Understanding Alzheimer's Disease

If you are caring for someone who has been diagnosed with Alzheimer's disease or related dementia, or are concerned because someone you love is beginning to exhibit symptoms of it, you probably have concerns and questions. One of the best things you can do is learn as much as you can about Alzheimer's disease and related dementia. This guide provides a basic overview of Alzheimer's disease, including early signs and symptoms, and stages and treatment of the disease. *Note*—This guide is not intended to be entirely comprehensive; it provides only basic information about Alzheimer's disease. Please consult a doctor regarding your or a loved one's individual situation or diagnosis.

What Is Alzheimer's Disease?

Alzheimer's disease currently affects about 4.5 million American adults. It is a progressive, degenerative disease that attacks the brain and results in impaired memory, judgment, language and behavior. Also known as AD, it is the most common form of dementia—a loss of intellectual capabilities (thinking, remembering and reasoning) that interferes with an individual's daily functioning and eventually results in death.

The disease was first described by Dr. Alois Alzheimer in 1906. Though there is still no known cure, researchers have developed an understanding of the brain and behavioral changes that characterize the disease. Through brain autopsy, researchers have discovered that in Alzheimer's victims, brain cells degenerate, causing the brain to become littered with debris known as neuritic plaques (dead or damaged tissue) and the surrounding neurofibrillary tangles, twisted bits of fiber found within brain cells. These plaques and tangles are found in areas of the brain that are important for memory and intellectual functions.

Scientists have also noted a loss of nerve cells in areas of the brain that are vital to memory and other mental abilities, and lower levels of chemicals that carry complex messages back and forth between nerve cells. It is believed that Alzheimer's disease may disrupt normal thinking and memory by blocking these messages between nerve cells.

In seeking to find a cause and cure, researchers have identified three possible risk factors: age, family history and genetics. Age is the greatest risk factor and, in fact, the vast majority of people who have Alzheimer's disease are older than 65. Family history and genetics may also play a role, as scientists have observed that Alzheimer's patients are more likely to have a relative with the disease. Additionally, some families show a pattern of Alzheimer's disease—a rare form of early-onset AD—that is inherited. This does not mean, however, that if you have a family history of Alzheimer's disease, you will get the disease. Researchers continue to focus on improving our knowledge of the disease—the causes and a cure—but at this point, nothing has been proven.

The likelihood of developing late-onset Alzheimer's (the most common form of the disease) approximately doubles every five years after age 65. By age 85, the risk reaches nearly 50 percent. Scientists have so far discovered one gene that increases risk for late-onset Alzheimer's disease.

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Fast Facts About Alzheimer's Disease

Below are some facts about Alzheimer's disease that have been collected by the Alzheimer's Association:

- A person with Alzheimer's disease will live an average of eight to 20 years from the onset of symptoms.
- The number of Americans with Alzheimer's disease continues to grow. By 2050 the number of individuals with Alzheimer's could reach 11.3—16 million.
- More than seven out of 10 people with Alzheimer's disease live at home.
- Annual costs of caring for individuals with Alzheimer's disease in the U.S. are at least $100 billion a year. Neither Medicare nor most private medical insurance policies cover the long-term care most patients need.
- Half of all nursing home residents have Alzheimer's disease or a related disorder.

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Early Signs and Symptoms of Alzheimer's Disease

The symptoms of Alzheimer's disease vary from person to person but include gradual memory loss, a decrease in a person's ability to perform familiar tasks, disorientation, difficulty learning new skills, loss of language skills, impaired judgment and personality changes. If you recognize any of these symptoms in a loved one, do not dismiss them as part of the normal aging process. They are not. They are a sign that he or she needs to be checked for Alzheimer's disease or dementia. Because the early symptoms of Alzheimer's disease closely resemble those of other treatable disorders, it is crucial to get an accurate diagnosis. Symptoms like confusion and forgetfulness can be caused by medications, depression or other diseases and imbalances that, unlike Alzheimer's disease, may be treatable.

Consult your doctor if your loved one:

- Asks the same question over and over again
- Repeats the same story, word for word, again and again
- Forgets how to do activities that were previously done with ease and regularity (e.g., how to cook, make repairs or play cards)
- Loses the ability to pay bills and balance a checkbook
- Gets lost in familiar surroundings, or misplaces household objects
- Neglects to bathe, or wears the same clothes over and over
- Relies on somebody else, like a spouse, to make decisions or answer questions they previously would have handled themselves

(Source: The National Eldercare Institute on Long Term Care and Alzheimer's Disease at the University of South Florida's Suncoast Gerontology Center.)

