

# Alzheimer's Disease and Dementia

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## Purpose

The purpose of this course is to provide a comprehensive overview of Alzheimer's disease, including symptoms, staging, treatments, and behavioral management.

## Goals

Upon completion of this course, one should be able to do the following:

- Differentiate between early and late onset Alzheimer's disease.
- List and describe at least 5 other causes of dementia.
- Explain the changes that occur within the brain in the course of Alzheimer's disease.
- List and explain the 7 stages of Alzheimer's disease.
- Discuss medication choices to treat Alzheimer's disease.
- Describe behavioral management techniques.
- Explain typical behavioral signs of Alzheimer's, such as wandering and sundowners.



## A daughter's story: Emma

Mom (Emma) came to live with me when she was 81, after my dad died. The first few years were good, Mom was independent and easy to get along with, but then there were little changes. I didn't realize at first what was happening to Mom. Sometimes, she just didn't seem like herself. She got upset if my daughter got "too much" attention and seemed jealous. That was so unlike her. She started to repeat things over and over and over and to do strange things, like getting up at night and moving things from one drawer to another and tying things up in bundles. Sometimes, I'd get up in the morning and she'd have all of her clothes lined up on the bed in packets, neatly tied with strips of fabric that she had torn off sheets and pillowcases. I thought I was losing my mind, so it was a relief to at least get a diagnosis of Alzheimer's so I could understand, but I had no idea really.

I had NO idea how hard the next 8 years would be.

Alzheimer's disease is one of the last diseases to become socially acceptable. People with AIDS, cancer, and even mental illness may speak publically about their disease or acknowledge it to family and friends, but people are often reluctant to admit that they or someone in the family has Alzheimer's disease. However, Alzheimer's disease will touch almost every family:

- **Late-onset Alzheimer's disease** is most common, occurring in those over age 65 and affecting 5 million Americans. By age 71, 16% of women and 11% of men have developed Alzheimer's disease. By age 80, almost 50% of people are diagnosed with Alzheimer's. Although more women have Alzheimer's disease than men, this is accounted for by women's longer life expectancy rather than a gender risk factor. The cause for Alzheimer's is not clear, but there appear to be a number of factors, such as lifestyle and risk factor genes, which may put a person at increased risk. There also appears to be a direct correlation between education and Alzheimer's disease. Those with higher education have lower rates of Alzheimer's, even when the data is adjusted for other factors; however, researches aren't sure why this is true.
- **Early-onset Alzheimer's disease** affects another 200,000 people, with onset before age 65. Usual onset is in the 50s although some may experience symptoms in their 40s and in rare cases as early as 29. Early onset Alzheimer's is inherited, related to a defective gene on chromosome 1, 4 or 21. The symptoms are the same as for late-onset Alzheimer's although the progression may be more rapid.

## What exactly is dementia?

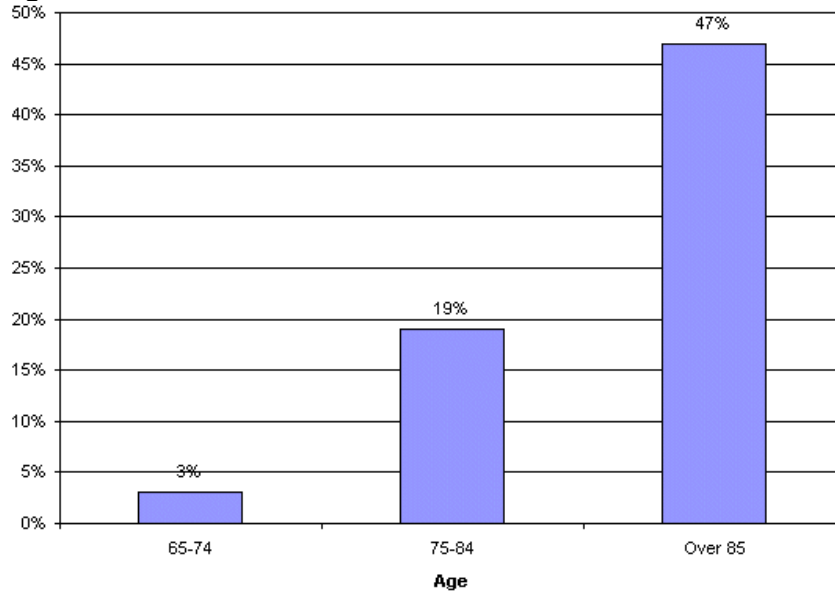
Dementia is a syndrome related to memory loss. Alzheimer's disease is the most common cause of dementia, implicated in 60-80% of those diagnosed with dementia. A definition of dementia must meet these criteria:

- A decline in memory and cognitive ability that involves at least one of the following:
  - Ability to speak coherently and understand spoken or written language.
  - Ability to recognize and identify objects.
  - Ability to execute motor activities and sensory functions with comprehension of tasks.
  - Ability to utilize abstract thinking, make sound judgments, and execute complex tasks.
- The decline in cognitive abilities impacts daily life.

