

ALZHEIMER'S DISEASE

OBJECTIVES

At the conclusion of this course, the learner will be able to:

1. Detail the etiology, pathophysiology, signs and symptoms of Alzheimer's disease.
2. Discuss how the diagnosis of Alzheimer's disease is made.
3. Describe pharmacological and nonpharmacologic interventions relating to Alzheimer's disease.

INTRODUCTION

Alzheimer's disease is a widespread and commonly occurring form of senile dementia, predominately found in older adults although it is occasionally diagnosed among middle-aged adults.

It is a progressive, irreversible neurological disorder that is marked with the loss of cognitive ability, disturbances of behavior and personality changes. Cognitive losses include declines in terms of language, thinking and decision-making.

Alzheimer's disease, first recognized in 1907 by German neurologist Alois Alzheimer, is not a function of the normal aging process.

INCIDENCE

Although the course of the disease varies among people, it is found that, on an average, a person will about 8 to 10 years after diagnosis, although some may live as long as 20 years after diagnosis. The symptoms generally begin to appear after 60 years of age with increasingly greater risk for onset, as the person grows older. The risk of the disease doubles for every 5-year increment after 65. The group at greatest risk is those 85 years of age and older. Some believe that almost half of those 85 years of age, and older, have dementia. About 3 percent of men and women ages 65 to 74 are affected by it.

At the current time, it is estimated that 4.5 million people have it. It is also estimated that, by the year 2050, 13.2 million people in our nation will have Alzheimer's disease should the increases in life expectancy materialize as it is expected to do.

At the current time, the direct and indirect costs of caring for people with Alzheimer's disease is about \$100 billion a year in our country. Society and families are also affected with this disorder. About half of all Alzheimer's are cared for in their own home. Caregiving family members experience physical, emotional and financial stress as they care for the person in the home. (United States NIA & NIH, 2003)

Alzheimer's disease consists of two types. They are:

- familial (late onset) and
- sporadic (early onset).

The *familial type* of the disease accounts for about 75% of cases while the *sporadic type* accounts for the remaining 25% of the diagnosed cases. The familial type of Alzheimer's disease usually occurs at an earlier age than the sporadic type, typically before the age of 60. The sporadic type typically presents in later years.

ETIOLOGY

In recent years medical researchers have conducted numerous intensive studies to determine what factor or factors cause this severely devastating and widespread neurological disorder. Although no conclusive evidence has been produced as a result of these research efforts, some factors have been identified as plausible and possible causative agents of Alzheimers.

The cause of late onset Alzheimer's disease is not fully understood, however, it is known that about half of children with an affected parent may develop early onset Alzheimer's when they are as young as 30, 40 or 50. These people have a mutation in one of the following genes which are associated with an excess beta-amyloid:

- APP gene (on chromosome 21)
- presenilin 1 gene (on chromosome 14)
- presenilin 2 gene (on chromosome 1)

It appears that beta-amyloid is toxic and when beta-amyloid plaques form in the brain, the damage to brain function occurs. The key to a cure, therefore, may lie in our ability to speed up beta-amyloid removal or to slow down its production. (United States NIA & NIH, 2003)

The genetic model.

Some evidence supports the fact that heredity plays a role in the development of Alzheimer's disease, particularly among individuals diagnosed at an early age. Studies have indicated that if a parent or sibling has or has had the disease there is a greater risk of developing the disease. However, having an affected sibling or parent does not necessarily mean that one will develop Alzheimer's with 100% certainty.

Families with several victims of this disease have been studied and it has been found that some members of the family may get it and others do not. It appears that although genetics and heredity may play a role in the development of Alzheimer's disease, it may involve more than heredity alone.

The toxin model.

Other researchers have explored the role of aluminum in the development of Alzheimer's disease. Investigations into the role of aluminum from environmental sources such as drinking water, cooking pans and pots, antiperspirants and antacids as a causative or contributory agent have not led to the gathering of conclusive evidence in support of this theory.

THE WARNING SIGNS OF ALZHEIMER'S DISEASE

According to the National Institute on Aging, there are seven warning signs associated with Alzheimer's disease. They are as follows:

1. "Asking the same question over and over again.
2. Repeating the same story, word for word, again and again.
3. Forgetting how to cook, or how to make repairs, or how to play cards — activities that were previously done with ease and regularity.
4. Losing one's ability to pay bills or balance one's checkbook.
5. Getting lost in familiar surroundings, or misplacing household objects.
6. Neglecting to bathe, or wearing the same clothes over and over again, while insisting that they have taken a bath or that their clothes are still clean.
7. Relying on someone else, such as a spouse, to make decisions or answer questions they previously would have handled themselves. (National Institute on Aging, 2005)

THE SIGNS AND SYMPTOMS OF ALZHEIMER'S DISEASE

The symptoms of Alzheimer's disease are often gradual and they may go unnoticed for many years. The first symptoms of Alzheimer's are forgetfulness and memory loss. The memory loss and forgetfulness is most often associated with recent events and novel information, rather than long-term memory. The affected individual may demonstrate a repetition of ideas in conversations or forget where they have left an object.

The person suffering from Alzheimer's may be unaware of any cognitive changes and often it is a family member, rather than the affected individual, who seeks medical help for the condition. As the disorder continues to progress, severe confusion and disorientation as well as personality and behavioral changes occur. A person may present with agitation, wandering, paranoia, depression, poor judgment, a lack of common or an inability to verbally express complex thoughts. They may no longer be able to perform simple activities of daily living like dressing, grooming, reading and writing.

Other treatable medical conditions, such as dehydration, malnutrition and a fever, mimic the symptoms of Alzheimer's disease so these conditions should be diagnosed and treated prior to a diagnosis of Alzheimer's disease.

The Alzheimer's Association lists the following signs of the early stage of the disease:

Recent memory loss that affects job skills.

It is normal to occasionally forget assignments, names, or telephone numbers and then remember them later. Those with a dementia, such as Alzheimer's disease, forget things with greater frequency and often fail to remember them even when reminded.

Difficulty performing familiar tasks.

Busy people can be so distracted from time to time that they may leave the carrots on the stove and only remember to serve them at the end of the meal. People with Alzheimer's disease may have difficulty going through the proper steps to prepare the carrots.

Problems with language.

