period. It can also be used to distract the person with dementia and reduce his or her anxiety.
6. Finally, if the person can return home, make sure you have complete instructions for follow-up care. You should review these written instructions and ask questions. If hospitalization is recommended, first find out if there is any way to avoid a hospital stay through outpatient or home care. If a hospital admission cannot be avoided, make sure staff will be available to check on the person frequently.

Coping with a Hospitalization

Quite clearly a hospitalization presents many risks to the person with dementia and may cause disruption within the rest of the family.

Although a person with Alzheimer's disease may be physically healthy to a remarkable degree for many years, there may be occasions when an acute illness requires admission to a hospital. These may be extraordinarily stressful times for someone with dementia as well as family caregivers. The acute illness itself may result in a temporary worsening of memory, thinking, judgment, language and behavior. The abrupt change from a familiar place to a busy and unfamiliar environment with dozens of strange people and a disrupted schedule can also provoke further decline. All of the confusion may result in agitation, which can interfere with diagnostic and treatment measures. Consequently, medications may be prescribed to control behavior, which can further impair thinking and behavior. Quite clearly a hospitalization presents many risks to the person with dementia and may cause disruption within the rest of the family. It may take weeks for all concerned to recover from such a traumatic experience.

There are steps, however, to ease the transition to a hospital. First, every effort should be made to avoid hospitalization by trying to diagnose and treat an acute illness on an outpatient basis. If conditions do not permit this possibility, notify the doctor and nursing staff about the specific needs of the person with dementia. For example, inform them about the predictable confusion brought on by the sudden change in environment and the need to maintain as much of a routine as possible. Give details about medication use, food preferences, and personal grooming habits. Identify yourself as the primary caregiver and tell staff that you must be consulted about diagnostic tests and treatment measures. In addition, be sure to provide staff with a copy of the person's completed power of attorney for health care form to underscore your rightful role as the designated decision-maker.

Due to the acute illness, different surroundings and any newly prescribed medications, the person with dementia is bound to be more disoriented than usual. Abilities such as eating, toileting, talking and walking may be diminished. It usually helps to have a familiar person available as much as possible for the sake of comfort and consistent care.

Accompanying the person to tests and providing help with meals and personal care may prevent or reduce stress and relieve staff from the need to be constantly vigilant. Also, family members can usually get permission to spend the night at the hospital if the person with dementia has a problem with sleeping.

No individual can or should take on total responsibility for such a high level of care when the person is hospitalized. This is the time to involve other family members and friends who are sympathetic to the needs of the person with dementia. Someone who can devote time, patience and understanding may be far more valuable than hospital staff who may be busy attending to so many others at the same time. Hiring a sitter from an agency may be called for in the absence of such helpers. Hospital stays should be kept to a minimum to return the person back to their home as soon as reasonably possible. Procedures or treatments that are not absolutely necessary and delay discharge should be discouraged. Planning for the return to one's place of residence should begin soon after admission. A social worker or nurse should be available to consult with you and the doctor about the most appropriate course of action and link you up with needed services.

A hospitalization may indeed restore the physical health of the person with dementia but a moderate worsening of cognitive status can usually be expected, too, in the course of recovering from an acute illness. In most cases, it will take several weeks for the person's overall condition to return to their previous level. Caregivers should serve as advocates and helpers during the hospital stay without interfering with the professional expertise of the staff. At the same time, caregivers need to make sure that steps are taken to care for themselves during this critical time.

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Getting Outside Help

Using Community Resources

Community agencies provide a wide range of services such as home care, adult day care, respite care services, counseling, financial assistance, transportation, and more.

At some point, most families look for help from outside sources. It is important to understand the kinds of help available and how to obtain it. Key sources of information include community agencies, health care professionals, support group leaders and other caregivers. Community agencies provide a wide range of services such as home care, adult day care, respite care services, counseling, financial assistance, transportation, and more. Organizations such as the Alzheimer's Association, the Illinois Department on Aging and the American Association of Retired Persons can be helpful in providing information or services. Many services are available for a fee and some are available at reduced cost or without charge. Eligibility may be based on age, place of residence, income or other factors. Health insurance may contribute to the cost of some services.