Most diagnoses of Alzheimer's disease involve first eliminating other causes, based on symptoms and other health markers. There are a number of disorders for which dementia is a primary symptom.

Type of Dementia	Characteristics
Alzheimer's	Progressive dementia beginning with short-term memory loss and difficulty remembering names. Progressing to: <ul style="list-style-type: none"> <li>• Impaired judgment,</li> <li>• Disorientation</li> <li>• Confusion</li> <li>• Behavioral changes</li> <li>• Difficulty understanding, reading, and using language</li> <li>• Dysphagia</li> <li>• Incoordination and inability to walk.</li> <li>• Incontinence</li> </ul>
Vascular dementia	Similar to Alzheimer's but memory loss may be less pronounced.
Dementia with Lewy Bodies	Cognitive and physical decline similar to Alzheimer's, but symptoms may fluctuate daily. May include visual hallucinations, muscle rigidity, and tremors.
Mixed dementia	Dementia mirror Alzheimer's and another type as well.
Parkinson's dementia	Impaired decision making. Difficulty concentrating, learning new material, understanding complex language, and sequencing. Inflexibility. Short or long-term memory loss
Fronto-temporal dementia	Changes in personality and behavior. Difficulty using and understanding language.
Creutzfeld-Jakob disease	Rapidly progressive with impaired memory, behavioral changes, and incoordination.
Normal pressure hydrocephalus	Ataxia, memory loss, and urinary incontinence.

Alzheimer's disease is the single most significant cause of dementia, and the percentage of those with dementia related to Alzheimer's disease increases with age:



US Department of Health and Human Services

The number of deaths attributed to Alzheimer's disease has shown a sharp increase and will continue to rise as the population ages. Most people live 4-6 years after the diagnosis, but the range is very wide, 3-20 years, so some people live with the disease for a much longer period of time.

Cause of death	2000	2005	% change
Alzheimer's	49,558	71,696	+44.7
Breast cancer	41,200	40,870	- 0.8
Heart disease	710,760	649,399	- 8.6
Prostate cancer	31,900	30,350	- 4.9
Stroke	167,661	143,497	- 14.4

## What happens to the brain with Alzheimer's disease?

The human brain has about one billion neurons with branches connecting at about one trillion points called synapses. The network of neurons is called the neuron forest, and this is where the damage of Alzheimer's disease occurs. Electrical charges are transmitted through the synapses with the release of neurotransmitters. In the brain of the Alzheimer patient, both the electrical charges and neurotransmitters are disrupted. With Alzheimer's disease, the cerebral cortex begins to shrink, especially in the area of the hippocampus, which controls storage of new memories, thus causing the marked impairment of short-term memory. Amyloid plaques (protein fragment clusters) form between neurons, and tangled strands of another protein occur as the neurons deteriorate and die.

- **Plaques** form from *beta-amyloid*, which is protein found in the fatty membrane surrounding neurons. Beta-amyloid is a sticky protein, causing

clumps to adhere together into plaques. The plaques and smaller groups of a few pieces are believed to block neurotransmission or trigger an immune response.

- **Tangles** form when the *tau* protein, which supports the transport system within a neuron, begins to collapse, causing the transport system to disintegrate and the cell to die. The tau collect in twisted strands called tangles.

Researchers believe that the plaques and tangles are responsible for the brain damage, but why they occur is not clear.

## What is the progression of Alzheimer's disease?

Alzheimer disease may be diagnosed by a primary care physician or a neurologist based on a complete physical exam and history. Dementia screening tests and mental status tests, such as the Mini-mental state exam (MMSE) and the Mini-cog are used as part of evaluation.

Test	Questions/directions
<b>Mini-mental state exam (MMSE)</b>	<ul style="list-style-type: none"> <li>• Remembering and later repeating the names of 3 common objects.</li> <li>• Counting backward from 100 by 7s or spelling "world" backward.</li> <li>• Naming items as the examiner points to them.</li> <li>• Providing the location of the examiner's office, including city, state, and street address.</li> <li>• Repeating common phrases.</li> <li>• Copying a picture of interlocking shapes.</li> <li>• Following simple 3-part instructions, such a picking up a piece of paper, folding it in half, and placing it on the floor.</li> </ul>
<b>Mini-cog</b>	<ul style="list-style-type: none"> <li>• Remembering and later repeating the names of 3 common objects.</li> <li>• Drawing the face of a clock with all 12 numbers and the hands indicating the time specified by the examiner.</li> </ul>

