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Purpose and Goals

The goal of this course is to increase awareness of health care professionals regarding the needs of persons with Alzheimer’s disease and their caregivers, whether at home, in long-term care facilities or hospital settings.

Author’s Philosophy

This course was written for healthcare professionals, working with the older adult population. Some may be in community settings and have regular contact with family caregivers who need information to understand the disease process and how to manage the various aspects of daily care for their loved one. And others may work in acute or long-term care settings with other health care professionals who need the same kind of information family caregivers do in order to maximize the remaining abilities of persons with dementia and enhance their quality of life. Or who may be caring for friends and relatives.

Alzheimer’s disease has been described in various ways. It has been called “the disease of the century,” “a funeral that never ends,” “another name for madness,” “the slow death of the mind.” The reality of life for most caregivers is reflected in the name of a popular book entitled “The 36-Hour Day.”

The trials and tribulations of caregiving are real, but never-ending caregiving responsibilities are not the whole story. There are many benefits that can come to those of us who care as family members, friends, and professionals, including countless opportunities for personal growth in the areas of patience, gentleness and faithfulness as we reach out to the Alzheimer’s sufferer with knowledge, understanding and compassion. Benefits can also come to our loved one, the client in the home, the nursing home resident and the hospitalized patient who have Alzheimer’s disease when we treat them with dignity and respect and take time to remember that each one who suffers is still a precious and unique person.

We believe the goal of both personal and professional caregiving is to care for the whole person, meeting needs and ministering through our care to broken bodies, souls and spirits. To that end, this course on caring for the person with Alzheimer’s disease is dedicated.

Instructional Objectives

Upon completion of this material the dedicated learner will:

2. Outline myths and misconceptions associated with Alzheimer’s disease.
3. Name signs and symptoms characteristic of early, intermediate and late stage Alzheimer’s disease.
5. Compare the difference between reversible and irreversible dementia and list examples of both types.
6. Name various procedures for differential diagnosis of dementia and explain the importance of early symptom recognition and assessment.
7. List the effect of cognitive changes on memory, language and the ability to communicate with others and list and describe strategies to enhance memory and facilitate communication with persons with dementia.

8. Define physical, psychosocial and environmental stressors that can increase confusion and disorientation and describe ways to eliminate, alleviate, and modify these stressors.
9. Outline helpful strategies to prevent and modify common catastrophic reactions and wandering behavior.
10. Identify interventions appropriate to each stage of Alzheimer’s related to specific symptoms.
11. List various medications commonly used to treat persons with Alzheimer’s disease including their actions and potential side effects.
12. Enumerate specific ways to modify the environment to enhance family and professional care giving and ensure optimum safety for the Alzheimer’s sufferer.
13. State the importance of emotional and spiritual support for both Alzheimer’s sufferers and family caregivers and define ways to enhance these types of support.
14. Identify practical procedures for caring for someone who is dying.
15. Distinguish between emotional reactions and coping styles and strategies for family caregivers.
16. Provide family and professional caregivers with appropriate educational and supportive care resources for care giving at home.
17. Identify major ethical, financial and legal dilemmas related to caregiving and assist families with options concerning placement.
18. Evaluate available resources when caring for a person with Alzheimer’s disease and develop strategies to enhance your ability to render optimal professional care.

Introduction

Anna Wilson was forever losing her car keys, her checkbook, and her glasses. But then, she had always had a habit of misplacing things and now that she was sixty-nine years old, it was to be expected that she’d forget where she put things on a regular basis. When you got older and retired, and your mind stopped being so active you did tend to forget more often. Anna wanted to believe that was true, at any rate.

What really bothered Anna though, more than the care keys and the checkbook and the glasses, were the people. She was simply forgetting people, names of friends and even, on occasion, relatives. Right this minute she was trying so hard to remember the name of her youngest grandchild, but she couldn’t.
What is Alzheimer’s?

Alzheimer’s disease is a complex, progressive, degenerative, irreversible brain disorder for which there is no definitive cause, no definitive treatment, and, to date, no foreseeable cure. It is considered the most common type of dementia-related illness for men and women over the age of 65. Approximately 5.4 million Americans are currently afflicted, including some under the age of 65, who have what is commonly known as early-onset or familial Alzheimer’s. Over 100,000 persons die annually from this disease that is considered the sixth leading cause of death in the elderly, after heart disease, cancer and stroke. The National Institute on Aging (NIA) projects that up to 16 million Americans may suffer from Alzheimer’s disease by the year 2050. Statistics are similar in other countries where life expectancy reaches into the sixties and seventies. Alzheimer’s is not a uniquely American phenomenon.

With the expected doubling of the over age 85 population in the next half-century, one out of every three persons in the United States may have at least one relative afflicted with Alzheimer’s disease. Currently the direct cost of caring for those with Alzheimer’s or other dementias, to families and society will total an estimated $200 billion annually.

Dementia, the broader diagnostic category of which Alzheimer’s disease is a type, can be defined as a multifaceted decline of intellectual functions of sufficient severity to interfere with a person’s activities of daily living, their social relationships, social activities and career. Dementia is not a disease itself, but describes a collection of symptoms that may accompany many specific disease processes. Other symptoms of dementia associated with global cognitive deterioration include specific impairments in memory, concentration, orientation, judgment and motor skills. Duration of chronic dementia varies from a few years to over 20 years before death.

The word dementia literally means “mind away” or “deprived of mind.” A person with an Alzheimer’s-type dementia usually experiences progressive loss of memory and judgment, marked personality changes, difficulty with abstract thinking and orientation, and a progressive inability to communicate verbally. It is a disease that bankrupts minds and the lives of entire families.

Knowledge of what actually is happening in the brain of normal aging individuals, as well as those with Alzheimer’s disease, can help dispel myths and misconceptions for both family and professional caregivers. As nurses become better acquainted with the anatomy and physiology of the brain and the pathological changes that can occur with the disease, they can become supportive and informative educators and advocates for families who often need help separating fact from fiction.

History of Alzheimer’s

The concept of mental deterioration (dementia) in older people has been recognized for centuries. Researchers today often point to Shakespeare’s King Lear as a classic case study of this disease state. Alzheimer’s disease, or dementia, was first described in 1907 by a German psychiatrist and neuropathologist, Dr. Alois Alzheimer. One of his patients, a 51-year-old woman, had experienced profound memory loss, confusion, and disorientation — symptoms normally associated at that time with what was commonly referred to as senile dementia in the elderly. This patient also suffered from depression, insomnia and hallucinations.

Chief Defining Characteristics

Distinctive pathological changes were also discovered by Dr. Alzheimer that are now considered to be the chief defining characteristics of Alzheimer’s disease. A brain autopsy he conducted, following the woman’s death at age 55, revealed both senile plaques and neurofibrillary tangles similar to those found in normal aging, but with differences in both quantity and location. Amyloid protein, the primary component of both plaques and tangles, was also present, as was granulovacuolar degeneration in the neurons.

The microscopic plaques and tangle formations discovered by Dr. Alzheimer had also been identified in greater than usual numbers in the autopsied brain tissue of much older people who had exhibited signs and symptoms of cognitive impairment; though at the time, all confusion in older adults was generally believed to be a result of a faulty blood circulation or the more common diagnosis of hardening of the arteries. The diagnoses of senility or chronic organic brain syndrome (COBS) were routinely used in the case of cognitive impairment in persons over age 65, while it was believed that Dr. Alzheimer’s patient had suffered from a type of presenile dementia that affected persons under age 65. Research in England in the 1960’s, however, revealed that the characteristic pathologic changes that occurred in the brains of older cognitively impaired adults were the same as those that occurred in cases of presenile dementia affecting persons under the age of 65. The diagnosis of Alzheimer’s disease, rather than hardening of the arteries, finally became widely recognized as the most common cause of dementia in persons over the age of 65.

The diagnosis of senile dementia of the Alzheimer’s type (SDAT) is sometimes used to describe the disease process when it occurs in persons under the age of 65. Dementia of the Alzheimer’s type (DAT) is a common term used that covers all age groups with similar symptoms.

The Brain

The brain consists of three main parts: the cerebrum, the cerebellum, and the brain stem. (See Figure 1)

The cerebrum, otherwise known as the large brain, consists of two hemispheres covered by the cerebral cortex, often referred to as “gray matter.” The cerebrum, associated with higher mental functions, almost fills the entire brain cavity.

The cerebellum is located below the cerebrum and in back of the brain cavity; the chief role is related to balance and the coordination of muscle activity. It is often referred to as the small brain.

The brain stem that controls breathing and circulation connects the cerebrum and cerebellum to the spinal column.

Billions of microscopic cells called neurons make up the brain’s composition. Each neuron consists of a number of parts: a cell nucleus, dendrites and an axon.

Cell nuclei are circular cell bodies situated...
inside each neuron of the brain. Short shoots resembling tree limbs branch out from cell nuclei; these free-floating branches are called dendrite receivers and dendrite transmitters. Prior to their branching out, dendrite transmitters are funneled through a long, threadlike structure called a cell axon. (See Figure 2).

The normal process of message transmission that occurs between and among neurons enables all the activities of daily living that involve memory, speech, emotions, and behavior to occur.

The desire to speak a sentence or to engage in an activity such as eating, getting dressed, or walking originates in one or more of the brain cell nuclei in the form of an electrical impulse. This impulse is then transmitted through a cell’s dendrite transmitters by way of a cell axon to the dendrite receivers of a neighboring cell. Located between each cluster of one cell’s dendrite transmitters and another cell’s dendrite receivers, is a space or a gap known as a synapse. In order for the impulse to pass from cell to cell, this synapse must be bridged. This occurs through the release of chemicals called neurotransmitters. These neurotransmitters attach to dendrite receivers at specific receptor locations, releasing high-energy chemicals that are responsible for stimulating an electrical impulse in the next cell. The end result of all this electrical and neurochemical activity is thought, speech and movement, and the expression of the wide range of emotions that uniquely characterize each person. (See Figure 3).

Many different neurotransmitters are believed to play a major role in the process of thinking and remembering, including acetylcholine, norepinephrine, serotonin, somatostatin, dopamine, gamma aminobutyric acid (GABA) and corticotrophin-releasing factor.

**Structural or Neuroanatomic Changes and Normal Aging**

Decreased brain weight is a normal structural change that occurs in the process of aging. The brain of an older adult with no cognitive impairment may weigh 7 to 8 percent less than that of a young or middle-aged adult.

Brain atrophy is also common in an aging brain. Both weight loss and brain shrinkage are associated with the loss or degeneration of cell neurons. These normal and anticipated losses, however, do not translate into symptoms associated with dementia, though they may produce some age-associated or benign senescent forgetfulness (BSF).

One specific change associated with normal aging that occurs in about 70 percent of persons over age 80 and less frequently in persons over age 65 is the presence of senile or neuritic plaques. These fibrous plaques, located between brain cells, are composed of terminal dendrites that surround fibrous waste products of a starch-like amyloid protein. A second, but far less common characteristic of normal aging, is the presence of fine nerve fibers or twisted filaments laid down within cell nuclei called neurofibrillary tangles.

Senile plaques and neurofibrillary tangles are common to Alzheimer’s disease; in the normal aging brain they may also occur but not to so great a degree that they cause cognitive dysfunction.

**Structural and Neurochemical Changes**

Brain weight in persons diagnosed with advanced Alzheimer’s disease has been known to decrease as much as 10 percent over and above brain weight in older persons with no cognitive impairment.

The loss of neurons primarily occurs in the hippocampus of the temporal lobe of the brain. The hippocampus is the part of the brain most important to short-term memory and thought processes and is also part of the limbic system. When activated by motivated behavior and arousal, the limbic system, often referred to as the “seat of the emotions,” can influence both hormones and the autonomic nervous system that controls involuntary functions. Neuronal loss can also occur in the frontal lobe.

Collective neuronal loss contributes to cortical atrophy and a diminishment of the brain’s surface area. The fibrous plaques and neurofibrillary tangles that are present to a greater degree in Alzheimer’s disease than in the normal aging brain are believed to disrupt the electrical impulses needed for message transference from neuron to neuron.

The greater the number of plaques and tangles, the more profound the disruption with associated symptoms of intellectual and behavioral impairments characteristic of dementia.

Neurochemical abnormalities also occur. The neurotransmitter acetylcholine (ACH) and choline acetyltransferase (CAT), the enzyme that synthesizes ACH from its precursors, are missing or present in decreased amounts in both the cortex and the hippocampus. This adversely affects message transfer across the synaptic space from neuron to neuron.

Other neurotransmitters that are thought to be deficient in persons with dementia are norepinephrine, serotonin, somatostatin and corticotrophin-releasing factor.

In addition to neuronal loss, plaque and tangle formation and neurochemical depletion, there may also be some degree of circulatory impairment related to the death of brain cells. This impairment is not a primary cause of dementia, but a contributing factor believed to be related to specific structural and neurochemical changes that have already taken place.

**Theories of Causation**

The cause or causes of Alzheimer’s disease remain a subject of research and a matter of much speculation for many caregivers who are understandably fearful that Alzheimer’s disease may be hereditary. Myths and misconceptions also abound with respect to theories of causation.

The following caregiver quote illustrates some of the concerns and fears surrounding this issue:

“I read some information about Alzheimer’s disease that said I had a good chance of getting it because my mother had it. Then I went to a conference where they talked about the..."
hereditary factor. I was so depressed when I came home, I spent the next four days in bed.”

Knowing about the current research can assist health care professionals to more intelligently and compassionately answer questions that clients and family raise about possible causes of Alzheimer’s disease. The following is a list of some “theories of causation”. These areas will give you the opportunity to conduct further research should you choose to do so.

They include: Neurotransmitter Deficiencies; Immunological Defects; Genetic Predisposition and Chromosomal Defects; Head Injury; Neurotoxic Metals and Viruses.

Signs and Symptoms

Alzheimer’s disease is characterized by a general and progressive decline in mental and functional abilities, usually over an extended period of time. The degree of progressive decline seems to be dependent on the degree of pathological involvement affecting neurons and varies from person to person.

There is no hard and fast rule that determines the stages of Alzheimer’s or even what signs and symptoms characterize each stage; authors of articles and textbooks describe anywhere from three to seven stages. Each person progresses through the disease at a different rate of speed and may not exhibit all the signs and symptoms associated with dementia. Some people with Alzheimer’s will remain relatively quiet and placid throughout the course of the disease; others may exhibit the full range of symptoms.

The following is an overview of signs and symptoms as the disease progresses through three primary stages.