Normal Forgetfulness vs. Dementia

Some forgetfulness is normal, especially as people grow older. Severe forgetfulness that interferes with a person's ability to function is not normal. To help distinguish between normal forgetfulness and possible signs of Alzheimer's disease or dementia, use this checklist of the warning signs of Alzheimer's disease developed by the Alzheimer's Association. Consult your doctor if your loved one exhibits one or more of these signs:

1. Memory loss. One of the most common early signs of dementia is forgetting recently learned information. While it's normal to forget appointments, names or telephone numbers, those with dementia will forget such things more often and not remember them later.
2. Difficulty performing familiar tasks. People with dementia often find it hard to complete everyday tasks that are so familiar we usually do not think about how to do them. A person with Alzheimer's may not know the steps for preparing a meal, using a household appliance or participating in a lifelong hobby.

3. Problems with language. Everyone has trouble finding the right word sometimes, but a person with Alzheimer's disease often forgets simple words or substitutes unusual words, making his or her speech or writing hard to understand. If a person with Alzheimer's is unable to find his or her toothbrush, for example, the individual may ask for "that thing for my mouth."
4. Disorientation to time and place. It's normal to forget the day of the week or where you're going. But people with Alzheimer's disease can become lost on their own street, not knowing where they are, how they got there, or how to get back home.
5. Poor or decreased judgment. No one has perfect judgment all the time. Those with Alzheimer's may dress without regard to the weather, wearing several shirts on a warm day or very little clothing in cold weather. Those with dementia often show poor judgment about money, giving away large sums to telemarketers or paying for home repairs or products they don't need.
6. Problems with abstract thinking. Balancing a checkbook is a task that can be challenging for some. But a person with Alzheimer's disease may forget what the numbers represent or what needs to be done with them.
7. Misplacing things. Anyone can temporarily misplace a wallet or key. A person with Alzheimer's disease may put things in unusual places, like an iron in the freezer or a wristwatch in the sugar bowl.
8. Changes in mood or behavior. Everyone can become sad or moody from time to time. Someone with Alzheimer's disease can show rapid mood swings—from calm to tears to anger—for no apparent reason.
9. Changes in personality. Personalities ordinarily change somewhat with age. But a person with Alzheimer's can change dramatically, becoming extremely confused, suspicious, fearful or dependent on a family member.
10. Loss of initiative. It's normal to tire of housework, business activities or social obligations at times. The person with Alzheimer's disease may become very passive, sitting in front of the television for hours, sleeping more than usual or not wanting to do usual activities.

(Source: "10 Warning Signs of Alzheimer's Disease." Reproduced with the permission of the Alzheimer's Association. Copyright 2004 Alzheimer's Association, www.alz.org, 800.272.3900)

Most people who have Alzheimer's disease or related dementia have a vague sense that their memory is failing, but few have a true sense of their impairment. They may write notes to help remember things, or even write out conversational crib sheets to leave by the telephone in order to hold "normal" conversations. Though they may still be able to carry out many of the tasks of daily living, the increased confusion and forgetfulness becomes worrisome. If someone you love is experiencing these symptoms, make an appointment with a doctor who can determine what is causing the physical and mental changes—and what can be done about it.

Diagnosing Alzheimer's Disease

If a person exhibits symptoms of forgetfulness or dementia, it does not necessarily indicate Alzheimer's disease. Dementia can be caused by other diseases and imbalances, many of which are curable. Unfortunately, no single test can accurately diagnose Alzheimer's disease; a doctor must first eliminate the possibility of the following diseases and/or causes of dementia—even rare ones—before making an accurate diagnosis:

- Drug interaction/overdose
- Multi-infarct dementia
- Parkinson's disease
- Huntington's disease
- Creutzfeldt-Jakob disease
- Pick's disease
- Normal pressure hydrocephalus
- Binswanger's disease

- Metabolic disorders
- Structural problems in the brain (brain tumors, bleeding, insufficient oxygen)
- Infections (syphilis, TB, meningitis)
- Poisons (carbon monoxide, drugs, alcohol)
- Psychiatric disorders (schizophrenia, depression)
- Multiple sclerosis

Testing for these diseases and/or other imbalances requires a complete medical examination. Though Alzheimer's disease can only be positively identified after death through brain autopsy, by process of elimination and a thorough medical history, doctors can make an accurate diagnosis of "probable Alzheimer's disease." To ensure an accurate diagnosis, choose a doctor who has experience with Alzheimer's disease or dementia. If your family physician is not qualified, ask for referrals to other doctors. A doctor will conduct a thorough medical examination to determine what may be causing the symptoms.