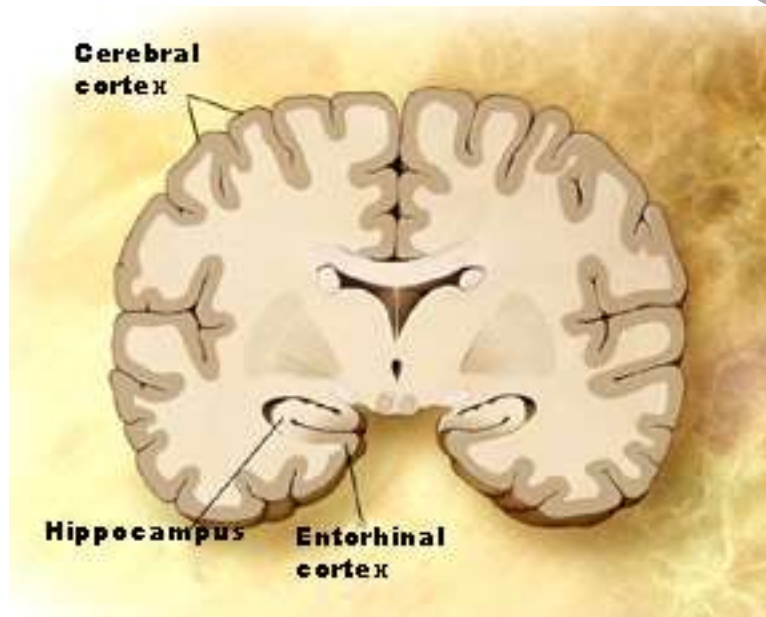
Currently, Alzheimer's disease is diagnosed based primarily on symptoms although MRI's can detect changes in the brain as the condition progresses, and brain-imaging with PET scan and a radioactive dye that attaches to amyloid deposits can diagnose the disease before it becomes symptomatic although this is not yet widely available. Other researchers have developed techniques to diagnose Alzheimer's disease with a special ophthalmoscope that detects beta amyloid plaques in the eye. Additionally, a test will be marketed within the next year that measures proteins associated with Alzheimer's. While the test has not

yet been extensively tested, it purports to test for both Alzheimer's disease and Parkinson's disease.

There are a number of different methods of staging Alzheimer's disease. One staging system utilizes pre-clinical, mild, moderate, moderately severe, and severe. Another classifies Alzheimer's disease as early stage, mid-stage, and late stage. The 7-stage classification system developed by Barry Reisberg, MD, and used by the Alzheimer's Association is widely-recognized and helpful in determining a patient's needs. It incorporates the other classification systems. It's important to understand that the staging only serves as a guide. Not everyone progresses in the same manner or exhibits the same symptoms.

### **Stage I: No impairment/pre-clinical**

During this very early stage, no impairment is evident. The person is able to function normally and cognitive functions appear intact. The brain is normal in appearance. However, slight changes may begin within the brain 20 years or more before diagnosis. Tangles and plaques may begin to form in the areas of the brain involved in learning, memory, thinking, and planning.



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### **Stage 2: Very mild cognitive decline**

The person may experience and be aware of more forgetfulness, such as misplacing items or forgetting words, but this impairment is not usually noticeable on medical examination, and friends and family may not be aware of any changes. The person is able to function within normal limits. These types of mild cognitive lapses may be the beginning of Alzheimer's or part of natural aging.

### **Stage 3: Mild cognitive decline (early –stage)**

This is usually the first stage at which a diagnosis can be made. Short-term memory impairment becomes more evident to friends and family and may be measurable in clinical testing. The areas of the brain involved in memory, thinking, and planning develop increasing numbers of plaques and tangles.

Typical signs include:

- Problems remembering names or words, especially names of newly-introduced people.
- Reading retention declines. May be able to read the words, but does not appear to understand content.
- Having trouble handling money and paying bills.
- Performance issues related to social or work settings.
- Losing or misplacing items, particularly valuable items such as money or jewelry.
- Difficulty planning or organizing.

#### **Stage 4: Moderate cognitive decline (Mild/early-stage)**

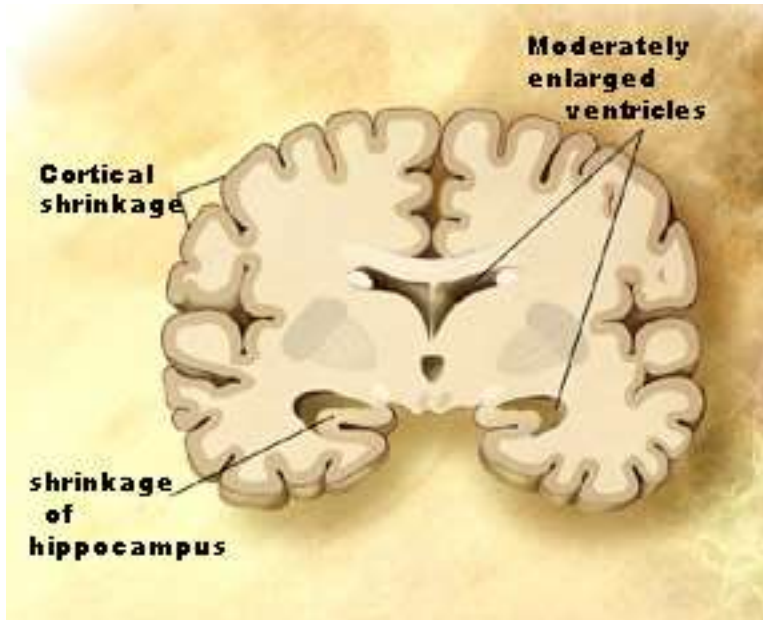
Impairment is more evident at this stage and clinical testing more easily identifies dementia. The period of mild to moderate decline may continue for 2-10 years. The person is usually able to attend to activities of daily living and personal hygiene and can manage most simple personal affairs. Typical signs include:

- Decreased knowledge of current events.
- Impairment in performing mental arithmetic, such as counting backwards or multiplying.
- Difficulty multi-tasking or completing complex tasks.
- Social withdrawal
- Forgetting personal history.

#### **Stage 5: Moderately-severe cognitive decline (Moderate/mid-stage)**

This is the stage at which intervention is often needed. The brain structures have begun to change with shrinkage of the cerebral cortex and hippocampus and enlargement of the ventricles.





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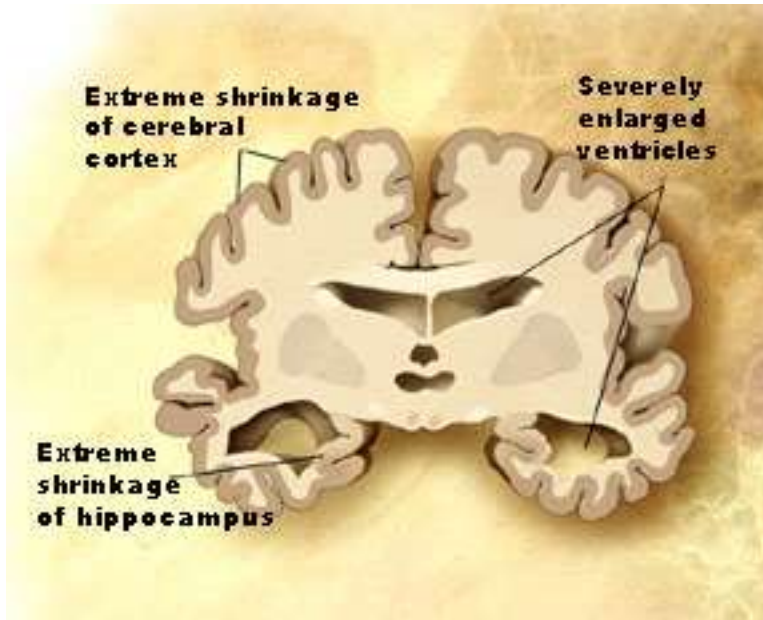
People often exhibit obvious signs of confusion and cognitive impairment, and assistance with daily activities is necessary to insure that they eat properly, maintain good hygiene, take medications, and are safe. People can usually dress and feed themselves without assistance. Plaques and tangles in the brain increase in areas controlling speech and spatial perception. Typical signs include:

- Forgetting important details, such as address, telephone number, and personal history although remembering their own name and the names of close family members.
- Increasing difficulty using and understanding speech.
- Losing perception of body in relation to objects.
- Disorientation to date, time, and place.
- Increasing difficulty with simple mental mathematics, such as counting backward from 20 by 2s.
- Dressing inappropriately for conditions.
- Forgetting to eat or eating a poor diet.

### **Stage 6: Severe cognitive decline (Moderately severe, mid-stage)**

Profound changes often take place during this stage of Alzheimer's disease. People are obviously confused and unable to care for themselves. These last two stages (6 and 7) may last for 1-5 years. People need help with all activities of daily living. At this point, brain has shrunk as neurons have continued to die.





NIA, NIH

Often people go through personality changes, acting in ways that are completely out of character. They may feel persecuted or become belligerent if challenged.

Typical signs include:

- Confusing fiction and reality, such as thinking what happens on TV is real
- Forgetting most recent experiences and lacking awareness of surrounding.
- Recalling their name but forgetting many aspects of personal history.
- Usually recognizing familiar faces but forgetting names or relationships.
- Dressing incorrectly, such as shoes on the wrong feet or underwear over clothes.
- Experiencing disruption of waking/sleeping cycles and sundowner's syndrome.
- Experiencing difficulties toileting and having episodes of urinary and fecal incontinence.
- Experiencing personality and behavioral changes, sometimes with paranoia, delusions, and hallucinations.
- Doing compulsive, repetitive actions, such as hand-wringing, dancing, or tearing paper.
- Wandering away and getting lost.
- Pacing obsessively.

