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Brain Autopsy: The Gift of Knowledge

Alzheimer's Disease Centers Autopsy Program Directory

The word "autopsy" stems from the Greek word *autopsia*, meaning to see with one's own eyes. Researchers have made significant progress in developing accurate tests to detect AD in living patients, and as a result, a diagnosis of "probable" AD now can be made with up to 90 percent certainty in specialized research facilities. However, the disease can be diagnosed conclusively only by examining the brain after death in an autopsy to see for sure the characteristic plaques and tangles that define AD. Autopsy provides valuable information that can educate and enlighten families, physicians, and researchers, who are working to discover more reliable tests for AD.

Information gained from autopsies is a vital part of the research conducted at the Alzheimer's Disease Centers (ADCs) supported by the National Institute on Aging (NIA). The autopsy results of AD patients who have been followed over time at an ADC are especially valuable. For these patients, doctors usually have substantial treatment and care

history which can give them insights into the disease course and provide information essential to the search for effective treatments and an eventual cure for AD.

In the past, brain tissue samples were essential for AD research because no animal model for AD existed. According to University of Pennsylvania ADC Director John Q. Trojanowski, M.D., Ph.D. "Autopsy may be even more important today than in the past. The animal models we now have for AD provide a good "caricature" of the disease, but it is essential that we be able to compare them to actual diseased human brain tissue obtained through autopsy."

Marcelle Morrison-Bogorad, Ph.D., Associate Director of Neuroscience and Neuropsychology of Aging Program, NIA agrees with Dr. Trojanowski and adds, "Ultimately, this research will uncover the chain of events that leads to AD and related dementias. Many families of dementia patients make the commitment in order to help further AD research by agreeing to donate the brain for research. It is vitally important that people without brain disorders also make tissue donations, so that we can understand how healthy brains work."

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Frequently Asked Questions about Brain Autopsy

Q. Who should get an autopsy?

A. AD patients and research volunteers without dementia.

Q. When should the autopsy be performed?

A. As soon as possible after death. The family should contact the autopsy coordinator immediately—day or night and send them the signed consent form.

Q. Will the autopsy procedure disfigure the body and delay the funeral?

A. No. The physician, a pathologist, removes the brain through an incision in the back of the head. The face is never touched or scarred during the procedure. An open casket is still an option. The examination will not delay preparation of the body for burial.

Q. Hasn't the patient suffered enough?

A. The person who has died suffered a great deal during his or her illness, but it is important to remember that he or she is no longer suffering and that the autopsy will provide valuable information to those who survive.

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News From the ADEAR Center
Alzheimer's Disease Education & Referral Center
A Service of the National Institute on Aging

Brain Autopsy

(Continued from page 1)

Benefits of Autopsy

To Families—Advancing medical knowledge often is cited as the most important benefit of autopsy. Family members also may feel a sense of relief once they know the exact cause of death and that their loved one was given appropriate care during his or her illness.

Findings from an autopsy can help family members understand genetic risk factors that can be associated with AD and related dementias, and provide an opportunity for genetic counseling.

Participation in brain autopsy can help family members attach meaning and purpose to the suffering that occurs with AD and related dementias. Autopsy can provide family members and loved ones with a sense of closure to facilitate the grieving process.

To Researchers and the Medical Community—Autopsy provides an important quality control tool by confirming the diagnosis. In AD clinical trials, autopsy results help researchers confirm that the people in the trial actually had AD and not some other dementia. Autopsy results can help researchers develop and test better, more accurate diagnostic tools.

Autopsies of non-demented persons and those in the early stages of AD can help scientists pinpoint the earliest signs of age-related brain changes and how they differ from brain changes in early AD. Research of this type may lead to interventions that might help in the earliest stages.

To Society—Autopsies provide more accurate disease rates of dementia, including vital statistics for State and national registries. Accurate diagnostic data from autopsy can provide information to those who advocate for laws and funding in support of AD patients and their families. As a result, society as a whole may benefit by additional services designed to ease the burden caused by AD and related dementias.

Planning For an Autopsy

The time immediately after the death of a family member is stressful and is

not the best time to start making decisions about an autopsy. Planning ahead allows family members time to reach a decision and prepare the needed paperwork. Putting things in place before the person's death helps ensure that brain tissue can be removed promptly.

A variety of professionals can help make the process of donating tissue through an autopsy service easier. Social workers, nurses, and other support staff at the ADCs are available to answer questions about the donation in advance. This may ease the decision-making process for the family. Often, ADCs have designated an autopsy coordinator who helps people through the entire process.

Once a decision to donate brain tissue is made, paperwork giving consent can start. If the patient is in a nursing home or other long-term care facility, staff there should be notified in advance of the family's wishes. Next, a funeral home is selected and notified of the arrangement.

Usually, within several weeks of the autopsy, a written report is presented to the family. The physician or support staff at the autopsy service often are available to discuss the findings.

For more information about planning for an autopsy or becoming involved in a research study, families may contact any ADC. For the most current listing of the ADCs, see page 4 or visit the ADEAR Center's Web site (<http://www.alzheimers.org/pubs/adcdir.html>).

Each of the ADCs provides autopsy services to patients who have participated in their research programs. Some of the ADCs offer broader autopsy services to patients who have been seen and followed by an ADC physician. In some cases, they will provide autopsy services to others by request.

