

Understanding Alzheimer's Disease:

IT'S NOT JUST FORGETFULNESS



Alzheimer's disease affects people's memories, but it involves far more than simple forgetfulness. It is a progressive, degenerative, and incurable brain disorder that ends in death. We still don't know why some people get this devastating disease.



Alzheimer's disease is the sixth leading cause of death among older Americans and the most frequent cause of irreversible dementia today.

An estimated 5.4 million Americans now have Alzheimer's disease. As our population ages, 15 million Americans could be living with Alzheimer's before the middle of this century.

This year alone, an estimated 454,000 people from all races and socioeconomic classes will be diagnosed as suffering from Alzheimer's disease.

The Stages of Alzheimer's Disease

Alzheimer's disease usually progresses gradually, lasting from two to twenty years, with an average of seven years.

Alzheimer's disease is difficult to diagnose. If you suspect that you or someone you know may have the disease, the first step is to see a doctor for a thorough medical exam.

Alzheimer's disease does not affect every patient in the same way. The following stages represent the general course it follows.

Presymptomatic Stage:

Physical conditions connected to Alzheimer's disease exist in a person's body long before symptoms are evident. From the patient's perspective, Alzheimer's can be described in three general stages of progression.

Stage 1

Early in the illness, people with Alzheimer's tend to lose energy and spontaneity, though often no one notices anything unusual. They exhibit



minor memory loss and mood swings and are slow to learn and react. After a while they start to shy away from anything new and prefer the familiar.

In this stage, Alzheimer's patients can still perform basic tasks independently but may need assistance with more complicated activities. Speech and understanding become slower, and patients often lose their train of thought in midsentence. They may also get lost while traveling or forget to pay bills. As they become aware of this loss of control, they may become depressed, fearful, irritable, and restless.

Stage 2

Eventually, people with the illness begin to be disabled by it. Though the distant past may be recalled, recent events become difficult to remember. Advancing Alzheimer's affects the ability to comprehend location, the

day, and the time. Caregivers must give clear instructions and repeat them often. As Alzheimer's patients' minds continue to slip away, they may invent words and not recognize formerly familiar faces.

Stage 3

During the final stage, patients become more and more unresponsive. Memory becomes so poor that no one is recognizable. Patients lose bowel and bladder control and eventually need constant care. They lose the ability to chew and swallow and become bedridden and vulnerable to pneumonia, infection, and other illnesses. Respiratory problems worsen, particularly when the patient becomes bedridden.

This terminal stage eventually leads to coma and death.

Essential Facts about Alzheimer's Disease

The Mystery of Alzheimer's Disease

It is still not known why Alzheimer's disease affects some people and not others. Researchers continue each day to search for its causes, as well as ways to prevent, diagnose, and treat it.

One research focus is on a protein called beta-amyloid, which appears to be abnormally processed in Alzheimer's-affected brains. This may lead to the accumulation of beta-amyloid plaques in the dying nervous tissue of the brain. These plaques are also found in disease-free brains, but they exist in much greater numbers in Alzheimer's-affected brains. What triggers beta-amyloid plaque formation in Alzheimer's disease has yet to be discovered.

Treatment

Physicians are not yet able to stop the progression of Alzheimer's disease or reverse its damage to the brain. Caregivers can only strive to make patients' last months or years more calm and pleasant.

The best approach involves treating some of the symptoms of the dementia, which may include wandering, sleeping problems,

and hallucinations. A number of medications are available to help with these problems. Currently there are also a number of drugs that may help slow cognitive decline but not cure the disease, including Cognex[®], Aricept[®], Exelon[®], and Namenda[®]. Patients can be made more comfortable, and the family can better care for the patient.

Hereditary Factors

There are two basic types of Alzheimer's disease: familial and late onset.

Familial Alzheimer's disease (FAD) is a rare form of the illness, affecting fewer than 10 percent of Alzheimer's patients. All FAD is early-onset, meaning the disease develops before age 65. FAD results from mutations in one or more of at least three genes (presenilin 1, amyloid precursor protein, and presenilin 2). If even one of these mutated genes is inherited from a parent, the child will almost always develop early-onset Alzheimer's disease.

The majority of Alzheimer's disease cases are late-onset, usually developing after age 65. Late-onset Alzheimer's has no known cause and shows no obvious inheritance pattern. Although a specific gene has not yet been identified as the cause of the late-onset type, genetic factors do appear to play a role in its development.