Early Alzheimer’s Disease

The average length of this initial stage of forgetfulness is between two to four years and actual diagnosis may not occur for several years as symptoms progress slowly over time. The person may be able to compensate for the various losses they are gradually experiencing and still be capable of maintaining a job though their performance level may be compromised. In some cases, however, the course of the disease proceeds rapidly.

Symptoms of Stage 1 can include the following:

Memory Impairment

Gradual change in the ability to remember is the most classic and universal symptom of Alzheimer’s disease. Recent, or short-term memory is initially affected. Forgetfulness and memory lapses are related to the names of acquaintances, appointments to be kept, bills that need to be paid or other correspondence, and the day and month of the year. Things become easily misplaced or lost as the disease progresses, and the person with dementia may blame others for “moving or stealing their possessions.”

People experiencing these symptoms in the very early stages are often aware that “something is wrong” and may compensate by writing reminders down on cards and frequently referring to them, though as the disease progresses, the cards themselves may be misplaced or forgotten and concealment is no longer possible. Long-term memory will remain intact for much of this time period, but processing new information or learning new things is difficult. Depression and anxiety may accompany this stage, if the person’s own awareness of failing memory is acute; and suicide ideation is not uncommon. Both rationalization and denial of symptoms can accompany memory loss.

Disorientation and Impaired Judgment

Early Alzheimer’s Disease patients may experience a growing inability to discriminate, understand and follow directions, easily becoming lost. For example, one may be able to find their way to a familiar place such as the library or the grocery store, but then be confused about how to get home. People with early dementia who are perfectly capable of driving a car have been known to wind up in no parking zones, or drive the wrong way on one-way streets. The ability to read is retained, but not the ability to understand what is read.

Changes in Mood

Personality changes like depression may be related to a person’s growing awareness that something is wrong with their minds. Interpersonal conflicts with outbursts of anger are also common during this stage. Suspicousness and paranoia are frequent symptoms caregivers identify as characteristics of their loved ones, as well as social withdrawal. Anxiety is also a common symptom and may be accompanied by restlessness and aimless wandering.

Difficulty With Task Completion

The everyday tasks of daily living that have become habitual may eventually be difficult to engage in, even routine activities such as bathing, dressing, or cooking a meal. This may be related to memory loss and simply forgetting that they have failed to bathe, or put on the proper clothes, or added the right ingredients to the cake recipe.

Companies sometimes offer early retirement to persons who seem to be “falling down on the job.” A person who has been an accountant, for example, may no longer be able to add or subtract correctly; a teacher may be ill prepared to teach because he is no longer able to develop lectures in a timely manner or in any organized fashion.

Attention span is usually extremely short; the ability to concentrate is gradually lost and will also spill over into the ability to maintain well-established hobbies and habits, such as reading a book or watching television. These behavior changes may be erroneously attributed to apathy or depression, eccentricity, stress or laziness.

Changes in Speech

Speech may gradually become impaired. Language skills gradually diminish and people may be unable to complete sentences with the correct words. They may not be able to remember the names of objects and may substitute other names that are familiar, or even make up words. This is known as confabulation.

Circumlocution is also common, where more words than necessary are used to express an idea.

It is important to remember that as the disease progresses, more is lost than the abilities to think, remember, behave, and speak in certain ways. Alzheimer’s disease has been described as a gradual loss of the self and loss of personal awareness of one’s own identity. Also anticipated is the loss of dignity. It can be a frightening and frustrating time for families as they struggle to make sense out of their loved one’s changed behavior and altered personality. It can be a terrifying time for the Alzheimer’s sufferer who, more than ever, needs to be assured that they are loved and accepted just as they are, and that they won’t be abandoned in the future as their disease progresses.

Intermediate Alzheimer’s

Stage one symptoms tend to intensify rather than disappear over time, and an intermediate stage of confusion is entered that may last from two to ten or more years. People with Alzheimer’s disease often are able to live alone with support from family, friends, and community resources during the first stage. As the disease progresses, safety becomes a major issue and is often the factor that triggers moving into a relative’s home, an adult care home, or nursing home. Assistance becomes necessary in this stage for not only complex tasks, but also routine activities like dressing, cooking, and eating.
Progressive Memory Impairment

Severe short-term memory impairment continues, and long-term memory eventually becomes impaired. Names of close friends and relatives are no longer remembered and a person’s spouse, or an adult child, may even be mistaken for someone else.

Eventually the person may fail to recognize him- or herself in a mirror and may exhibit a lack of self-consciousness when spoken to by name. Everyday objects are also not recognized by name. This lack of person and object recognition is called agnosia. Forgettingness becomes a way of life for the person.

Extreme Disorientation and Confusion

Progressive inability to carry out activities of daily living such as dressing, eating, and bathing will occur in the course of the disease. Overlearned skills are often retained for a long time, for example, the ability to play a piano, to knit a sweater, to drive a car.

Catastrophic Reactions

Pronounced personality changes and emotional lability may characterize this stage. Restlessness and anxiety may increase and be accompanied by paranoia, angry outbursts and physical violence. Psychotic symptomatology may include hallucinations, delusions and manic-depressive mood swings.

Restlessness and Wandering

Aimless wandering or pacing occurs and may intensify in the late afternoon, in the evening or at night. The person may wander or run away from their home and become lost.

Atypical Behaviors

Hiding and hoarding things is a characteristic behavior associated with advancing dementia. Repetitious, ritualistic or erratic movements or gestures can occur as the disease progresses, such as foot or finger tapping, lip smacking and constant chewing movements.

This repetitive behavior often applies to household tasks such as washing the same dish over and over, or folding and refolding the same piece of laundry. Hyperorality may occur as appetite seems to increase in direct proportion to the degree of purposeless activity.

A person may not be able to discriminate between food and inedible objects. Inappropriate behavior usually leads to urinary and bowel incontinence in places other than the bathroom. Inappropriate sexual and social behavior are also common.

Speech and Language Impairment

As pathology progress into areas of the cortex and hippocampus responsible for language and memory, there is often inability to construct a complete sentence, and expressive vocabulary becomes impaired. Speech may become nonsensical, or garbled and rambling. The continuous repetition of words or phrases known as echolalia is common. Many people with more advanced dementia may still be able to recite the alphabet, count without difficulty, or quote a lengthy poem from memory. These remaining and seemingly intact abilities may relate to the concept of automaticity. Things learned that have been often repeated no longer depend on conscious awareness or intact cognitive function to exist — even though the person may not be able to construct a word with the letters of the alphabet, do simple mathematics, or be able to state what the recited poem was about. Some people may simply cease to speak altogether and become partially aphasic or mute.

Motor Impairment

Motor deficits often manifest in the form of apraxia (the inability to perform previously known, purposeful and skilled activities or motor tasks). Agraphia, the inability to write, may occur. The person may be gradually unable to bathe, dress, eat or engage in other purposeful activities. These losses are now related to affected motor function and coordination in addition to forgetfulness. Gait changes, stiffness and stooped posture accompanied by a slow, shuffling walk are typical, which places the person at risk for injury both when ambulating and even when sitting in a bed or chair.

Late Stage Alzheimer’s Disease

The final, or terminal, stage of Alzheimer’s disease is characterized by extreme physical wasting and mental deterioration, and the person may no longer be able to walk. Skin breakdown, contractures, and urinary tract infections are frequent complications. Speech may be incoherent or non-existent. Malnutrition and dehydration are not uncommon and in the final stages of the disease, the gag and swallowing reflexes may disappear.

The person will need to be fed and often tube feedings are needed. Seizure activity may also occur in the final stages of dementia. Death is often precipitated by an infectious process such as pneumonia that may be related to aspiration of food or fluid, or some other infectious process related to general debilitation.

If families have not already done so, they may need help, preferably before this final stage occurs, to explore issues related to terminal care including decisions about continued home care, facility placement, and issues related to nutrition and hydration if their loved one can no longer swallow.

Break Through the Denial

“I ignored the symptoms for a good while. Henry was so obstinate I knew he wouldn’t willingly go to the doctor and I figured we’d get along okay and maybe he’d just kind of mellow out and not get any worse. But I was wrong. He did get a lot worse. When our daughter came home to visit us after two years in California she was horrified that I’d let the situation get so bad. We had an awful scene and finally I did get Henry to the hospital clinic and they diagnosed him as having Alzheimer’s. It would have been a lot easier on all of us if we had known exactly what was going on earlier and my daughter could have come home and been a support. Our relationship is still pretty shaky but I’m trying. I’m trying. And Henry is getting some help now.”

Family members have a natural tendency to deny the changes they may be seeing in their loved one or, because they are so close to the situation, take subtle and gradual changes for granted. They may put off taking their loved one in for an initial evaluation for any number of reasons, including their own fears. Like Henry, a person with a developing dementia may also be extremely difficult to convince they need help. Physically getting a person to a physician can be an emotionally trying and sometimes a physically exhausting experience.

Often a crisis, such as a death in the family or a major illness, will cause a person in the beginning stages of Alzheimer’s to more visibly manifest their lack of coping skills and can be the trigger that alerts other family members or health care workers that something is indeed wrong.

Denial can be dangerous, particularly when the person with a developing dementia lives alone and may be experiencing memory loss severe enough to create safety hazards for them.

Caregivers often tell stories of loved ones setting wastebaskets on fire and burning pots and pans because they fail to turn off the stove or oven. The arrival of the fire department is often the “last straw” that helps a family realize the time has come to get some help.

There are other important reasons in addition to safety issues for obtaining an early evaluation: the need for family planning the need to receive an accurate diagnosis.
The Need for Family Planning

Caring for a person with Alzheimer’s is a family affair; the burden of responsibility should not rest on only one person. Involving all relevant family members in developing a plan of care following a diagnosis of Alzheimer’s can enhance well-being for both the person with dementia, as well as their primary caregiver, who is usually the spouse or a daughter. Role changes will be inevitable. During this time family members need written information and counsel about the disease to provide them with the necessary information for decision-making and to help clear up myths and misconceptions they may have.

Early recognition of Alzheimer’s disease can help families deal with their fears more realistically. One reason Alzheimer’s is so fearful is that it makes people feel out of control. The best way to allay fear and retain some sense of control is through knowledge and understanding of the disease itself.

The person in the early stages of Alzheimer’s may be able to benefit from participating in current research. Experimental drug trials are underway in many parts of the country. Persons who gain the most from these drugs that may help slow the disease process or alleviate some of the symptoms associated with cognitive impairment are those in the early stages of Alzheimer’s. Local support groups often have information about what is available in their community and the National Alzheimer’s Association can also direct people who are interested in appropriate resources (See Resources).

Families should think about intermediate and long-term caregiving decisions before a crisis occurs. Early in the disease is the time to explore the various options available in their community for different types of care in the home, as well as community options such as adult day care, adult homes, and long-term care facilities if they are needed in the future.

Memory loss is not instantaneous, but gradual. In the early stages of the disease a person with Alzheimer’s is still capable of making rational decisions and should be given every opportunity to do so. Financial and legal issues will need to be addressed. Insurance coverage rarely pays for the type of custodial care a person with dementia will need in the future either at home or in a health care facility. A durable power of attorney should be obtained by someone in the family to enable them to take charge of their loved one’s affairs when it becomes necessary. The person with Alzheimer’s may also want to formulate appropriate advance directives in consultation with their family with respect to decisions about resuscitation and life support.

These are difficult decisions made easier when the whole family can support the person in their decision-making efforts.

Needing an Accurate Diagnosis

A surprising number of acute and chronic disease processes mimic the symptoms of Alzheimer’s. Prior to 1980, Alzheimer’s was probably one of the most under-diagnosed of all diseases; today it may be one of the most over-diagnosed. It is, unfortunately, not unusual for older persons to be told they have Alzheimer’s disease, but be suffering instead from something that causes similar symptoms.

Blood tests sometimes reveal hypercalcemia. Thiazide diuretics taken to treat hypertension can contribute to this condition. Complete reversal of mental symptoms can occur, once serum calcium levels are returned to normal.

There are, in fact, dozens of different disorders that can cause dementia-like symptoms; some of these disorders are chronic and irreversible, but many others can be treated and their symptoms reversed.

Healthcare professionals need to be knowledgeable about other disorders to be able to assist families who may need a second opinion and a more extensive diagnostic evaluation for a loved one with symptoms of dementia. Some of the reversible causes of dementia may also co-exist with Alzheimer’s disease, exaggerating symptoms. It is also important for health professionals to be familiar with the process of dementia diagnosis, including lab and imaging tests.

A diagnosis of Alzheimer’s may not be made immediately even after exhaustive testing. There is often a need to wait several months in order to follow the progress of the dementia; sometimes other underlying causes that may have been missed during the first round or battery of tests may surface given time.

Chronic and Irreversible Dementias

There are a number of chronic disease processes that produce dementia-like symptoms that can be mistaken for Alzheimer’s. In certain cases, symptoms can be controlled with medication or surgery and the disease progression slowed.

Vascular Dementias

Multi-infarct dementia (MID) is one type of vascular dementia and is believed to be the second most common cause of chronic irreversible dementia. It is caused by multiple strokes or infarcts in the brain related to an atherosclerotic process that narrows arteries feeding brain cells and is often a corollary to untreated diabetes or hypertension. Symptoms associated with MID may seem to appear suddenly when, in fact, multiple-stroke activity has been occurring over an extended period of time. Unlike the progressive, general, global decline associated with Alzheimer’s dementia, persons suffering from multi-infarct dementia often experience plateaus where there is no perceptible change in intellectual impairment or behavior. There may even appear to be some improvement between periods of plateauing as collateral circulation kicks in. When stroke activity does occur there may be evidence of specific local or focal neurological impairment related to specific areas of brain involvement such as slurred speech patterns or muscular weakness in an arm or leg. Alzheimer’s disease and multi-infarct dementia frequently co-exist in what is called a “mixed dementia”.

Mild dementia may account for 15-20 percent of all existing chronic dementias. Differentiating between the two dementias through various neuroimaging techniques is of great importance. Though multi-infarct dementia is not considered reversible, further stroke activity and progression of dementia may be preventable.

Risk factors for multi-infarct dementia, unlike risk factors for Alzheimer’s disease, have been identified and include hypertension, vascular disease, and diabetes. Pharmacologic as well as surgical interventions may be indicated if it is known that stroke activity, rather than senile plaques and neurofibrillary tangles is the root cause of deteriorating symptoms.

Binswanger’s disease or leukoaraiosis is a vascular dementia related to persistent, severe hypertension. Diabetes, cardiovascular disease and recurrent hypotension are also risk factors. Pathologic changes occur in the frontal subcortical white matter of the brain related to advanced atherosclerosis in the medullary arteries. Symptoms include dysarthria (difficulty articulating words) and dysphagia (difficulty swallowing).