Where to go for help

The Alzheimer's Association is a nonprofit organization with chapters nationwide. Its national office is located in downtown Chicago, while the local chapter is based in Skokie, Illinois. The Alzheimer's Association was established to meet the following goals:

- To provide support and services for those with Alzheimer's disease and their families.
- To stimulate and fund research aimed at finding the cause and cure for Alzheimer's disease.
- To advocate for legislation and public policy sensitive to the needs of those effected by the disease.
- To increase public awareness and educate professionals and family caregivers about the disease.

The Greater Illinois Chapter's services (described below) provide help to families and professionals caring for those with Alzheimer's. Information about other chapters can be obtained by calling the National Alzheimer's Association in Chicago, (312) 335-8700 or 1-800-272-3900.

- **The Helpline:** A telephone service that provides information and referrals to diagnostic centers, research programs, legal advisers and community resources such as adult day care and respite programs. A trained volunteer will respond to your call weekdays from 9 a.m. to 5 p.m., and an answering service will take your message during the evening and on weekends. The telephone number of the Greater Illinois Chapter is (847) 933-1000.
- **Support groups:** Family support groups are made up of relatives, friends and other caregivers of people with dementia. In an atmosphere of support and encouragement, caregivers help each other solve problems and learn about various community resources. There are over 40 support groups in convenient locations in the city of Chicago, suburbs and outlying areas. Some groups are limited to spouses or adult children. The groups usually meet once a month under the guidance of trained leaders. There is no cost. For more information about times and meeting places, call the local chapter.
- **Safe Return:** Helps identify, locate and return those who may wander away from home due to confusion. The program provides an identity bracelet or necklace; clothing labels; registration in a national database; a 24-hour toll-free 800 number to contact when a person is lost or found; and a local response team to notify police departments and emergency rooms. The cost is $40.00. Call the local chapter for details.
- **Chapter newsletter:** This quarterly publication offers practical information and caregiving strategies for families and professionals, as well as up-to-date reports on research and legislative activities.
- **Speakers bureau:** In addition to conferences and seminars, the chapter maintains a speakers bureau which offers presentations to both family caregivers and professionals.

Respite Services

Respite care refers to temporary care of an impaired person on behalf of a caregiver. It allows the caregiver an opportunity to rest for a while. Respite services can be provided in many differ-

"Respite care" is temporary care of an impaired person on behalf of a caregiver. It allows the caregiver an opportunity to rest for a while.

ent settings, including the familiar surroundings of the caregiver's home or at other locations in the community. Respite care services are available from various agencies, usually on a fee-for-service basis. In-home respite care consists of periodic supervision of the person with dementia by a sitter, companion, homemaker or home-health aide. Such people help the person with dementia carry out their daily routine and ensure their comfort and safety. The care may involve help with meals, toileting, bathing, exercise and recreation. The training and experience of respite aides varies, so it is recommended that you interview them first. It is best to employ someone who is knowledgeable about Alzheimer's disease and is capable of managing difficult behaviors. Above all, you will want to employ someone who can communicate effectively and can create a positive environment for the impaired person. The cost of this service ranges from $10 to $18 per hour, but low-income people may qualify for a state subsidy. In-home respite care is also available for a maximum of five days for Chicago residents who are receiving in-home services through the Chicago Department on Aging or the state-run Community Care Program. For information about this in-home respite care, contact the Chicago Department on Aging Information and Referral Center, (312) 744-4016.

Another option is to place the person with dementia in a residential facility for a few days or weeks. The facility may be a specialized unit of a nursing home or hospital or a private home that has been approved for this purpose. Guest residents are encouraged to participate in group activities and are given assistance with personal care. Such 24-hour supervision enables caregivers to take an extended break. This arrangement can also be a "trial run" to see if the person with dementia might adjust to living in a nursing home. The cost of this service averages $125 to $160 a day, depending on the facility and the level of care required. The Area Agency on Aging has a listing of facilities offering short-term institutional care in the Chicago area. Call (312) 744-4016 for information.

At Hines Veterans Affairs Hospital in Maywood, Illinois, inpatient respite care is offered to military veterans for up to four weeks a year. Call (708) 343-7200 for information about this service, which usually has a long waiting list. Many private nursing homes accommodate people on a short-term basis, with some variation in costs and admission criteria.