Everyone has trouble finding the right words sometimes, but people with Alzheimer's disease forget simple words or substitute inappropriate words, making their sentences difficult to understand.

Disorientation to time and place.

It is normal to occasionally forget the day of the week or how to get where you are going. However, people with Alzheimer's disease may become lost in familiar surroundings, not knowing where they are, how they got there, or how to get back home.

Poor or decreased judgment.

People can become so immersed in an activity that they temporarily forget about something else that they are supposed to be doing at the same time, such as watching a child. People with Alzheimer's disease may entirely forget about the child under their care. They may also dress inappropriately for the weather or put on several shirts or blouses.

Problems with abstract thinking.

Balancing a checkbook may be disconcerting when the task is more complicated than usual. Someone with Alzheimer's disease may completely forget what the numbers are and what needs to be done with them.

Misplacing things.

Anyone can temporarily misplace a wallet or keys. A person with Alzheimer's disease may put things in inappropriate places. For example, they may place a carton of ice cream in a kitchen cabinet or they may put the milk in the freezer.

Changes in mood and behavior.

Everyone becomes sad or moody from time to time. Someone with Alzheimer's disease can exhibit rapid mood swings - from calm to tears to anger, for no apparent reason.

Changes in personality.

Personalities may change slightly with age. However, a person with Alzheimer's disease can change drastically, becoming extremely confused, suspicious, or fearful.

Loss of initiative.

It is normal to tire of housework, business activities, or social obligations, but most people regain their initiative. People with Alzheimer's disease may become very passive and require cues and prompting to become involved. (Alzheimer's Association, 2005)

Although the signs and symptoms of Alzheimer's disease can vary, the early signs and symptoms of the disease usually progress from short-term memory loss and personality changes to more severe degrees of debilitation. Those affected may demonstrate a diminishing ability to perform activities of daily living. They may have progressive loss of decision-making powers and display poor judgment. Aphasia, hostility, emotional instability, depression and agitation are also frequently seen.

Early Stage (Mild Form) Signs and Symptoms

The person:

- “Loses spark or zest for life - does not start anything.
- Loses recent memory without a change in appearance or casual conversation.
- Loses judgment about money.
- Has difficulty with new learning and making new memories.
- Has trouble finding words - may substitute or make up words that sound like or mean something like the forgotten word.
- May stop talking to avoid making mistakes.
- Has shorter attention span and less motivation to stay with an activity.
- Easily loses way going to familiar places.
- Resists change or new things.
- Has trouble organizing and thinking logically.
- Asks repetitive questions.
- Withdraws, loses interest, is irritable, not as sensitive to others' feelings, uncharacteristically angry when frustrated or tired.
- Won't make decisions. For example, when asked what she wants to eat, says "I'll have what she is having."
- Takes longer to do routine chores and becomes upset if rushed or if something unexpected happens.
- Forgets to pay, pays too much, or forgets how to pay - may hand the checkout person a wallet instead of the correct amount of money.
- Forgets to eat, eats only one kind of food, or eats constantly.
- Loses or misplaces things by hiding them in odd places or forgets where things go, such as putting clothes in the dishwasher.
- Constantly checks, searches or hoards things of no value.” (National Institute on Aging, 2005)

During the intermediate stage of Alzheimer's disease, long-term memory may become affected in addition to the already present short-term memory loss. The individual affected with Alzheimer's disease may become progressively more socially isolated and incapable of performing even the most basic activities such as bathing, cleaning the home and safely cooking their meals. They may become increasingly more disoriented and perhaps even have a tendency to wander and get lost.

Psychological and behavioral symptoms that began to appear in the early stages of the disease may progress, causing the individual to become severely aggressive, agitated and hostile. At this point, the safety and physical well being of the person as well as their quality of life becomes progressively more jeopardized as the disease continues on its course.

Intermediate Stage (Moderate Form) Signs and Symptoms

- “Changes in behavior, concern for appearance, hygiene, and sleep become more noticeable.
- Mixes up identity of people, such as thinking a son is a brother or that a wife is a stranger.
- Poor judgment creates safety issues when left alone - may wander and risk exposure, poisoning, falls, self-neglect or exploitation.
- Has trouble recognizing familiar people and own objects; may take things that belong to others.
- Continuously repeats stories, favorite words, statements, or motions like tearing tissues.
- Has restless, repetitive movements in late afternoon or evening, such as pacing, trying doorknobs, fingering draperies.
- Cannot organize thoughts or follow logical explanations.
- Has trouble following written notes or completing tasks.
- Makes up stories to fill in gaps in memory. For example might say, "Mama will come for me when she gets off work."
- Maybe able to read but cannot formulate the correct response to a written request.
- May accuse, threaten, curse, fidget or behave inappropriately, such as kicking, hitting, biting, screaming or grabbing.
- May become sloppy or forget manners.
- May see, hear, smell, or taste things that are not there.
- May accuse spouse of an affair or family members of stealing.
- Naps frequently or awakens at night believing it is time to go to work.
- Has more difficulty positioning the body to use the toilet or sit in a chair.
- May think mirror image is following him or television story is happening to her.
- Needs help finding the toilet, using the shower, remembering to drink, and dressing for the weather or occasion.
- Exhibits inappropriate sexual behavior, such as mistaking another individual for a spouse. Forgets what is private behavior, and may disrobe or masturbate in public.” (National Institute on Aging, 2005)

In its most severe form, Alzheimer's disease may completely limit the ability of the individual to remain independent and perform some self-care activities. They may be unable to perform even simple activities of daily living, including ambulation. Severe psychosis with delusions, hallucinations and paranoia has been found to occur in about 10% of those affected with Alzheimer's disease. Safety continues to be a major concern. During the terminal phase of Alzheimer's disease long term and short term memory may be completely absent. Patients may have difficulty eating and swallowing, thus placing them at risk for malnutrition, dehydration and aspiration.

Additional challenges face those who provide care to this patient population in terms of assessment skills. Alzheimer's patients are often unable to communicate symptoms of illness so it is important to continuously assess and monitor these patients for the signs and symptoms of infection and disease. Typically, the end stage of Alzheimer's disease results from an infection that eventually leads to coma and death.