Here is a general list of what you can expect during the exam:

- A thorough medical history. Be prepared to answer questions about your loved one's diet, fluid intake, medications, previous illnesses or surgeries, allergies, family history, behavioral and mood changes, etc. You will also be asked when symptoms began and which ones are causing the most concern.
- A thorough physical and neurological exam to check blood pressure, heart, lungs, abdomen, vision and hearing.
- A mental status test to evaluate orientation, attention, recent recall and the ability to calculate, read, write, identify, copy drawings, repeat, understand and make judgments.
- A psychiatric assessment to rule out psychiatric disorders.
- A blood sample to test for anemia, metabolic imbalances, thyroid problems, infections and other conditions.
- A urine specimen to rule out kidney and bladder infections.
- A stool sample and rectal exam, possibly, to rule out intestinal cancer but is not necessarily directly relevant to a dementia exam.
- An electrocardiogram to evaluate the action of the heart.

Though most experts agree that a careful, thorough physical examination and a complete medical history are sufficient, some doctors may suggest a CAT (computerized axial tomography) scan to detect tumors, blood clots or other problems in the brain. Speak to the doctor about what to expect from the medical examination and what fees are involved.

Once all the tests are in, the doctor will probably be ready to report the diagnosis. If the dementia is caused by a disease other than Alzheimer's, learn as much as you can about that disease and ask your doctor about potential treatments and cures. If the diagnosis is probable Alzheimer's disease, it may be upsetting, but remember, help is available. First come to terms with what the diagnosis means to you, your loved one and your family; then gather information about the disease from your doctor, hospital, library, support groups or the Alzheimer's Association, which has local chapters throughout the country. (For more information, please see the "Helpful Resources" section at the end of this guide.)

Stages and Treatment of Alzheimer's Disease

Although Alzheimer's disease affects each individual differently, the progress of the disease can generally be characterized in three stages. Some individuals, especially those under age 60, progress through the stages rapidly, while others, particularly older victims, move through the stages more slowly. Though the average length of the illness is eight years, some people may live up to 20 years after the onset of symptoms.

Stage One

In the first stage of the disease, victims gradually show signs of losing their mental faculties but are usually still alert, social and capable of living independently. They may display minor memory loss and mood swings and have less energy, drive and spontaneity than usual. They tend to shy away from new situations and prefer the familiar. They become increasingly forgetful, have noticeably slower speech and exhibit difficulty with complex tasks that require decision making or calculations, such as balancing a checkbook. Short-term memory also fades, making it difficult to learn new information or skills. Though most Alzheimer's patients can still live independently at this stage, many become frustrated, afraid and depressed.

Stage One: Your loved one may be forgetful or have difficulty learning new skills. He or she may exhibit poor judgment or seem awkward in social situations.

Tip: Learn as much as you can about the disease and how to get help. Let your loved one know that you understand his or her frustrations.

Stage Two

As people with Alzheimer's disease progress into the second stage of the disease, they typically require more care and supervision. Short-term memory becomes poor, yet the distant past may remain clear (and even seem like the present). Dates, time of day and seasons may be forgotten, and some patients may forget where they are and get lost while traveling. Most patients eventually fail to recognize family members and people they've known for many years. Stories or actions may be repeated monotonously, and Alzheimer's patients may invent words, making communication difficult. Hygiene is often neglected and assistance with personal care is required. Agitation sets in. Coordination starts failing, creating a risk for falls and accidents. Sleep patterns fall out of sync, and wandering and pacing become common.

Stage Two: Your loved one will need help attending to the tasks of daily living—as well as your love, patience and support.

Tip: Establish routines and stick to a regular daily schedule.

Stage Three

By this stage, Alzheimer's patients become totally dependent on others for care and may need to be monitored 24 hours a day. They may be disoriented and have difficulty finding their way around. Hallucinations (seeing or hearing things that don't exist), delusions (irrational or unfounded beliefs) and paranoia are all possible. Speech and motor coordination is typically gone, as is memory. Eventually, they may be unable to get out of bed or feed themselves, and at this point they are typically incontinent. As the disease progresses into the terminal stage, patients typically become vulnerable to infections and illnesses like malnutrition and pneumonia.

