

CONNECTIONS

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Early Results from Alzheimer's Disease Neuroimaging Initiative (ADNI)

Researchers may be able to reduce the time and expense associated with clinical trials, according to early results from the Alzheimer's Disease Neuroimaging Initiative (ADNI), a public-private research partnership organized by the National Institutes of Health. ADNI researchers are using serial magnetic resonance imaging (MRI); positron emission tomography (PET) scans; measurement of various biological compounds in blood, cerebrospinal fluid, and urine; and clinical and neuropsychological assessments to track mild cognitive impairment (MCI) and early AD progression.

ADNI researchers will compare neuroimaging, biological, and clinical information from the participants, looking for correlations among the data to develop

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In remembrance of two leading Alzheimer's researchers:

Dr. Leon Thal (1944-2007)

Dr. Leonard Berg (1927-2007)

Legal and Financial Planning for the AD Patient: How the Health Care Team Can Help

A diagnosis of Alzheimer's disease (AD) all too often finds the patient and caregiver unprepared to deal with the important legal and financial decisions that eventually will need to be addressed. Indeed, many people have not taken time to plan ahead to communicate their wishes clearly if a major neurodegenerative disease strikes, according to recent national surveys. Even if a person has taken some of the necessary steps to create planning documents, chances are these plans need to be thoroughly reviewed and updated in light of a diagnosis of dementia.

Over time, cognitive decline strips AD patients of the ability to think clearly and make major decisions. Ideally, major legal and financial decisions should be made before judgment and emotion are clouded, when the person with AD can think clearly and can still make decisions. Of course, no one plans



to get AD. It is usually not until after a diagnosis of AD that most patients and families address legal and financial issues, such as making a will, creating a living trust, and adopting advance directives.

The news of a diagnosis can prompt many strong emotions in patients and families. The health care team can use its unique position of trust and influence to find the right emotional context to convey the importance of basic legal and financial planning. To introduce concepts of advance legal and financial planning early on, professionals must use their training and experience to identify a time when patient and caregiver

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Planning

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can begin to absorb this vital information. Treatment plans can include discussions that go beyond the medical and behavioral symptoms of the disease. The health professional team also may need to initiate these discussions a number of times before family members are able to process and act upon the information.

Start Discussions Early

Because the rate of cognitive decline is unpredictable and can differ for each patient, experts agree that health care professionals should advise patients and families about their legal and financial options as soon after initial diagnosis as possible. Advance



planning with early-stage AD patients can often involve the patient, caregiver, and family members in the decision-making process. The early-stage AD patient is still often mentally capable of understanding many aspects and consequences of difficult issues. But this is often also a time when certain defense mechanisms, such as denial, may be strongest.

"The days and weeks after an AD diagnosis are a time when patients and caregivers are coming to grips with a number of issues of immediate and high priority. It is also a time of emotional stress. We can use our experience and

professional judgment to gauge when it's right to introduce the concept of advance planning for newly diagnosed AD patients and their caregivers. We cannot act as their legal or financial advisors, but we can encourage patients and families to make well-informed decisions about future health care choices, financial arrangements, and end-of-life care while the AD patient is able to participate in the decisions," commented David Knopman, M.D., Department of Neurology at the Mayo Clinic's Alzheimer's Disease Center.

These discussions can provide a plan, address potentially troubling situations, and reduce stress and daily emotional pressures. Some experts say that involving the person with AD and the family in advance planning gives them a way to feel more in control and take care of "unfinished business." That said, however, it is necessary to make sure the recently diagnosed person is emotionally stable and has grasped the significance of the diagnosis before legal and financial discussions can begin.

"The newly diagnosed patient with AD may sometimes lack the ability to make decisions. Not all patients are at the very mild stage when they are diagnosed. While we want to encourage as full participation in planning as possible, it is also important to realize that some patient decisions may already be problematic from a capacity



standpoint," says Daniel Marson, J.D., Ph.D., Professor of Neurology, and Director, Alzheimer's Disease Research Center, University of Alabama at Birmingham. "Nonetheless, the patient's participation and, where appropriate, assent should be solicited even if legally he/she is no longer the decision maker in a particular matter." Dr. Marson also recommends that, where possible, advance planning actually begin prior to dementia diagnosis—at the mild cognitive impairment (MCI) stage or even before. Dr. Marson notes that most MCI patients "will likely retain decisional autonomy in most areas and will have only modest cognitive impairments interfering with their participation in planning."