Many of the ADCs refer patients from outside their programs to the pathology departments of their institutions. Typically, this is a fee-for-service arrangement. Other ADCs refer families to local Alzheimer's Association chapters, area brain banks, and State medical examiners. 🚩

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- Q. Are there religious objections to brain donations?**
- A. Often, there are cultural or religious concerns that practitioners need to address in order to help the family feel more at ease with the decision. Most religions and cultural traditions agree that organ donation is valuable. Your own religious advisor is the best person to guide you. You are encouraged to talk with your own minister, priest, or rabbi.
- Q. Who may grant permission for an autopsy?**
- A. The consent for an autopsy is legally binding only when it is signed after death by the legal next-of-kin. Check with your lawyer or the facility performing the autopsy since these laws differ for each State. The following is an example of persons, in order of priority, who may provide such consent:
- Spouse
 - Adult son or daughter
 - Either parent
 - Adult brother or sister
 - Guardian of the deceased at the time of death
 - Any other person authorized or under obligation to dispose of the body
- Q. What can the family expect to learn from the autopsy report?**
- A. The report will explain the final diagnosis and any major changes found in the brain. It will say whether or not the diagnosis of Alzheimer's disease was confirmed and if there were any other conditions affecting the brain. The primary, attending physician, or pathologist can interpret the report.
- Q. How much will the brain autopsy cost the family?**
- A. Costs usually range from \$500 to \$1,500 (can be higher) for the autopsy, which does not include transportation costs. Research programs at medical institutions like the ADCs offer free services to those who qualify. 🚩

Autopsy Resources:

Dementia Postmortem Network, Web Sites, and ADC Autopsy Program Directory

The Michigan Dementia Post-mortem Network helps families of people in Michigan who are affected by dementing diseases. It was established to help people to obtain an autopsy.

The network includes four types of medical professionals and volunteers: referral liaisons, autopsy liaisons, pathologists, and neuropathologists. Each is trained to help families by providing a specific service. Referral liaisons—usually social workers, nurses, or Alzheimer's Association chapter volunteers—provide general information about brain autopsy in Michigan and help the family complete enrollment. Autopsy liaisons—often pathology assistants or funeral directors—help coordinate arrangements for the autopsy. Services include obtaining patient medical information and consent for autopsy, and helping the family arrange transportation for the body. At autopsy, pathologists (doctors specializing in the study of tissue) remove the brain. Neuropathologists (doctors with additional training in studying brain tissue) examine the brain cells, make a diagnosis, and complete an autopsy report for the patient's physician and family.

The Michigan Dementia Post-mortem Network serves Michigan residents, but it has an informative Web site available to families and professionals across the country. The Web site, <http://www.mdpn.msu.edu> includes information about the value of autopsy, answers frequently asked questions and offers guidance on how to talk to other family members about whether to have an autopsy performed. On the Web site, network advisors emphasize the importance of deciding in advance whether to request a brain autopsy and include a checklist for family members considering autopsy.

The Network's Web site also provides information, referrals, a list of publications, and recommendations from the Michigan Postmortem Examination Workgroup. All of the information on the site is free to the public.

The following is a sample of other web sites that offer information about brain autopsy.

List of Web sites:

Alzheimer's Association Greater Washington, D.C. Area Local Brain Autopsy Network
<http://www.alzheimersdcmd.org/localbrain.html>

Alzheimer's Association List of Local Chapters
<http://www.alz.org/chapter/>

Alzheimer's Association San Diego Chapter
http://www.sanalz.org/support_services/services7.html

The Diagnostic Center for Alzheimer's Disease and Neuropathology Laboratory at the University of Oklahoma Health Sciences Center in Oklahoma City Autopsy Network
http://w3.ouhsc.edu/pathology/dept_labs/diagnostic_center_for_alzheimer.htm#Autopsy Assistance Network

Tulane University Medical Center Autopsy Service
<http://www.tmc.tulane.edu/departments/pathology/Services.html/autopsy.html>

Florida Alzheimer's Disease Initiative Brain Bank (affiliated with Suncoast Gerontology Center)
<http://www.med.usf.edu/suncoast/alzheimer/brainbnk.htm>

University of Virginia Health Services Department of Neurology Brain Research Facility
<http://www.med.virginia.edu/medicine/clinical/neurology/facilities/brain-resource.html>

A Checklist for Family Members

- Discuss the autopsy decision with all involved family members, physician(s), your religious leader, and/or people in your support group.
- Identify the patient's legal next-of-kin.
- Obtain a consent form from the facility that will perform the autopsy.
- Keep a copy of the consent form in an accessible place.
- Give your family members and physician a copy of the consent form.
- Become familiar with the procedure for signing the consent form at the time of death. Though you will not sign the consent form until after death occurs, it will be helpful to identify the method you will use.
- Request to place an information sheet that explains the procedures to follow at the time of death and an alert sticker in the patient's chart.
- Give your family members a copy of the procedures to be followed at the time of death.
- Find out who you need to call at the time of death and how to reach the appropriate person during the daytime, evening hours, weekends, or holidays.
- Discuss arrangements and costs involved with transportation of the body with the facility performing the autopsy.
- Contact the funeral director and explain that you are planning a brain-only autopsy for your family member.
- Notify the director or administrator, director of nursing, hospice nurse, and social worker of the nursing home or other institution of your plans for autopsy (if applicable).
- Notify the physician who will need to complete required paperwork.

Alzheimer's Disease Centers Autopsy Program Directory

The National Institute on Aging currently funds 30 Alzheimer's Disease Centers (ADC's) at major medical institutions across the Nation. Researchers at these Centers are working to translate research advances into improved care and diagnosis for Alzheimer's Disease (AD) patients while, at the same time, focusing on the program's long-term goal—finding a way to cure and possibly prevent AD.