More than Senility

Alzheimer's is a disease and should not be confused with old age or "senility." Some of the early symptoms of the disease, such as forgetfulness, do correspond with old age. The memory loss caused by Alzheimer's, however, is far more severe and progressive.

Eventually, Alzheimer's disease destroys not just the memory of details, but all memory of an event itself.

A Degenerative Disease of the Brain

Though psychiatric symptoms are a significant part of the illness, Alzheimer's is a degenerative disease of the brain and not a mental disorder. It leads to a loss of intellectual abilities and to personality changes that are severe enough to interfere with social and occupational functioning.

Caring for an Alzheimer's Patient

All Alzheimer's patients are individuals, and their caregivers and families should do their best to realistically assess their loved one's situation, seeking outside help if necessary.

Caring for Alzheimer's patients at home usually helps them adjust to the loss of mental and physical abilities. Currently, approximately 70% of people with Alzheimer's and

other dementias are cared for at home. So, it is important for caregivers to familiarize themselves with Alzheimer's disease and understand what they will encounter emotionally and financially.

As the disease progresses, patients eventually need around-the-clock care. Community resources—such as support groups; adult day care; respite (short-term) care services; and nursing homes—can be a great source of help in dealing with the present and can assist in planning for the future.

Not all families have the resources to properly care for their loved one at home. Some eventually have to call upon outside care when the disease reaches the final stages.

Nursing home care may be an alternative for Alzheimer's patients, although it can be quite expensive. Families choosing nursing homes should visit the facilities to determine the quality of care and their ability to meet the special needs of Alzheimer's patients.

The Caregiver

Caring for an Alzheimer's patient is draining, both physically and emotionally. As the disease progresses, patients require 24-hour-a-day care. Caregivers can experience feelings of isolation, loneliness, and depression, which can seriously affect their own health. Arranging for respite (short-term) care allows primary caregivers

time for themselves, an essential step for emotional and physical strength.

This separation benefits both the caregiver and the Alzheimer's patient. Even a friend taking over for a few hours can offer the break a caregiver needs and deserves.

Home/Nursing Home Care

Providing care for Alzheimer's patients can require substantial financial resources. Patients and families have two main choices:

- provide care for the patient in a home setting, or
- arrange for care in an assisted living facility, nursing home, or other health care facility.

Care in the family home is less costly than a nursing home, although the expenses are still considerable. For example, many families ultimately have to pay for some kind of adult day care services for the patient. The average national

cost for a home health aide is \$21 per hour. In addition, paying for items such as medicine and adult diapers quickly adds up.

The average cost of a private room in a nursing home in the United States is \$229 per day or \$83,585 annually.

The average cost for residing in an assisted-living facility with Alzheimer's and dementia care is \$57,144 annually. Of course, these numbers are national averages, and the price for health care services can vary widely by geographic location.

Many families ultimately deplete their life savings because of the costs and the duration of the disease.

Covering the Cost of Care

Many traditional health insurance policies cover only the medical costs associated with a patient's condition, like medications and doctor visits. Health insurance generally does not cover the supervisory care and the help with daily living Alzheimer's patients need, so many people consider long-term care in their financial planning.



Getting Help

If your loved one has Alzheimer's disease, the first step is to talk to the physician who made the diagnosis, who should be able to direct you to community support groups, social services, long-term and respite care, and other resources.

The Alzheimer's Disease Research program offers a variety of educational booklets and brochures. They provide a basic understanding of the disease and contain detailed information on where to go for help in dealing with Alzheimer's. These publications can be ordered by calling 1-800-437-2423 or by visiting our website at www2.ahaf.org/adpubs.

Your state Area Agency on Aging is another excellent resource. The agency can give you specific information on services in your area and connect you with a local Agency on Aging, if one exists in your community. A directory can be found at www.caring.com/local/area-agency-on-aging.

Other good resources include the reference librarian at your local library, social workers, insurance companies, the local government mental health or social services department, religious groups, community service organizations, and most of all, your friends.

Remember to check the telephone book. You may find "community services" grouped at the beginning of the book, or they may appear under a variety of headings. Some possibilities include: aging, medicine, Alzheimer's, mental health, senior citizens, geriatric, senior center, health, social services, home health, and social security.



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