Late Stage (Severe Form) Signs and Symptoms

- “Doesn't recognize self or close family.
- Speaks in gibberish, is mute, or is difficult to understand.
- May refuse to eat, chokes, or forgets to swallow.
- May repetitively cry out, pat or touch everything.
- Loses control of bowel and bladder.
- Loses weight and skin becomes thin and tears easily.

- May look uncomfortable or cry out when transferred or touched.
- Forgets how to walk or is too unsteady or weak to stand alone.
- May have seizures, frequent infections, falls.
- May groan, scream or mumble loudly.
- Sleeps more.
- Needs total assistance for all activities of daily living.” (National Institute on Aging, 2005)

PATHOPHYSIOLOGY

It is now believed that Alzheimer's disease is associated with a loss of cells in the hippocampus, cerebral cortex and the subcortical sections of the cerebrum and with cells in the locus ceruleus and nucleus raphis dorsalis in the brainstem. These are the areas of the brain associated with memory, cognition and thought processes. It is also believed that those with Alzheimer's disease may have less than normal cerebral glucose use. It is not clear whether this reduction follows or precedes the cellular destruction within the brain.

Although consensus among the members of the scientific community has not yet been reached, some researchers believe that beta-amyloid deposits may cause the cognitive deterioration seen in Alzheimer's. Amyloid is a starchlike protein that forms within and adjacent to the blood vessels in the affected areas of the brain. Amyloid protein deposits are notable for their staining properties and are composed of filaments or fibrils arranged in a twisted beta-pleated conformation. It is not known whether the presence of amyloid deposits in the brain is a primary cause of Alzheimer's or simply a feature of the disease.

Researchers have also explored the presence and frequency of neurofibrillary tangles and senile plaques among those with and without Alzheimer's disease. Neurofibrillary tangles are bundles of fibrous proteins found in the nerve cell bodies in the hippocampus, cerebral cortex and in the areas of the brainstem involved with the release of certain neurotransmitters.

Senile plaques are scattered bits of cellular debris, degenerating nerve terminals, amyloid deposits and glial cells that are associated with inflammatory reactions. These plaques tend to be localized in the area of the axons and dendrites rather than within the nerve cell bodies.

It has been found that neurofibrillary tangles and senile plaques, commonly seen phenomena associated with the normal aging process, appear to be more numerous and frequent in those persons diagnosed with Alzheimer's. These plaques and tangles play a role in the progressive pathology of the disease.

Protein abnormalities have also been found in patients with Alzheimer's disease. In addition, a reduction of choline acetyltransferase, somatostatin, corticotropin-releasing factor and several neurotransmitters has also been documented. Although the normal aging process is associated with some decreased neurotransmission, the multiple neurotransmission defects seen in patients with Alzheimer's are far greater and more severe.

Recent research indicates that apolipoprotein E2 (apoE2), previously known for its biochemical role in cholesterol transport, may serve as a protective mechanism against the disease. A variant, apoE4 may indicate susceptibility because apoE4 attaches to beta-amyloid, a protein associated with the development and onset of the disease. (Beers & Berkow, 2005)

DIAGNOSIS

The diagnosis of Alzheimer's disease is complex and challenging, particularly in its early stages. It is difficult to differentiate normal forgetfulness and a slowed rate of learning from pathological cognitive deficits associated with the disease itself.

Diagnosis involves a synthesis of information from a complete medical history and physical examination, laboratory tests, brain scans, neuropsychological tests that measure problem solving skills, counting, language and memory.

The only definitive diagnosis for Alzheimer's disease is a post-mortem brain tissue biopsy, which reveals the plaques and tangled brain tissue characteristic of Alzheimer's disease. Any diagnosis of Alzheimer's disease is a probable or possible one until the person is dead. Before a probable diagnosis is made, however, other possibilities such as thyroid disease, an untoward side effect of a medication, depression, brain tumors and other medical conditions must be ruled out.

The following diagnostic criteria developed by the Alzheimer's Association helps to facilitate early and accurate diagnosis. Before these strict diagnostic criteria were imposed, Alzheimer's disease was misdiagnosed up to 50% of the time. Now, it is accurately diagnosed by specialists up to 90% of the time.

1. Dementia established by clinical examination; documented by the Mini-Mental State Examination, Blessed Dementia Scale, or a similar examination; and confirmed by neuropsychologic tests.
2. Deficits in two or more areas of cognition.
3. Progressive worsening of memory and other cognitive functions.
4. No disturbance of consciousness.
5. Onset between the ages of 40 and 90 years, most often after age 65.
6. No systemic disorders or brain diseases that could account for the progressive deficits in memory and cognition. (Alzheimer's Association, 2005)

Until a definitive test is available, a number of other diagnostic tests can be performed to rule out other causes of the dementia. Some of the tests include electrolyte levels, CBC (complete blood count), folate and B12 levels, thyroid function tests, urinalysis, VDRL (Venereal Disease Research Laboratories) and an EKG. An MRI or CT is also done when a brain mass, infarct or hematoma is suspected. After the testing and assessment has eliminated all other causes of the dementia, a diagnosis of Alzheimer's disease is generally made.

A current research goal is the development of a noninvasive and accurate test for the disease. This test may involve the identification of some biological markers, such as a specific kind of protein, or a more advanced form of medical imaging than is now available.

THE PHARMACOLOGICAL TREATMENT OF ALZHEIMER'S DISEASE

As stated previously, there is no cure for Alzheimer's disease. It is unrelenting and progressive. There are, however, some medications that can prevent the symptoms from worsening, at least for a period of time.

These medications include:

- tacrine (Cognex),
- donepezil (Aricept),
- rivastigmine (Exelon),
- galantamine (Razadyne)
- memantine (Namenda)

Other medications are used to help control some of the disturbing behavioral changes relating to the disease, such as depression, agitation, wandering and anxiety. The goals of this therapy is to make the lives of the affected individual and their caregivers less problematic and more comfortable, whenever possible. CNS depressants, antidepressants and antipsychotic medication, however, can produce greater lethargy and confusion so caution and monitoring is necessary.

Tacrine (Cognex), donepezil (Aricept), rivastigmine (Exelon) and galantamine (Razadyne) are cholinesterase inhibitors. It appears that this classification of medication may prevent the breakdown of acetylcholine until the Alzheimer's disease progresses to a point when acetylcholine is only minimally produced by the brain, thus rendering the medication less useful or useless. Acetylcholine chemically enhances memory and other cognitive processes.