This stage can be very prolonged in some people before the final stage. This stage is particularly difficult for caregivers, often family members, who may be often stressed, over-tired, and desperate for help.

### **Stage 7: Very severe cognitive decline (Severe of late-stage)**

This is the stage at which people are completely dependent upon others for care and are often bedridden or wheelchair bound. People need help with all activities of daily living and frequently must be fed. Typical signs include:

- Losing most speaking ability although may say words or phrases.
- Experiencing frequent or complete urinary and fecal incontinence.
- Losing ability to stand, walk, sit unsupported, or hold head up.
- Choking easily because of increasing dysphagia.
- Experiencing increasing muscle weakness and rigidity.

## What medications are available for Alzheimer's disease?

There is no cure at the present time for Alzheimer's, but there are medications that can, in many cases, relieve some symptoms and slow the progression of the disease. Medications must be monitored carefully as they sometimes worsen symptoms. Patients, families, and care providers must be patient as response to medications varies, and if one medication doesn't work, another one may. The effectiveness for the individual patient may be hard to evaluate as no change may indicate either that the drug is not working or that progression has slowed. However, studies of large groups of people show Alzheimer medications slow disease progress by 6-12 months in many people with some people showing even more dramatic improvement.

### A daughter's story: Medications

When the doctor suggested I try Aricept® for Mom, I was really hopeful, but within a week, her behavior started getting bizarre. She was more combative, fearful, and delusional. One day, I found her in her room, sobbing and trying to pack a suitcase, insisting that I had told her she had to get out of the house. It took hours to get her to stop crying and calm down. I stopped the medication and within a week, she was back to her normal self. Then, the doctor wanted to try Exelon®, and that was even worse. She got out of bed and ran out of the house in her nightgown one night, and I found her huddling under a tree in one of the neighbor's yard, terrified and crying. After that, I refused to try medications, but months later the doctor convinced me to try Namenda®, and it was like a miracle! I felt as though she'd just gone back in time to where she had been a year before. Her incontinence decreased, and she was more alert, less fearful. It didn't last, of course, but it was over a year until she deteriorated to the point she had been before the medication, so that was such a blessing.

### Alzheimer drugs

The Food and Drug Administration has approved two types of drugs for treatment of Alzheimer's disease (cholinesterase inhibitors and memantine). A number of clinical trials have taken place to determine the effectiveness of current medications and other approaches to treatment, such as the use of Vitamin E, atypical antipsychotics, estrogen, and antiinflammatory drugs. Both current types of drugs target neurotransmitters. Medications must be taken daily. In many cases, people may take two types of drugs, often Aricept® or one of the other cholinesterase inhibitors along with Namenda, but the medicines should be monitored carefully for side effects, especially tacrine, which can cause liver damage.

Type of Drug	Indications	Side effects
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<b>Cholinesterase inhibitors</b> (Prevents breakdown of acetylcholine, needed for learning and memory)	<ul style="list-style-type: none"> <li>• Donepezil (Aricept®): All stages of Alzheimer's.</li> <li>• Rivastigmine (Exelon®): Mild to moderate disease.</li> <li>• Galantamine (Razadyne): Mild to moderate disease.</li> </ul>	Nausea, vomiting, loss of appetite, and frequent bowel movements.
<b>Cholinesterase inhibitor</b>	<ul style="list-style-type: none"> <li>• Tacrine (Cognex®): Mild to moderate disease.</li> </ul>	Nausea, vomiting, and possible damage to the liver.
<b>Memantine</b> (Affects glutamate, involved in learning and memory)	<ul style="list-style-type: none"> <li>• Namenda®: Moderate to severe</li> </ul>	Headache, confusion, dizziness, and constipation.

## Antipsychotics

Although the FDA has approved no drugs for the treatment of behavioral or psychiatric symptoms of dementia, antidepressants and antipsychotic drugs, such as Ativan®, Seroquel®, and Haldol®, are very frequently prescribed for patients with Alzheimer's disease, especially if they are institutionalized, in the belief that these drugs will control behavior and reduce agitation. However, in many cases, the drugs simply exacerbate symptoms or create new ones, often prompting additions of even more drugs. Patients who are sedated are at increased risk of falls and injury. Many drugs are associated with significant side effects, especially among the elderly. Additionally, studies have demonstrated that antipsychotics put those with dementia at increased risk of stroke and death.

Antipsychotics or other sedatives should never be used as chemical restraints—although this is probably their most common use. Researchers and the governmental guidelines suggest that these types of medications should be used very infrequently and in minimal doses for short periods of time for the following conditions only:

- Symptoms are related to mania or psychosis.
- Symptoms are so severe as to pose a danger to the person or others.
- Symptoms render the person into a state of constant distress and functional decline and interfere with receiving needed care.