Areas of investigation range from the basic mechanisms of AD to managing the symptoms and helping families cope with the effects of the disease. Center staff conduct basic, clinical, and behavioral research.

Each of the ADCs provides autopsy services to dementia patients and volunteers without dementia who are enrolled in clinical research studies and trials. Some of the ADCs offer autopsy services to a broader range of people in the community both with and without dementia.

Autopsies of non-demented persons and those in the early stages of AD are helping ADC



Alzheimer's Disease
Education & Referral Center
PO Box 8250
Silver Spring, MD
20907-8250
800-438-4380

researchers find the first signs of age-related brain changes and how they may differ from brain changes in early AD. Research of this type may lead to interventions that might help in the first stages of the disease.

For patients and families affected by AD, many ADC's offer:

- ◆ Opportunities for AD patients and those without dementia to volunteer to participate in drug trials and other clinical research projects.
- ◆ Diagnostic and medical management (costs may vary). Many Centers accept Medicare, Medicaid, and private insurance.
- ◆ Opportunities for AD patients and their families to participate in support groups and other special programs.

For more information, you may contact any of the Centers on the following list. While the name of the person who coordinates autopsies has been listed, you may ask for information about any of the activities described above and about offices and satellite clinics at other locations throughout the country.

For the most current listing of the ADCs visit the ADEAR Center's Web site at: <http://alzheimers.org/adear/adcdir.html>

ALABAMA

University of Alabama at
Birmingham (UAB)
South Birmingham, AL

Jo Self
Coordinator of UAB Brain Resource
Program
Telephone: 205-934-7359
[http://main.uab.edu/
show.asp?durki=11627](http://main.uab.edu/show.asp?durki=11627)

Cost: Free to those enrolled in ADC
research; \$425 for those not enrolled.

CALIFORNIA

Stanford University
Stanford, CA

Edna Chung
Brain Donor Program Coordinator
Telephone: 650-852-3234

Cost: Free to those enrolled in ADC
research.

University of California at Davis
Sacramento, CA

Mary Beth Stamps
Clinical Program Administrator
Telephone: 916-734-5496
[http://alzheimer.ucdavis.edu/
adc/autopsy.htm](http://alzheimer.ucdavis.edu/adc/autopsy.htm)

Cost: Free to those enrolled in
ADC research.

University of California at Irvine
Irvine, CA

Brian Cummings, Ph.D.
Outreach Scientist
Telephone: 949-824-5032
<http://www.alz.uci.edu/Repository.html>

Cost: Free to those enrolled in
ADC research.

University of California, Los
Angeles, Los Angeles, CA

Michael Mega, M.D., Ph.D.
Imaging Sub-Core Director
Telephone: 301-794-4001
<http://www.adc.ucla.edu/>

Cost: Free to those enrolled in ADC
research.

**University of California, San Diego
La Jolla, CA**

Mary Sundsmo, M.B.A.
Assistant Chief
Telephone: 858-622-5800
<http://adrc.ucsd.edu/>

Cost: Free to those enrolled in ADC research; \$1,500 for those not enrolled.

**University of Southern California
Los Angeles, CA**

Jenny Tang, M.S.
Program Specialist
Telephone: 323-442-1602
http://www.usc.edu/dept/gero/ADRC/neuro_dementia.htm

Cost: Free to those enrolled in ADC research.

FLORIDA

**Mayo Clinic
Jacksonville, FL**

Laura Makavrov, CRC
Francine Parfitt, M.S.H., CRCC, Director
Telephone: 904-953-7103
http://www.mayo.edu/research/alzheimers_center/

Cost: Free to those enrolled in ADC research. Transportation costs may apply in some cases.

Note: The ADC may make exceptions for others.

GEORGIA

**Emory University
Atlanta, GA**

Felicia D. Flagler, B.S.
Autopsy Coordinator
Telephone: 404-728-4881
<http://www.emory.edu/WHSC/MED/ADC/>

Cost: Free to those enrolled in ADC research and to those with a medical record at Emory; \$500 for others.

Note: Other community cases may be eligible who have made pre-arrangements and have sent medical records ahead of time.

ILLINOIS

**Northwestern University
Chicago, IL**

Laura Herzog, Ph.D.
MDRC Coordinator
Telephone: 645-695-2343
<http://www.brain.nwu.edu/core/endowment.htm>

Cost: Free to those enrolled in ADC research. Fee-for-service is available for others on a limited basis and costs approximately \$700.

Note: The State of Illinois funds 10 autopsies each year for patients not enrolled in ADC research.

**Rush-Presbyterian-St. Lukes
Medical Center
Chicago, IL**

Beth Howard, Brain Bank Coordinator
Danielle Werge, Study Coordinator
Telephone: 312-942-4463
http://www.rush.edu/patients/radc/brain_bank.html

Cost: Free to those enrolled in ADC research and to those who make pre-arrangements and send medical records ahead of time.

INDIANA

**Indiana University
Indianapolis, IN**

Francine Epperson, Research and Autopsy Coordinator
Telephone: 317-274-1590
<http://www.pathology.iupui.edu/ad/>

Cost: Free to those enrolled in ADC research. Fee-for service is available for others.

KENTUCKY

**University of Kentucky
Lexington, KY**

David R. Wekstein, Ph.D.
Associate Director
Telephone: 859-323-6040
<http://www.coa.uky.edu/>

Cost: Free to those enrolled in ADC research or in the ADC's Memory Disorders Clinic; \$700 for others at the University of Kentucky Pathology Department.

MARYLAND

**The Johns Hopkins Medical
Institutions
Baltimore, MD**

Dorothy Wickham, Administrator
Telephone: 410-955-5632
Web site: under development

Cost: Free to those enrolled in ADC research; approximately \$700 for others at the Johns Hopkins Pathology Department.