Tacrine

Tacrine (Cognex) improves cholinergic neurotransmission and provides some improvement for patients with mild to moderate dementia. Tacrine inhibits the enzyme cholinesterase, an enzyme responsible for the breakdown of acetylcholine in the synapse of nerve cells. Tacrine allows acetylcholine to remain in the synapse thereby temporarily improving cognitive function.

The initial dosage is 10 mg four times a day and can be increased up to 40 mg four times a day until the desired effects are achieved. Tacrine should be discontinued with those patients who develop jaundice. Since the medication may increase transaminase levels, caution should be exercised when administering Tacrine to patients with a history of abnormal liver function tests. Once the patient is on Tacrine therapy it is necessary to monitor liver function.

Other adverse effects to tacrine (Cognex) include bradycardia, peptic ulcer, ataxia, nausea, vomiting, diarrhea, anorexia, dyspepsia and myalgia. Toxicity is marked with a severe cholinergic crisis accompanied by severe salivation, sweating, bradycardia, nausea, vomiting, hypotension, convulsion and muscular weakness. In its most severe form toxicity could lead to respiratory arrest.

The recommended antidote is a titrated solution of IV atropine sulfate until the desired reversal of toxic symptoms has been achieved. It is recommended that Tacrin be taken between meals since its absorption is inhibited by the presence of food in the stomach.

Donepezil

Donepezil (Aricept) acts in the same manner as Cognex.

The initial dosage is 5 mg per day at bedtime. The dosage can be increased to 10 mg a day after 4 to 6 weeks of treatment that has not achieved its therapeutic effect.

Some of the side effects of this medication include:

- CNS effects (insomnia, headache, seizures, tremors, aggression, vertigo, nervousness, fatigue, ataxia and abnormal bouts of crying)
- GI effects (nausea, diarrhea, anorexia, GI bleeding, fecal incontinence and vomiting)
- Cardiovascular effects (hypotension, hypertension, atrial fibrillation, chest pain, vasodilation and hot flashes)
- Eye effects (cataracts, blurred vision and eye irritation)
- Urinary effects (urinary frequency)
- Hematological effects (ecchymosis)
- Respiratory effects (bronchitis, dyspnea)
- Metabolic effects (weight gain)
- Integumentary effects (urticaria, diaphoresis, pruritus)

This medication is contraindicated with hypersensitivity and it must be used cautiously if the patient has a history of asthma, COPD, cardiovascular disease and/ulcers.

Rivastigmine

Rivastigmine (Exelon), another cholinesterase inhibitor, should be used cautiously with asthma, GI and urinary obstructions, cardiovascular disease, hypotension, a history of ulcers, seizures, epilepsy, uncontrolled diabetes and thyroid problems.

Typically, this medication is taken two times a day, best taken with meals and at regular times each day. The initial dosage is usually 1.5 mg twice a day. It can be increased up to 6 mg a day, as indicated. Rivastigmine toxicity can lead to convulsions, severe nausea and vomiting, muscular weakness, diaphoresis, excessive salivation, seizures and shock (large pupils, irregular breathing, dramatic hypotension and a rapid weak pulse).

Some of the side effects of Rivastigmine (Exelon) include:

- GI effects (anorexia, stomach pain and cramping, diarrhea, nausea, vomiting, indigestion, weight loss, GI bleeding, constipation)
- Cardiovascular effects (hypertension)
- CNS effects (fainting, confusion, convulsions, trembling, depression, headache, dizziness, insomnia)

Galantamine

The side effects of galantamine (Razadyne) include:

- GI upset
- Diarrhea
- Anorexia
- Weight loss
- Fatigue
- Dizziness
- Headaches
- Tremors
- Abdominal pain
- Depression
- Insomnia
- Dysuria
- Hematuria
- Seizures
- GI bleeding

Drinking six to eight glasses of water every day while taking galantamine can decrease the risk of GI side effects.

Memantine

Namenda (memantine) is quite different from the four above cholinesterase inhibitors. This medication is an N-methyl D-aspartate (NMDA) antagonist. This medication offers some patients the hope of being able to continue some activities of daily living for a longer period of time. For example, it may enable people to dress themselves for a longer period of time than they would have been able to without this medication.

It is believed that this medication regulates excessive levels of glutamate, a chemical that leads to cellular brain tissue death. The recommended therapeutic dosage of Namenda is 20 mg per day after lesser doses have been tolerated. A dosage of 5 mg a day is taken as a single dose; larger doses are taken divided q 12 hours. .

It can be taken with or without food, but it should be taken with at least one full glass of water. The patient should use caution with driving and the operation of machinery as well as other hazardous activities because this medication can cause dizziness, fainting and drowsiness,

Some of the side effects of Namenda (memantine) include:

- fainting,
- dizziness,
- drowsiness,
- nausea,
- vomiting,
- headache,
- hypertension,
- constipation,
- confusion,
- coughing, and
- hallucinations.

CARING FOR THE PERSON WITH ALZHEIMER'S DISEASE

There is no cure for Alzheimer's disease. The disease is progressive with increasing levels of cognitive decline and debilitation. During the initial stages of the disease the affected individual should be encouraged to remain as active and self sufficient as possible. Modifying the environment for safety and security is advisable. The use of alarms and signals is advised for those who wander and get lost.

Other modifications include the elimination of clutter and help with activities of daily living when necessary. Additional treatments include individual and family counseling, orientation therapy, physical exercise to decrease restlessness, music therapy, occupational therapy, reminiscence and socialization groups.

Additionally, the health care team (nursing, home health, rehabilitation, physicians and dietitians, social workers and mental health counselors) should involve the patient's family and caregivers. Often they are in need of such things as assistance, guidance, support and education in order to cope with the physically and emotionally demanding aspects of this devastating disease. Respite care, day care and long term care facilities should be suggested when the need arises. Often a nursing home, especially one with a special unit for Alzheimer's residents, becomes a difficult but necessary decision for the family.

Generally speaking, people with Alzheimer's disease do better in a familiar environment with predictable routines. Below are some care guidelines that should be used by professional healthcare workers as well as caregivers in the home.