Gait disorders, frequent falls and urinary incontinence are also early symptoms. Like MID, Binswanger’s disease is plateau-like in progression and is of relatively long duration. Preventive measures can help slow or halt the progression of this disease that can be diagnosed with magnetic resonance imaging.

Infectious Processes

Acquired immune-deficiency syndrome (AIDS) dementia is believed to occur when the human immunodeficiency virus (HIV) infects certain brain cells resulting in encephalopathy. Memory loss and decreased ability to concen-
tate are common with progressively more severe neurological symptoms occurring with increased neuronal involvement.

Bacterial, fungal, and parasitic infections of the brain associated with a compromised immune system can also contribute to AIDS-related dementia.

Neurophillic dementia was a primary type of dementia prior to the discovery of penicillin and sulfad drugs. In the 1850’s, over half of all patients in mental institutions suffered insanity secondary to syphilis. Syphilis may also occur today as a secondary infection in persons with AIDS. Early signs include memory loss and symptoms of epilepsy. Late neurophillic results in marked personality changes and a general paresis.

**Slow Viruses**

Creutzfeld-jakob disease is a rare form of dementia believed to be caused by a virus. Unlike Alzheimer’s, Creutzfeld-jakob disease progresses rapidly and death usually occurs within a year of diagnosis. Symptoms are similar to those of Alzheimer’s and include memory impairment, behavioral changes and poor coordination. Microscopic examination of brain tissue on autopsy reveals pathologic changes unique to this disease. Kuru is another rare form of dementia believed to be transmitted by a slow virus.

**Neurotransmitter Abnormalities**

Parkinson’s disease is caused by a specific disease process related to the absence of the neurotransmitter dopamine that controls muscle activity.

In the early stages of Parkinson’s there may be cognitive changes that often manifest in slowed or delayed thinking processes. Unlike the Alzheimer’s sufferer, the person with Parkinson’s, given time, will be able to reason and remember, though speech may be slower than normal. The two diseases are often confused in both early and late stages.

Parkinson’s sufferers may also actually develop Alzheimer’s disease and persons with Alzheimer’s disease may exhibit symptoms characteristic of Parkinson’s disease such as joint stiffness, bradykinesia (slow movement), difficulty walking and complete immobility. The tremors associated with Parkinson’s disease are not usually present in people with Alzheimer’s disease and may be one feature that assists health professionals in making a differential diagnosis.

Medications such as levodopa can improve symptoms associated with muscular activity. Antidepressants may also help alleviate symptoms such as apathy and depression that may be associated with a response to the disease as well as specific changes that occur with the disease.

**Hereditary Dementias**

Huntington’s disease is a related disorder that is hereditary. It involves early stage cognitive changes with memory impairment as well as involuntary facial and limb movements. Paranoia, hallucinations and depression may also be early symptoms. Mental deterioration may progress over the course of the disease.

A genetic marker identified on chromosome Four has been linked to the Huntington gene. Huntington’s disease, like Alzheimer’s, is progressive in nature though symptoms associated with abnormal muscle movement may be controlled with various drugs.

**Other Related Dementias**

Frontal temporal dementia (FTD), formerly known as Pick’s disease, is caused by progressive nerve cell loss in the brain’s frontal and temporal lobes. Temporal atrophy is also present, but more marked than that in Alzheimer’s. Behavior symptoms that are specifically associated with FTD are disinhibitions with respect to sexual behavior and inappropriate social behaviors. Memory loss is not as profound as that seen in people with Alzheimer’s though presenting symptoms are often similar.

**Lewy Body Dementia**

Dementia with Lewy bodies (DLB) is a type of progressive dementia that leads to a decline in thinking, reasoning and independent function because of abnormal microscopic deposits that damage brain cells over time. DLB is the third most common cause of dementia after Alzheimer’s disease and vascular dementia, accounting for 10 to 25 percent of cases.

Named after Frederick H. Lewy, M.D., the neurologist who discovered them while working in Dr. Alois Alzheimer’s laboratory, Lewy bodies are comprised primarily of Alpha-synuclein protein. Symptoms include changes in thinking and reasoning, Parkinson’s symptoms such as hunched posture and shuffling gait, visual hallucinations and delusions.

**Reversible Causes of Dementia**

Many of the conditions that cause dementia-like symptoms can be reversed or cured. A thorough physical, neurological and psychological assessment including appropriate tests is important in order to identify and provide appropriate treatment if the disease is not Alzheimer’s or a related irreversible dementia.

Some family caregivers may feel it is a waste of time going through the laborious and often difficult process of ruling out other potential causes of dementia, especially if both they and their physician are reasonably sure it is Alzheimer’s. But there are many benefits associated with this process, not the least of which is alleviation of guilt that can occur later if a family member feels they might not have done everything possible to help their loved one. Receiving a diagnosis of Alzheimer’s and ruling out other causes also encourages the Alzheimer’s sufferer and their family to tap into a number of helpful resources including Alzheimer’s support groups and a wealth of written materials available through national, state and local Alzheimer’s Associations.

**Arriving at a Diagnosis**

Actual confirmation of Alzheimer’s disease can occur only upon microscopic examination of brain tissue following autopsy or by means of a brain biopsy. Brain biopsies are rarely done due to the risk of hemorrhage or infection.

There are, however, numerous steps that can be taken that can result in a probable diagnosis. It is a laborious but necessary process of elimination and exclusion that should include a comprehensive history and physical, neurological and psychological testing, various tests on body fluids, and neuroimaging techniques.

**Comprehensive History**

The most important diagnostic tool for evaluating dementia is a detailed medical and social history. It is important for health care providers to include a family member or knowledgeable friend in this step as well as the patient who, because of a failing memory, may be unable to give accurate details about the changes that have been occurring in their life. In the early stages of dementia a person may also be fairly adept at concealing signs of memory loss and confusion in a controlled situation like a doctor’s or nurse practitioner’s office or clinic. This is an understandable response to loss of self-esteem and fear associated with memory changes. A family member who has not seen the person for a period of time may be better able to notice changes than a family member who lives with the person and has gotten used to the gradual decline, or who may be denying the decline because it is too painful for them to face.

Family members can be encouraged to think through and write down information in order to give as complete a history as possible about the changes in behavior their loved one has experienced and information about the onset and pattern, or progressive nature, of those changes. A sudden onset of memory loss or increased confusion, for example, is not indicative of Alzheimer’s dementia but could lead to a diagnosis of a brain tumor, a recent
If the person has been experiencing increased confusion that seems to plateau for long periods of time rather than progress, they may be having multiple-stroke activity. The following categories and related questions could serve as a checklist. Many are designed specifically to rule out other causes of dementia, some of which may be reversible. Community health nurses can be especially helpful in guiding families through the process of reconstructing their loved one’s history.

- **Attitude and Affect**—Has the person been unusually anxious, agitated, apathetic, depressed or withdrawn? If so, when were symptoms first noticed? Did any major events or crisis situations occur prior to the onset of symptoms, e.g., an illness, the death of someone close to them, relocation or retirement?
- **Behavior**—Have there been noticeable changes in the person’s routine activities of daily living? Is the person behaving in any way out-of-the-ordinary for them? Is there any evidence of the person forgetting things? What specifically is forgotten? How frequently does the forgetfulness occur? Has the person ever wandered off and gotten lost?
- **Communication**—Have there been any changes in the person’s ability to communicate? Do they have any problems remembering words; do they substitute wrong words for right words in a sentence? Have speech patterns changed in any way, for example, has speech become slurred or garbled?
- **Decision-Making**—Has the person been making errors in judgment with respect to routine activities of daily living such as paying bills? If the person drives a car, are they able to do so safely?
- **Drugs**—Is the person on any medications, either prescription or over-the-counter? Is there any evidence of acute or chronic withdrawal effects? Is there any history of blood transfusions? Is there any evidence of alcoholism?
- **Environment**—Is there any evidence in the environment that there have been behavioral changes? If they live alone, is there evidence that they are eating enough, and drinking an adequate amount of fluid?
- **Family and Friends**—Have any other people close to the person been aware of any behavior changes? Have co-workers, friends or other relatives noticed any changes?
- **Grooming**—Has the person become neglectful in the areas of bathing, toileting, dressing and overall grooming? Have they been urinating more frequently than usual, or have they experienced incontinence?
- **Gait**—Have there been any changes in the person’s ability to walk or to maintain their balance?
- **Habits**—Has the person altered their normal everyday routine in any way that is unusual? Do they continue to do routine tasks they have always done without difficulty such as balancing a checkbook, paying bills, or grocery shopping? Has the person altered their normal routine in any way with respect to social relationships? Are familiar hobbies engaged in without difficulty?
- **Illnesses**—Has the person experienced any noticeable symptoms that might indicate an acute, chronic or infectious illness such as a fever, congestion or incontinence? Does the person have a personal or family history of any of the following: dizziness or fainting, stroke activity, metabolic disorders such as diabetes or thyroid disease, heart or lung abnormalities, headaches, seizures? Is there any evidence of acute or chronic alcoholism?

**Neurological Examination**

A complete medical and social history should be followed by a comprehensive physical exam that should include a neurological examination. The neurological examination is often done prior to more invasive tests and will probably include some type of mental status examination as well as tests that focus on certain aspects of neurological functioning.

A mental status examination includes tests of psychological functioning that help to indicate the ability of different parts of the brain to function and can give evidence of both the progression and possible causes of dementia. Specifically measured is cognitive function or the person’s ability to reason, remember, perceive and make judgments, conceive and imagine. Initially used as a tool for diagnostic purposes, mental status exams may also be repeated over time to determine disease progression.

There are a number of different mental status tests in use. One of the most common is known as the Folstein Mini-Mental Status Exam that is often used in hospital and nursing home situations by nurses and in nursing research projects to evaluate mental status. A more comprehensive examination is called the Wechsler Adult Intelligence Scale. Mental status exams are used to test cognitive function in a number of different areas: orientation, memory, mathematical skills, abstract reasoning and judgment, language skills, reading, writing and drawing skills.

**Orientation to time, place, object and person**—Examples of questions asked relate to the day of the week, month of the year and the year itself. People are asked their own name and the name of a parent. They may be asked where they live and their phone number. They may be shown several objects such as a pencil or a watch and be asked to name them.

**Remote and recent memory**—Questions about personal history include queries about where and when were born. They may be asked the name of the current and the former President and the dates of World Wars I and II. They may be asked to repeat from memory a short series of numbers or list a number of objects several minutes after being told what those numbers or objects were.

**Mathematical skills**—A series of simple math problems may be given. The person may be asked to count forward or backward in multiples of 3 or 7.

**Abstract reasoning and judgment and language skills**—The person may be given a hypothetical situation that requires them to make a decision and be asked what they would do, for example, if they walked into the kitchen and there was a fire on the stove. Or they may be given a simple proverb and be asked to explain what it means. They may also be asked to name common objects.

**Reading, writing and symbolic drawing skills**—The ability to both read and comprehend what they have read may be tested. They may be asked to write a sentence or copy a simple design. Drawing a clock face and penciling in numbers for the time of day may be requested.

Specific neurological tests may also be directed to test a person’s sense of smell, believed to be impaired in the early stages of Alzheimer’s disease. The snout reflex might be elicited by tapping or stroking the patient’s lips or the area beneath the nose. Grimacing or puckering of lips indicates a positive finding. These reactions are normal in early infancy; in an older adult they suggest diffuse organic brain disease.

A psychiatric interview may also be needed if depression is suspected; symptoms of classical depression that mimic those of early stage Alzheimer’s disease include apathy, memory lapses, and impaired mental processes involving thinking, concentration and judgment. Physical symptoms such as generalized weakness and fatigue, uncontrollable episodes of crying, insomnia, anorexia and weight loss often coincide with depression. Feelings of helplessness and hopelessness, unworthiness and guilt often accompany depression. There may also be verbalizations of suicide. Manic forms of depression can also result in mood
changes that can mimic those of Alzheimer’s disease.

Depression-induced dementia is called pseudodementia or the dementia of depression. A Geriatric Depression Scale may be used for screening. It is important to try and differentiate between Alzheimer’s related early dementia and early symptomatology triggered by acute or chronic depression.

Depression can also accompany Alzheimer’s disease and exacerbate symptoms. Antidepressant therapy may be used in cases of primary depression as well as in cases where Alzheimer’s disease is present.

Many reversible disorders can be identified by more invasive diagnostic procedures that include tests conducted on blood, urine and spinal fluid. Neuroimaging techniques can be especially useful for diagnosing both reversible and irreversible forms of dementia.

**Blood Tests**

A complete blood count (CBC) and sedimentation rate (ESR) should always be done for any suspected case of cognitive impairment. Examples of abnormalities that can be detected with this test include acute or chronic infectious processes, anemia and blood cancers. Low hemoglobin and hematocrit levels resulting in oxygen deprivation to brain cells may also be detected.

Abnormally high or low levels of circulating calcium or low sodium levels can trigger electrolyte imbalances that can cause hypercalcemia, hypocalcemia, or hyponatremia and can contribute to the development of confusion. Cognitive impairment may also be related to compromised kidney or liver function that can be detected through blood urea nitrogen and creatinine levels.

A variety of tests related to gland function may uncover abnormalities that can contribute to marked personality changes, irritability and confusion. Diabetes and other endocrine disorders can trigger dementia-like symptoms.

Hypoglycemia can compromise neuronal function by limiting glucose uptake in the brain, resulting in confusion. Abnormally high or abnormally low levels of thyroid hormone frequently cause reversible dementia. Glucose tolerance and thyroid stimulating hormone tests are two recommended procedures for differentiating causes of dementia.

Low Folic acid, or folate, (B-complex vitamin) levels can cause dementia as can low vitamin B12 levels associated with pernicious anemia; symptoms include depression and irritability. Serum levels of both folic acid and vitamin B12 can be measured if a history and physical examination indicate a need for them.

Drug toxicity is the most frequent cause of reversible dementia, both in institutional settings and at home where older people in particular may be taking any number of prescribed medications from several physicians, as well as numerous over-the-counter drugs such as laxatives that can contribute to severe fluid and electrolyte imbalances. Decreased filtration in the kidneys, slower metabolism, lower levels of liver detoxification, and diminished circulation contribute to medication buildup and symptoms such as depression and disorientation. Medication overdose can also contribute to vitamin and mineral deficiencies if absorption is adversely effected. One example of this is thiamine deficiency triggered by unregulated use of antacids.

Common medications that can simulate or exacerbate existing dementia include insulin and oral hypoglycemic agents, medications to treat various forms of cancer, and excessive doses of some fat-soluble vitamins such as vitamin A and Toxic levels of medications or associated electrolyte imbalances can frequently be detected in the blood.

