



Fact Sheet: Alzheimer's Disease

Overview

Alzheimer's disease (AD) is a neurological condition in which the nerve cells in the brain die. The onset of AD is typically gradual, and the first signs of it may be attributed to old age or ordinary forgetfulness. As the disease advances, cognitive abilities, including the ability to make decisions and perform everyday tasks, are eroded, and personality changes and difficult behaviors may emerge. In its later stages, AD leads to dementia and eventually death.

Facts

An estimated four million people nationwide have been diagnosed with AD. Alzheimer's disease is most common in individuals who are over 65; however, it can also occur in people much younger. The incidence of dementia increases rapidly beyond age 65. In 1998, the percentage of older persons with moderate or severe memory impairment ranged from about 4 percent among people aged 65-69 to about 36 percent among people aged 85 or older. AD is the ninth leading cause of death among those aged 65 and older.

Nationally, direct and indirect costs of caring for patients with Alzheimer's have been estimated at \$100 billion. The average lifetime cost for an individual with AD is estimated at \$174,000, according to the Alzheimer's Association.

Symptoms

People with Alzheimer's live an average of eight years after diagnosis, although some people may live for as many as 20 years after being diagnosed. To help people understand the changes that occur as the disease progresses, AD is broken into stages: early, middle and late. It is important to remember, however, that the development of symptoms will differ from person to person and that each stage will gradually progress over a period of years. It is also not unusual for people with AD to have "good days" and "bad days." For example, a person with early-stage AD may not show any symptoms one day; the next he or she may have trouble remembering your name or finding the milk in the refrigerator.

The following summarizes the most common symptoms at each stage:

Early-Stage Alzheimer's

- Trouble remembering recent events and conversations
- Difficulty remembering the month or day of the week
- Loss of ability to manage finances
- Withdrawal from social situations and general apathy
- Cooking and shopping become more difficult
- Poor judgment - difficulty making wise decisions

- Tendency to lose things
- May become disoriented in familiar surroundings

Middle-Stage Alzheimer's

- Difficult behaviors emerge
 - Anger, suspiciousness, overreacting and paranoia (e.g., believing that family members are stealing money or spouse is having an affair)
 - Wandering
 - Repeating questions or statements
 - Sundowning (i.e., restlessness or agitation in the evenings)
 - Fear of bathing
 - Hallucinations
 - Eating problems
 - Incontinence
 - Hoarding belongings
 - Inappropriate sexual behavior
 - Violent behavior
 - Will go from needing help choosing clothes and remembering to change clothes to needing help getting dressed.
 - Will progress from needing reminders regarding personal care to needing help bathing, taking medication, brushing teeth, toileting, etc.
 - Increased difficulty in verbal expression and comprehension
 - Spatial problems (e.g., having trouble setting the table)
 - Loss of reading, writing and arithmetic abilities
 - Loss of coordination
 - Will need care or supervision 24 hours a day, seven days a week
 - May not recognize family and friends at times

Late-Stage

- Inability to communicate
- Inability to recognize people, places and objects
- Cannot participate in any personal care activities

- Loses ability to walk
- Loses ability to smile
- Muscles may become contracted
- May lose ability to swallow
- Seizures may occur
- Weight loss
- Majority of time spent sleeping
- May exhibit a need to suck on items
- Incontinence

As the symptoms of AD increase, the demands placed on the caregiver increase. Care becomes more physically demanding and more time-consuming. At some point, most caregivers require outside help.

Diagnosing Alzheimer's Disease

A diagnosis of Alzheimer's disease is reached through a combination of tests. It must be differentiated from the occasional forgetfulness that occurs during normal aging, and from depression, malnutrition, or the side effects of medications, all of which can cause symptoms similar to those of early-stage AD. The physician often begins the evaluation by taking a history and performing a physical examination, as well as evaluating the patient's cognitive abilities. This approach can help the doctor determine whether further testing is needed. A primary care physician may suggest that a more extensive examination be performed at a designated Alzheimer's evaluation center or by a dementia or geriatric specialist. The examination will likely include a thorough medical evaluation and history followed by extensive neurological and neuropsychological assessments. A dementia evaluation should include interviews with family members or others who have close contact with the person being evaluated.

Treatment After Diagnosis

Presently, researchers cannot definitively say what causes Alzheimer's disease, and there is currently no cure. However, considerable progress has been made in the field of AD research in recent years, including the development of several medications for early-stage AD. While the ideal medication for AD would

either prevent or cure it, have no side effects, be inexpensive and be readily available, researchers have not yet discovered the ideal treatment.