Bathing

- “Try to follow as many of the person's old routines as possible (morning vs. evening; bath vs. shower)
- Simplify tasks and try to do one step at a time. (e.g. run water, towels ready, undress, etc.)
- Allow as much independence as possible. Remember to respect the person's privacy and sense of dignity.
- Try to be as calm and gentle as possible. Try not to rush or force the person through the task. Talk him through, if needed.
- Adjust your expectations, if need be. A bath may not be necessary every day, though it is important to keep them clean. If the person is incontinent, it will be especially important to keep the genital and buttocks area clean to promote good health.
- Be flexible and creative. A sponge-bath can serve the same purpose as a bath or shower, but may be more acceptable to the person being bathed, because she can remain partially covered.

- Work towards a safe and inviting environment - be sure the room is warm, that the water is a comfortable temperature, and that the tub is equipped with non-skid surface and a grab bar. Do not leave hair dryers or razors within reach of a confused person. “ (National Institute on Aging, 2005)

Mouth Care

- “Check to make sure the person brushes his teeth regularly. Remind and/or talk him through each task as needed.
- Be sure dentures fit well. A trip to the dentist to ensure good fit may be worthwhile, especially if the person's weight has changed significantly since the original fitting.
- Be sure to include fruit, such as apples, in the person's diet. They can help to clean the teeth and gums.
- If you need to assist the person in cleaning his teeth, you may find the task less pleasant by wearing thin plastic gloves. This is also more sanitary.
- Be sure to inform the dentist if the person is likely to become agitated or upset by a dental appointment. It may be necessary for you to stay in the room for reassurance while work is being done.” (National Institute on Aging, 2005)

Dressing

- “Allow the person to dress herself as long as she can, even if it takes more time than it would with your help.
- If the person needs help, give step-by-step instructions and take one task at a time. Or, you might try arranging clothes by laying them out in the order they are to be put on.
- Encourage the person to choose her own clothes, but make the choice easier by avoiding a large selection from which to choose. Keep only seasonal clothes in the closet. If they insist on wearing the same outfit everyday, try buying the same pieces in duplicate so they can be rotated.
- Clothing should be comfortable, but attractive. Watch for changing size needs subsequent to weight loss or gain.
- As the person becomes more impaired, try easy-care clothing, like sweat-suits, slip on shoes or those with Velcro closing, pants or skirts with elastic waists, Velcro closings.
- Keep the room warm and well-lit while the person dresses. Draw blinds or close door for more privacy.
- Try to conduct dressing at a regular time - part of the day's routine.” (National Institute on Aging, 2005)

Eating

- “Try to reduce noise, glare, and other distractions from eating. (e.g. Turn the television or radio off during meals, although some people may find that soft music is calming during a meal.)
- Avoid patterned placemats, plates, and tablecloths. Serve only one food at a time. Set place with only those utensils that are necessary.
- For some people, bowls will work better than plates. You may also wish to try dishes with rubber rims on the bottom, or placing a damp washcloth under the plate to reduce sliding. You may try large handled silverware or flatware with rubber tubing on the handle, which is easier to grip.
- Bendable straws or cups with lids and spouts may make liquids easier to handle.
- Try feeding five or six small meals a day for the those who eat too little or want to eat constantly.
- Watch chewing and swallowing carefully. Storing food in the mouth and swallowing difficulties can lead to choking.
- Be sure the person gets enough liquids.
- For those with trouble with using utensils, try "finger foods." Examples are as follows: French fries, cheese cubes, fruit slices, small sandwiches, fried chicken, spare ribs, chicken "nuggets," fish sticks, raw vegetables cut into sticks, crackers, hard boiled eggs, pickles, bread sticks, cookies, hot dogs,

pizza, soup or juice in cup, stuffed meat rolls (e.g. cheese rolled slice of ham), pita bread sandwiches.”
(National Institute on Aging, 2005)

Incontinence

- “React to episodes of incontinence with calm understanding. Scolding will only make the person more upset and lower his self-esteem.
- Check with your physician to be sure the incontinence is caused by progressing dementia, and not another underlying medical problem.
- Keep track of when accidents occur...could they be avoided by a nightlight in the bathroom? Establish a routine of taking the person to the bathroom based on when accidents occur.
- Limit caffeine intake, especially before bedtime. Do make sure the person gets plenty of fluids during the day, but try limiting them just before bedtime.
- Continue to maintain balanced nutrition and exercise - this may help bowel incontinence.
- Try products designed for adult incontinence. Examples include adult diapers or rubber pants, rubber sheets, or home health equipment like portable commodes or elevated toilet seats with grab bars.
- If necessary, remove wastebaskets and/or flower pots from high visibility areas.
- Keep the door to the bathroom open to provide the person with extra visual cues.
- Watch for non-verbal cues like restlessness, pacing or undressing.”(National Institute on Aging, 2005)

Wandering

- “Make sure the person carries some form of identification with their name, address, phone number, and pertinent medical information in it. Ideally, the person should wear a medical bracelet or necklace, purchased at a drug store. They could also carry an identification card in their pocket, wallet, or purse.
- Keep a clear recent photo on hand to help police and neighbors with identification should the person become lost.
- Change your door latch or lock - often people with Alzheimer's disease are unable to learn how to use a new lock. You may also consider placing alarms and bells on outside doors.
- Leave a nightlight on in the hall and bath to prevent "losing the way" at night. If the person does lose their way during the night, gently redirect them back to bed.
- Put knives, matches, scissors, etc. that could cause injury. Some caregivers may find it necessary to lock doors to the kitchen, basement, or other potentially dangerous areas.
- Put a stop sign on the outside doors, or camouflage them with a curtain or screen.
- Be sure the person gets exercise daily - this should help reduce excess energy and encourage restful sleep.”(National Institute on Aging, 2005)

Sleep Problems

- “Create an atmosphere that encourages sleep. Try a warm bath, soothing music, warm milk, comfortable blankets and pillows, low lighting.
- Be sure the person gets exercise during the day, especially if fresh air is involved, as weather permits. Try to limit daytime naps.
- Limit caffeine intake during the day -- switch to decaffeinated coffee, tea or soda.
- Be sure to take the person to the bathroom just before bed.
- If they become restless at night, reassure and coax them back to bed when possible. If restlessness continues, you might try resting them in a comfortable chair with the radio or TV on softly. Some people with AD find a recliner more secure for sleep than a bed.
- Place a nightlight in the hall and bathroom to provide the person with visual cues to help guide them to the bathroom and back.
- Keep the bedtime routine and morning wake-up time part of the person's regular schedule.
- Use medications with caution. Consult with your physician for suggestions on sleep-aids. Some over-the-counter remedies may make the person drowsy during the daytime and disrupt normal sleep/wake patterns.” (National Institute on Aging, 2005)