In-home abuse of alcohol or injudicious use of over-the-counter cough medicines or liquid vitamin supplements containing alcohol may also cause confusion, especially when combined with certain medication.

Lead, mercury, manganese and aluminum have all been implicated as causes of confusion when blood levels are abnormally high. Environmental substances such as pesticides, carbon monoxide and industrial pollutants can also cause confusion.

Syphilis was believed to be the primary cause of confusion in the 19th century. With the introduction of penicillin, this is no longer the case. A blood test (VDRL), however, is routinely done in a dementia workup to rule out chronic venereal disease as a possible contributing factor.

A more recent contributing factor to the development of dementia is the infectious process associated with acquired immune deficiency syndrome (AIDS). Blood tests for the human immunodeficiency virus (HIV) might be indicated. Exploration of risk factors can be done with a detailed history related to transfusions of blood products prior to 1985 and/or a detailed sexual history.

**Urine Tests**

One of the most common sources of confusion, especially in the elderly, is acute urinary tract infection. Drug overdose may also be detected through urine testing. Abnormally high glucose and acetone in the urine should trigger the need for more extensive blood work and suspected diabetes.

**Neuroimaging Techniques**

A thorough examination that may include one or more neuroimaging techniques, in addition to various blood tests, can help rule out other reversible or irreversible causes of dementia.

Electroencephalograms (EEG) that measure electrical activity in the brain may show abnormally slow electrical activity if a person has Alzheimer’s disease. One of the primary uses of the EEG is to differentiate between dementia and delirium, or various types of seizure disorders. Some older people with epileptic seizure disorders display symptoms of dementia like increased confusion, but the epilepsy itself has gone undiagnosed because the confusion was erroneously attributed to “the process of aging.”

Computerized axial tomograms (CT or CAT scans) are computer-drawn x-rays of the brain itself done without any infusion. They can provide an outline of the brain surface as well as the ventricles, and provide images of the brain at various levels or planes.

CT scans may indicate the presence of brain atrophy or shrinkage in presenile forms and advanced stages of Alzheimer’s disease by revealing space between the skull and the brain that results from a widespread loss of nerve tissue in the cerebral cortex. Atrophy can range from mild to severe and generally depends on the degree of Alzheimer’s dementia. Frontal and parietal lobes are most affected.

The ventricles, or the inner spaces of the brain where cerebrospinal fluid normally circulates, may also enlarge with Alzheimer’s. This can occur as brain substance decays and is replaced by fluid.

Because there is often brain atrophy in the normal aging brain, CT scans in the early stages of dementia may not provide any proof that Alzheimer’s exists, but CT scans can rule out other causes of dementia that are mechanical or vascular in nature.

Magnetic resonance imaging (MRI or NMR) is another, more recent technique for examining the brain that provides a more detailed picture than a CT scan and may be ordered if CT scan results are judged insufficient to make a diagnosis. Either a CT scan or an MRI will be considered by most neurologists as a routine evaluation tool.

The MRI is an especially useful diagnostic procedure for ruling out some reversible causes of dementia. One example is normal pressure hydrocephalus (NPH) that may be caused by a head injury, meningitis or encephalitis.

Symptoms of NPH may include difficulty walking, urinary incontinence and cognitive impairment due to pressure on the brain from
fluid build-up secondary to obstructed flow of cerebral spinal fluid. A shunt may correct the problem and eliminate all symptoms.

Positron-emission tomography (PET scans) may also be done though, due to their expense, this is generally associated with Alzheimer’s research. In this procedure, a vein or artery is injected with radioactive glucose and studies are conducted to determine what areas of the brain can metabolize the glucose. No metabolism may occur in certain dead areas of the brain affected by plaques and tangles associated with Alzheimer’s; temporal and parietal lobes are most commonly affected. PET scans have also indicated diminished blood flow and decreased oxygen consumption in the brains of persons believed to have Alzheimer’s disease. Any or all of these changes may contribute to symptoms associated with the disease.

Single photon emission computerized tomography (SPECT) is one of the more recent diagnostic tools used to distinguish reversible and treatable types of dementia from irreversible types such as Alzheimer’s or Pick’s disease. As might be expected, any of the neuroimaging procedures may be extremely difficult to do on a person with dementia, even though, for the most part, they are noninvasive procedures.

Family members or the patient will be asked to sign consent forms for some tests such as the spinal tap. Health professionals can make sure they understand the procedures and give reassurance.

A family member or health care worker should also go with the person with dementia for a neuroimaging procedure to provide emotional support. Sometimes sedation is needed to calm the person.

Pain Assessment

Understandably, dementia patients are often unable to communicate to others when they are in pain and health care practitioners must use alternative means to make accurate pain assessments. A useful scale to measure pain of confused patients is the PAINAD scale. See Appendix A for details.

Cognitive Changes and Communication

“...One of the first symptoms we noticed early in the progression of my wife’s disease was word substitution. This continued for a long time. She’d say something like ‘I need to go out and get the bird’ when she meant she had to go out and get the mail. Or she needed to ‘cook the car’ when she meant she needed to cook dinner. I could usually figure out what she meant, but she sure confused a lot of other people.”

Memory Loss

Memory is not lost all at once, but gradually fades over time. As losses are recognized, accepted and acknowledged, interventions to help people maintain the memory they have for as long as possible are in order. Many of these interventions consist of various types of prompts that may jog the memory enough to enable the person to continue functioning. As the disease progresses, more complex interventions are needed.

Memory prompts can take many forms and can be used in home, hospital, adult home and nursing home settings. Some memory prompts will be helpful in the early stages of the disease. When the ability to read and comprehend instructions is still reasonably intact; other suggestions may help jog the memory when verbal communication is no longer possible.

To orient a person to TIME, consider the following:

- Hang large wall calendars in a room; days can be marked off to further orient the person. In the early stages of Alzheimer’s they may be able to do this themselves and appreciate the sense of control they have in being able to do so.

- Post a list of a normal day’s routine in a conspicuous place. People in the early stages of dementia may also profit from note cards with memory-jogging information on them. They will often remember to mark off things on a list that have been done and be able to go safely on to the next task. In the early stages of the disease this technique has successfully worked for people who cook; they have recipes written on cards and can mark the ingredients off as they use them.

- Consider using digital clocks rather than those with hour and second hands. The person may still be able to read the time but not be able to figure it out for them-selves and can become upset trying to do so.

- If the person lives alone and takes medication, pillboxes labeled for each day of the week and time of day may be appropriate in the early stages of the disease; these can be monitored more easily than bottles of pills. Phone call reminders may also be necessary and can give a sense of security to both the Alzheimer’s sufferer and the one calling.

- Consider using digital clocks rather than those with hour and second hands. The person may still be able to read the time but not be able to figure it out for them selves and can become upset trying to do so.

Changes in the Ability to Communicate

The effects of cognitive impairment on the ability of a person with Alzheimer’s to communicate their needs and concerns are progressive, multiple and profound. Communication difficulties have been cited repeatedly in the literature as a primary problem for family caregivers that affect every other area of caregiving.

Difficulty communicating can result in neglect and verbal abuse if family members or health care staff find themselves consciously or unconsciously ignoring a person, or becoming angry with them. Researchers who have
conducted nursing home and hospital-based studies in the United States, Canada and Great Britain have all observed low levels of social interaction among nursing home residents, hospitalized patients and nursing staff that tended to be reinforced by the traditional task-oriented approach to nursing. Primary conversations that occurred were among staff members at the expense of interactions between staff and residents or patients.

Residents who were independent in functioning and mentally alert interacted more frequently with staff while those with dementia were rarely spoken to. Communication is basic to our human nature and helps define who we are.

**In order to better understand the person with Alzheimer’s disease:**

Pay attention to body language. If the person is unable to communicate verbally, they may still be “speaking” by their actions and reactions. Pain, for example, may be detected by facial grimaces, restlessness, guarding an area that hurts, or a moan or groan. If you suspect the person may be in pain, ask them and point to, or gently touch, the suspected area. If you sense a person is upset but they aren’t able to verbally communicate their feelings, respond to the feeling-tone they are conveying with empathy; let them know you care.

If you find the person becoming frustrated because they are searching for a word or a phrase, try supplying the word or phrase for them to ease their anxiety.

If speech seems totally nonsensical, listen carefully. You may be able to pick up some repeated words or phrases that you can repeat back to the person; this can communicate that you are listening to them and may serve to reassure them. People who are bicultural may also revert to their primary language; what you perceive as nonsensical may not be. Assess a person’s language fluency upon admission to a unit. It will be helpful as the disease progresses to familiarize yourself with certain words or phrases in the person’s native tongue and to include those in the care plan for other staff.

Repetitive speech can be annoying. Both family and professional caregivers may ignore the person who is constantly saying the same thing over and over again. Assess these patterns carefully: sometimes they may have hidden meanings. Music may also be helpful for decreasing repetition. A radio tuned to a religious music station can have a soothing effect.

Looking for ways to preserve and enhance the memory that still exists in order to both facilitate communication and enhance quality of life is an attainable goal that can help maintain dignity and respect for the person who is suffering memory loss in multiple ways.

### Anxiety and Catastrophic Reactions

"I remember taking my father to restaurants. I was trying to make him feel better about himself, so I would always ask him to choose what he wanted to eat. But instead of feeling better he became frustrated and upset because there were too many things to choose from. He couldn’t process all that information, and once he even started to cry. When I finally understood what was happening, we still went out, but I simply ordered for both of us."

Restlessness and agitation usually accompany anxiety in a person with Alzheimer’s. Anxiety can be triggered by the cognitive impairment itself, or responses to cognitive impairment as the person is faced with the unsettling reality that they are gradually losing their very sense of self. Symptoms of anxiety might include excessive verbalizations of distress, aimless pacing, hand wringing, and episodes of crying. People in this early stage of dementia are not able to cope with what might otherwise be considered everyday stressors of life.

Catastrophic reactions also commonly occur and can range from brief episodes of extreme anxiety to angry verbal outbursts that may include aggressive behavior and physical violence. Stubbornness and combative behavior can occur in response to perceived threats by well-meaning caregivers. There seems to be an accompanying loss of impulse control that can precipitate aberrant behaviors and verbal outbursts of profanity that are uncharacteristic of a person’s previously known personality.

Catastrophic reactions are frequently triggered by situations that seem to overload a person’s already compromised ability to cope. Changes and stressors related to the disease progression itself, interpersonal relationships, environmental factors, physical stressors, and even spiritual distress, can all trigger both generalized anxiety and exaggerated and bizarre behaviors. Preventing or minimizing the effects of catastrophic reactions necessitates continuing assessment of these potential triggers and documenting the nature, duration and frequency of the reactions in order to plan for careful interventions.

With appropriate care interventions, the quality of life for both the Alzheimer’s sufferer and family and health-related caregivers can be enhanced; catastrophic reactions can often be prevented or their magnitude modified.

### Hiding and Hoarding Behavior

"When I go grocery shopping, Mom usually goes with me. I push her ahead of me in her portable wheelchair and pull the grocery cart behind us. When our shopping is completed, I carefully check her and the sleeves of her sweater before checking out. Mom has a tendency, often when I’m busy looking in the frozen food section, to reach out and touch the assortment of packaged cakes and cookies in the middle of the aisle. If a package is small, colorful and looks good to eat, my mother might pocket it for future consumption."

Rummaging, pillaging, and hoarding behavior is common in the Second stage of Alzheimer’s. Food, articles of clothing, car keys, jewelry, silverware - all portable items can be stashed away in dresser drawers, under mattresses, in wastebaskets and are quickly forgotten. In the hospital and nursing home, rummaging and pillaging can be particularly problematic behavior if the articles taken belong to another patient or resident. These items may include glasses, hearing aids and dentures. On units where there are people with dementia who have a habit of wandering, periodic checks that residents have all their own equipment are needed. Some type of label or identifying marker on residents’ glasses and all items of clothing should be required.

In homes, family members need to keep valuable and other irreplaceable items in safe places. Duplicates of car and house keys should be made. Attaching large and colorful key rings can aid in searches if keys are lost. Important papers should also be inaccessible to the person who tends to rummage, rip and toss things in the garbage.

Lock what doesn’t need to be opened to eliminate hiding places. This might include certain rooms in the house.

Don’t expect the person with dementia to remember where they put a lost item. Asking them, scolding them, or demanding from them will only precipitate a catastrophic situation. Become aware of typical hiding places and do your own search, or offer to hunt with them if they are persistent on searching themselves.

Periodically check cupboards or drawers for spoiled food. Common hiding places are folds of sofas, chairs and under pillows.

Rummage boxes or rummage drawers in dressers have been useful solutions for some people with dementia who seem content to simply pull things out of drawers and put them back in. Include a variety of items that are both familiar and safe.

### Sundowning

"The worst time of day for my father was between four and five in the afternoon. My mother would always pace back and forth by the kitchen or living room door and say, over and over again, ‘When are we going? When..."
are we going? When are we going to go? ’ If the door hadn’t been locked, I’m sure my mother would have been out the door, on the road and headed for who knows where. So every day around 5:15 my Dad would help my mother and off they’d go for a drive. Mom was usually quiet in the car.”

Confusion and disorientation heighten and wandering, agitation or extreme restlessness frequently increases in the late afternoon and early evening in both home and institutional settings for persons with dementia. This can be a particularly trying time for both family caregivers and health care workers. Both patience and understanding is needed to appropriately meet the needs of the person who may be experiencing what is commonly known as sundowning.

The reasons for sundown are unclear, but there are a number of possible contributing causes that have implications for therapeutic interventions including physical considerations, sensory changes and overstimulation.

Physical Contributors to Sundowning

Simple fatigue may be a contributing factor to sundowning; though encouraging a person to rest when they are experiencing extreme agitation is usually ineffective. Encouraging a mid-morning or early afternoon nap may help alleviate late-afternoon restlessness.

Three of the most obvious and correctable physical catalysts that can trigger sundowning behaviors, but often the three most overlooked, are hunger, thirst and the need to urinate or defecate. Careful monitoring of habit patterns in the late afternoon when sundown occurs and the effects of any interventions used, such as decreased restlessness and agitation following toileting or a high-carbohydrate snack, can give clues about what might contribute to sundowning behavior.

Physical restlessness can also contribute to sundowning behavior. If possible, assign one or two assistants on a rotating basis to walk with restless residents, or to monitor their safety while they walk around. Encourage your activities department to schedule their time on the location of the person. Consider a quiet area near the bathroom. Turning on an overhead light directly in the line of traffic. Sitting quietly in their own room for an hour before supper may also be a welcome relief from the busyness in the house or in the halls.