MASSACHUSETTS

**Boston University
Bedford, MA**

Judy DeCarteret, Administrator
Telephone: 781-687-2927
http://www.xfaux.com/Alzheimer/Brain_Quest.htm

Cost: Free to those enrolled in ADC research and others. Transportation costs may apply depending on distance.

Note: Brain donations accepted from out-of-State.

**Harvard Medical School/
Massachusetts General Hospital
Boston, MA**

John H. Growdon, M.D.
Telephone: 617-726-1728
Web site: under development

Cost: Free to those enrolled in ADC research.

Note: Brain donations accepted from others on a case-by-case-basis and fee-for-service varies.

MICHIGAN

**University of Michigan
Ann Arbor, MI**

Chris Campbell, Brain Bank Coordinator
Telephone: 734-764-5479
<http://www.med.umich.edu/madrc/neuropathology.html>

Cost: Free to patients enrolled in ADC research.

Note: Fee-for-service available from the University of Michigan Pathology Department and the Michigan Dementia Program Postmortem Network at: (<http://www.mdpm.msu.edu/>).

MINNESOTA

Mayo Clinic
Rochester, MN

Kris Johnson, R.N.
Telephone: 507-284-1324
http://www.mayo.edu/research/alzheimers_center/

Cost: Free to those enrolled in ADC research.

MISSOURI

Washington University
School of Medicine
St. Louis, MO

Jan Palmer
Telephone: 314-286-2683
<http://www.biostat.wustl.edu/adrc/index.html>

Cost: Free to those enrolled in ADC research.

NEW YORK

Columbia University
New York, NY

Arlene Lawton, R.N.
Autopsy Coordinator
Telephone: 212-305-9086
<http://pathology.cpmc.columbia.edu/taub/gift.htm>

Cost: Free to those enrolled in ADC research.

Mount Sinai School of
Medicine/Bronx VA Medical Center
New York, NY

Lucia Capitelli
Telephone: 718-579-0511
<http://www.mssm.edu/psychiatry/adrchome.html>

Cost: Free to those enrolled in ADC research.

Note: The ADC is affiliated with the Alzheimer's Disease and Schizophrenia Brain Bank operated by the Psychiatry Department of the Mount Sinai and Bronx VA Medical Center.

New York University
New York, NY

Sadia Faiz, M.D., M.P.H.
Autopsy Coordinator
Telephone: 212-263-5108 or 212-263-6262
<http://aging.med.nyu.edu/>

Cost: Free to those enrolled in ADC research.

University of Rochester
Rochester, NY

Eileen Johnson, R.N., M.S.N.
Nurse Clinician
Telephone: 716-760-6228
<http://www.urmc.rochester.edu/adrc/index.html>

Cost: Free to those enrolled in ADC research.

Note: For others, if the primary physician has privileges at Strong Memorial Hospital, there is no charge for the autopsy, but families pay for transportation.

NORTH CAROLINA

Duke University
Durham, NC

Mari Szymanski, R.N., C.
Nurse Coordinator
Telephone: 919-286-3228
Toll-free: 1-866-444-2372
<http://www.medicine.mc.duke.edu/adrc/BB.htm>

Cost: Free to those enrolled in ADC research.

OHIO

Case Western Reserve University
Cleveland, OH

Adrienne Schaffer
Research Operations Manager
Telephone: 216-844-6411
<http://www.ohioalzcenter.org/autopsy.htm>

Cost: Free to those enrolled in ADC research. Families of those **not** enrolled but who have been seen by an ADC physician will only pay for transportation; \$700 plus transportation for others.

OREGON

Oregon Health Sciences University
Portland, OR

Herlene Benson, M.P.A.
Brain Bank Coordinator
Telephone: 503-494-6923
<http://www.ohsu.edu/som-alzheimers/br-bank.html>

Cost: Free to those enrolled in ADC research; donation requested from others once the autopsy has been completed.

Note: The ADC is affiliated with the Oregon Brain Bank.

PENNSYLVANIA

University of Pennsylvania
Philadelphia, PA

Gayle Viale
Telephone: 215-662-4708
<http://www.med.upenn.edu/cndr>
<http://www.med.upenn.edu/ADC/>

Cost: Free to those enrolled in ADC research.

University of Pittsburgh
Pittsburgh, PA

Leslie Dunn, M.P.H.
Administrator
Telephone: 412-692-2700
<http://www.adrc.pitt.edu/>

Cost: Free to those enrolled in ADC research; \$600 to \$650 plus the cost of transportation for others.

TEXAS

Baylor College of Medicine
Houston, TX

Suzanne Powell, M.D.
Assistant Professor of Pathology
Telephone: 713-394-6486
<http://www.bcm.tmc.edu/neurol/struc/adrc/adrc5f2.html>

Cost: Free to those enrolled in ADC research. The hospital will assess the cost for others.

University of Texas, Southwestern
Medical Center, Dallas, TX

Doris Svetlik, R.N., M.S.
Administrative Director
Telephone: 214-648-7444
<http://www2.swmed.edu/alzheimer/>

Cost: Free to those enrolled in ADC research.

WASHINGTON

University of Washington
Seattle, WA

Nancy Brown
Research Study Coordinator
Telephone: 206-277-1491
<http://depts.washington.edu/adrcweb/>

Cost: Free to those enrolled in ADC research. Transportation costs may apply depending on travel distance.