Communication

- “Choose short simple sentences, but speak to the person as an adult. Speak slowly and repeat if needed, using the same wording.
- Give the person extra time to respond to your statement. It sometimes takes a person with a memory impairment a little longer to process information and formulate an answer.
- Carefully monitor your tone of voice. Even when the person has trouble understanding your words, they can and are adept at reading emotional messages like irritation and anger. Try to remain calm and speak in a low tone.
- Give the person one instruction at a time. If necessary, break down instructions into separate tasks.
- If you cannot understand the verbal content of what the person says, try to respond to the emotional content. This can help the person feel better understood.
- Do not bombard him with questions -- you could cause a catastrophic reaction.
- Watch for signs of frustration. Try to use statements rather than questions. Try "It's time to take your bath now" rather than "Would you like to take your bath now or later?"
- Do not assume he cannot understand what is being said. Do not talk about him as if he is not there. Always treat him with respect since lucid or insightful periods can continue well into the course of the dementia.” (National Institute on Aging, 2005)

Repetitive Speech and Gestures

- “Using a calm voice, respond to the questions with a brief simple statement. Try using touch and direct eye contact when you respond. They may just need some extra reassurance. Try and respond to the emotional content of the statements.
- Try distracting the person with a pleasurable activity such as going for a walk, having a snack, looking through old pictures, or going for a drive. Play music, or give the person a repetitive and simple task, like separating or rolling coins, sweeping, vacuuming, folding towels, etc.
- Use a simple written message for those who can still read. (e.g. "Joanne will be home at 5:00)
- Do not discuss plans for activities or appointments until just prior to the event. This will help the person avoid asking about it days ahead of time.
- Try ignoring the behavior. This can make the person angry or agitated, but sometimes questions will stop if they are not reinforced by your behavior. Ignoring may be an especially good idea when the caregiver is irritated, as it keeps the patient from picking up on angry tones of voice.
- Check with your physician. Sometimes movements like rocking or tongue rolling are related to medications.” (National Institute on Aging, 2005)

Catastrophic Reactions

- “Remove the person from the stressful situation or place. Simply the environment by reducing extra people, clutter, noise, activities.
- Keep tabs on when the catastrophic reaction occurs. Is there a pattern (e.g. time of day, type of activity, specific person) that can be identified and altered?
- Distract the person with a calming and pleasurable activity. Try soft music, a walk outside, a favorite snack.
- Try to establish and stick to a regular daily routine. Schedule the more stressful activities during times when the person is most rested. (e.g., plan baths for the morning if they tend to be tired and irritable at night.)
- Encourage daily exercise to reduce excess stress and energy.
- Do not try to reason with the person. The ability to reason logically is impaired in a person with dementia. Trying to reason with them may only make things worse. If you feel threatened, remove sharp and dangerous objects from the area and stay out of reach.
- Try to calm them with slow movements or gentle touch. Approach the person from the front and use a soothing, reassuring voice.

- Limit choices and state directions clearly. Offer activities that the person is able to do and watch for frustration levels.” (National Institute on Aging, 2005)

Hiding Things

- “Limit the number of possible hiding places by locking drawers and cabinets, closets and extra rooms.
- Carefully check clothes baskets, hampers and trash cans before emptying.
- Lock up valuables when possible. Try to limit the amount of money carried by the person.
- Do not scold or accuse the person of hiding things. Do not try to reason with them. Instead, reassure them and help them look. In this way, you may become familiar with favorite hiding places.
- When possible, keep spares of frequently misplaced items on hand, like glasses, keys, etc.
- Try to distract the person with other activities.
- Do not become defensive if the person accuses you of taking things. This is a normal reaction to gaps in memory and increasing confusion. Try to remember that the person is not being purposely malicious. He cannot remember what happened to his things, and it protects his waning self esteem to blame it on someone else.” (National Institute on Aging, 2005)

Aggressive Behaviors

- “Try to distract the person with a pleasurable topic or activity. Arguing with him won't help and will likely make things worse. If necessary, leave the room and give the person time to calm down.
- Look for patterns in behavior. Does the person always get angry at bath time? Try to narrow down to the specifics about what makes him angry. Would more privacy or independence be possible?
- If an activity or topic can be avoided, do so. If not, get help from other family members and friends. Try to schedule the activity when most rested.
- Try to stick to a regular routine when possible. This will help minimize the number of unexpected and stressful events he must handle.
- Try to ignore the angry behavior, if distraction and support do not work. If the situation is threatening, try to make sure he is unlikely to harm himself and stay clear until he calms down.” (National Institute on Aging, 2005)

Sundowning

- “Be sure the person is getting adequate rest or "down time" during the day. Fatigue will increase the likelihood of late afternoon restlessness.
- Schedule more involved or taxing activities for earlier times during the day. For example, baths can be done earlier in the morning or large family meal could be held midday.
- Try a late afternoon snack or an earlier dinner. Even a glass of milk may reduce agitation.
- Distract the person with activities she enjoys. Invite her to assist you with simple tasks, like putting the plates on the table.
- Be calm and reassuring in you interactions.
- Be sure the person gets some physical activity during the day. Suggest going for a walk. If all else fails, allow the person to pace where you can keep an eye on her.
- You might also try soothing or familiar music.
- Be sure the person's environment is well-lit. You may find it helpful to draw curtains and turn on inside lights as it grows dark outside.” (National Institute on Aging, 2005)

Inappropriate Sexual Behaviors

- “Even though the behavior may be upsetting or embarrassing for you, try not to overreact. The person is likely reacting to what feels good and does not remember the rules we were taught about proper social behavior. As a result, it is usually best to remain calm, distract the patient with another activity, or remove her from the situation.
- Respond to improper sexual advances calmly and firmly.