Consider the value of a “rummage box” (similar to a rummage drawer but portable) filled with soft things like washcloths and towels, balls of yarn, pictures and stuffed animals. Many residents in nursing homes and home settings will be content to simply take things out of boxes and replace them; towels and washcloths may be folded and refolded and yarn wound and unwound. Rummage boxes can be used in lounge areas and in the person’s own room.

There is some debate in the literature about the effectiveness of using simplified versions of previously learned crafts or reminders of previous occupations. Residents in the early stages of dementia, who may still be aware of their diminishing abilities, may find these to be unpleasant reminders of their loss and increase their anxiety.

The primary goal is finding simple and safe things for people to do that will occupy their hands and their minds for a period of time, and enable them to work off some excess energy while maintaining their dignity and respecting their individuality.

Music can have a calming effect and can also act as a distraction for some people who like to sing or have always enjoyed listening to music. Capitalize on the gifts and interests of staff members. Encourage family members and friends who have similar interests and abilities to bring them into the home or hospital to enhance the quality of life for people with Alzheimer’s and to minister their souls and spirits.

Wandering

Life-long patterns of behavior may determine wandering patterns for the person with Alzheimer’s disease. People who may have walked to the grocery store daily, or who have always walked to work at the office or taken a daily walk in the woods, may wander away from home or a care facility guided by agenda behavior.

Talk with family members about lifelong behavior patterns that might trigger wandering and plan interventions that take these patterns into account. Reassure families that you are aware wandering behavior is normal and natural so they will be truthful with you about this behavior if it has occurred at home.

Nighttime Wandering and Sleep Disturbances

Diurnal sleep-waking cycles are frequently disturbed in persons with Alzheimer’s and nocturnal wandering can become a problem if they are napping frequently during the day.

Afternoon naps are often the routine in a nursing home setting. They may, however, interfere with sleep patterns. Some studies have shown that during sleep at night, people with Alzheimer’s have very little rapid eye movement (REM) sleep; lack of REM sleep results in symptoms of irritability and restlessness during the day. Morning naps are believed to result in increased REM sleep and can contribute to rest for the person, even if they do engage in nighttime wandering.

Each person is unique; try more exercise rather than less in the late after-noon for nocturnal wanderers. Assign one nursing assistant on a rotating basis to ambulate residents in the halls before supper or after the evening meal. In the home care setting, encourage an outdoor walk in the late afternoon. Some special care units have provided special circular pacing areas to work off excess energy.

Use nightlights if the person is able to sleep with them; place one close to the bed and one near the bathroom. Turning on an overhead light to change a bed and giving care during evening and night hours, may be interpreted by the person that it’s morning and time to get up. Nightlights also serve as added safety precautions.

Locate the wander-prone resident’s room in both hospitals and nursing homes close to the nursing station and as far as possible from exit doors. Units should develop policies and
need for change-of-shift snacking. and crackers can often curb nocturnal hunger, carbohydrates such as a sandwich or cheese leaving home or a care facility. can also prompt some people to pack it and getting fully dressed before they begin their shoes can unobtrusively be removed at night hanging in the closet may need to be removed. A wandering resident can be especially situation to others who may be upset by their nocturnal behavior. Spend some time carefully assessing the wandering patterns of your residents; you may become aware of situations that trigger wandering. They may simply be hungry, thirsty or looking for a bathroom in the middle of the night. Remember that wandering will be worse immediately following a new admission to any type of facility and may lessen as the person becomes more comfortable in their surroundings. Be especially vigilant with the new resident or patient and assign someone to watch for wandering behavior on all shifts.

Sedatives, hypnotics and psychotropic medications should be used only as a last resort for managing wandering behavior; their side effects are often identical to the behaviors you want to control, for example, restlessness and insomnia. Oversedation can also occur, further disrupting sleep-wake cycles.

If the person suffers from some other condition such as arthritis, consider pain medication at night on a regular basis. Pay attention to things in the environment that may trigger wandering responses. A coat hanging in the closet may need to be removed. Shoes can unbobtrusively be removed at night for wanderers who always make a habit of getting fully dressed before they begin their nocturnal rounds. A suitcase sitting in a closet can also prompt some people to pack it and leave home or a care facility.

A warm bath or shower prior to retiring may help the person relax. A glass of warm milk, herbal tea, or a snack consisting of complex carbohydrates such as a sandwich or cheese and crackers can often curb nocturnal hunger, assure a good night’s sleep and eliminate the need for change-of-shift snacking.

A bedside radio tuned softly to a classical music station, a religious radio station or to the type of music the person has always enjoyed may induce sleep.

People who are hospitalized may be able to sleep if loved ones are present in the evening; the normal hospital visiting hour rules may need to be readjusted for persons with dementia. Sometimes a phone call to the patient from a family member may serve to reassure them that they are safe.

Identification of the person with Alzheimer’s is important in any setting if they wander away from their home or care facility and become lost. Families should have current photographs of their loved one on hand. Resident photos should also be available on nursing units to assist in searches on other units or outside the facility if necessary. The activities department is a good source to assist with this safety measure.

Identification or Medic-Alert bracelets that include the home or facility name, the address where the person lives and the phone number can be inexpensively purchased through drugstores and home care equipment stores; these bracelets can also be engraved with the phrase “memory impaired” or “Alzheimer’s memory impaired”. People who do become lost and are confused are often treated for some other suspected medical problem like diabetes or drunkenness.

Bracelets are better than necklaces and should be loose enough not to cut off circulation but snug enough that the person is not able to remove them. Most clothing can also be sensitively labeled with a name and address or phone number to call. ID cards may be useful for some people but they can be easily lost or thrown away by the confused person and are usually not a good substitute for the ID bracelet. Home caregivers should notify local emergency rooms if their loved one wanders off as some Good Samaritan may take them there if they find them wandering in the road.

If you do need to guide a wandering loved one, patient or resident back to the home or facility, stay calm. Avoid running up to the person and grabbing them; this will only precipitate a catastrophic reaction.

If the person is calm to begin with, simply fall into step with them and guide them back to where you want them to go. If they are agitated it may be because they know they are lost. A gentle, reassuring manner is called for coupled with the assurance that you can help them find the way back home, where they probably really want to be.

Foresight, planning and practical strategies can help maintain a relatively safe and secure environment for the perpetual or nocturnal wanderer, enable home caregivers to get some needed rest and lessen the strain on professional caregivers.

Inappropriate Sexual Behavior

Loss of impulse control may cause a person to engage in inappropriate sexual behavior that they are not aware of because of their state of disorientation. This inappropriate behavior is not common, but it does occur and can be particularly distressing for families who need help in understanding more about the disease and reassurance that their loved one in a health care facility will continue to be treated with dignity and respect. Often behavior that may appear to be sexual in nature is engaged in for other reasons altogether. For example, the person who wanders around partially clothed or with clothing unbuttoned or unzipped may have simply forgotten how to dress himself or herself and because of the degree of their dementia, be totally unaware of their state of undress.

A calm, gentle but firm approach to reorient a person back to their room or to a bathroom where you can assist them in redressing is usually all that is needed to solve the problem. Trying to redress a person in the hall or a dining area will often precipitate a catastrophic reaction; the person may think you are trying to molest them.

Masturbation may also occur in public places and is engaged in simply because it feels good to the person. It could also be prompted by poor genital hygiene or itching related to a urinary tract infection that prompts rubbing the genital area for relief. Distraction will often work if the person’s attention is redirected to something else to touch or hold. Carefully assess possible underlying physical reasons for this behavior including the adequacy of hygiene. Provide the person with privacy in his or her own room if needed.

Sexual overtures, or what are interpreted as sexual overtures, may be exhibited by a person with dementia to other patients, visitors and staff members. Often the person will mistake other people for a spouse and treat them accordingly. They may climb into bed with another resident of the opposite sex, simply because they have always slept with their spouse and now have no idea that this is not their own room and their own bed. This can be particularly upsetting for the person’s real spouse as well as the person they climb into bed with.

A gentle but firm approach can guide the person with dementia back to his or her own room and bed; the rights of other residents need to be protected but the affection and relationship needs of the person with dementia should also be addressed. Providing routine opportunities for closeness and companionship with the person’s real spouse, other family members,
other residents and staff may help to decrease or eliminate this nocturnal need for affection.

Be aware of a spouse’s need for counsel and ventilation of feelings and refer to appropriate people. Nurses can be advocates in situations that others may ignore because of embarrassment or lack of sensitivity to the needs of the whole family, not just the person with Alzheimer’s.

Staff may need to monitor their own behavior. Is anything being done or said by staff, for example, that might lead the person to respond to them in a sexual way? It is not unusual in some facilities for staff to engage in teasing behaviors that serve to foster inappropriate sexual behavior in residents; this is sometimes prompted by their own embarrassment. Good in-service education programs are needed to help staff understand sexual behavior of the person with dementia, and appropriate ways to deal with various expressions of sexuality.

As with all symptoms, assess them carefully for underlying causes and exercise preventive measures when possible. At all times, strive to maintain a person’s dignity and respect, and remember that love and affection are basic human needs that can be met in many different ways, including companionship and conversation.

Safety Issues

What is a safety hazard for one person may not be for another. A wife with Alzheimer’s may not have the urge to rummage through her husband’s toolbox; a husband who has never cooked a meal may stay out of the kitchen. Safety hazards may also change as the disease progresses.

Safety and Driving

One of the primary safety issues for home caregivers is related to driving a car. Being told you cannot safely drive can be a tremendous blow to a person’s ego. Regardless of the degree of memory impairment, people respond on a feeling level when personal identity is threatened and not being able to drive a car can be a major threat to one’s sense of identity. Most people with Alzheimer’s do not readily relinquish the car keys.

When is it time for a person to stop driving? If there are obvious impairments in any areas that involve judgment, concentration and coordination, as well as time, place and person orientation, the ability to drive safely will also be impaired. Alzheimer’s sufferers who drive can easily get lost and they will usually not be able to respond quickly or logically to a sudden, unexpected event in order to avoid an accident.

Caregivers need to remember that driving is a learned activity that quickly becomes unlearned and is an extremely dangerous activity for anyone with dementia. As hard as it may be emotionally for families to “take away the last vestige of their loved one’s independence,” it is necessary to do so before their loved one’s independence takes away their own, or someone else’s life.

Falls

Falls are a common problem as cognitive impairment affects balance and the ability to ambulate in both early and late stage Alzheimer’s. In more advanced stages, gait apraxia is common. Include the family in discussions and planning for the resident when they are at risk for falls.

Risk factors for each person will differ and should be carefully assessed. Care plans should include specific and individualized fall precautions.

Falls are inevitable in any setting when a person develops dementia. All health care staff and family members should know the signs and symptoms of a fracture that can include:
- pain or tenderness in the injured area that increases with pressure or movement
- deformity, for example, a fractured hip may cause the leg to shorten and externally rotate
- swelling, discoloration or bruising
- exposed bone ends that have broken through the skin
- symptoms of shock including cold, pale, clammy skin, rapid pulse, shallow breathing, low blood pressure

In the case of suspected fracture or head injury, no attempt should be made to move the person unless adequate provision is made for full support of the affected area and no further damage is incurred by the move itself. Call emergency services and make the person as comfortable as possible by supplying them with rolled up blankets and supportive pillows for injured limbs, a blanket for warmth and a person who can stay with them to reassure them, and help them remain as quiet and immobile as possible.

Other Safety Hazards

In addition to decreasing the danger of falls there is a need to minimize cuts and bruises, prevent accidental poisoning and prevent burns from fire, liquids and electricity. Any objects that may become safety hazards for the resident or others around the resident should be evaluated and eliminated.

Examples of items in the home and health care facility that should not be kept in the rooms of persons with Alzheimer’s and should be carefully stored in other parts of the house or facility are: matches and lighters, razors, electrical equipment such as hair dryers and electric shavers, cleaning supplies and drinkable toiletries like after shave.

As discriminatory sense of hot and cold diminishes, the temperature on water heaters may need to be turned down if the person has a habit of running water in a sink and frequently washing their hands.

In homes and on special care units in facilities, knobs may need to be removed from stoves for people who wander into the kitchen and try to cook. Coverings for electrical outlets should be used. Cuts and bruises can be minimized by locking up knives, power tools and other sharp objects. Furniture corners may need to be padded. Glassware should be checked periodically for cracks.

Many plants are poisonous and can become a safety hazard. Some people with dementia are attracted to colorful objects and will readily eat flowers. Poisonous cleaning supplies should be stored in inaccessible places. Family and professional caregivers should have the name of the poison control center easily accessible and be aware of the typical signs and symptoms of poisoning that may include:
- nausea, vomiting, diarrhea
- severe abdominal pain, cramping
- slow breathing and slow pulse
- profuse sweating or salivation
- obvious burns or stains around the teeth
- odors on the breath, such as kerosene or turpentine
- unconsciousness
- convulsions

First-aid kits for poisoning or poison antidotes should be readily available that can include syrup of ipecac and activated charcoal.

Safety is an issue in any setting; when neglected it can spell catastrophe for the person with dementia. The key to safety for both the family and professional caregiver is prevention - more than just an ounce.

Nutritional Support

Mealtime management can be a challenge for family and professional caregivers as mental function alters, and chewing and swallowing become more difficult. But problem eating behaviors are not confined to more advanced stages of the disease.

In the early stages of Alzheimer’s people who live alone may neglect to eat altogether, and malnutrition and dehydration can result, heightening confusion and disorientation. For people living alone, Meals-on-Wheels programs can offer nutritional meals, or families may prepare frozen dinners that can be easily warmed in an oven or microwaved if the person is still able to follow written directions and do so safely.

But sooner or later, people with Alzheimer’s
will no longer be able to warm up prepared meals safely, even with daily phone calls to remind them to eat, and someone will need to take responsibility to ensure adequate nutrition. Observable weight loss coupled with safety issues (like leaving an oven or burner on overnight, and scorched pots and pans in cupboards) eventually alert family members and friends that the time has come to provide either in-home care or move the person with Alzheimer’s into a relative’s home or nursing care facility.

Mealtime management becomes progressively more difficult as the disease progresses, but with some thoughtful interventions and careful assessment it is not impossible.

Personal Hygiene

Assistance with personal care needs increases as dementia progresses. However, it may actually be more difficult for caregivers to assist the person in the earlier stages of the disease when they retain a degree of cognitive functioning, but may also be prone to catastrophic reactions and paranoia, and particularly resistive to help from others.

Neglect of personal care needs is another situation that triggers the need for increased assistance in the home.