Caregiver Resources

New from the National Institute on Aging

Alzheimer's disease puts enormous demands and stress on the caregiver. Caregiving takes an incredible amount of time and energy, so that taking care of oneself can also become challenging. Caregivers may not recognize their own needs, and even when they do, they don't always know where to find help. The following new resources from the National Institute on Aging (NIA) may help caregivers protect their health and contribute to their own well being.



NIA Exercise Kit: A Video and Guide

Exercise provides great physical and emotional health benefits. Regular exercise is especially important for people coping with the extra stresses of caregiving. The NIA Exercise Kit includes a 48-minute videotape and a 100-page guide that promotes the benefits of physical activity for older people and explains safe exercise while showing the viewer how to do strength and balance exercises properly. Led by Margaret Richard—from PBS's exercise show, *Body Electric*—the video begins by explaining the basics of exercise and includes four components of a complete exercise program: endurance or aerobic activities, strength exercises, balance exercises, and stretching exercises. The exercise portion of the video consists of a gentle warm-up, strength and balance exercises, and a cool-down and final stretch.

Throughout the video, Ms. Richard focuses on safety and proper form, and she gives information about how to adapt the exercises to the individual's ability. The guide parallels the video, explaining the benefits of exercise and offering safety precautions for various chronic illnesses. It includes illustrations of the exercises with safety tips, nutrition information, charts to track progress and target heart rate, and a list of resources.

To order the NIA Exercise Kit containing a VHS videocassette and guide, send a check or money order (prepaid orders only) for \$7.00 to: NIA Information Center Dept. C, PO Box 8057, Gaithersburg, MD 20898-8057.

For those who would like to receive just the guide, a single free copy is available from the NIA Information Center at 800-222-2225 or 800-222-4225 (TTY); or fax or mail the order form on the back of this newsletter.

Who? What? Where? Resources for Women's Health and Aging

Most caregivers are women, usually wives and daughters. Women who are AD caregivers may likely be at a time of life, at menopause or after, when they need to pay close attention to their own health. *Who? What? Where? Resources for Women's Health and Aging* is a 36-page booklet from the NIA and the Alliance for Aging Research. It provides current telephone numbers, addresses, and Web sites for nearly 100 organizations that can be of help with osteoporosis, menopause, nutrition, depression, and taking medications, as well as caregiving, sexuality, injury prevention, finances, and widowhood.

To order a free copy of *Who? What? Where? Resources for Women's Health and Aging*, call the NIA Information Center toll-free at 800-222-2225; 800-222-4225 (TTY); or fax or mail the order form on the back of this newsletter.

Coping With Emotions and Stress: A Resource List for AD Caregivers

Timely resources for caregivers are included in this revised ADEAR Center publication. It includes personal accounts that may help caregivers prepare and cope with the challenges of caring for a person with AD.

Coping With Emotions and Stress: A Resource List for AD Caregivers gives an overview of many available books, articles, guides, videos, and audiocassettes about coping with AD. Twenty resources are listed that fit into four categories: caregiver coping, coping when a spouse or parent has AD, humor and positive attitude, and spirituality and coping.

A full description and ordering information are given for each resource listed. Examples include: *Alzheimer's Sourcebook for Caregivers: A Practical Guide for Getting Through the Day*; *Do I Know You?: Living Through the End of a Parent's Life*; *Magic of Humor in Caregiving*; and *God Never Forgets: Faith, Hope, and Alzheimer's Disease*.

All of the items included in *Coping With Emotions and Stress: A Resource List for AD Caregivers* have been reviewed for relevance, accuracy, timeliness, and importance. Readers may be able to borrow or rent some of the items in the resource list from a local Alzheimer's Association chapter, hospital, or library. Otherwise, they can be purchased from the organization listed in the "available from" section of each entry.

To receive a free copy of the resource list, call the ADEAR Center, toll-free, at 800-438-4380; or fax or mail the order form on the back of this newsletter.

Update: NIA Clinical Trials Database

As reported in *Connections Summer/Fall 1999*, the NIA, in conjunction with the U.S. Food and Drug Administration, has launched an Alzheimer's Disease Clinical Trials Database of AD studies in progress at sites across the United States. The Database now includes 13 trials currently recruiting participants.

Each trial in the Alzheimer's Disease Clinical Trials Database includes information about the sponsoring organization, a description of the purpose, eligibility requirements, design of the trial, and a list of sites where the research will be conducted. Some trials have direct electronic links to scientific articles that form the basis of the trial.

As of March 2000, all trials in the Alzheimer's Disease Clinical Trials Database also are posted on ClinicalTrials.gov, a comprehensive listing of clinical studies sponsored by the NIH, other Federal agencies, the pharmaceutical industry, and nonprofit organizations. ClinicalTrials.gov is provided through the NIH's National Library of Medicine.

You can access the Alzheimer's Disease Clinical Trials Database on the ADEAR Center's Web site at: www.alzheimers.org. Click on the link for "Clinical Trials." This page can be searched by location, type of therapy, study characteristics, and entry requirements. On this page, you may sign up to receive online updates about new clinical trials and information on drug developments.


The following two trials are actively recruiting participants:

NINDS AD Clinical Trial

Researchers at the National Institutes of Neurological Disorders and Stroke (NINDS), NIH, are seeking adults diagnosed with AD, aged 50

to 89, for a research study. The study is intended to find out whether a new experimental drug, nefiracetam, improves memory and/or slows the progression of AD. To be eligible to take part in the study, adults must be otherwise healthy. Participants must have a companion to help monitor their progress in the study. The study is free of charge and takes place at the NIH Clinical Center in Bethesda, Maryland. For more information, please call the NIH Clinical Studies Call Center at 800-411-1222 and ask for the NINDS AD study.