Adult Day Care

Perhaps the most popular form of respite care, because of its significant benefit to most participants, is adult day care. These programs are available outside the home, but in a home-like environment. Adult day care consists of a coordinated program of social and health-related activities led by trained professionals. The programs are designed to maximize the strengths and abilities of the impaired person through a variety of therapeutic activities. As a general rule, adult day care may be useful when one or more conditions are present:

- The person with dementia seems unable to provide a structure or routine for their daily activities.
- The individual is isolated or unable to interact comfortably with family or friends.
- The person with memory loss cannot be safely left alone at home.
- The caregiver works outside the home or needs a regular break.

Transportation to and from the adult day care center is often provided, within certain boundaries. A typical adult day care center is open seven to 10 hours daily, Monday through Friday. The cost averages $45 to $55 per day. Discounts may be available for those who use the service frequently, and some programs offer a sliding-fee scale. Help in paying for adult day care for people with limited resources may be available through the Illinois Department on Aging or the U.S. Department of Veterans Affairs. Those seeking assistance from these sources must meet specific eligibility requirements. For information about the Illinois Community Care Program call 1-800-252-8966. Eligibility through the U.S. Department of Veterans Affairs can be determined by calling 1-800-827-1000.

Approaching the person about adult day care will depend greatly on your comfort level as well as the person's ability to understand the value and purpose of the program. It is often helpful to discuss ways of handling this with the staff of the adult day care program. When proposing adult day care to the person with dementia, it is best to use a positive, calm and reassuring manner. Brief and simple explanations are usually the most effective, such as: "It would be nice to meet some friendly people," or "The doctor thinks it might be helpful."

There are many adult day care centers in and around the Chicago metropolitan area. Some specialize in caring for people with dementia. The Rush Alzheimer's Disease Center keeps a current listing of all local programs. Call (312) 942-4463 for details. Outside the Chicago area, information about local adult day care centers is available through the Illinois Department on Aging or your local Area Agency on Aging. The National Council on Aging also maintains an extensive listing; call (202) 479-1200 for more information.

Geriatric Care Managers

Services of a geriatric care manager may be helpful when the person with dementia has no local family member available for support. Assessment normally includes a home visit and a comprehensive evaluation of the person's social, medical and health care needs. A geriatric care manager functions as an advocate if the person's safety or well-being are at risk. A geriatric care manager is a professional with a graduate degree in social work, psychology, gerontology or nursing. The manager is certified or licensed for independent practice in his or her profession. This person should be fully trained and experienced in the assessment, coordination, monitoring and direct delivery of services to the elderly.

Geriatric care managers work closely with trust officers, physicians, attorneys and other specialists to coordinate, implement and monitor a plan of care appropriate to the person's needs. This may include assistance with arranging for home care or nursing home care. Services are provided for a fee, beginning at about $70 per hour. The National Association of Professional Geriatric Care Managers in Tucson, Arizona, (602) 881-8008, provides names of private care managers throughout the country.

Counseling

Learning to live with and care for a person with dementia can be a difficult task and often requires the support of others. Sometimes that support is needed in the form of professional guidance and counseling. Discussing one's private concerns and feelings with an experienced professional in a confidential atmosphere may help alleviate the stresses associated with caregiving. Do not be afraid to ask for this help. Counseling is available through family service agencies, community mental health centers and therapists in private practice. When seeking a counselor, it is advisable to check out credentials such as licensure and accreditation through state regulatory departments and professional organizations. The Rush Alzheimer's Disease Center has a list of therapists in the Chicago area who have a knowledge of Alzheimer's disease. To obtain this list call (312)942-4463.

Discussing one's private concerns and feelings with an experienced professional in a confidential atmosphere may help alleviate the stresses associated with caregiving. Do not be afraid to ask for this help.

Eldercare Locator

The Eldercare Locator is a resource for families who want information about services for a relative who lives in another community. The service will provide information about home health care services, adult day care, senior center programs, elder abuse prevention and other services. The number is 1-800-677-1116.

Understanding Government Benefits

The financial costs involved in caring for a person with Alzheimer's disease is typically covered by the individual and their families. However, federal and state governments may help pay for certain health care and social services. The person you care for may be entitled to receive the benefits of these programs.

The Illinois Department on Aging

This is the state agency responsible for planning and funding services for older adults. Among the programs it funds is the Community Care Program, which helps pay for adult day care and homemaker services for people with limited financial resources. Besides meeting the financial criteria, the person must be 60 years or older and a resident of Illinois at the time of application. This agency also is responsible for investigating suspected cases of abuse, neglect and financial exploitation against persons age 60 and older. For more information, call 1-800-252-8966.

