



DEL MAR CAREGIVER RESOURCE CENTER
A program of Health Projects Center

Fact Sheet

Alzheimer's Disease: Early Stage

Overview

A diagnosis of Alzheimer's disease for yourself or a loved one can be difficult to accept. As you read through this fact sheet, we encourage you to keep an open mind and remember that you are not alone. Organizations that provide assistance and support to people with AD and their families are located in communities all across the nation. You'll find contact information for service organizations at the end this Fact Sheet under *Community Resources*.

Facts

Alzheimer's disease (AD) is a slowly progressing disease that results in the loss of nerve cells in the brain, eventually leading to impairment in memory, judgment and decision-making, orientation to physical surroundings, concentration and language. Though the loss of nerve cells is irreversible, medications are available that may slow the disease's progress.

AD can affect your ability to perform day-to-day tasks and can lead to changes in behavior and mood. While symptoms often interfere with social, family and work activities, many AD patients and caregivers have learned a variety of strategies that have helped them maintain an active and productive life. This Fact Sheet offers information about this medical condition as well as practical tips for coping with its effects.

Stages

AD affects people in different ways. The progress of the disease and its symptoms may differ from person

to person. However, the general course of the disease is often divided into stages (early, middle and late) based upon memory, thinking, and your ability to care for yourself. Long-term memory (e.g., events from childhood and early adulthood) is not affected in the early stages of AD.

Early Diagnosis and Intervention

Although scientists have not found a cure for AD, certain important actions and resources can be helpful to you and your family. The first step is to get a full medical examination to rule out potentially reversible causes of memory loss (e.g., depression, reaction to medication, etc.). In addition, early diagnosis and intervention allow you to:

- Improve your understanding—and the understanding of those around you—about the changes that are taking place.
- Increase your knowledge of AD.
- Access community resources that help AD patients and caregivers.
- Take advantage of medications. Several prescription drugs may delay, for a time, the worsening of symptoms in people with AD.
- Make plans for the future (e.g., financial and health care planning).
- Increase your awareness of local and national research projects and clinical trials of new medications.
- Increase your awareness of safety issues and health.

Del Mar Caregiver Resource Center

Serving Monterey, San Benito and Santa Cruz Counties

831.459.6639 • Toll Free 1.800.624.8304 • www.delmarcaregiver.org

Early-Stage Symptoms

The following is a list of skills and tasks that may become increasingly difficult for you. The list is intended to help you identify potential difficulties in order to help you plan for future changes and continue living your life to the fullest.

- *Memory for recent events.* Examples: remembering appointments, details of a recent conversation and names.
- *Carrying out tasks with multiple steps.* Examples: managing money and balancing your checkbook, taking medications as prescribed, shopping and cooking.
- *Decision-making and problem-solving.* Example: making quick decisions in response to an emergency, such as responding to a flood or fire in your home.
- *Spatial ability and orientation.* Examples: following a map or following directions, judging the distance of objects while driving, and feeling lost in familiar environments.
- *Language.* Examples: finding the right word, writing letters, understanding what you have read or what others have said.
- *Behavior and/or mood.* Examples: loss of interest in new projects, withdrawing in social situations, feelings of anxiety and depression. Keep in mind that anxiety and depression are often treatable, so speak with your physician if these feelings arise.

Transitions

It may be necessary to change your daily routine in the early stages of AD. Although a time may come when you must rely more on others for assistance with some tasks, you will want to stay involved in making decisions that affect your life. The following tasks may require adjustments in your lifestyle:

Driving: Some states have laws requiring physicians to report individuals with a diagnosis of AD to the Department of Motor Vehicles. The intent is to ensure that you and those around you are safe. If you continue driving, ongoing evaluation of your driving abilities and ongoing consultation with your physician are critical. It is also wise to pay attention to the suggestions of those close to you; they may

recognize changes in your driving ability before the changes become apparent to you.

In-home responsibilities: Household management may become increasingly difficult for you. Tasks such as cooking and taking medications may pose safety risks.