It is possible, however, to reduce some of the common symptoms of early-stage AD with medications. As of January 2002, the FDA had approved four drugs designed to improve memory and slow the progression of AD. The first one, approved in 1993, tacrine (Cognex) has many side effects, including potential liver damage and has shown disappointing memory results. For these reasons it is seldom prescribed. Three newer drugs, donepezil (Aricept), rivastigmine (Exelon) and galantamine (Reminyl), have proved beneficial in improving memory, and have fewer side effects. Unfortunately, these drugs are not effective for everyone, and their effectiveness is limited to the early and middle stages of AD. Talk to your physician about whether or not one of these may be appropriate.

New medications are tested on an ongoing basis. People interested in participating in clinical trials should discuss the pros and cons with their physician and family. Information on clinical drug trials and other research is available from the Alzheimer's Disease Education and Referral Center (ADEAR). Many universities and medical schools are conducting research projects as well. Your physician may know of research trials seeking participation from Alzheimer's patients and/or their family and caregivers.

It currently is possible to reduce some of the common emotional and behavioral symptoms associated with AD. For example, a doctor may prescribe drugs such as tranquilizers to reduce agitation, anxiety and unpredictable behavior. Drugs also can be prescribed to improve sleeping patterns and treat depression. Physicians may recommend taking Vitamin E, which may have some positive effects without unwanted side-effects if taken in reasonable quantities.

The dose of any medication given must be monitored closely. Older persons are affected

differently by drugs than are younger persons—too much medicine may be dangerous. When a person is taking medication, it is important to keep the doctor informed of any changes in behavior or new symptoms

The Alzheimer Caregiver

Alzheimer's disease is often called a family disease, because the chronic stress of watching a loved one slowly decline affects everyone. Comprehensive treatment must therefore address the needs of the entire family. This includes emotional support, counseling, and educational programs about Alzheimer's disease for individuals and family members as they strive to provide a safe and comfortable environment at home.

Through training, caregivers can learn how to control unwanted behaviors, improve communication, and keep the person with Alzheimer's safe. Research has shown that caregivers benefit from training and support groups and that participation in these groups allows caregivers to care for their loved one at home longer. The resources listed at the end of this fact sheet can help you find classes and support groups.

The role of the caregiver changes over time as the needs of the person with AD change. The following suggestions can help caregivers prepare for the future.

Caregiving in the Early Stage

During the early stage of AD, both the caregiver and the care recipient can adjust to the diagnosis and make plans for the future:

- Learning: The more you know about AD, the easier it will be for you as a caregiver. Learn as much as you can about the early and middle stages of AD—don't worry about the late stage yet. Finding other caregivers to talk to can also be a great way to learn about and make sense of your own experience. One of the most difficult things to

learn is to differentiate between the disease and your loved one: especially in the early stage, caregivers may find themselves thinking, "He's doing this to spite me!" or "She is just being lazy." In these cases, the behavior that is upsetting to the caregiver is usually a result of the disease process, not an attempt by the person with AD to hurt or frustrate the caregiver.

- Emotional Support: A diagnosis of AD can be a heart-wrenching experience for both the person diagnosed and the caregiver. Getting appropriate emotional support through counseling, a support group or other family members is extremely important. The goal is to establish a system of emotional support that will grow and change with you as your caregiving role and the emotional challenges of that role expand and change.
- Family Roles: As the disease progresses, it will be harder for the person with AD to fulfill the roles they have typically played in the family. For example, if he or she was the only driver in the family, it will be important for family members to find alternative means of transportation (e.g., learning how to drive, recruiting volunteer drivers from among family and friends, using public transportation, etc.) If the person with AD was in charge of household finances, someone else will need to assume this role. If the person with AD customarily prepared all of the meals, now is the time for the caregiver to begin learning how to cook. Focusing on these issues early will allow the person with AD to help the caregiver prepare for the future.
- Finances: AD can be an extremely costly disease. The life span of someone with Alzheimer's can range from two to more than 20 years. It is important to begin mapping out strategies for meeting the increasing financial demands

placed on the family as the disease progresses. Financial planning should include reviewing your insurance coverage (e.g., health, disability, long-term care, etc.). Be aware that Medicare does not cover long-term care or custodial care. Health insurance counseling is available free to seniors. To locate help in your community, call the Eldercare Locator at (800) 677-1116 or HICAP at (800) 434-0222.

- Legal: Eventually the person with AD will need help paying the bills, getting medical care, and making decisions. Two legal documents, Power of Attorney for Finances and Power of Attorney for Healthcare, can ensure that the person with AD is cared for by trusted family members or friends. Without these documents, caregivers may have to go through court proceedings to get the right to make decisions on behalf of the person with AD. The family may also lose access to bank accounts. Free and low-cost legal services are available to seniors. See the resource section of this fact sheet for organizations that can help with legal questions and services.