The Illinois Department of Human Services

This state agency offers in-home and adult day care services for impaired people who are under 60 years old and with limited financial resources. Call (312) 793-1533 for further information.

Medicare

The Medicare program is the federal health insurance program for people age 65 and older. It provides hospital coverage for acute health care needs (Part A) and medical coverage for other health care services (Part B). People under 65 are eligible for Medicare if they have been receiving Social Security disability benefits for 24 months.

Medicare Part A:

- Pays most hospital costs after an annual deductible is met. The amount of the deductible is adjusted periodically.
- Pays for brief stays in a skilled nursing care facility for certain types of acute illnesses or conditions. Alzheimer's disease is not one of these conditions.

- Pays for home health care services if the person is homebound and has other conditions requiring services of a licensed health care provider.
- Pays for hospice care for the terminally ill.

Medicare Part B:

- Pays 80 percent of approved charges for physician's services, diagnostic tests, laboratory fees, X-rays, and durable medical equipment such as wheelchairs, hospital beds and walkers.

Services that Medicare does not cover:

- Custodial care for people who need help with daily living activities such as bathing, dressing, toileting, and walking.
- Respite care and adult day care.
- Medications and medical supplies such as incontinence pads.
- Most long-term care or care in a nursing home.

Qualified Medicare Beneficiary Program

Additional financial help is available to people with low incomes through the Qualified Medicare Beneficiary Program. Only those covered by Medicare can qualify. Call the public aid office in your community for information or assistance in making an application or call the Illinois Department of Human Services at 1-800-638-6833.

The program helps pay for all or some of the following:

- Medicare premiums, that is, the amount taken out of the Social Security check each month.
- Deductibles or the amount that must be paid before Medicare starts coverage for inpatient and outpatient services.
- Coinsurance or the amount that needs to be paid after Medicare pays its share.

Social Security Disability

If the person with dementia is under age 65 and unable to work, they may qualify for disability benefits through Social Security. Someone is considered disabled when their impairments prevent them from working for a year or more. Alzheimer's disease is considered such a disabling condition. Monthly benefits continue indefinitely since disability is not reversible in cases of

Alzheimer's disease. Certain members of the disabled worker's family may also qualify for disability benefits on the basis of the worker's job record. Also, Medicare coverage is available to people who have been entitled to disability benefits for 24 months, regardless of age.

To qualify for disability benefits, a person must have worked long enough and recently enough under Social Security to be insured. The number of years of work credits needed to qualify for benefits depends on one's age at the time of disability. Application for disability benefits should be made as soon as disability occurs. The local Social Security office should be contacted to determine if an application should be made by telephone, mail or in person. A spouse or other relative may make the application on behalf of the disabled person. After an application is made, medical evidence will be reviewed to determine if the conditions for disability benefits are met. It usually takes about three months to reach a decision. Benefits generally start with the sixth full month of disability. Back payments can be made for up to 12 months before the month of application. For further information, call the Social Security Administration at 1-800-SSA-1213 or contact one of its local offices.

Supplemental Security Income

The Social Security Administration has another program that makes monthly payments to people in financial need who are disabled, blind or age 65 or older. Medical requirements to receive supplemental security income (SSI) disability checks are the same for Social Security. However, there are certain differences between the programs. For example, no work history is needed for SSI, but there are limits on assets and income for people to be eligible for SSI.

Medicaid

A joint federal and state program called Medicaid assists the states in providing health care to those with low incomes. Medicaid is administered by each state and financed jointly with the federal government. Major changes in Medicaid rules are anticipated due to recent laws enacted by the U.S. Congress. Therefore, any information described below may become outdated. Federal law requires the states to provide a minimum benefit package that includes hospital inpatient and outpatient services, long-term institutional care, physician services and transportation services. In Illinois, Medicaid is administered by the Illinois Department of Human Services, which has offices throughout the Chicago area. Call 1-800-252-8635 for information.

Federal law offers financial protection to the spouses of nursing home residents.

Illinois law offers financial protection to the spouses of nursing home residents. The law provides for an allowance from a couple's assets that is exempt from consideration in determining Medicaid eligibility. This amount was $87,000 in 2001. An income allowance is also provided for the spouse still living at home. The 2001 allowance was $2,175 a month. The couple's home, which is being used as a primary residence, and household furnishings, are exempt from determination of assets. The income and asset allowance is revised every year. Other states also offer similar financial protection for spouses.