NIA's Alzheimer's Disease Anti-Inflammatory Prevention Trial (ADAPT)

The NIA is sponsoring a nationwide trial looking at the effectiveness of certain nonsteroidal anti-inflammatory drugs (NSAIDs) to delay or prevent the onset of AD. The study, which will begin recruiting in January 2001, will take place over a period of several years. Investigators will follow participants and monitor whether those taking NSAIDs such as naproxen or celecoxib are less likely to develop AD. Adults age 70 and older may be eligible to enroll if they have no current diagnosis of dementia, senility, or AD, and have a blood relative such as a parent or sibling with a history of dementia. About 2,800 participants are needed. The study will take place in the following cities: Baltimore, MD, Boston, MA, Rochester, NY, and Sun City, AZ. Information on patient recruitment for this trial is available through the ADEAR Center at: 800-438-4380. 



Pressure Points: Alzheimer's and Anger

Caregivers experience a wide variety of emotions: grief, sadness, uncertainty, love, joy, frustration. Less discussed, but often experienced, is anger. *Pressure Points: Alzheimer's and Anger* by Edna L. Ballard, MSW, ACSW, Lisa P. Gwyther, MSW, LCSW, and T. Patrick Toal, MSW, is a new guide from the Joseph and Kathleen Bryan Alzheimer's Disease Research Center at Duke University Medical Center.

In 70 easy-to-read pages, *Pressure Points: Alzheimer's and Anger* discusses such issues as setting limits, managing anger, identifying risk factors for anger in AD care, and what to do when children or professionals get angry at the person with AD. It offers tangible steps to take for responding appropriately instead of abusively when angry. This booklet is full of personal vignettes from participants in AD support groups at the Duke Family Support Program. They share helpful techniques for coping and enlightening anecdotes about caring for a loved one with AD.

Caregivers, family members of AD patients, pastors, and health professionals may benefit from this new publication. Physicians may want to suggest it to family members and other caregivers.

Pressure Points: Alzheimer's and Anger is available from the ADEAR Center for \$12.50. To order the book, send a check or money order (prepaid orders only) for \$12.50 to the ADEAR Center, PO Box 8250, Silver Spring, MD 20907-8250.

CHID Highlights Fall 2000

Autopsy

Brain Autopsy: A Guide for Funeral Directors.

Chicago, IL: Alzheimer's Association. 1999. 2 p.

Available from the Alzheimer's Association. 919 North Michigan Avenue, Suite 1100, Chicago, IL 60611-1676. (800) 272-3900; FAX: (312) 335-1110. Internet: <http://www.alz.org>. PRICE: 1 copy free. \$8 per 100. Contact your local Alzheimer's Association chapter. Item Number: PF211Z.

This document is designed to help funeral directors work with families who request a brain autopsy for a family member with Alzheimer's disease. First, it outlines the reasons why families may request a brain autopsy, including confirmation of diagnosis, research advancement, and accurate reporting. Then, it answers some of the questions families may have about whether a brain autopsy can cause disfigurement, whether it will delay funeral arrangements, how long it will take to get the results, how much it costs, and whether the organs can be donated. Finally, it suggests ways the funeral director can assist families when the necessary pre-arrangements have, and have not, been made.

You Can Give the Gift of Knowledge.

Los Angeles, CA: University of California Los Angeles. 1999.

Available from the University of California Los Angeles. Alzheimer's Disease Center, 760 Westwood Plaza, Los Angeles, CA 90024-9972. (310) 206-5238; FAX: (310) 206-5287. Internet: <http://www.adc.ucla.edu>. PRICE: Free.

This brochure produced by the

University of California, Los Angeles (UCLA) Alzheimer's Disease Center (ADC), is primarily for families of Alzheimer's disease patients in southern California, but also may be of interest to families in other geographic areas. The brochure addresses concerns of many families, including costs, whole-body donations, embalming, and whether autopsies delay funeral plans or permit open caskets. It also explains what information researchers can gain from autopsy results. Contact information for the autopsy program at the UCLA ADC is included. This brochure is available in English and Spanish.

Caregiver Resources

Steps To Understanding Financial Issues: Resources for Caregivers.

Chicago, IL: Alzheimer's Association. 1999. 23 p.

Available from the Alzheimer's Association. 919 North Michigan Avenue, Suite 1100, Chicago, IL 60611-1676. (800) 272-3900; FAX: (312) 335-1110. Internet: <http://www.alz.org>.

PRICE: 1 copy free. \$20 per 100. Contact your local Alzheimer's Association chapter.

This brochure discusses the financial issues that people with Alzheimer's disease and their families may face. The first section lists the legal and financial documents that should be collected and reviewed and explains how to talk about financial issues with the person who has AD, other family members, and professionals. The second section looks at potential expenses and autonomy when deciding how

to structure the loved one's finances. The third section considers a range of financial resources such as insurance—health care, disability, long-term care, and life insurance; personal resources—employment, employee benefits, retirement benefits, and investment assets; government assistance—Social Security Disability Income, Supplemental Security Income, Medicaid, veteran's benefits, State and local programs, and tax benefits. It also discusses financial help from the caregiver and other family members, and community resources.

Who? What? Where?: Resources for Women's Health and Aging.

Washington, DC: Alliance for Aging Research. Bethesda, MD: National Institute on Aging. 2000. 36 p.

Available from the National Institute on Aging Information Center. PO Box 8057, Gaithersburg, MD 20898-8057. (800) 222-2225; TTY: (800) 222-4225; FAX: (301) 589-3014. Internet: <http://www.nib.gov/nia>. PRICE: Free.