Stage Three: Your loved one needs constant care and supervision.

Tip: Plan for 'round-the-clock care and prepare your family for the death of your loved one. Take advantage of all supportive services available to help you cope.

Medical Research on Alzheimer's Disease

Although there is no known cure for Alzheimer's disease, in recent years several drugs have been studied to determine if the disease can be slowed down, or if some of the unpleasant symptoms can at least be alleviated. A few drugs, which may help alleviate symptoms in some people—especially when taken in the early stages of the disease—have been approved by the Food and Drug Administration (FDA). Some may help alleviate severe agitation, violence, hallucinations or psychosis in patients who have dementia. Ask your doctor about drugs available to help alleviate the symptoms of Alzheimer's disease.

Additionally, experimental drugs and treatments are being researched and tested every day, hopefully bringing scientists closer to a cure. Ask your doctor to keep you abreast of new drugs, treatments or current clinical trials and contact the Alzheimer's Association and the Alzheimer's Disease Education and Referral Center (sponsored by the National Institute on Aging) for up-to-date medical information. (For information on how to contact these organizations, please refer to the "Helpful Resources" listing.)

If you are interested in FDA-approved or other experimental drugs, have a thorough discussion with your doctor about the benefits, risks and costs associated with each drug and ask the following questions:

- What are the potential benefits and risks of each drug?
- What is the proper dosage? What happens if a dose is missed?
- Should any activities or foods be avoided while taking the drug?
- Is it safe to take with other medications (prescription and/or over-the-counter)?
- How long should it take for the drug to have an effect and how will we know if it is working?
- What are the known side effects and how long will they last?
- If the side effects are unpleasant, can the patient stop taking the drug immediately? Or is it addictive?
- How might it affect other medical conditions?
- What changes in the patient's condition should be reported immediately?
- Are these drugs readily available, and are they permitted in nursing homes or other care facilities?
- What are the costs associated with each drug?

In addition to traditional medication, there are also alternative therapies, including vitamin supplements and exercise that can help manage the symptoms of Alzheimer's disease. Talk to your doctor for more information.

Caring for a Loved One With Alzheimer's Disease

In addition to medications that can help slow the progression of Alzheimer's disease, research has uncovered extensive information about what to expect from Alzheimer's patients and how to better care for victims of the disease. If you are caring for someone who has been diagnosed with Alzheimer's disease or dementia, a wide range of strategies have been developed to care for Alzheimer's patients—and to help reduce the impact of the disease on caregivers. There are also numerous private and public organizations dedicated to helping Alzheimer's patients, their families and caregivers. For more information, please refer to additional guides in our educational series. Additionally, the "Helpful Resources" section on the next page can provide additional assistance.

Helpful Resources

Alzheimer's Association
National Headquarters
225 N. Michigan Avenue, Floor 17
Chicago, IL 60601
800-272-3900
www.alz.org

A nonprofit organization dedicated to researching the preventions, cures and treatments of Alzheimer's disease and other related disorders, and providing support and assistance to afflicted patients and their families. There are 200 local chapters in the United States. Call the toll-free number or visit the web site to find the chapter nearest you.

Alzheimer's Disease Education and Referral Center (ADEAR)
PO Box 8250
Silver Spring, MD 20907
800-438-4380
www.alzheimers.org

This nonprofit organization provides information on Alzheimer's disease and related dementia, including research and treatments, support groups and various publications. It can also refer you to other organizations and/or services that can help.

The Alzheimer's Store
3197 Trout Place Road
Cummin, GA 30041
800-752-3238
www.alzstore.com

The Alzheimer's Store is dedicated to providing unique products for those caring for an individual with Alzheimer's disease or dementia. Products target safety, forgetfulness, fall prevention and educational activities.

American Health Assistance Foundation (AHAF)
22512 Gateway Center Drive
Clarksburg, MD 20871
800-437-2423
301-948-3244
www.ahaf.org

A national, nonprofit organization dedicated to funding scientific research and educating the public about age-related and degenerative diseases, particularly Alzheimer's disease. It offers numerous publications.

MedLine Plus
National Library of Medicine, National Institutes of Health
8600 Rockville Pike
Bethesda, MD 20894
www.nlm.nih.gov/medlineplus

The MedLine Plus web site offers an A-Z index of diseases and conditions, including detailed overviews, latest research findings, disease management and treatment information, clinical trials and more.

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