Most assets that have been transferred more than 36 months prior to application for Medicaid are exempt in establishing eligibility for this benefit. However, major changes in laws may soon affect financial protection for spouses. Generally speaking, rules regarding transfer of assets can be complicated. Expert legal advice is recommended.

Veterans Benefits

If your family member is a veteran of the United States Armed Forces, it may be worthwhile to investigate services provided by the Department of Veterans Affairs (VA). As a general rule, a veteran's eligibility is based on his or her income and any service-connected disability. Several kinds of services may be available, including long-term care at a VA facility or at a nursing home, financial help toward the cost of adult day care, up to four weeks a year of residential care at a VA medical center at no cost. This is designed primarily as respite for family caregivers and can be divided into single weeks during the year. In the

Chicago area, applications for in-patient respite care can be made to Hines VA Medical Center. Call (708) 343-7200. Also, some veterans may be entitled to nursing visits in their homes. These are typically referred to as hospital-based home care programs. Veterans may be entitled to medication or equipment for a nominal fee, if they are under the regular care of a physician. For more information about these benefits, call the Veterans Affairs Regional Office at 1-800-827-1000.

Finding the Best Living Arrangement

Today, there are several types of group-living options, each with unique features to meet the various needs of a growing population of older Americans.

As the American population ages, the number of housing options for older people is increasing. Until recently, the only alternative for those who could no longer stay in their own home was to move in with a family member or to a nursing home. Originally designed like hospitals to care for the physically ill, traditional nursing homes have an institutional atmosphere. Such an environment is often unappealing to residents and their families, and it may be inappropriate for residents with dementia who benefit from a more home-like atmosphere.

The increased demand for something beyond the traditional nursing home has given rise to some creative alternatives. Today, there are several types of group-living options, each with unique features to meet the various needs of a growing population of older Americans.

Retirement Communities

These communities were built for healthy, independent older individuals. They usually offer studios and one or two-bedroom apartments. Housekeeping and transportation services are often available. Most retirement communities have a common dining area and meal plan. Leisure time activities are also organized for the residents. Fees are paid on a monthly basis and there are no entry fees.

Traditional retirement communities are free-standing entities with no additional levels of care. However, in recent years there has been a gradual shift toward accommodating residents of retirement communities who have mild disabilities. Although many retirement communities have added a nursing home wing or a separate health care facility, there are many without additional levels of care.

Most retirement communities have adapted to the changing population by forming relationships with outside agencies that provide additional services, such as personal care on a fee-for-service basis. Such agencies offer a range of services from a bath once a week to monitoring medication on a daily basis. These services are typically not included in the monthly fee and must be paid for privately. In other retirement communities, assisted living programs have also sprouted up that allow for certain services to be provided on-site at a fixed monthly fee.

Assisted Living Facilities

Like retirement communities, assisted living facilities (ALFs) offer private rooms or apartments and communal dining. In addition, they provide some personal assistance and 24-hour supervision. By establishing relationships with private agencies, ALFs provide additional services, such as personal care to their residents. These services may include such things as monitoring medication or assistance with bathing.

The State of Illinois currently has no regulations governing assisted living facilities, but legislation is under consideration. As a result, the definition of assisted living differs from facility to facility. For example, most retirement communities today indicate that assisted living services are available by paying an extra fee to a home-care agency on the premises. On the other hand, some retirement communities have opted to create sections within their facilities or on their campus that cater exclusively to persons needing assistance with medications and personal care tasks. Other facilities providing so-called "sheltered care" are bound by state regulations and are sometimes marketed as ALFs. The different meanings associated with the term assisted living have created confusion among consumers in Illinois. Therefore, it is wise to shop around in order to ensure that appropriate services are available to match one's particular needs.

Persons in the early to middle stages of Alzheimer's disease may benefit from living in ALFs. These facilities are not designed to care for persons with advanced dementia, so transferring to a nursing home may be necessary in the future. Both present and future needs should be considered when making decisions about the best living arrangement.

The care offered in ALFs is sometimes just as costly as nursing home care, but most ALFs aim to operate at a lower cost. Typically, payment for assisted living is based strictly on a private, out-of-pocket basis. At this time, there are just a handful of ALFs that will accept Medicaid as part of a demonstration project.