You may, for example, forget to turn off the stove or forget to take a dose of medication. However, it may be possible to continue to participate in household activities with a minimal amount of assistance from another person. Some individuals may choose to have family or friends assist in certain areas; others may choose to hire help from outside the home. It may be necessary to consider moving to another living situation in order to simplify your lifestyle or to be in closer proximity to family or friends. You may want to start discussing these options with those who are close to you.

Financial responsibilities: Balancing a checkbook, dealing with insurance, and paying bills may become frustrating and overwhelming. Having a trusted family member or friend to help with these tasks is extremely important. A *Power of Attorney* should be established so that this trusted person can act on your behalf during times when you cannot.

Be sure to include this person in the process very early so that he or she has time to learn what needs to be done. Like driving, managing our own finances is a sign of independence. It can be difficult to allow someone else to do these things for you, but there is no shame in admitting you may need help. The people who are close to you may recognize your need for help before you do.

Treatment

Presently, researchers cannot definitively say what causes AD, and there currently is no cure. However, considerable progress has been made in the field of AD research in recent years resulting in the development of several medications for AD.

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 this ideal treatment. It is possible, however, to improve memory and slow the progression of AD with medications. As of the beginning of 2002, four drugs had been approved by the FDA. Tacrine (Cognex), approved in 1993, has many side effects, including potential liver damage,

and has proved disappointing with regard to improving memory. For these reasons it is seldom prescribed. Three newer drugs, donepezil (Aricept), rivastigmine (Exelon) and galantamine (Reminyl), have been more beneficial in improving memory with 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 medications may be appropriate for you.

New medications are constantly being tested. If you are interested in participating in clinical trials, you should discuss this with both your physician and the people close to you. 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 conduct research projects as well. Your physician may know of research studies seeking participation from people with AD.

It is currently possible to reduce the emotional and behavioral symptoms sometimes associated with AD. For example, a doctor may prescribe drugs to reduce depression, anxiety and sleep problems. Exercise, diet, education programs, and support groups also help address some problems caused by AD.

Ways of Coping

- Educate yourself about the disease and resources in the community.
- Discuss with family members or other trusted persons your preferences about decisions affecting your life. (For more information on discussing your preferences, see the Fact Sheet Making Choices About Everyday Care.)
- Continue to explore ways to fulfill your needs for intimacy and closeness. The desire for close relationships with others continues throughout the disease.
- Be patient with yourself.
- Exercise can contribute to good physical health and coordination, and can reduce stress. See your physician for an exercise program that will best fit your needs.

- Find productive ways to release anger and frustration—talk with a close friend, a counselor, or join a support group especially for people with AD.
- Use visible and/or accessible reminders—write notes to yourself, leave messages on your answering machine, or set the alarm on a watch as a reminder about an upcoming appointment.
- Engage yourself in meaningful activities—documenting your life story by creating a scrap book, tape recording your autobiography, or keeping a journal can be wonderful ways to reflect upon your life and share yourself with those close to you. Your children and grandchildren will treasure these keepsakes.
- Keep your mind active—do puzzles, write, etc.
- Know that you are not only a “person with AD”—focus on the many and varied personal attributes that you have, such as integrity, kindness, humor.
- Become an advocate for yourself and other individuals with AD. Write letters and make phone calls to local and state representatives, assist community agencies in training staff and professionals about AD, or become involved in a research program.
- Establish a *Power of Attorney for Healthcare* and *Power of Attorney for Finances*. These documents will help your loved ones provide you with the type of care you want and need in the future.
- Continue social activities—get together with friends and family as much as possible.
- Maintain an open mind and positive attitude—focus on your present abilities and avoid excessive worry about what might happen in the future. Know that there are many ways to live an active and productive life.

Community Resources

Alzheimer's and senior service organizations: The *Eldercare Locator*, (800) 677-1116, is a free service which will put you in touch with a local Area Agency on Aging or other local sources of help. You can also call the *Alzheimer's Association* at (800) 272-3900 to receive contact information for the appropriate state or regional chapter. *Family Caregiver Alliance's National Center on Caregiving* offers help in locating services as well—call (800) 445-8106 or e-mail *info@caregiver.org*. If either you or your caregiver resides in California, you will find help through your local *Caregiver Resource Center* by calling (800) 445-8106.

