

Alzheimer's Disease Resources

Organizations

! Alzheimer's Association

Phone: 1-800-272-3900 Web site: www.alz.org

The Association is comprised of approximately 200 chapters throughout the United States. The Association sponsors a network of support groups for family caregivers and provides information, referral, and other educational services. Some chapters also offer respite services. The Association also promotes advocacy and research into the causes, treatment, and prevention of Alzheimer's disease (AD).

! Alzheimer's Disease Education and Referral (ADEAR) Center

Phone: 1-800-430-4380 Web site: www.alzheimers.org

The ADEAR Center is a service of the National Institute on Aging and serves as a clearinghouse of information and publications about AD and related dementias. The ADEAR Center offers information about a variety of topics including AD research centers and clinical trials.

! Eldercare Locator

Phone: 1-800-677-1116 Web site: www.eldercare.gov

This centralized registry lists a variety of community-based services throughout the United States.

! Religious and community organizations

A growing number of nonprofit organizations offer services to family caregivers on a voluntary basis. Check out the churches and synagogues in your community or contact your local Area Agency on Aging.

! Home care agencies

Most home health agencies provide skilled services that are reimbursed under Medicare. Many of these agencies offer services that are paid for privately. In addition, some agencies cater exclusively to fee-for-service clients. Ask your local Area Agency on Aging or a local hospital's discharge planning or social service department for information about agencies in your area.

! Adult day care

Adult day care refers to a community-based program that offers therapeutic activities and individualized services in a group setting for older adults with a variety of disabilities. Adult day care also enables caregivers to receive much needed respite. Information about local centers can be obtained from the Eldercare Locator, the state Department on Aging, or the National Council on Aging at (202) 479-1200.

! Medicaid waiver programs

Services through a home care agency range from \$10-20 per hour and adult day care costs \$45-60

per day. Medicare *does not* cover these cost so most people have to pay out of their own pockets. Financial assistance for community-based services may be available for those with low

incomes and assets through public sources such as the state Department on Aging or Human Services.

! U.S. Department of Veterans Affairs

Phone: 1-800-827-1000 Web site: www.va.gov/health/elig/benefits.html

Military veterans who meet certain financial eligibility criteria may also be entitled to certain home-based services. Contact your federal or state Department of Veterans Affairs for details.

! Alzheimer's Disease Centers (ADCs)

Phone: 1-800-438-4380 Web site: www.alzheimers.org/adccdir.html

The National Institute on Aging currently funds 29 Alzheimer's Disease Centers and three affiliates at major medical institutions across the United States. Clinicians and researchers at these centers are working to translate research advances into improved care and diagnosis for AD patients while also focusing on better treatments and prevention of the disease.

Books, Articles, and Pamphlets

For Module One:

1. *Progress Report on Alzheimer's Disease*. Bethesda, MD: National Institutes of Health, National Institute on Aging, NIH.
This report is updated annually. To obtain a free copy, call the ADEAR Center (1-800-438-4380), or view it on the Web site at www.alzheimers.org.
2. Mace, N.L. & Rabins, P. (1999). *The 36-Hour Day*. Third edition, Baltimore: The Johns Hopkins University Press.
3. National Institutes of Health. (1994). *Working with Your Older Patient: A Clinician's Handbook*. Department of Health and Human Services, NIH Publication 93-3453. Bethesda, MD: National Institutes of Health. This publication is out of print, but you can view it online at: www.nia.nih.gov/health/pubs/clinicians-handbook/.
4. Kuhn, D.R., Ortigara, A., & Farran, C.J. (1997). A continuum of care in Alzheimer's disease. *Advanced Practice Nursing Quarterly*, 2, 15-21.
5. National Institute on Aging. (2002). *Talking with Your Doctor: A Guide for Older People*. Bethesda, MD: National Institutes of Health. Available through the ADEAR Center (1-800-438-4380) or online at: www.nia.nih.gov/health/pubs/talking/talkwithdoc.pdf.