Continuing Care Retirement Communities

Like assisted living facilities, continuing care retirement communities (CCRCs) offer more care than traditional retirement communities. They were established to provide a continuum of care as needed, leaving the healthy residents to live as independently as possible while simultaneously providing nursing care to residents who require it. The level of care ranges from minimal to that of a skilled nursing facility and is provided on the same campus, allowing residents to remain a part of the community. The basic premise of continuing care is that older people in reasonably good health may first enjoy independent living in the retirement section while having the security of nursing care, if necessary, in an adjacent section of the same facility.

The retirement home section of a CCRC may be appropriate for persons in the early stage of dementia, while those requiring more assistance may need services available in other levels of care. Married couples who include one spouse with dementia may be well served in the retirement section as long as the well spouse can manage the day-to-day needs of care. Although the retirement home section offers minimal services, additional services, such as personal care, can typically be purchased on a fee-for-service basis through an outside agency. Some facilities require that all residents be relatively independent at the time of admission, while others may accept those with different levels of need.

Most CCRCs require an entrance fee plus a set monthly fee with the guarantee that any needed care will be provided indefinitely. Such an arrangement offers lifetime security for a fixed cost. Other facilities base their fees on the level of care a resident requires; in other words, residents who need more health care will pay a higher fee than those who require less care. Some facilities accept Medicaid for nursing care after residents deplete their assets, while others accept private payment only.

Selecting a Nursing Home

Perhaps one of the toughest decisions you may need to face is whether to move the person with dementia to a nursing home. Reasons for placing someone with dementia in a nursing home include: serious illness or the need for constant care; behavioral problems that may endanger the person's safety; incontinence; or the exhaustion or illness of the caregiver.

Before deciding on a nursing home, it's a good idea to look around and educate yourself about the services offered. Visit several facilities to compare what is available. You may want to gather this information even if the person in your care never needs a nursing home. It's best to be prepared in case there is a crisis someday, requiring the person to be placed in a nursing home immediately. Many nursing homes have waiting lists so planning ahead is very helpful.

Step One: Gathering Information

Before you visit a facility, do some research. Acquaint yourself with the three types of nursing homes: skilled nursing, intermediate care and sheltered or residential care. A growing number of facilities incorporate all three levels of care under one roof.

1. Skilled nursing facilities provide 24-hour nursing care delivered by registered nurses, licensed practical nurses and certified nursing assistants. The emphasis on medical nursing in these facilities may include physical, occupational and speech therapy.
2. Skilled nursing facilities often incorporate intermediate care sections as well. Intermediate care is required for people who are not capable of independent living, but who still have some skills and abilities. Licensed practical nurses and certified nursing assistants provide most of the care. The activities and rehabilitative services emphasize maintaining the residents' abilities.
3. In sheltered or residential care facilities, residents must be able to dress and bathe themselves and remember when meals are served. They cannot be at risk for wandering. Some sheltered homes give people minimal assistance with personal care and there is generally some medical care provided. These facilities encourage people to socialize and participate in activities.

Keep in mind that some long-term care facilities have units just for Alzheimer's patients. These are called "special care" units. They are supposed to emphasize people's abilities and minimize their disabilities through a focus on activities. Special care units vary in size and program implementation and have specially trained staff. They may cost more per day than other units in the facility. A fair question to ask when considering a special care unit is: "What exactly makes this unit special compared to the other units in the facility?"

A facility that does not have a unit specially designed for Alzheimer's patients but mixes people with dementia with other patients is called "integrated." Thus far, there is no solid research to indicate whether "special care" units or "integrated" units are more effective in providing quality care to people with dementia. You will want to find out the cost per day of certain nursing homes and whether there are extra charges (e.g., for incontinence supplies). Does the home accept Medicare? Does it accept Medicaid reimbursement? If the person with dementia is on Medicaid, will they be moved to a designated area of the home? If needed, find out if the facility has a contract with the U.S. Department of Veterans Affairs.

Can families be actively involved in caregiving activities?

Does the facility have "resident care plan" conferences and are families encouraged to attend?

Does the facility have support groups and educational opportunities for families?

Step Two: Visiting Nursing Homes

Now that you've gathered some information about nursing homes, arrange to visit several places. Before visiting a facility, call first and ask if the home admits people with dementia and whether the home has openings now or a waiting list. If you're interested, set up an appointment. Make sure a qualified staff person shows you the facility and answers your questions. Ask a friend or family member to accompany you. Getting another person's impressions of a place is helpful and you'll appreciate the support. It's a good idea to spend at least an hour visiting a facility. You might also consider making an unscheduled visit to see how the facility operates at varying times of the day.