Having to depend on others to meet their personal care needs can be an embarrassing and stressful situation for an older person, especially when that other person is a son or daughter. The person with dementia may be more amenable to personal care given by a stranger rather than by a member of his or her own family. Sons and daughters also frequently have difficulty with role reversal and associated personal and intimate care giving needs; they may need to be assured that this is a normal response and they should not feel guilty requesting assistance from community health agencies and the help of home health aides.

All interventions related to personal care should be designed to help the person remain independent for as long as possible. Abilities to accomplish certain tasks in one area may be noticeably diminished, but the person may be relatively independent in carrying out another task. Interventions should be adapted to various levels of function.

Paraprofessional workers including CNA’s, home health aides and orderlies may need special in-service education to help them work with difficult patients.

Encouraging the person to brush their own teeth for as long as possible with a soft-bristle brush to prevent gum damage is the best intervention; if they are unable to do so, caregivers will need to try and do this for them. If they refuse and fight care giving you can exercise other options for oral care. Encourage drinking water after all meals and snacks. Fresh fruits like apples can be given after meals. Some people who may resist a toothbrush may be amenable to flavored mouth swabs or mouth swabs dipped in mouthwash. Dentures should be removed for overnight soaking and to provide an opportunity to check the mouth and gums for irritation.

Xerostomia (dry and cracked oral mucosa) is a side effect that can occur due to decreased salivary flow related to certain frequently ordered medications. Specific drug categories that can cause dry mouth are antidepressants and antipsychotics, antihypertensives, bronchodilators and antispasmodics can cause similar symptoms. Glycerol mouthwash can be an effective antidote and water based lubricants can be used for dry and cracked lips.

As with other care needs, individualized care plans that foster as much independence as possible are needed to help maintain good skin integrity. For family caregivers frustrated with their inability to heal their loved one’s mind, care for their loved one’s body can, in itself, be a ministry of healing they may want to personally participate in, or entrust to the care of others who will respect and honor the body that is still the person.

Bowel and Bladder Issues

Impaired bowel and bladder function often accompanies progressive dementia related to sensory motor impairment and changes in mobility. Incontinence can be embarrassing for caregivers, especially when it occurs in a public place, and has been identified by caregivers as a primary factor that triggers institutionalization. Caregivers often need some basic suggestions to help them with management. The primary goals are to help a person maintain bowel and bladder continence for as long as possible, to maintain natural emptying of the bladder and bowel, and to maintain dignity. These goals remain the same no matter what the setting.

When a person is admitted to a hospital or nursing home, an assessment of normal bowel and bladder habit patterns should be done with the family.

If the person with dementia cannot verbally communicate their needs, do they have any mannerisms that might indicate a need to void or defecate? Base your plan of care on this assessment and make appropriate changes as you get to know the person better.

Medication Management

There is no known cure for Alzheimer’s disease, though biomedical and psychopharmacologic research is being conducted. Numerous drugs have been or are currently being tested with the intent of retarding symptoms. Although Alzheimer’s disease still has no cure, several drugs hold promise for slowing (in some cases reversing) the disease. Currently, donepezil (Aricept), Exelon, and galantamine (Razadyne) are the drugs currently approved by the FDA indicated to treat Mild to Moderate Alzheimer’s. Namenda is prescribed for moderate and severe dementia and sometimes in combination with another Alzheimer’s drug.

Donepezil (Aricept): In clinical studies, up to 80% of patients who participated had their symptoms stabilize or improve. It also appears to be better tolerated than tacrine. Its action is believed to inhibit the enzyme acetylcholinesterase in the CNS, increasing the concentration of acetylcholine and temporarily improving cognitive function. It is unclear how soon donepezil begins to take effect, but research reveals that the drug can benefit a patient for up to two years.

Dosage: For adults, initially 5mg P.O. daily at bedtime. After four to six weeks, dosage may be increased to 10mg daily.

Adverse Reactions: Headache, dizziness, diarrhea, nausea, and vomiting which are usually mild and go away a few days after starting the medication.

Patient Teaching: Patients and caregivers should understand that the drug does not alter underlying degenerative disease but can alleviate symptoms. Effects depend on administration of the drug at regular intervals. Advise patients/caregivers to immediately report adverse effects or significant changes in overall health status and to inform the health care team that the patient takes drug before any anesthesia.

Galantamine (Razadyne) This drug, which is already available in some European countries, may slow Alzheimer’s progression for up to one year. Patients may see improvement as early as six weeks after starting therapy. Much like tacrine, this drug works by inhibiting the enzyme that metabolizes acetylcholine. An added benefit is that it seems to be less toxic to the liver. Clinical trials are under way in the U.S., but more details about the drug are not currently available.

Rivastigmine (Exelon), a cholinesterase inhibitor, improves the function of nerve cells in the brain. It works by preventing the breakdown of a chemical called acetylcholine.

There is also Exelon Patch (rivastigmine transdermal). The skin patch offers a novel approach to treating mild to moderate Al-
zhermer’s disease. It maintains steady drug levels in the bloodstream, improving tolerability and allowing a higher proportion of patients to receive therapeutic doses compared to the capsule form of the medication. It is applied to the back, chest or upper arm, and provides smooth and continuous delivery of medication through the skin over a 24-hour period.

This therapy is the first and only transdermal treatment for this degenerative condition affecting millions of people in the US. Exelon Patch offers effective treatment based on placebo-controlled clinical trial results showing significant benefits to patients in terms of their memory and overall functioning.

Memantine (Namenda) is used to treat moderate to severe Alzheimer’s dementia. This drug regulates the activity of glutamate, an essential chemical messenger in the brain that is associated with memory and learning. It is the only current drug available for late stage Alzheimer’s disease. It is hoped that this drug will slow deterioration and improve cognitive skills. To learn more about this and other meds that have recently been released by the FDA or to check on dosage changes visit www.DrugGuide.com.

Other drug mechanisms being evaluated are calcium channel blockers, receptor agonists, metabolic enhancers, antioxidants, anti-inflammatoryatories, nerve cell protectors, and cell membrane stabilizers. Refer patients and families to the Alzheimer’s Association that provides information about drugs being studied, what is involved in participation in a study, and study sites available nationwide.

These therapies show improvement of symptoms, and in the future, we may have even better therapies to offer.

In many people with Alzheimer’s, secondary psychiatric symptoms and aberrant behaviors are controlled with various medications.

Symptoms that may respond to medication treatment include sleeplessness, aggressive behavior and paranoia, depression, and extreme agitation, though non-pharmacological interventions are always preferable to pharmacological interventions.

Drug treatment, particularly with psychotropic medications, should not be used as a substitute for other treatment interventions. In nursing homes and hospitals inadequate staffing may be an underlying contributor to the use of these medications as more time and attention is needed to facilitate other types of supportive measures.

Research is continually being conducted in various parts of the country with experimental drug trials, usually in the early stages of dementia. Families can contact the Alzheimer’s Association or their local medical center for information.

Three broad categories of medications used to enhance cognitive processes include: Cholinergic Agents, nootropics and miscellaneous agents that act on catecholaminergic, peptidergic, aminergic, or unknown sites. For details go to www.drugs.com. There are several links for patients as well as advanced information for health professionals.

Cholinergic Agents

Research has also been conducted using oral physostigmine, a cholinesterase inhibitor substance that prevents the breakdown of acetylcholine and imitates its action. Some people experienced limited, short-term improvement in memory and cognition, but overall results have been inconclusive; side effects are significant and can include hypotension, bradycardia and paralysis of muscles, including the diaphragm. Sweating, flushing and abdominal cramps are milder side effects. Researchers note the narrow therapeutic window and toxicity require careful management of well-controlled studies.

Tetrahydroaminoacridine (THA) is a synthetic cholinesterase inhibitor that crosses the blood-brain barrier with similar effects, but often results in hepatotoxicity or elevated liver enzymes that frequently require the drug to be discontinued.

One frequently advertised non-pharmacological supplement in health food magazines is lecithin or choline, an acetylcholine precursor thought to increase cholinergic activity in the brain.

Nootropic Agents

Piracetam, another experimental drug that treats memory disorders, is a nootropic agent thought to improve the acquisition, storage and retrieval of information. Piracetam and other nootropic drugs like Tenilsetam and aniracetam may enhance dopaminergic and cholinergic function.

Cognitive Enhancers and Miscellaneous Agents

Hydergine, a combination of halogenated ergot alkaloids, was once often routinely ordered by physicians to treat all forms of dementia, including Alzheimer’s, when it was erroneously believed that all dementias had underlying vascular causes. Even though there is some reduced cerebral blood flow with Alzheimer’s disease, Hydergine has not been proven effective as a cerebral vascular stimulant.

Calcium channel blockers, medications that increase the availability of dopamine, noradrenaline, and serotonin, have also been tested in persons with Alzheimer’s disease on an experimental basis.

L-depenryl has been tested in the early stages of Alzheimer’s with some improvement noted in neuropsychologic measures, activities of daily living and some aspects of behavior. Angiotensin-converting enzyme (ACE) inhibitors like captopril are currently under investigation and may show promise. Captopril is an anti-hypertensive agent.

Medications and non-drug therapies are also available to reduce some of the behavioral symptoms associated with Alzheimer’s, such as depression, sleeplessness and agitation. Clinical trials for new medications have been largely unsuccessful therefore, focus is on diagnosis and prevention.

Medication for Depression

Not all medications are specifically related to improving cognitive processes associated with the pathology of dementia. Tricyclic antidepressants are often prescribed for home and institutional use to treat accompanying depression in persons with Alzheimer’s. Nor-tripryline and desipramine are two common secondary amines. Unlike their parent compounds, amitriptyline and imipramine, they have fewer anticholinergic side effects, such as blurred vision, drowsiness and constipation.

Side effects to monitor for all antidepressants are cardiac arrhythmias and orthostatic hypotension. People should be encouraged to come to a standing position slowly and sit on the side of the bed before standing.

Fall precautions are generally instituted if these medications are used in a more advanced stage of the disease. Constipation is also a problem with these medications; increased fluid intake and assisted ambulation can help prevent it.

If there is no noticeable effect from tricyclic antidepressant use, monoamine oxidase inhibitors (MAOI’s) may be ordered. MAOI’s can lead to hypertensive crisis from interactions with various foods containing tyramine such as aged cheese, fermented sausages, raisins, bananas, beer and red wine. Care must be taken if these drugs are used with people with dementia who may pick up these foods to eat from someone else’s tray.

Behavioral Disruptions

Behavioral disturbances, including agitation, have been reported in up to 90% of patients with dementia, which can result in patients becoming distressed and aggressive, putting an immense strain on caregivers and affecting their ability to care for the individuals. Assess carefully to determine if it is acute Delirium or Dementia.

One disorder that frequently accompanies
Alzheimer’s disease is delirium that results from metabolic disturbances that are often erroneously attributed to cognitive changes. Psychotropic drugs given to quiet combative behavior that may accompany delirium, may instead exacerbate the symptoms. Medication overdoses, urinary tract infections, respiratory infections and fecal impactions can also alter mental status and contribute to delirium; hospitalized elderly are especially prone to these complications. People with Alzheimer’s generally are alert and wakeful during the day; delirium often manifests itself by daytime drowsiness. Careful physical assessments should accompany mental status assessments to search for underlying causes of delirium.

Delirium may also contribute to auditory or visual hallucinations. An example of a hallucination is a person who is seen talking to someone but there is no one there; delusional behavior, on the other hand, is often more related to Alzheimer’s disease and other dementias.

An example of delusional behavior is the elderly resident who accuses the staff of stealing his clothes. Pharmacological interventions are generally not recommended for either hallucinations or delusions.

However, when necessary, Neuroleptic drugs such as thioridazine and haloperidol may be ordered for paranoid behavior, hallucinations and extreme agitation. Side effects include severe sedation, tachycardia, orthostatic hypotension, movement disorders, and urinary retention. Extrapyramidal side effects like akathisia (motor restlessness), dyskinesia (abnormal voluntary movements), dystonias (abnormal muscle tone producing spasm of the tongue, face, neck) and Parkinson’s syndrome are not uncommon; tardive dyskinesia or involuntary movements of the mouth, tongue, extremities and trunk may result from long-term use of high doses, especially in the elderly.

Seroquel (quetiapine) bears mention as a possible med for dementia-related psychosis since it’s used frequently in clinical practice. Studies reveal data supporting use of Seroquel, an atypical antipsychotic, it’s use in treatment of agitation in elderly patients with dementia. Patients, including those with Alzheimer’s disease, experienced improvement in symptoms of agitation. Additionally, patients treated with Seroquel had no cerebrovascular adverse effects (CVAEs), which have been associated with the use of some other atypical antipsychotics in this patient population. Closely monitor the patient for signs of toxicity. Older adults metabolize antipsychotics more slowly and metabolites can accumulate and cause lethargy.

### Sleep Enhancers

Sedative-Hypnotics are generally used with caution to reduce anxiety and to induce and enhance sleep. People who are already receiving daily doses of antidepressants or neuroleptics may not need a sedative-hypnotic, but simply need a readjustment of their current medication dose. Medications that may be prescribed for sleep are chloral hydrate, antihistamines like diphenhydramine and short-acting benzodiazepines. Dizziness, ataxia and over sedation are adverse reactions.

### Anxiety

Benzodiazepines alone are also effective in controlling acute agitation and are better tolerated than the typical antipsychotics. IM lorazepam (Ativan) acts as quickly and as effectively as IM haloperidol in most instances, and oral lorazepam acts much more quickly than oral haloperidol. Recent studies have shown that lorazepam with risperidone (Risperdal) is generally equivalent to lorazepam with IM haloperidol in controlling acute agitation; given the greater tolerability of risperidone, this combination may eventually become the treatment of choice. Several medications in addition to the ones listed above have been used for longer-term treatment of agitation in the chronically confused patient. Beta-adrenergic receptor antagonists like Propranolol (Inderal) have been used to control impulsivity and agitation, but use must be monitored carefully for potentially dangerous effects on cardiovascular function such as bradycardia, hypotension, congestive heart failure and pulmonary edema are major side effects; dizziness and insomnia also can result.

Both carbamazepine (Tegretol) and divalproex (Depakote) have been used effectively, with divalproex often chosen due to its relatively benign side effect profile. Both should be used as second-line agents in patients with inadequate response to antipsychotic agents.

Over-medication and medication interactions are common but also less likely to be recognized in an elderly person with dementia because medication side effects so frequently mimic the actual effects of the disease process itself. Extreme vigilance is needed on the part of caregivers to assess responses to medications when given.