- Note the environmental circumstances of the behavior. Is the person removing their clothes simply because they are too warm? Is she touching her genitals because she needs to void? Do the clothes fit correctly?
- A counselor may help the caregiver sort out conflicting or ambiguous feelings toward a spouse with dementia. They may also suggest alternative forms of intimacy, other than intercourse. Your support group may also provide suggestions and emotional support.
- If the person becomes overly aggressive (or conversely fearful of intimacy) it may be necessary for the spouse to sleep in a separate bed or bedroom.
- Consult your physician. In some cases, medication may temper sexually aggressive or violent behaviors.
- Decide ahead of time how you will react if sexually inappropriate behavior would occur in public or private. Thinking things out will help you remain calm if problems arise.
- Protect yourself. Being a caregiver does not mean you should tolerate abusive behavior. Try to anticipate problems before they arise and seek help, as needed.
- Remember that although dementia will ultimately affect the sexual and intimate aspects of the marriage, both the person with dementia and their caregiver will still have the basic human desire for touch, warmth, and intimacy.” (National Institute on Aging, 2005)

Fear

- “Reassure the person. Face him, using eye contact, a gentle touch or hug, and a calm and soothing voice.
- Try to determine what is precipitating this response. Remember that nearly anything in the environment can be misconstrued as threatening.
- Try to avoid loud or confusing noises. Do not have the TV volume turned up loud. Sometimes TV shows scare people who cannot separate a TV situation from real life.
- Try to shop and run errands on off hours, like first thing in the morning. Avoid malls on Saturday afternoon.
- Let the person know that you will be there to protect and look after him.
- Try to distract him with an activity he enjoys.
- Some people with dementia find it reassuring to have a cuddly stuffed animal or security object, like a purse or favorite hat.” (National Institute on Aging, 2005)

Shadowing

- “Clinging behavior may be caused by an environment that is overwhelming for the person. If he is scared or confused, he will likely seek out and stay with a familiar reassuring caregiver. Reduce excess noise, activity or clutter.
- Provide the person with a cuddly "caregiver substitute". Examples include soft dolls or furry stuffed animals. Pets may also provide a friendly distraction and be both a source and object of affection. Try an audiotape of the caregiver in the kitchen, or other familiar sounds.
- Other activities may divert the person. Provide him with a meaningful but repetitive job, magazines, or photo albums. Old, familiar songs may also give pleasure and reassurance.
- Reassure. Let the person know that you love him and you will not abandon him.
- Remember to schedule regular time away or yourself. Clinging behavior can be very stressful.” (National Institute on Aging, 2005)

Hallucinations and Delusions

- “Do not argue with the person over what they see, hear, feel, or smell. For the person, these visions and thoughts seem very real. Reassure her and respond to her feelings about it. "I don't see the bear in the back yard, but it must be scary. Don't worry -- I won't let it harm you."

- Reduce clutter, extraneous noises, or confusing aspects in the environment. Check out any real basis to the fear. For example, the person may "hear people" in the next room because the television is on, or may see someone because of a shadow on the wall.
- Do not argue with someone over false belief. The person will not be able to remember your reasoning or rationally weigh your points. Say, "I know you are afraid I might leave. I won't," rather than "How could I possibly have the time for an affair?" Respond to the emotional content of the statement and distract the person with other activities or another topic.
- Be aware that the person may believe her parents are still alive. Reminding her they died twenty years ago may be like hearing the news for the first time. Again respond to the emotional content and distract. "Your mother was a great lady -- I know you miss her." (National Institute on Aging, 2005)

Profanity and Obscenity

- "The person may forget social skills of a lifetime or respond on impulse. As a result, he may resort to the use of profanity or obscenity, especially when he is upset or agitated. Remember that the person is not deliberately trying to upset you, but is affected by a disease that compromises his behavior and impulses control.
- Try to remain calm. You can try to correct the use of profanity by gently requesting the person refrain from using it. If that does not work, try to ignore it. If the person receives no reinforcement for such behavior, he may stop with time.
- Explain to those present (grandchildren, etc.) that "grandpa" has an illness that prevents him from behaving the way that he would like to, and that he occasionally uses words he should not.
- If the situation becomes pronounced, distract the person with a different topic or activity and if necessary, remove him from the situation." (National Institute on Aging, 2005)

Activities

- "Do not try to teach new skills or re-train for old hobbies. Some long-term memory is better preserved than short-term memory. Try to build on well-learned and preserved abilities. Some people, for example, can sing or play instruments that they learned long ago.
- Look for activities that last no longer than half an hour. The person's attention span is shorter than normal.
- Try activities that are familiar, simple, repetitive, and do not require much decision making. Examples include sweeping, vacuuming, folding towels, raking, picking up sticks, stringing beads, rolling coins, stuffing envelopes, walking the dog, and shelling peas.
- Break tasks down into component steps if necessary. For example, "set the table" can be broken down into placemats, plates, napkins, silver, glasses.
- Help get the person started by verbally guiding her or demonstrating the desired behavior.
- Try to keep activities on an adult level. Allow the person to continue doing as much as she can by herself. Household or yard work helps her remain as a contributing member of the household.
- Adjust your expectations to fit the remaining ability. The task may not be done as well as it would have if you had done it, but remember the importance of the person's self-esteem.
- Be patient and flexible. Give the person a little more time to do things. Be on the lookout for how to adapt tasks so she can participate.
- Watch for frustration. If the person becomes upset or agitated, step in to help or distract with another, pleasurable activity, break or snack. Remember, outings and passive entertainment can be quite successful." (National Institute on Aging, 2005)

Driving

- "Offer to drive for the person.
- Gently tell the person that you are concerned about his eyesight (concentration, memory, reaction time) and feel safer for you to drive.
- Take the keys from the person and substitute another set of keys that doesn't fit the car if needed. This lets him keep keys while making driving impossible. Sell or remove the car if necessary.
- Dismantle the car (install kill switch, disconnect the battery, remove the distributor cap) so it won't start.
- Have their physician advise them not to drive.