Caregiving in the Middle Stage

During middle stage of AD, the caregiver's role will expand to full time. Keeping the person with AD safe will become a priority. Both the person with AD and the caregiver will need help and support.

- Emotional Support: People caring for loved ones with AD frequently feel isolated, and it is common for caregivers to suffer from grief and loss as the person they are caring for changes. Getting emotional support and taking periodic breaks from the responsibilities of caregiving is crucial to the mental and physical health of caregivers. Be sure to speak to your physician if you feel depressed or anxious.

- **Respite Care:** Caregivers need breaks, which is what “respite care” really is. Respite care includes adult day care programs, in-home help, and short nursing home stays. Other family members or friends, professional caregivers, or volunteer caregivers can provide respite care. The local Area Agency on Aging can provide information about the options available in the local community. See *Community Care Options* fact sheet to learn about programs that can help ease the demands placed on the caregiver.
- **Safety:** Creating a safe and comfortable environment is important. An occupational therapist can provide advice and help in making the home safer for both the caregiver and care recipient. Ask your physician, the local Alzheimer’s Association or the Area Agency on Aging for a referral to a professional experienced in home modification and assistive devices. For people with AD who wander, the local police should be advised, and the person should be registered with the Alzheimer’s Association’s Safe Return program.
- **Medical Care:** The person with AD will need ongoing medical care both for AD and for any other health problems that might arise. The caregiver will become the spokesperson for the person with AD. It is important to develop relationships with physicians and other health care professionals who understand the caregiver’s role and who work with the caregiver as a team member in providing appropriate medical care. If the physician does not listen to you and respect your role as a caregiver, find a new physician. The stress of caregiving can affect your health. Be sure to take care of yourself. If you need to be hospitalized or need time off from your caregiving duties, emergency respite care can be arranged. Caregivers whose health is seriously affected may

need to look at options for having a residential facility provide care for your loved one.

- **Planning for the Future:** Many caregivers wish to keep their loved one at home with them; however, this is not always possible. If more care—or a different type of care—is needed than what you can provide at home, look into residential care options. Many facilities have special programs for individuals with dementia. Another option is to hire in-home help. For more information, see *Out-of-Home Care Options* and *Hiring In-Home Help* fact sheets.

Caregiving in the Late Stage

- **Hospice:** Hospice services are designed to support individuals at the end of life. Services may include support groups, visiting nurses, pain management and home care. Hospice services are usually arranged through the treating physician, and are usually not available until the physician anticipates that a person has less than six months to live. Several organizations specialize in helping families deal with the challenges involved in end-of-life care. See *End-of-Life Decision Making* fact sheets and refer to the resource section at the end of this fact sheet for more information.
- **Placement:** Families caring for a loved one with end-stage Alzheimer’s should give thoughtful consideration to placement in a skilled nursing facility, where adequate management and supervision can be provided.

Alzheimer’s disease poses challenges for both the person diagnosed with AD and the caregivers. However, it does not mean that there will no longer be times of joy, shared laughter and companionship. AD develops gradually, which means that there is time to plan ahead, time to adjust to the diagnosis and time to enjoy being with each other.

Credits

Alzheimer's Disease Education and Referral Center, (2001). Progress Report on Alzheimer's Disease: Taking the Next Steps. Alzheimer's Disease Education and Referral Center (NIH Publication No. 00-4859), Silver Spring, MD.

American Medical Association, (1999). Diagnosis, Management and Treatment of Dementia: A Practical Guide for Primary Care Physicians. American Medical Association, Program on Aging and Community Health, Chicago, IL.

Doody, R. S. et al., (2001). Practice Parameter: Management of Dementia (an Evidence-Based Review) Report of the Quality Standards Subcommittee of the American Academy of Neurology. *Neurology*, v. 56, pp. 1154-1166.

Federal Interagency Forum on Aging-Related Statistics (2000). Older Americans 2000: Key Indicators of Well-Being. Federal Interagency Forum on Aging-Related Statistics, Hyattsville, MD.

Petersen, R. C. et al., (2001). Practice Parameter: Early Detection of Dementia: Mild Cognitive Impairment (an Evidence-Based Review), Report of the Quality Standards Subcommittee of the American Academy of Neurology. *Neurology*, v. 56, pp. 1133-1142.

National Center for Health Statistics, (2000). Deaths and Death Rates for the 10 Leading Causes of Death in Specified Age Groups, by Race and Sex: United States, 1998. *National Vital Statistics Reports*, v. 48, no. 11, pp. 27-29.