After receiving medication, what are the noticeable effects? Pharmacists are often excellent resource people for family caregivers to call if they suspect a problem and have questions about medication in addition to the prescribing physician.

Special precautions are also needed for the person with Alzheimer’s who may have trouble swallowing pills, or may simply decide not to take them, or to hide them in a corner of their mouth and remove them when the caregiver leaves the room. Always make sure a medication has been swallowed, not merely taken, before you leave a person.

Request liquid medications if needed and know what medications can be crushed and mixed in applesauce, jelly or ice cream. Some calming medications may also be administered topically and absorbed transdermally.

Mixing medication in food at meal times is generally not a good idea; the food will usually taste bad as a result and overall nutrition may suffer if the person suspects you of poisoning them or ruining their appetite. Caregivers may need to experiment with various forms of medications but it will be worth the time and effort to avoid medication-prompted catastrophic reactions.

### Alternative Medicine

Since dementia-related agitation and aggression can occur from many causes, it is important to identify any contributing factors that can be modified without the use of medication. Nonpharmacologic interventions are based on the principle that a clinical care system, serving patients with dementia must address issues in the physical environment and the care system (and its policies) that may contribute to the emergence of symptoms of agitation and aggression. Research has shown that verbal/vocal behaviors may be associated with pain, loneliness, or depression. Agitation may be associated with boredom and the need for activity and stimulation. Aggressive behaviors may be associated with avoiding discomfort, the communication of needs, or a demand for personal space. All treatment approaches should start with rigorous attempts to identify any reversible causes of these behaviors and eliminate or mitigate these factors.

Typical precipitants of agitation and aggression include pain, medical illness, boredom, loneliness, depression, and social and environmental stressors. Identified causes should be addressed through individualized and/or systemic efforts to mitigate the triggers of agitation and/or aggression. Other individualized nonpharmacologic interventions for the person with dementia include tools to improve or stabilize cognitive function, behavior modification, self-affirming exercises such as reminiscence therapy, and structured socialization such as pet therapy and visualizing family videotapes.

Some of the more popular alternatives for Alzheimer’s disease and other forms of dementia are:

**Vitamin E.** Some studies have shown that vitamin E can slow the progression of Alzheimer’s disease, while other studies have shown no benefit. Doctors warn against taking it.
large doses of vitamin E, especially if you’re taking blood thinners, because of an increased risk of bleeding.

Omega-3 fatty acids. Omega-3s are a type of polyunsaturated fatty acid (PUFA) found in fish and nuts. Research has linked certain types of omega-3s to a reduced risk of heart disease, stroke, dementia and cognitive decline. The Food and Drug Administration (FDA) permits supplements and foods to display labels with “a qualified health claim” for two omega-3s called docosahexaenoic acid (DHA) and eicosapentaenoic acid (EPA). The FDA recommends taking no more than a combined total of 3 grams of DHA or EPA a day, with no more than 2 grams from supplements. Theories suggest why omega-3s might influence dementia risk include their benefit to the heart and blood vessels, anti-inflammatory effects, and support and protection of nerve cell membranes. Preliminary evidence also shows that omega-3s may help reduce symptoms of depression. It’s thought this is because it’s an essential nutrient for brain function.

Ginkgo. Ginkgo contains two sets of important phytochemicals known as bilobalides and ginkgolides. These two classes of compounds have anti-inflammatory and antioxidant properties which can be useful for protecting brain cells and structures from damage. The benefits of Ginkgo for memory are disputed in some studies and effectiveness is only shown with long-term use.

B-vitamins. Specific benefits of B vitamins for memory include improving oxygen and nutrient transport to brain cells by increasing the production of red blood cells. Additionally, the B vitamins serve a protective role in the central nervous system by keeping homocysteine levels low in brain cells.

Vitamin B9 and B12 deficiencies are strongly associated with cognitive decline and memory loss. In a large-scale study published in the American Journal of Clinical Nutrition, each of the 700 volunteers recruited were given either a placebo or a combination of vitamins B9 and B12. The study result showed that the vitamin combination was effective for improving short-term memory after 24 months.

Meeting Spiritual Needs

The focus in nursing for the cognitively impaired home-bound or institutionalized elderly has clearly been on safety issues, concerns with nutrition, hydration and elimination, and medication management to try to control behavior. Interpersonal aspects of caring for people with dementia have been more recently addressed, though to a lesser degree, with an emphasis on validation therapy and a focus on types of psychosocial approaches that will ameliorate rather than aggravate symptoms.

A significant area of interpersonal relationships that has been virtually ignored in the literature, have been aspects of a demented person’s spirituality or relationship with God. This may well be related to a lack of any theoretical framework from which to understand what might be happening to a markedly confused person with respect to the self in relation to God, and consequent difficulty assessing spiritual concerns and/or making spiritual diagnoses.

In the last few decades there have been more published studies specifically addressing the spiritual dimension of the cognitively impaired person, though numerous studies have been published addressing the spiritual concerns of their caregivers.

Ignoring spiritual concerns of mentally ill clients because of an inability to differentiate them from pathology is unjustifiable and necessitates a refinement of assessment skills.

A similar dynamic may be occur when typical behaviors are seen as aberrant. They are often treated traditionally with the use of psychotropics and various behavior management techniques such as distraction and redirection, when in fact they may be expressing forms of spiritual distress.

The classification of spiritual distress from the National Group for the Classification of Nursing Diagnosis relates spiritual distress to two phenomena. One is the conflict between religious or spiritual beliefs, and prescribed health regimen, an admittedly difficult if not impossible area to directly assess with someone with advanced dementia if no background information is available. The other is the inability to practice spiritual rituals. Knowing what spiritual or religious rituals are or have been important to a person in the past can be extremely helpful when assessing present spiritual concerns.

One fairly common example is the wandering resident who may be following a long-established habit pattern of going to church or daily Mass.

Assessing and diagnosing spiritual needs of people with dementia require a different approach and different assessment tools than those traditionally used with people who are able to carry on a conversation about spiritual or religious concerns and verbally respond to assessment questions a nurse might ask. The most important step in the assessment process is observation and an inter-disciplinary approach to assessment that will include the person’s friends, family and/or spiritual support system.

The following categories of assessment can serve as a guide for making observations:

Affect and Attitude

What does the person look like? Do they seem angry, depressed, anxious or agitated? Behaviors that may be commonly associated or attributed to dementia can in actuality be expressions of spiritual distress or concern.

Behaviors

What is the person doing? What kinds of behaviors are they manifesting that may be indicators of spiritual concern, spiritual need or habit patterns?

Conversational Clues

In the natural course of a conversation a cognitively intact person may speak about God, their faith, church, suffering, prayer or other issues associated with spirituality. They may do this directly in a nurse-resident interaction, or conversational clues of this nature may be picked up if the person is overheard talking to roommates, friends or relatives.

Residents with dementia, particularly in more advanced stages, may no longer be able to express themselves in meaningful and complete sentences, but “religious words” may often be used and can serve as clues to underlying faith.

Denominational Affiliation

Specific denominational affiliation is useful knowledge that can aid in designing specific interventions. This information should be readily available on a resident’s chart, but this is rarely the case other than the broad categories of Protestant, Catholic, Jewish and other. It is important to know the specific affiliation and, more specifically, the particular church, synagogue or parish. Family can be a helpful source of information.

Environmental Clues

What did the resident bring with him to the nursing care facility? Does the resident have a Bible, a rosary or other religious medals, a prayer book or other devotional books? Are there pictures on the wall with religious significance? What kinds of cards does the resident receive? Does mail include Sunday bulletins?

Family, Friends and Faith Community

Family and friends are vital sources of information about the spiritual concerns and practices of people with dementia. Who visits? How often? What do they talk about? Family
members can also be questioned about the spiritual needs, concerns and habit patterns of their loved one or may offer information spontaneously. Do representatives from the resident’s faith community visit? Does their spiritual leader or advisor ever come?

Awareness of this need on the part of professional health care providers in relation to persons with dementia is an essential element of caring and a contributor to spiritual well being.

It is also important to remember that God meets spiritual needs directly. The role of health care professionals is simply to facilitate that relationship by helping a person get in touch with and be touched by God with appropriate spiritual care interventions.

The ministry of God to persons with Alzheimer’s disease must be the ministry of memory for them, reminding them they are loved. In appropriate situations, nurses can do this by praying with and for the person with dementia, by reading Scriptures, by enabling them to participate in the Sacrament of the Mass or communion, and by ensuring their presence in worship services that are places of collective memory where remembrances of God are shared through praise and song.

Ministering to the spirit is part of caring for the whole person; meeting spiritual needs and alleviating spiritual distress should be an integral part of the care planning for the person with dementia.

Caring for the Dying

Anne sat at the kitchen table. The wick in the kerosene lantern flared, casting a warm glow over the chilled room. The storm had abated but the electricity was still out. Anne sat, stared at the flame, and thought about her mother’s death in the nursing home several days earlier.

Her mother’s death had been a lot like that flickering wick... a lot like the dimly burning candle that sat on the mantel in the dining room.

Death had not come easily for Ruth. Neither had life. She had always worked so hard. Worked hard raising three children. Worked hard on the farm with her husband. And when she developed Alzheimer’s disease, Ruth worked incredibly hard, for many years, to cover it up.

In the end, Ruth struggled hard - laboring to breathe, to stay alive, to keep the fire of life burning.

Anne remembered that some of her friends, children of parents with Alzheimer’s, said death was a relief. It was a release from years of suffering, Anne wasn’t so sure. It didn’t seem that way for her mother. What was death really like? What would it be like for her? Was it a foe to be fought or a friend to be welcomed?

Anne lowered the wick in the kerosene lantern and watched as the smoke curled around the inside the glass globe. She walked over to the candle on the fireplace mantel. One blow. Two. A third finally snuffed out the candle.

Just like Mom, thought Anne. Just like most of us - working hard to keep our candle burning.

For some people with Alzheimer’s, death will come quickly. For others it will come only with more struggles, more suffering. For family caregivers death is not something they can easily explain or understand or even, necessarily, welcome, in spite of the many years of suffering both they and their loved one may have endured.

They can only wait, prepare as best they can and pray that they can make death a little easier for their loved one and for themselves. And family caregivers look to professional caregivers for help in making the transition from life to death an easier way of passage.

At the time of death, if families have made earlier arrangements for a brain autopsy, nurses will need to ensure that all procedures are carried out within a certain period of time to preserve brain tissue. Procedures vary depending on the receiving agency, which is usually a major medical center. Families can receive information for planning, prior to the terminal stage of Alzheimer’s, from their Alzheimer’s chapter or medical center. All health care personnel should be aware if these arrangements have been made and what is expected of them at the time of death.

Caring for someone with Alzheimer’s disease who is approaching the final days of life is not very different from caring for any other very ill person. Keeping them comfortably positioned, dry, clean and as pain free as possible are primary goals.

The following are things to remember and to teach, if needed, in any setting:

- Keep the person’s room well aired and well lighted. Good ventilation makes breathing easier and provides a more pleasant environment for the family caregiver to visit and the professional caregiver to work in. A dark room can be a frightening place for someone who is dying, especially someone with Alzheimer’s.
- Remember that circulation may be impaired. Keep the person warm with lightweight blankets and comforters as needed.
- Turn the person in bed frequently, at least every two hours. Give soothing back rubs. Pay special attention to skin over bony prominences like the hips, bottom of the spine, heels, elbows, shoulders and even the back of the head and ears. Consider obtaining a water, air or foam rubber mattress for the bed to prevent skin breakdown.
- Heels and elbows can be padded and wrapped with gauze if the person thrashes against the side rails. Sheepskin and foam boots may also be used. If the person is experiencing seizures, pad side rails well.
- Position the patient with extra pillows to increase comfort and decrease pressure on arms and legs. Family caregivers may need instructions on positioning from a physical therapist, or visiting nurse, if their loved one is dying at home.
- Bowel and bladder control will diminish until there is total incontinence. A catheter may be needed at home to help prevent skin breakdown and may be well tolerated at this stage of the disease.
- When swallowing becomes more and more difficult, offer puddings, yogurt, pureed fruits, ice cream and sherbet. Sometimes milk products and citrus fruit juices will increase mucus production and cause drooling or choking. Switch to non-dairy products and non-citrus juices, such as apple or cranberry.
- Ice chips may be welcome if sucking can be done without danger of choking. When swallowing becomes more and more of a problem, moisten gauze in ice water, hold the gauze firmly, and let the person suck on it. Placing a very light layer of petroleum jelly on lips and around nasal passages may help prevent cracking of skin.

If family members are primary caregivers they may want to invest in a good nursing-assistant manual that gives practical tips on all aspects of caregiving. Any local nursing home can direct them to the most updated source.

Playing music they have loved, frequent expressions of touch from caregivers including holding and stroking a hand, reading to them from a favorite book or passages of comfort from the Bible, singing to them, telling them you care — all can be expressions of comfort, even though there may be no visible response from the person that they hear or understand what is being said and done.

People with Alzheimer’s who are dying are walking through the valley of the shadow of death; they should not have to walk through it alone. Remind them in word and in deed that they are not alone.

Support the Family Caregiver

“Sometimes you feel like you are the only person in the world with a family situation like yours. And then you go to a support group meeting and you realize there are other people very much like you.”

“Dad was very aggressive. He mellowed...
somewhat as he got older, but his temper got worse as the Alzheimer’s disease came on. It was very hard on my mother. She was the type of person who would take everything and wouldn’t fight back. But there were times when she would go into her room, shut the door, cry, and scream and scream - just to get rid of the tension. I don’t know why she didn’t have a nervous breakdown. Ten years, and no respite.”

“I joined a small group to strengthen my own faith, and found it was like going to a well once a week and getting replenished. I love that metaphor of getting fresh water for my soul, refreshing myself as I learn about God with others.

“I’m finding things in the Bible that mean different things, now that my husband has Alzheimer’s. I can personalize the things I’m reading. I can apply the teachings of Jesus to my life.”

Personal, educational and spiritual support for both family and health-related caregivers is available from many sources. Receiving help from outside sources can strengthen caregivers for their responsibilities and ease what may seem to be an unbearable burden. There are, in fact, many ways to lighten the load. Examples include:

Support Groups

Support groups can help people realize they are not alone; others are having or have had very similar experiences. They can contribute to emotional and spiritual well-being of caregivers and give help in very practical, material ways as caregivers share with each other tips for managing behaviors and personal strategies for coping. They can also help caregivers think through the difficult decisions that may need to be made such as nursing home placement, institution of tube feedings, and planning for a brain autopsy at the time of death. For many who are no longer caregivers, the Alzheimer’s support group may continue to be a place of social support and provide them an opportunity to continue to feel needed as they are now able to more fully support others who are facing the slow, but inevitable decline of their loved one.