## **How can behavioral problems be managed?**

Managing behavioral problems is one of the most difficult parts of care giving. Healthcare providers need to understand different strategies to use when caring for patients with Alzheimer's. Additionally, they need to provide guidance to other caregivers, such as family members, who may be overwhelmed and unsure of how to care for the patient as confusion increases. Agitation and combative behavior is often related to the person's feeling confused and frightened. Caregivers may become very impatient, especially if they expect the person to do more than the person is capable of doing. Sometimes caregivers believe that people with Alzheimer's are being purposefully uncooperative, so the healthcare provider must provide support to caregivers as well as information and education about the disease and disease management. Alzheimer's patients are at risk for physical, sexual, emotional, and financial abuse because they often cannot speak for themselves or are too frightened to do so. Although state laws regarding reporting may vary, the healthcare provider is obligated to report any suspected abuse.

Alzheimer patients who are hospitalized for other medical problems, such as heart attack or fractured hip, pose particular problems for staff because the patients are often more confused when outside of their usual environments and frightened of the treatments. They may be very agitated, combative, calling out frequently, trying to climb out of bed, and pulling out intravenous lines and catheters. They may be unable to articulate their discomfort, so the Alzheimer patient must be assessed routinely for evidence of discomfort to ensure proper pain management. In many cases, family members or sitters may need to stay with Alzheimer patients to reassure them and prevent them from injuring themselves.

## **Confusion/agitation**

Confusion can't be eliminated, but there are a number of steps that people can take to prevent some of the agitation that often accompanies confusion.

### **Environment**

- Simplify the environment and reduce clutter and loud noises, such as blaring television or radio. Some people become obsessed with moving their belongings about or going through them repeatedly. Sometimes, simply going through drawers, closets, and bookshelves and removing excess or unnecessary items—when the person is not present—can reduce this type of behavior or make it more manageable for the caregiver.
- Make signs and labels (if the person can still read and comprehend), such as labeling drawers or writing "Flush the toilet" in the bathroom. Label

- pictures of family members and friends with names to help keep the person oriented to person. Alternately, pictures may be used instead of words, such as placing the person's picture on the door to his/her room.
- Remove dangerous items, such as scissors, matches, and knives.
  - Sometimes, children's gates can be placed across a doorway to keep the person from entering a room, such as a kitchen; however, some people climb over the gates, so the person must be evaluated and observed carefully.

### **Behavior**

- Keep the person to a regular schedule and avoid changes when possible. Changes in routines are often very stressful to those who are confused. Unavoidable changes, such as a visit to the doctor, should be scheduled at the time during the day when the person is the most cooperative, often in the morning.
- Analyze agitation. Often agitation has patterns--that is it may occur at certain times, or with certain people, or with specific activities. Once the pattern is determined, then the caregiver can try different methods to alleviate the person's distress and evaluate the responses to determine the best method.
- Don't ask the person to make unnecessary choices, such as which clothes to wear or what foods to eat, when the person is unable to make decisions. It adds to the person's stress.
- Explain and give directions in simple language with only one or two steps.
- Allow the person to pace if he/she is compelled to do so. Sometimes, distracting the person with another activity can reduce the pacing, but many patients persist. If possible, it is good to take the person out for a walk rather than having him/her just walking back and forth in the home or hallways.
- Provide an alternative. For example, the patient is hospitalized and has an IV or catheter that he/she is pulling, sometimes just fastening empty tubing where the person can grab it and pull it will keep the person occupied.
- Distract the person by using games, humor, songs, snacks, or some activity that the person enjoys.
- Use simple clothes without zippers and buttons to make it easier for the person to dress as well as for the caregiver to assist the person with dressing. People with Alzheimer's often complain of feeling cold, so sweat pants and sweat shirts are a good choice.
- Break up tasks. If the person resists bathing and refuses to shower, wash part of the body each day or part in the morning and part at night. Using Comfort Bath®, or other disposable moistened washcloths that can be warmed in the microwave and don't require rinsing can make bathing easier.

### **Support**

- Allow the person comfort items. For example, some people, especially women, with Alzheimer's enjoy having a doll or stuffed animal and may carry it about them.
- Find activities that the person enjoys, such as folding clothes, matching cards, or coloring, and encourage the person to "work" or "play."
- Engage the person by talking to him/her, showing the person pictures, playing simple games, throwing a ball, or whatever the person enjoys. People with Alzheimer's often respond positively to attention.
- Don't try to "fix" the person's perception or convince the person that he or she is wrong because it just adds to the confusion. It's a complete waste of time and energy.
- Don't use the television just to occupy a person's time. If confusion is pronounced, the person may believe that the events on TV are real and happening and may become very frightened or upset. Some people enjoy musicals or even children's movies, but this is very individual, so the best approach is to carefully observe the person's reaction and degree of engagement while a movie is playing.
- Hold the person's hand or arm when walking, especially in stores, hospitals, or places that may be confusing. This provides the person a sense of security and prevents the person from bolting if frightened.
- Don't be embarrassed about the person's behavior or ashamed. Alzheimer's is a disease, not a moral failing. If the person is being very disruptive or combative in public, often simply stating, "She has Alzheimer's" is sufficient. Healthcare providers, such as doctors and nurses, are prevented by privacy regulations from disclosing such personal information, but family members can be encouraged to be more open.