This booklet focuses on health-related issues critical to women as they age. Topics include age changes and health promotion, common disorders of later life, taking charge, and research on women's health. A special section highlights Alzheimer's disease and other brain disorders that affect older women. A list of helpful strategies for caregivers of older people is included. Also included are lists of resources, support groups, organizations, and suggested readings with each topic.

Caregiving Strategies

Alzheimer's Caregiving Strategies.

Minneapolis, MN: HealthCare Interactive, Inc. 1998.

Available from HealthCare Interactive. P.O. Box 19646, Minneapolis, MN 55419. (888) 824-3020. PRICE: \$29.95 plus \$5.00 shipping and handling.

This interactive program on CD-ROM is intended for caregivers of people with Alzheimer's disease and related dementias. The CD-ROM is divided into six sections. The first section explains how to effectively use the program. The second section provides basic information on dementia, including symptoms, causes, diagnosis, treatment, and disease progression. Caregiving is the focus of the third section; topics discussed include enhancing caregiving skills, managing caregiver stress, and caring for the caregiver. In the fourth and fifth sections, users determine the functional level of the person they are caring for and receive caregiving tips based on functional ability. An assessment scale ranges from one to six, with one representing normal functioning, and six representing a bedridden person who requires complete care. To determine functional level, caregivers can view videos of patients at each level and read about common symptoms. The final section includes advice from professionals and caregivers on issues such as behavior management and nursing home placement.

Reaching Communities With Alzheimer's Education: A Comprehensive, Advanced Train-the-Trainer Manual. Second Edition.

Marks Carlson, D.; Foster, B. Reno, NV: Eymann Publications. 2000. 488 p.

Available from Eymann Publications. PO Box 3577, Reno, NV 89505. (800) 354-3371; FAX: (702) 358-1476. Internet: <http://www.care4elders.com>. PRICE: \$189.95.

This manual is intended to help professional caregivers train colleagues, family members, and community members about Alzheimer's disease and the caregiving process. The manual contains didactic and case-simulated clinical experiences, which can be used in a variety of settings, a brief summary of adult teaching and learning principles, background on family issues, and basic and advanced-level information about AD and creative caregiving strategies. It is divided into 11 freestanding units that build upon one another; elements from any unit can be used separately. The unit topics include the following: adult teaching and learning principles; understanding AD and other dementias; providing care for individuals with AD in various settings; family issues; applying meaningful communication techniques with individuals who have AD; assessment and management of challenging behaviors and medication use; enhancing personal, physical, and nutritional care; principles of therapeutic 24-hour programming; terminal care; and legal and ethical issues in advanced AD. It also includes units on caring for professional and family caregivers. The final section offers selected resources for AD training materials. Ninety-six handouts and 53 transparencies are included.

Diagnosis and Treatment

Diagnosis, Management and Treatment of Dementia: A Practical Guide for Primary Care Physicians.

Chicago, IL: American Medical Association. 1999. 47 p.

Available from the American Medical Association. Program on Aging and Community Health. 515 North State Street, Chicago, IL 60610. (312) 464-5563. Internet: <http://www.ama-assn.org>. PRICE: \$5 for non-AMA members, \$3 for AMA members. ISBN: 1579470866.

This AMA-accredited continuing medical education booklet is intended to teach primary care physicians about the management of dementia and working with AD patients and their families. It includes sections on making the diagnosis and informing patients, managing comorbid conditions, and treating cognitive problems. It details ways of making the office visit more comfortable, supporting family caregivers, handling concerns about driving and wandering, and preventing and responding to elder abuse. It also addresses community resources for people with dementia and their families and end of life issues. The booklet has lists of educational resources, 14 references, and a selected bibliography.

Dementia in Primary Care.

London, England: Alzheimer's Disease International. 1999.

Available from Alzheimer's Disease International. 45/46 Lower Marsh, London, SE1 7RG, United Kingdom. +44 20 7620 3011; FAX: +44 20 7401 7351. Internet: <http://www.alz.co.uk>. PRICE: Free.

This videotape is for primary care physicians who diagnose and treat various dementias. The first section explains how to screen for dementia using the Abbreviated Mental Test. The second section discusses the role an informant (friend, relative, neighbor, or spouse) plays in the dementia screening. It describes how informants may help the physician assess the patient's functional and behavioral status. The third section covers differential diagnosis of the three most common dementias: Alzheimer's disease, vascular dementia, and dementia with Lewy bodies. The fourth section covers the pharmacologic management of these dementias and treatment of concurrent conditions, such as depression. The final section describes how primary care physicians can assist caregivers; topics include the physician-caregiver relationship and referring caregivers to support groups and other community resources.

Family Caregiving

Alzheimer's: A True Story.

Princeton, NJ: Films for the Humanities and Sciences. 1999.

Available from Films for the Humanities and Sciences. PO Box 2053, Princeton, NJ 08543-2053. (800) 257-5126, (609) 275-1400; FAX: (609) 275-3767. Internet: <http://www.films.com>. PRICE: \$149.00 (purchase), \$75.00 (rental).

This documentary chronicles the mental deterioration of Malcolm, a

husband, father, professor, and gifted pianist, who was diagnosed with Alzheimer's disease in 1992 at age 51. The film tells of his first symptoms as chronicled in his journal then tracks their progression until his death in 1999. Barbara, his wife and primary caregiver, expresses her feelings about the changes in her husband. She experiences physical and emotional strain in dealing with his personality changes and losses in everyday functioning. She turns to respite care, and eventually, nursing home placement. Music therapy proves useful until he no longer is able to play the piano. This documentary shows Malcolm's relationships with his family in a very realistic manner, depicting Barbara's unyielding commitment to her husband.