Many support groups also engage in educational activities in the community, sponsoring community awareness days and workshops. Many support group members are willing to be speakers for churches and service clubs. Others become active politically, lobbying through letters at the local, state and national levels for bills to support Alzheimer’s research and caregivers.

Not every caregiver is ready for a support group for reasons that relate to personal needs for privacy or concerns about being overwhelmed by hearing about how “bad it might get” when their loved one is yet in the early stages of the disease. Most support groups are aware of these concerns and individuals from groups are usually more than willing to talk on the telephone, send written information, visit in another care-giver’s home, and give support and needed information about the disease and caregiving issues.

Support groups are available in some parts of the country for teenagers who are increasingly becoming members of families touched by Alzheimer’s through a grandparent who may be living with them or even a parent. The Alzheimer’s Association has many helpful written materials for teenagers.

Alzheimer’s Association

The Alzheimer’s Association is the only national, voluntary health organization dedicated to research for the causes, cures, treatments and prevention of Alzheimer’s disease and to providing education and support services to affected individuals and those who provide their care. It is also an excellent source of information for nurses and other health care workers.

They publish a monthly newsletter filled with practical care giving ideas, research updates and information about the latest publications about Alzheimer’s designed for the caregiver. If a person needs information about local or state Alzheimer’s chapters, the national association can put them in touch with a contact person close to them; this organization also has helpful information about how to start a local support group. Special care units in nursing homes and nurses working directly with Alzheimer’s clients also would benefit from being on the mailing list and can do so for a minimal donation.

Professional Specialists

It is not unusual for caregivers to require a more personal level of support from caring and knowledgeable professionals. In most communities there are mental health teams and psychiatrists and psychologists who are geriatric specialists. Many pastors have received special training in gerontology. Social workers can also guide families through the intricacies and confusion related to financial management and legal issues.

Home Care

One of the keys to keeping a loved one at home for as long as possible is the opportunity, when needed, for caregiver relief and respite. Caregivers repeatedly share that the “straw” that often breaks them or triggers institutionalization of a spouse or parent is the caregiver’s health care needs. Attention to their own physical, mental and spiritual health is often neglected for a variety of reasons that can include beliefs that “no one can care for my loved one the way I can,” to lack of available resources to pay for outside help. Their loved one may also become increasingly dependent on them and become resistant to having anyone else in the house. The community health nurse, or a nurse who is a friend of the family, can help sort through the various options for help in the home available in their community.

Ideally, home care services should support the informal network of caring relatives, friends and neighbors by providing both practical hands-on help and education and help delay, or prevent, unnecessary institutionalization.

Formal in-home services delivered through city, county and community agencies include various types of nursing services, home-health and personal care aides, respite workers or companion sitters and home-makers/housekeepers.

Some caregivers also provide respite for each other with a type of caregiver exchange program. Mealtime help may be provided through Meals-on-Wheels or other community sponsored nutrition programs that provide cold and hot delivered meals to people with disabilities and often their spouses.

Adult Day Care is an option in many communities and utilized more and more by caregivers who also work outside the home.

Some long-term care facilities have respite beds available for families who may need to take time off from caregiving responsibilities for a week or month. The primary role of the nurse is to help families assess their own strengths and limitations on an ongoing basis.

In addition to coping with the grieving process and working through stages of denial, anger and depression, primary caregivers may, at some point, suffer from physical fatigue and may develop significant health problems of their own.

To maintain persons with Alzheimer’s disease in their own homes or in family-home situations for as long as possible is a primary goal, but not at the expense of the health of the primary caregiver.

Spiritual Support

People with Alzheimer’s disease can experience spiritual distress; caregivers can, too. Having spiritual needs met is a universal need and can be even more acute for a person faced with years of care giving responsibilities. Spiritual needs that often rise to the surface in a caregiver’s life include:

- the need to make sense of life in general and of their loved one’s suffering in particular
- the need for love and relationship for themselves
- the need for a sense of safety and security
in an unsafe and insecure situation
• the need for hope in the present and the future
• the need to be free from guilt, resentments, depression, fears and anxiety.

Support for the Professional Caregiver

Caring for people with Alzheimer’s disease is not an easy task for the family caregiver; it is not an easy task for the professional caregiver either. It can be physically draining and emotionally exhausting. But it can be emotionally and spiritually rewarding. Nurses and other health care professionals need education and support for themselves. This includes literature related to dementia, support groups of various kinds to meet needs individually, from each other as they work in hospitals, the community and long-term care facilities, and from God.

The suggested reading at the conclusion of this course includes articles that give updated and useful information on caring for persons with dementia.

The Alzheimer’s Association has already been identified as the best resource for both family and professional caregivers who are in need of educational materials. Local chapters and local support groups can also be contacted and are often able to supply hospitals and nursing homes with resource people for in-service education programs. Local support groups may also welcome nurses who want to know more about the disease or who are in a position to facilitate a group or provide some teaching about personal care issues.

Get to know family caregivers personally, including those who are in the community and those who have already placed a loved one in a nursing home. Work with them to meet the needs of their loved one. Learn from them. Care about them. Support them. Be strengthened and educated by them. Let your relationship with them be a mutually beneficial one of sharing and caring together.

Form a positive support group at work with other health care professionals and paraprofessionals who want to develop more creative ways to meet the needs of people with Alzheimer’s disease. Meet for lunch or after work to brainstorm and support each other. Formal care planning meetings in facilities are needed but it is often in the informal give and take of collegial relationships that true ministry is born and quality of life can be improved as creative ideas flow about what caregiving should really be. Use these opportunities to support and educate each other. Reaching out as nurses to nursing assistants is especially needful, especially in homes where they are not included in regular resident planning meetings, to make them feel a vital part of the team and to honor their contributions.

Pay attention to your own spiritual needs and concerns. Questions about the meaning of suffering and death are not asked exclusively by family caregivers; professionals working on a daily basis with people with dementia ask these questions too and need to think through and often work through their own beliefs and philosophy of life and death.

As we care for our patients and loved ones with Alzheimer’s disease, we also need to remember to care for ourselves. Drawing on the available resources can be one way to help nourish our own minds, hearts and spirits and remind us that we are also whole people with needs to be met. The more we prepare and strengthen ourselves, the better able we will be to meet the special needs of those entrusted to our care.

Current Alzheimer’s Research — the Search for Answers

The quest for research to better diagnose, treat and possibly prevent or cure Alzheimer’s Disease is robust. According to the Alzheimer’s Foundation, current research is looking at targeting both Beta Amyloid and Tau proteins and also at inflammation and Insulin resistance.

Beta-amyloid is the chief component of plaques. Scientists now have a detailed understanding of how this protein fragment is clipped from its parent compound amyloid precursor protein (APP) by two enzymes — beta-secretase and gamma-secretase. Researchers are developing medications aimed at virtually every point in amyloid processing. This includes blocking activity of beta-secretase enzyme; preventing the beta-amyloid fragments from clumping into plaques; and even using antibodies against beta-amyloid to clear it from the brain.

One such drug in clinical trials is called Solanezumab, a monoclonal antibody designed to lower the level of beta-amyloid in the brain. These antibodies bind to beta-amyloid, preventing the formation of plaques. At the time of this writing, several studies of this drug are under way with the goal of determining if Solanezumab improves participants’ cognition (thinking and memory) and functioning.

Some studies look at interrupting an enzyme called Beta-Secratease (BACE). This enzyme allows formation of Beta Amyloid formation. An experimental study drug, labeled MK-893, is a BACE inhibitor and inhibits the ability of the beta-secretase enzyme.

Other drug therapies are targeting tau proteins, the chief component of tangles in the brain. Tau protein helps maintain the structure of a neuron, including tiny tube-like structures called microtubules that deliver nutrients throughout the neuron. Researchers are investigating mechanisms to prevent tau protein from collapsing and twisting into tangles, eventually destroying the neuron. A vaccine intended to attack abnormal tau proteins to stabilize the neurons is currently in clinical trials.

Inflammation is another possible culprit to Alzheimer’s disease since plaques and tangles activate the immune response and release microglial cells in response. While microglia help clear beta-amyloid in the brain, they may become overactive in the presence of beta-amyloid and produce compounds that damage nearby cells. Researchers are exploring medication that might modulate inflammation and reduce formation of plaque deposit.

It is well known that Insulin resistance is a common feature of Alzheimer’s disease. For reasons researchers do not completely understand, the brain becomes resistant to the normal effects of insulin, including the conversion of glucose to energy that brain cells can use to fuel cell functioning. Some research suggests that beta-amyloid decreases the body’s ability to use insulin. Other research has found reduced levels of insulin in the brain.

It bears noting that although research efforts hold promise, the pharmaceutical industry has been thwarted from being able to produce safe and effective medication to harness the onset or progress of Alzheimer’s disease as many hopeful study drugs in recent years have failed clinical trials. The last FDA approved medication, Namenda, was released in 2003.

Reducing Risk of Dementia

While scientists continue to pursue pharmaceutical treatments and vaccines, a realm of research related to brain health and lifestyle practice has opened up - exploring the ramifications that exercise, diet, mental activity and socialization pose for optimal cognitive function and risk reduction for Alzheimer’s and related dementias.

Physical exercise is a known component for brain health and in some studies is shown to diminish risk of dementia by half. Hundreds of studies have looked at the impact of various types of exercise, including aerobic and strength training. The effect of physical exercise is two-fold - it increases oxygenation to areas in the brain critical to memory and higher thought processing and it also ramps up the expression of a naturally-occurring brain substance called brain derived neurotrophic factor (BDNF).

BDNF is a protein molecule which acts on
certain neurons of the central nervous system and the peripheral nervous system, helping to support the survival of existing neurons, and encourage the growth and differentiation of new neurons and synapses. In the brain, it is active in the hippocampus, cortex, and basal forebrain—areas vital to learning, memory, and higher thinking. Scientists have come to refer to BDNF as the “Miracle Gro” of the brain as it seems to prime the brain for learning. Exercise, particularly aerobic, increases levels of BDNF and some studies suggest that it also serves as a protective element against amyloid activity.

The notion that diet and nutrition play a role in brain health is a new one but many studies are looking at how food affects brain health. Of particular interest is the strong correlation between Diabetes and Alzheimer's; individuals with Diabetes have a significantly elevated risk of dementia in later life. A compendium of studies point to the recommendation of adapting a Mediterranean Diet for optimal brain health - high in fresh fruits, vegetables, fish, lean meats and “healthy fats” such as olive oil and low in processed or sweetened food products.

Mental activity, in the form of “brain games” and commercially developed programs are somewhat controversial as to whether or not they actually benefit brain function. Most neuroscientists favor mental activities that are novel and challenging to the participant - such as learning new skills, trying different hobbies, traveling and otherwise engaging the brain by going outside of its learned comfort zone. Examples include learning a foreign language, playing a musical instrument, or studying a subject that one knows nothing about. The idea is to “push” the brain by introducing unfamiliar tasks, thus creating new neural pathways.

The effects of stress and socialization on brain health are also widely studied. Long periods of chronic stress are detrimental to cognition since continual release of the stress hormone cortisol can cause erosion in the hippocampus, the area of the brain responsible for new learning and short-term memory. It is also known that those who have areas of social connection - through friends, family, work or volunteer groups - have better cognitive (and physical) outcomes than those who are socially isolated. Researchers have looked into a plethora of stress-relieving and social activities in their brain health research including meditation, music and yoga practices.

Cognitive decline, ranging from mild cognitive impairment to dementia, can have profound implications for an individual’s overall health and well-being. Older adults and others experiencing cognitive decline may be unable to care for themselves or conduct necessary activities of daily living, such as meal preparation and money management. Limitations with the ability to effectively manage medications and existing medical conditions are particular concerns when an individual is experiencing cognitive decline or dementia. If cognitive decline can be prevented or better treated, lives of many older adults can be improved.

Opportunities for maintaining optimal cognitive health are growing as public health professionals gain a better understanding of cognitive decline risk factors. The public health community should embrace cognitive health as a priority, invest in its promotion, and enhance our ability to move scientific discoveries rapidly into public health practice.

Resources

Alzheimer’s Foundation of America

866.AFA.8484 (toll-free)

National Memory Screening Day is a collaborative effort spearheaded by the Alzheimer’s Foundation of America to promote early detection of Alzheimer’s disease and related illnesses, and to encourage appropriate intervention. AFA carries out this event in collaboration with organizations and healthcare professionals across the U.S.—bringing them together for care. Participating sites offer free confidential memory screenings, as well as follow up resources and educational materials to those concerned about memory loss. Together, we hope to improve quality of life. This is an annual event held each November.

Dementia Care Professionals of America (DCPA)

This resource offers membership, training, qualification and other benefits to healthcare professionals involved in dementia care.

DCPA's goals are to:
- Raise the bar on dementia care in the U.S.
- Provide practical training to healthcare professionals
- Set standards of excellence through AFA qualification program.
- Keep professionals abreast of emerging breakthroughs in treatment and care
- Offer networking and advocacy opportunities
- Support professionals as they support those in need

Alzheimer’s Association

800.272.3900
or http://www.alz.org

Formed in 1980, the Alzheimer’s Association advances research to end Alzheimer’s and dementia while enhancing care for those living with the disease.

National Institute on Aging

https://www.nia.nih.gov/

National Mental Health Association

http://www.nmha.org

Healthy Brain Initiative-Progress Report


References and Suggested Readings


De Haan J, Friesen PK. God can use us!. J Christ Nurs, Oct-Dec 2014, 31(4) p218

Drugs to Treat Alzheimer’s Disease [In Process Citation]. J Psychosoc Nurs Ment Health Serv, Apr 1 2016, 54(4) p19-20


Lane D.Watching a Friend Fade Away. Am J Nurs, Jan 2016, 116(1) p72

Lin SY, Becker M, Belza B. From dementia fearful to dementia friendly: be a champion in your community. J Gerontol Nurs, Dec 2014, 40(12) p3-5


McNair T. Early Intervention for Caregivers of Patients With Alzheimer’s Disease, Home Healthc Now, Sep 2015, 33(8) p425-30

Narayan M. Alzheimer’s be not proud. Home Healthc Nurse, Feb 2014, 32(2) p130-1


Powell SK. Ode to Healing Music in Health Care [In Process Citation] Prof Case Manag, Jan-Feb 2016, 21(1) p1-2


Wolf ZR, Czekanski KE. Bathing Disability and Bathing Persons with Dementia. Medsurg Nurs, Jan-Feb 2015, 24(1) p9-14, 22