When evaluating a nursing home and meeting with its staff, be honest. Describe the person with dementia in a candid way that allows the staff to understand the kind of care needed. As you describe the person's behaviors, ask such questions as "How would you care for someone who wanders and is combative when you try to bathe her?" Look for answers that sound logical and realistic.

The following questions are meant to serve as a guide as you evaluate a nursing home:

Care of residents

- Do residents appear happy and alert? Are they responsive to the people around them?
- Are the staff and residents enjoying each other?
- Are residents clean and well groomed?
- How is mobility encouraged? Are there range-of-motion exercises for residents?
- Are residents moved to different parts of the facility as their needs change? How is this determined?

Staff support

- What is the staffing ratio: nurses to residents and nurses aides to residents? The recommended ratio of nurses aides to residents is 1-to-8 or less.
- What percentage of the nursing staff is from an agency, which means they are not employed by the home but help fill in for vacant positions or vacationing staff? (It is recommended that the number not exceed 25 percent.)
- Does staff speak understandable English?
- Is the staff specifically trained to work with people who have Alzheimer's disease? What kind of in-service training is in place and how often does it occur?
- How does the staff handle residents who wander or who are combative?

Activities available

- Does the facility have a full calendar of large-group and small-group activities that emphasize cognitive, physical and psychosocial needs?
- What is the ratio of activity staff to residents?
- Does the facility provide field trips? Are there weekend activities and intergenerational programs?
- Are worship services offered?

The nursing home environment

- Is the home a cheerful place and is it clean and well maintained?
- Are the activity rooms spacious and well equipped?
- How many residents to a bedroom? Can residents bring belongings from home, such as furniture?
- Is the facility safe? Do doors have safety alarms?
- Is there an enclosed yard or garden area that is regularly used for walking and outdoor activities?

Legal/ethical issues

- Does the home honor a living will or a durable power of attorney for health care?
- What is its policy regarding tube feedings and "Do Not Resuscitate" orders?

Facility certifications

- Ask to see copies of the home's license and certification. Each state inspects and licenses nursing facilities according to state standards.
- Is the home accredited by the Joint Commission on Accreditation of Healthcare Organizations? Does it have a quality assurance program that monitors the delivery of care?
- Has the facility's license been suspended in the last two years because of violations? Ask the administrator or the local department of public health for the facility's latest inspection report.

Step Three: Coping with Admission Day

Admission day into the nursing home is often described by families as very stressful. To make the transition from home to nursing home easier, consider the following:

- Think about placing the person in a nursing home directly following hospitalization when they may not realize the change. People who have attended a day care program may also feel less stressed by the move. If the person is entering a facility directly from home, however, you may want to explain that the doctor has ordered the move to the facility for medical tests.
- Assure the person that you still love them and that you will be visiting often.
- For support on admission day, bring along another family member or a good friend.

- Ask the facility for the best time of day for admission: 10 a.m. to 11 a.m. is often a convenient time because you can then leave at the lunch hour.

Resources

For further information about nursing homes, contact these resources in your area:

- The local chapter of the Alzheimer's Association (ask for a copy of the booklet Family Guide for Alzheimer's Care in Residential Settings.
- An Alzheimer's disease assessment center.
- A local hospital's social service department or discharge planning department.
- Local area agency on aging.
- Senior centers or adult day care centers.

Hospice Care

A chief aim of hospice is to help the dying person be as comfortable as possible and to play a supportive role for the family.

Persons with Alzheimer's usually deteriorate slowly and may remain physically healthy for many years into the disease. However, they ultimately may become totally dependent on others for basic needs and have difficulty with walking, talking or swallowing. Such complications create a risk for falls and infections like pneumonia, which may cause death. Caregivers face difficult decisions at this critical point: Should these recurring problems be treated or should the disease be allowed to run its course? If the latter option is chosen, hospice may be the best source of help.

Hospice refers to a home-based program that tends to the physical, emotional and spiritual needs of people who are expected to live six months or less in the opinion of their physician. It is available to people who live in their own home and to people who live in a long-term care facility. A chief aim of hospice is to help the dying person be as comfortable as possible and to play a supportive role for the family. It does not try to hasten death or extend life through artificial means, but regards dying as a normal part of the life cycle.