### **Sundowner's syndrome and sleep-wake cycle disruption.**

Disruption of the sleep-wake cycle is very common and often includes sundowner's syndrome, in which the person becomes increasingly agitated and restless in the evening. Sometimes, the sleep-wake cycle is disrupted because people get up to urinate at night and then just stay up. Other times, people may nap on and off through the daytime and are not sleepy at night. Often, the caregiver is repeatedly disturbed or awakened and becomes exhausted.

Management techniques include:

- Turn bright lights on before dusk to mimic daylight.
- Utilize any methods that soothe the person in the evening, and this may be very individual.
- Keep the person awake during the daytime. This may require consistent attention for 1-2 weeks to keep the person engaged and awake in order to reestablish a pattern of sleeping at night.
- Do not use side rails or restraints, as patients are more likely to fall climbing over the rail than climbing out of bed. Movement sensors can be attached to the person or bedclothes, especially if the person is hospitalized, so that an alarm sounds if the person climbs out of bed.

- Restrict fluids after dinner if the person gets up frequently to use the toilet. Try getting the person up to the toilet on a schedule, such as at midnight, to reduce restlessness and then putting him/her back to bed.
- If the person is able to fall asleep in a chair and all else fails, just let the person sleep. Sometimes, moving a comfortable recliner into the bedroom may encourage the person to sit and fall asleep.

## Wandering

Wandering is a frequent problem associated with Alzheimer's disease. People may wander away from home or patients walk out of hospitals in their hospital gowns. Frightened, lost, and confused, they may compound the problem by hiding from those looking for them. The reasons people wander are often unclear. Sometimes, they may believe they have a purpose, such as going home, or they may simply go for a walk and get lost. They may be responding to a need, such as trying to find a bathroom or some water to drink. They may be frightened or delusional. Sometimes medications given to calm patients make them more confused and prone to wandering. Most long-term care facilities that house Alzheimer's patients have locked doors to prevent people from wandering, but this is not the case in acute hospitals, at home, or in other facilities.

### A daughter's story: Wandering

One morning while Mom was still pretty active, I got up and Mom wasn't there. Her bed was made and the front door was unlocked, but she was gone. Mom's usual morning routine was to get up and go get the paper for me, but we had a house full of company and a motor home parked in front of the house, and this had really confused her. The night before, she had asked, "What is that big thing out there?" about 50 times. That morning, the paper was missing, so I knew she had picked it up, but she had apparently gone in the wrong direction. I ran up and down the street yelling, and then my family and I got in cars and drove all around, but we couldn't find her anywhere. We live near a forested area and the ocean, and I was so scared! We looked for about 15 minutes and then I called the sheriff's department and found out that they had picked an elderly woman up from the service station a couple of blocks (and across a busy highway!) from my house an hour earlier. She didn't know her name or where she lived, so they had taken her to the emergency department at the hospital. When I got to the hospital and walked into the examining room, Mom threw her arms around me and started to cry. She was so confused and frightened, but she was still clutching the paper. Poor thing. I felt so bad.

That afternoon, I put latches and alarms on the doors.

Sometimes, the cause of wandering can be identified, especially if it happens at the same time, such as the person who attempts to leave for work at 8 AM each morning. In that case, the person may be distracted, but many times, there is no safe way to ensure that the wandering will stop and other methods must be used:

- Alarms, locks, and latches may be necessary. Alarms may frighten the person, increasing stress, so the best type is one that rings in another room, such as the caregiver's bedroom or (if hospitalized) at the nursing station. Simple hook latches near the top or bottom of a door are often

very effective as the person who is confused does not think to look for them.

- Baby monitors can be very useful for monitoring sounds and movement if the caregiver is in another room. Most monitors are very sensitive to sound, and they are quite inexpensive.
- Curtains, sheets, or drapes may be hung over doors. If the person doesn't see the door, he or she often forgets it was there.
- Gates may be placed by stairwells, doorways, and hallways (if the caregiver is sure the person won't climb over them).
- Identification bracelets should be worn at all times.

All Alzheimer's patients who wander should be registered with the Alzheimer's Association Medic Alert, Safe Return program. The fee of \$50.00 covers a Medic Alert bracelet, identification cards, and registry in a national database, as well as access to a 24-hour hotline to report wandering and an emergency response number so the police can notify family if a person is found wandering. In many cases, Alzheimer's Association will notify local police and send a copy of the person's picture as well as contact information. In smaller areas, caregivers may notify the local police directly. Notifying the police that the person has Alzheimer's is very important because a person who is confused may become very combative when approached by the police or someone he/she doesn't know. Healthcare providers should be sure that caregivers are provided information about this program.