Zarud, E., (2001). New Treatments of Alzheimer Disease: A Review. *Drug Benefit Trends*, v. 13, no. 7, pp. 27-40.

Recommended Reading

Alzheimer's: A Love Story, Ann Davidson, (1997). Carol Publishing, 120 Enterprise Avenue, Seacaucus, NJ 07094, (201) 866-0490.

The Best Friends Approach to Alzheimer's Care, Virginia Bell and David Troxel (1997). Health Professions Press, P.O. Box 10624, Baltimore, MD 21285-0624, (888) 337-8808. The Complete Guide to Alzheimer's Proofing Your Home, Mark L. Warner (1998). Purdue University Press, 1207 South Campus Courts-E, West Lafayette, IN 47907-1207, (800) 933-9637.

Moving a Relative with Memory Loss by Laurie White and Beth Spencer (2000). Whisp Publications, P.O. Box 5426, Santa Rosa, CA 95402, (707) 525-9633.

Pressure Points: Alzheimer's and Anger, Edna Ballard, M.S.W., A.C.S.W., Lisa Gwyther, M.S.W., L.C.S.W., and T. Patrick Toal, M.S.W. (2000). Duke Family Support Program, Durham, NC 27710, (800) 672-4213.

The 36 Hour Day: A Family Guide to Caring for Persons With Alzheimer Disease, Related Dementing Illnesses, and Memory Loss in Later Life, Nancy Mace and Peter Rabins, Revised Edition (April, 2001), The Johns Hopkins University Press, 2715 N. Charles Street, Baltimore, MD 21218-4319, (800) 537-5487.

Resources

Mountain Caregiver Resource Center
2491 Carmichael Drive, Suite 400
Chico, CA 95928
(530) 898-5925
(800) 995-0878
www.caregiverresources.org

Mountain Caregiver Resource Center offers a full complement of family services designed to assist caregivers of adults with brain disorders. Most services are offered free or on a low-cost sliding scale.

Services include: specialized information, family consultation and care planning, support groups, short-term counseling, respite care, legal and financial assistance, in addition to family and professional training.

Family Caregiver Alliance
690 Market Street, Suite 600
San Francisco, CA 94104
(415) 434-3388
(800) 445-8106
www.caregiver.org
info@caregiver.org

Family Caregiver Alliance (FCA) seeks to improve the quality of life for caregivers through education, services, research and advocacy.

FCA's National Center on Caregiving offers information on current social, public policy and caregiving issues and provides assistance in the development of public and private programs for caregivers.

For residents of the greater San Francisco Bay Area, FCA provides direct family support services for caregivers of those with Alzheimer's disease, stroke, ALS, head injury, Parkinson's and other debilitating brain disorders that strike adults.

Alzheimer's Association
919 N. Michigan Ave., Suite 1000
Chicago, IL 60611-1676
(312) 335-8700
(800) 272-3900
www.alz.org

The Alzheimer's Association provides education and support for people diagnosed with the condition, their families and caregivers. Chapters across the country provide local support.

Alzheimer's Disease Education and Referral Center (ADEAR)
P.O. Box 8250 Silver Spring, MD 20907-8250
(301) 495-3311
(800) 438-4380
www.alzheimers.org
ADEAR@alzheimers.org

The ADEAR Center provides information about Alzheimer's disease, including current research and clinical trials.

American Health Assistance Foundation
15825 Shady Grove Road, Suite 140
Rockville, MD 20850
(800) 437-2423
(301) 948-3244
www.ahaf.org
eberger@ahaf.org

Provides emergency financial assistance to Alzheimer's disease patients and their caregivers.

Eldercare Locator
(800) 677-1116
www.eldercare.gov

The Eldercare Locator helps older adults and their caregivers find local services including health insurance counseling, free and low-cost legal services and contact information for local Area Agencies on Aging.

National Academy of Elder Law Attorneys
1604 N. Country Club Road
Tucson, AZ 85716
(520) 881-4005
www.naela.com

NAELA publishes consumer information on estate planning and has an online database of Elder Law Attorneys.

Partnership for Caring: America's Voices for the Dying
475 Riverside Drive, Suite 1852 New York, NY 10115
(212) 870-2003
(800) 989-9455 (option 1)
www.partnershipforcaring.org/HomePage
pfc@partnershipforcaring.org

Partnership for Caring operates a crisis and information hotline dealing with end-of-life issues and provides state-specific living wills and medical powers of attorney.
Websites (See additional links above)

Alzheimer's Disease International
www.alz.co.uk/alzheimers

Alzheimer Society of Canada
<http://www.alzheimer.ca>

Dementia Advocacy and Support Network
www.dasninternational.org

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