- Have the physician write a letter to the Department of Motor Vehicles requesting the person be road tested in light of the diagnosis.
- Distract the person with another activity.” (National Institute on Aging, 2005)

Handling Money and Valuables

- “Look into long-term tools for financial management like durable powers of attorney, trusts or conservatorship, or joint bank accounts. Consult your attorney, your accountant, or a financial counselor for the best options for your individual situation.
- Remove credit cards from the person's purse or wallet.
- Keep lots of family pictures and identification cards in the person's wallet. Keep a small amount of money. Small bills may seem like more. For example, try a five and five ones instead of a ten dollar bill.
- Arrange for direct deposit of checks when possible. Watch the mail carefully for checks you are expecting.
- Locate valuables such as stock and bond certificates, wills, deeds, titles, life insurance policies, good jewelry, etc. and place them in a safety deposit box.
- Notify the bank that the person is memory-impaired and that you should be notified of any (large) transactions before they are processed.” (National Institute on Aging, 2005)

Holidays

- “Do not give gifts that require a lot of care or attention. Be aware that expensive or fragile gifts may be broken or lost.
- Be realistic as to how much holiday activities the person with dementia (and the caregiver) can handle. Holidays are stressful for everyone and caregivers may need to adjust expectations about how much holiday entertaining they can do.
- Avoid too much food, drink, and people.
- Gift ideas for caregivers include: tickets to a show, concert, movie; "respite visits" to give the caregiver time off; offers to run errands for the caregiver; dinner out or dinner delivered to the home; books; housekeeping tasks done or paid visits by a housekeeping service; subscription to favorite magazine; coupon for 1 day (or more) at an adult day care; telephone gift coupon for long-distance calls.
- Gift ideas for the person with dementia include: an identification bracelet; a taxi charge; a stuffed animal to hug; a picture album filled with family pictures; exercise equipment (a stationary bike, jump rope, membership to a swimming pool); comfortable, easy care clothes; music, tapes or records -- especially familiar old tunes; radio; tickets to a musical or concert; favorite food; a pet; home health equipment (safety bars for bath or shower); lap robe; bird feeder. “(National Institute on Aging, 2005)

Visiting the Doctor/Dentist

- “Look for ways to prevent catastrophic reactions before they occur. If the person often becomes agitated in a room full of people, is there an anteroom where the family can wait privately (or an unused exam room)?
- Bring favorite snacks and activities (e.g., photo album) with you to distract the person or occupy waiting time.
- Avoid telling the person far ahead of time. This only increases the likelihood that the person will worry about the appointment unnecessarily.
- Do not argue, but distract with a different topic or gloss over verbal objections. Be matter of fact. "It's just your turn for a check-up."
- Take someone with you who can stay with the person while you speak with the physician, or who can help you look after them if needed. Do not leave a memory-impaired person alone in the waiting room.
- Let the receptionist and physician know ahead of time that the person is confused.
- Try to make the appointment for the least busy time of the day. Make the appointment for the person's best time of the day. If the person tends to sundown, try a morning appointment.” (National Institute on Aging, 2005)

ALZHEIMER'S RESOURCES

Alzheimer's Association
225 North Michigan Avenue
Suite 1700
Chicago, IL 60601-7633
1-800-272-3900
Web address:
<http://www.alz.org>

This nonprofit association supports families and caregivers of patients with AD. Almost 300 chapters nationwide provide referrals to local resources and services, and sponsor support groups and educational programs. Online and print versions of publications are also available at the web site.

Alzheimer's Disease Education and Referral (ADEAR) Center
PO Box 8250
Silver Spring, MD 20907-8250
1-800-438-4380
301-495-3334 (fax)
Web address:
<http://www.alzheimers.org>

This service of the National Institute on Aging is funded by the Federal Government. It offers information and publications on diagnosis, treatment, patient care, caregiver needs, long-term care, education and training, and research related to AD. Staff answer telephone and written requests and make referrals to local and national resources. Publications and videos can be ordered through the ADEAR Center or via the web site.

Children of Aging Parents
P.O. Box 167
Richboro, PA 18954
1-800-227-7294
Web address:
<http://www.caps4caregivers.org>

This nonprofit group provides information and materials for adult children caring for their older parents. Caregivers of people with Alzheimer's disease also may find this information helpful.

Eldercare Locator
1-800-677-1116
Web address:
<http://www.eldercare.gov>

The Eldercare Locator is a nationwide, directory assistance service helping older people and their caregivers locate local support and resources for older Americans. It is funded by the Administration on Aging (AoA), which also provides a caregiver resource called *Because We Care - A Guide for People Who Care*. The AoA Alzheimer's Disease Resource Room contains information for families, caregivers, and professionals about AD, caregiving, working with and providing services to persons with AD, and where you can turn for support and assistance.

Family Caregiving Alliance
180 Montgomery Street

Suite 1100
San Francisco, CA 94104
1-800-445-8106
Web address:
<http://www.caregiver.org>

Family Caregiver Alliance is a community-based nonprofit organization offering support services for those caring for adults with AD, stroke, traumatic brain injuries and other cognitive disorders. Programs and services include an Information Clearinghouse for FCA's publications.

The National Institute on Aging Information Center
P.O. Box 8057
Gaithersburg, Maryland 20898-8057
1-800-222-2225
1-800-222-4225 (TTY)
Web address:
<http://www.nia.nih.gov>

The National Institute on Aging (NIA) offers a variety of information about health and aging, including the *Age Page* series and the [NIA Exercise Kit](#), which contains an 80-page exercise guide and 48-minute closed-captioned video. Caregivers can find many *Age Pages* on the NIA Publications ordering website at www.niapublications.org. NIASeniorHealth.gov is a senior-friendly website from NIA and the [National Library of Medicine](#). Located at www.niaseniorhealth.gov, the website features popular health topics for older adults.

The Simon Foundation for Continence
P.O. Box 815
Wilmette, IL 60091
1-800-237-4666
Web address:
<http://www.simonfoundation.org>

The Simon Foundation for Continence helps individuals with incontinence, their families, and the health professionals who provide their care. The Foundation provides books, pamphlets, tapes, self-help groups, and other resources.

Well Spouse Foundation
63 West Main Street, Suite H
Freehold, NJ 07728
1-800-838-0879
Web address:
<http://www.wellspouse.org>

Well Spouse is a nonprofit membership organization that gives support to wives, husbands, and partners of the chronically ill and/or disabled. Well Spouse publishes the bimonthly newsletter, *Mainstay*.

SUMMARY

Alzheimer's disease is a common progressive neurological disorder with a high incidence among the elderly. As Americans enjoy a longer life expectancy the incidence of Alzheimer's disease has increased. The symptoms of this complex disease and the impact on both the patient and the family requires that healthcare professionals understand the disease and the ways we can care for those affected by the disease.

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