Information about the program can be found at this link:

[Medic Alert Safe Return](#)

## **Driving**

A person who is confused for any reason should NEVER be allowed to drive. Family members should do whatever they need to prevent this, such as hiding the keys, disabling the car, or removing the car. If this is not possible, the state department of motor vehicles should be notified. Each state has different regulations regarding driving, but if a report is filed, the person is usually retested to ensure he/she is safe to drive. The usual argument that, even though the person doesn't know his son's name or how to dress himself, he is a "safe driver," is patently absurd. Many people with Alzheimer's continue to drive long after they should because physicians and family members are reluctant to confront this issue. However, it is the responsibility of healthcare providers to advise the person and family about safety issues. The person who is confused is often unaware of the safety concerns or the degree of impairment, but allowing the person to continue to drive can result in tragedy for both the person and others. Sometimes, elderly spouses or children are afraid to intervene and are unaware of legal liabilities if the person with cognitive impairment drives and is involved in an accident.

## **Managing medications and treatment**

The goal with Alzheimer's patients, as with all others, is to allow them to be as independent as possible within the limits of safety. In the earlier stages of



Alzheimer's disease, people may be able to manage their own medications and treatments, but at any sign of confusion, a caregiver should provide medication containers and prepare the medications, and then supervise to make sure they are taken correctly. If the person begins to forget medications or take them incorrectly, then someone else needs to assume responsibility for giving medications and treatment. This can pose special problems for those who need frequent medications or injections. Caregivers may need to be taught to prepare or give insulin, for example. People with Alzheimer's often become resistive to taking medications and may spit out pills, so alternatives, such as liquid medications, may be needed. Some medications can be ground and given with applesauce, ice cream, or other foods.

## **Incontinence**

Both urinary and fecal incontinence are almost inevitable problems for Alzheimer's patients and their caregivers as the condition progresses. This can be really difficult to deal with, but there are steps that can help:

- Monitor fluid intake as excessive intake or inadequate fluid intake can increase urinary incontinence, especially as dehydration may increase the chance of urinary infection. Reduce fluids after dinner if the person is incontinent or urinating frequently at night.
- Monitor bowel function and provide stool softeners if needed but avoid laxatives. Ensure that diet is well-balanced and has adequate fibre. Yogurt, prune juice, and bran may be added to diet.
- Do scheduled toileting. Take the person to the toilet on a regular schedule, such as every 2-3 hours during the daytime and encourage the person to try to urinate/defecate.
- Use incontinence pads or adult diapers as needed. Sometimes people are resistive to wearing pads or diapers, so the caregiver may need to try different products to find one that the person will wear. Some feel more like underwear than others. If the person pulls them off during the night, having the person wear them in the daytime under the clothing may help the person to adjust to wearing them.
- Provide protective coverings for mattresses, box springs (because sometimes people sit on the side of the bed and urinate), and chairs.
- Place plastic non-slip runners over carpets or floors in areas where the person is frequently incontinent, such as between the bed and the bathroom.
- Remove inappropriate "toilets," such as wastebaskets or chairs that the person confuses with the toilet.
- Provide a portable commode if the bathroom is at a distance from where the person spends time.
- Carry extra clothing and incontinence pads/diapers with the person when outside of the home environment.

## **Summary**

Alzheimer's disease affects more than 5 million Americans. The most common type is late-onset, which occurs after age 65. Early onset is much less common and occurs before age 65, with onset most often during the 50s. Early onset is an inherited form of Alzheimer's disease. There are many causes for dementia, but Alzheimer's is by far the most common, accounting for 60-80% of dementia cases. The brains of those with Alzheimer's disease form beta-amyloid plaques and tau protein tangles that disrupt electrical charges and neurotransmitters and cause the death of neurons, resulting in shrinkage of the cerebral cortex. There are a number of different ways to classify Alzheimer's but the 7-stage classification used by the Alzheimer's association is widely-recognized:

1. No impairment.
2. Very mild cognitive decline.
3. Mild cognitive decline.
4. Moderate cognitive decline
5. Moderately severe cognitive decline.
6. Severe cognitive decline.
7. Very severe cognitive decline.

There is as yet no cure for Alzheimer's disease, but there are specific medications that can reduce symptoms or slow the progression of the disease in some people. Medications include Aricept®, Exelon®, Razadyne®, Tacrine®, and Namenda®. Antipsychotics are frequently used but are not FDA-approved for treatment of dementia and often worsen symptoms. There are many behavioral problems associated with Alzheimer's, such as agitation and combativeness, wandering, sundowner's syndrome and sleep-wake cycle disruption, and incontinence.

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