For Module Two:

1. Davis, R. (1989). *My Journey into Alzheimer's Disease*. Wheaton, IL: Tyndale House Publishers. ISBN: 0842346457.
2. Kuhn, D. (1999). *Alzheimer's Early Stages: First Steps in Caring & Treatment*. Alameda, CA: Hunter House Inc. Publishers. ISBN: 0897932625.
3. Post, S. G. (2000). *Moral Challenges of Alzheimer's Disease: Ethical Issues from Diagnosis to Dying* (second edition). Baltimore: The Johns Hopkins University Press. ISBN: 0801864100.
4. Rau, M.T. (1993). *Coping with Communication Challenges in Alzheimer's Disease*. San Diego: Singular Publishing Group, Inc. ISBN: 1879105764.
5. Strauss, C.J. (2002). *Talking to Alzheimer's: Simple Ways to Connect When You Visit with a Family Member or Friend*. Oakland, CA: New Harbinger Publications. ISBN: 1572242701.
6. Robinson, A., Spencer, B. & White, L. (1988). *Understanding Difficult Behaviors: Some practical suggestions for coping with Alzheimer's disease and related illnesses*. Ypsilanti, MI: Geriatric Education Center of Michigan. ISBN: 9991249508.

For Module Three:

1. White, L. and Spencer, B. (2001). *Moving a Relative with Memory Loss*. Santa Rosa, CA: Whisp Publications. ISBN: 0970760906.
2. Alzheimer's Association (2001). *Residential Care: A Guide for Choosing a New Home*. Chicago: Alzheimer's Association.
3. Coughlan, P.B. (2000). *Facing Alzheimer's Disease: Family Caregivers Speak*. iUniverse.com, Inc. ISBN: 0595008038.
4. Haisman, P. (1998). *Alzheimer's Disease: Caregivers Speak Out: A Guide to Understanding and Coping*. Chippendale House Publishing. ISBN: 0966227204.
5. National Institute on Aging. (2002). *Caregiver Guide: Tips for Caregivers of People with Alzheimer's Disease*. NIH Publication No. 01-4013. Available from the ADEAR Center (1-800-438-4380) or online at www.alzheimers.org/pubs/careguide.htm.

Glossary:

- Alzheimer's Association. (1995). *Terms and Tips: An Alzheimer Care Handbook*. Chicago, IL: Alzheimer's Association. Call the Association at (800) 272-3900.

Videos

For Module One:

- *The Alzheimer's Care Kit: Signs and Symptoms of Alzheimer Disease*. This 33-minute video is the first in a series. It shows Peter Rabins, M.D. talking with several individuals at different stages of Alzheimer's disease. This is a good introduction to the progression of the disease. Forgetfulness, confusion, loss of ability to do simple tasks, and other cognitive impairments are both demonstrated and explained. To purchase or rent this video call Video Press at 1-800-328-7450.

For Module Two:

- *Alzheimer's Disease: Inside Looking Out*. This 18-minute video produced by the Cleveland Area Chapter of the Alzheimer's Association features several individuals in the early stage of the disease as well as interviews with their family members. This is a very personal view of the disease from the perspective of those directly affected. Meaningful activities and social support to enhance the quality of life for those with the disease are emphasized in this fine video. This video is available through the Cleveland Area Chapter (216) 721-8457 or through Terra Nova Films at 1-800-779-8491.
- *Assessing the Mental Status of the Older Person*. In this 34-minute video, Dr. Peter Rabins uses the Mini Mental State Examination (MMSE) to assess the brain functions of several older individuals who vary from normal to severely impaired. The MMSE is the most widely used screening tool for dementia. The video describes how to administer this tool and illustrates the range of symptoms commonly seen among people with dementia. To purchase or rent this video call Video Press at 1-800-328-7450.

For Module Three:

- *Losing It All: The Reality of Alzheimer's Disease*. This film was produced by Home Box Office (HBO) in 1988 but still has currency today. The 15-minute segment involving a woman with AD living alone in her home in Oregon raises important issues about autonomy, safety, and the role of the family. Call Ambrose Video Publishing at 1-800- 526-4663.

- *Complaints of a Dutiful Daughter*. This 45-minute documentary was nominated for an Academy Award in 1995 and has won numerous other awards. Filmmaker Deborah Hoffman chronicles her mother's Alzheimer's disease from the point of caring for her at home to the transition to a nursing home. The last 15 minutes of this video focuses on the difficult decision of placing a loved one in a nursing home. Call Women Make Movies at (212) 925-0606.