Support groups and counseling services: Support groups for those with early Alzheimer's disease can be primarily discussion-oriented or can offer a variety of creative activities including planned outings. Caregiver support groups and education programs are also available in the community for those family members or friends who are assisting you in some way.

Volunteer programs: Volunteer opportunities for persons with AD are now available in some areas. You may enjoy the chance to contribute your time and talent to your local community.

Artistic programs: Expressing yourself through work in clay, paint or photography, for example, may be beneficial to you and can provide you opportunities for self-expression.

Structured day programs: Adult day programs include activities such as art, music, gardening, exercise, discussion groups, and assistance with physical health needs.

Professional assistance: Take advantage of health care professionals who assist with maintaining your physical strength and coordination, such as occupational therapists and physical therapists.

Legal and financial assistance: Again, forming a *Durable Power of Attorney for Health Care* and a *Durable Power of Attorney for Finances* are essential first steps. Call the Eldercare Locator at (800) 677-1116 to find an Area Agency on Aging that provides free and low-cost legal services for seniors in your community. For more information see FCA's Fact Sheets *Durable Power of Attorney & Revocable Living Trusts* and *Legal Planning for Incapacity*.

Care management: A care manager experienced in the field of AD can provide education, assistance with transitions, emotional support and guidance in locating and coordinating community resources.

Credits

Alzheimer's Disease Educations 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.

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.

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

Resources & Reading

Alzheimer's Early Stages: First Steps in Caring and Treatment, Daniel Kuhn (1999). Hunter House Publishers, P.O. Box 2914, Alameda, CA 94501-0914, (800) 266-5592.

Alzheimer's: The Answers You Need, Helen Davies and Michael Jensen, (1998), Elder Books, P.O. Box 490, Forest Knolls, CA 94933, (800) 909-COPE.

Early Alzheimer's: An International Newsletter on Dementia, Alzheimer's Association of Santa Barbara, 2024 De la Vina Street, Santa Barbara, CA 93105, (800) 563-0020.

Perspectives: A Newsletter for Individuals with Alzheimer's Disease, Alzheimer's Disease Research Center, University of California, San Diego, 9500 Gilman Drive - 0948, La Jolla, CA 92093-0948, (858) 622-5800.

Speaking Our Minds: Personal Reflections from Individuals with Alzheimer's, Lisa Snyder, (1999), W.H. Freeman and Company, 41 Madison Ave., New York, NY 10010, (888) 330-8477.

Organizations

MONTEREY COUNTY

Health Projects Center's

Del Mar Caregiver Resource Center

(831) 424-4359

Web site: www.delmarcaregiver.org

SANTA CRUZ COUNTY

Health Projects Center's

Del Mar Caregiver Resource Center

(831) 459-6639

Web site: www.delmarcaregiver.org

SAN BENITO COUNTY

Health Projects Center's

Del Mar Caregiver Resource Center

(831) 459-6639

Web site: www.delmarcaregiver.org

Del Mar Caregiver Resource Center supports and assists caregivers of brain-impaired adults through education, research, services and advocacy.

For residents of Central California, Monterey, Santa Cruz and San Benito Counties, Del Mar CRC provides direct family support services for caregivers of those with Alzheimer's disease, stroke, head injury, Parkinson's and other debilitating brain disorders that strike adults.

Alzheimer's Association

(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)

(800) 438-4380

www.nia.nih.gov/alzheimers

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

Bright Focus Foundation

(800) 437-2423

www.brightfocus.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.

Websites (See additional links under Organizations)

Alzheimer's Disease International

www.alz.co.uk/alzheimers

Alzheimer Society of Canada

www.alzheimer.ca

Dementia Advocacy and Support Network

www.dasninternational.org

Prepared by Family Caregiver Alliance in cooperation with California's Caregiver Resource Centers. Funded by the California Department of Mental Health. Reviewed by Daniel Kuhn, M.S.W., Education Director, Mather Institute on Aging, Mather LifeWays. Revised January 2002. © All rights reserved.