The philosophy of hospice is in stark contrast to the prevailing attitude in our society that medical technology should be used to sustain life at all costs. For example, hospice emphasizes comfort measures instead of the use of feeding tubes or breathing machines. Those who care for family members with Alzheimer's disease usually prefer hospice care instead of advanced medical technology in the final stage.

Hospice services typically include visits from a team consisting of a nurse, physician, social worker, pastoral counselor, home health aide and trained volunteers. Any needed medications, medical equipment and supplies may also be provided. Bereavement services are usually available to families for up to one year. A majority of the 1,700 hospice programs in the United States are certified for reimbursement through Medicare, Medicaid or private insurance. There is no charge to the recipients.

For more information about hospice programs, contact the Illinois State Hospice Organization at (773) 324-8844 or National Hospicelink at 1-800-331-1620.

Selected Resources

Selected Books

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Warner, M. *The Complete Guide to Alzheimer's-Proofing Your Home*. West Lafayette, IN: Purdue University Press, 1999 (second edition)

For Children and Teens
Ages 3-8

Fox, M. *Wilfrid Gordon McDonald Partridge*. Brooklyn: Kane/Miller Book Publishers, 1985.

Kroll, V. *Fireflies, Peach Pies, and Lullabies*. New York: Simon & Schuster Books, 1995.

Potaracke, R. *Nanny's Special Gift*. New York: Paulist Press, 1993.

Schwartz, N. *Old Timers: The One That Got Away*. Tampa, FL: Tumbleweed Press, 1997.

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Ages 9-12

Bahr, M. *The Memory Box.* Morton, Grove, IL: Albert Whitman & Co., 1992.

Ballman, S. *The Stranger I Call* GRANDMA. St. Cloud, FL: Jawbone Publishing Corporation, 2001.

Bauer, M. *An Early Winter.* New York: Clarion Books, 1999.

Park, B. *The Graduation of Jake Moon.* New York: Atheneum Books for Young Readers, 2000.

Other Resources for Children & Teens

Talking with Children and Teens About Alzheimer's Disease: A question and answer guidebook for parents, teachers, and caregivers by J.M. McCrea, 1994, 75 pages. Available for $15 from Generations Together, University of Pittsburgh, 121 University Place, Suite 300, Pittsburgh, PA 15260, Phone: (412) 648-7150.

Just for Children and Just for Teens - Helping you understand Alzheimer's disease by the Alzheimer's Association. Two factsheets available for free from the Alzheimer's Association, 919 N. Michigan Avenue, Suite 1000, Chicago, IL 60611, Phone: (800) 272-3900 or (312) 335-5796.

Fading Memories: An adolescent's guide to Alzheimer's disease. Available for $5.00 from the American Health Assistance Program, 15825 Shady Grove Road, Suite 140, Rockville, MD 20850, Phone: (800) 437-2423.

Through Tara's Eyes: Helping children cope with Alzheimer's disease. Available for $5.00 from the American Health Assistance Program, 15825 Shady Grove Road, Suite 140, Rockville, MD 20850; Phone: (800) 437-2423.

Videos

Many videos are available for viewing at the Rush Alzheimer's Disease Center. In addition, the McCormick Educational Technology Center at the Rush-Presbyterian-St. Luke's Medical Center has a collection of over 50 titles on Alzheimer's disease available for loan. Call (312) 942-6799 for a complete listing and to discuss details of the loan program.

The Alzheimer Association's Library, Benjamin B. Green-Field Library is an excellent resource center. They have numerous books, articles and videos available for use. Please contact the Alzheimer's Association for listings and availability. (www.alz.org)

Internet Resources and Web Sites on Alzheimer's

The Rush Alzheimer's Disease Center:
Clinical, educational and research activities of the Center and other resources.
www.rush.edu/patients/radc

Alzheimer's Disease Education and Referral Center (ADEAR):
Federally funded clearinghouse for information about resources throughout the United States.
www.alzheimers.org

National Alzheimer's Association:
National organization coordinates the activities and resources of over 200 local chapters throughout the United States.
www.alz.org

Greater Illinois Chapter of the Alzheimer's Association:
The local offices provide information and resources for local services.
www.alzheimers-illinois.org

Clinical Trials:
The National Institute of Health provides current information about clinical research studies.
http://clinicaltrials.gov/ct/gui

Alzheimer Europe:
Site provides much information in 11 different languages.
www.alzheimer-europe.org