Family Caregiver's Guide to Planning and Decision Making for the Elderly.

Wilkinson, J. A. Minneapolis, MN: Fairview Press. 1999. 260 p.

Available from Fairview Press. 2450 Riverside Avenue, Minneapolis, MN 55454-1400. (800) 544-8207. EMAIL: press@webex.fairview.org. PRICE: \$16.95. ISBN: 1577490770.

This book is a family caregiver's tool for planning and decision making for older people. It includes practical advice, forms, and checklists that caregivers can use to collect and organize information needed to make informed decisions. It addresses home safety, financial planning, medical history, medications, home healthcare and other services, Medicare and Medicaid, assisted-living and other housing options, powers of attorney, living wills, long-distance caregiving, types of health professionals, key documents, and support networks. A list of eldercare organizations and other community resources, hotlines, and helpful Internet sites are included.

Special Care Units

Performance Improvement in Long Term Care, Subacute Programs, and Dementia Special Care Units.

Oakbrook Terrace, IL: Joint Commission on Accreditation of Healthcare Organizations. 1998. 163 p.

Available from the Joint Commission on Accreditation of Healthcare Organizations. One Renaissance Boulevard, Oakbrook Terrace, IL 60181. (630) 792-5800. Internet access:

<http://www.jcabo.org>. PRICE: \$40.00. ISBN: 0866885900.

In this book, the Joint Commission on Accreditation of Healthcare Organizations presents a framework for performance improvement and its application in long-term care, subacute programs, and dementia special care units. The first chapter provides an overview of the history and basic principles upon which the framework is built and its primary components: the external environment, the internal environment, and the cycle for improving performance. The subsequent five chapters explore each stage of the improvement cycle, which include designing new processes, measuring how these processes perform, assessing data about performance, and improving performance based on this assessment. Each chapter includes examples adapted from experiences in actual long-term care facilities, dementia special care units, and subacute programs across the country. Appendices contain information about teamwork skills essential to improvement efforts and a sample of performance-monitoring forms.



February 8-9, 2001

Alzheimer's 2001: Translating
Science to Practice
Durham, NC

Contact:

Bryan Alzheimer's Disease Research
Center
Box 3600
Duke University Medical Center
Durham, NC 27710
919-660-7510

February 23-26, 2001

American Association for Geriatric
Psychiatry Annual Meeting (AAGP)
San Francisco, CA

Contact:

American Association for Geriatric
Psychiatry
7910 Woodmont Avenue,
Suite 1050
Bethesda, MD 20814
301-654-7850 ext.106

March 8-11, 2001

First Annual Conference of
American Society on Aging and
The National Council on The Aging
New Orleans, LA

Contact:

American Society on Aging
833 Market Street,
Suite 511
San Francisco, CA 94103-1824
415-974-9600

March 8-11, 2001

Council on Social Work Education
Annual Program Meeting:
Workshops on Aging
Dallas, TX

Contact:

Council on Social Work Education
1725 Duke Street, Suite 500
Alexandria, VA 22314-3457
703-683-8080

March 27-30, 2001

National Conference of the
Alzheimer's Association of Australian
Capitol Territory: Together on a
Journey
Canberra ACT, Australia

Contact:

Secretariat of the National
Conference of the Alzheimer's
Association of Australian Capitol
Territory - ConSec
PO Box 3127
Belconnen Delivery Centre
ACT 2617 Australia
61-2-6251-0675 (phone)
61-2-6251-0672 (fax)

April 21-24, 2001

American Association of
Neuroscience Nurses 33rd Annual
Meeting
San Francisco, CA

Contact:

American Association of
Neuroscience Nurses
4700 West Lake Avenue
Glen View, IL 60025-1485
888-557-2266

May 9-13, 2001

American Geriatrics
Society/American Federation for
Aging Research Annual Scientific
Meeting
Chicago, IL

Contact:

American Geriatrics Society
770 Lexington Avenue, Suite 300
New York, NY 10021
212-308-1414

July 15-18, 2001

10th National Alzheimer's Disease
Education Conference:
New Directions in Alzheimer Care
Chicago, IL

Contact:

Alzheimer's Association
919 North Michigan Avenue,
Suite 1100
Chicago, IL 60611-1676
800-272-3900 or 312-335-5790





**NATIONAL INSTITUTE ON AGING
NATIONAL INSTITUTES OF HEALTH**

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31 CENTER DR MSC 2292
BETHESDA, MD 20892-2292

Order Form

Alzheimer's Disease Education and Referral Center

- Coping with Emotions and Stress: A Resource List for AD Caregivers (R-09)

National Institute on Aging Information Center

- Who? What? Where? Resources for Women's Health and Aging (HP-11)
 Exercise: A Guide from the NIA (NIA-48)

You may ask the ADEAR Center for a topical search (a list of materials) on another subject related to Alzheimer's disease. Outline the subject for your search in the space below.

To ensure that we can contact you with any questions regarding the search, please provide a daytime telephone number: (____) _____.

Name: _____

Title: _____

Organization: _____

Address: _____

- Check here if you are a health professional or a professional caregiver and would like your name added to the ADEAR Center mailing list to receive future issues of *Connections*.

To order any of the above materials send this page to:

ADEAR Center, PO Box 8250, Silver Spring, MD 20907-8250

You also may call our toll-free telephone number: 800-438-4380; reach us by fax: 301-495-3334; or contact us on the Internet: e-mail = adear@alzheimers.org and Web site = <http://www.alzheimers.org>