Many planning decisions are integrally related to whether or not the patient remains legally capable (has "capacity") of making particular kinds of decisions. It is the legal profession and in particular judges who ultimately make these legal determinations. However, clinicians with expertise in both AD and capacity can carry out clinical evaluations of capacity in these patients, and provide guidance to patients, families, the care team, and attorneys and judges. For more information on legal capacity, see the American Bar Association listing at the end of this article.

Who Can Help?

Attorneys—There are many good reasons to retain the services of a lawyer when preparing advance planning documents. For example, a lawyer can help interpret different State laws and suggest ways to ensure that the patient's and family's wishes are carried out. It's important to understand that laws vary by State, and that changes in situation, for instance, a divorce,



relocation, or death in the family, can influence how documents are prepared and subsequently maintained. Experts urge families to remember that changes in circumstances as well as State laws may require periodic document updates, and it's good practice to review these documents every few years anyway.

"Once a person has been diagnosed with AD, we recommend that the person and his or her family seek the advice of an elder law attorney—a lawyer qualified to handle the special legal needs of older people—to devise plans. For instance, an attorney can help people understand what Medicare will and will not cover, how to cover expenses like long-term care, and the differences between skilled and custodial care. An elder law attorney can also provide advice to help the well spouse avoid becoming impoverished while trying to care for an ill loved one," commented Ronald Fatoullah, a New York attorney with the National Academy of Elder Law Attorneys. The Academy and the American Bar Association can help families find a qualified lawyer. See the Resources section at the end of this article for contact information.

Geriatric Care Managers—

Geriatric care managers can be another resource in dementia care. These professionals usually are trained as social workers and/or are licensed nurses. They can help the person with AD and the family

discuss sensitive or difficult topics. Geriatric care managers also can help families:

- evaluate in-home care facilities and logistics
- select and evaluate in-home care personnel
- make referrals and coordinate medical services.

In addition, they can serve as a liaison between the person with AD and his/her caregivers, and other family members. They are trained to work with complex family situations and relationships and can help discuss emotional concerns, such as loss or grief. Geriatric care managers can also facilitate family discussions about short-term and long-range planning, living arrangements, and relieving caregiver stress. For more information on geriatric care managers, see the Resources section at the end of this article.

Legal, Financial, and Health Care Planning Documents

When families begin the legal planning process, there are a number of strategies and legal documents they will need to discuss. Depending on the family situation and the applicable State laws, some or all of the following terms and documents may be introduced by the lawyer hired to assist in this process. Broadly speaking, these documents can be divided into two groups:

- documents that communicate the health care wishes of someone who may no longer be able to make health care decisions, and
- documents that communicate the financial management and estate plan wishes of someone who may no longer be able to make such financial decisions.

Health Care Planning

Advance directives for health care communicate the health care wishes of a person who can no longer make health care decisions. These documents must be prepared when the individual still has legal capacity to execute them. Advance directives for health care include **Living Wills**, the **Durable Power of Attorney for Health Care** (sometimes referred to as a **Health Care Proxy**), and **Do Not Resuscitate** orders.

A **Living Will** is a record of a person's wishes regarding specific medical circumstances and treatment at or near the end of life. It can specify future decisions about life-sustaining treatment and major health care decisions when the patient becomes terminally ill or permanently unconscious.

"The Living Will creates the legal framework for a terminal patient to die with dignity and protects the physician or hospital from liability for withdrawing or limiting life support," says Jason Karlawish, M.D., of the University of Pennsylvania Alzheimer's Disease Center. "Perhaps one of the most important things a person can indicate in a living will is how much leeway or discretion is given to the trust proxy over decisions. Most people would



like their trust proxy to exercise some discretion over decisions. The key then is thinking about what kinds of values and considerations should guide that discretion."

A Durable Power of Attorney for Health Care

is a document in which an individual designates an agent, or proxy, to make future medical and other health care decisions, when the individual is no longer capable of doing so. While most regular powers of attorney become invalid upon the mental incapacity of the executor, this document in contrast, because of its "durability," continues in effect. A Durable Power of Attorney for Health Care can be highly detailed in its instructions and can carefully limit the scope of action of the agent. Some



of these go into effect immediately upon execution, while others, called "springing," only go into effect upon the occurrence of a future defined event (often formal clinician determination of incapacity of the individual).

Depending on how the Durable Power of Attorney for Health Care is drafted, the agent can have the "final say" regarding everything from minor health concerns to major medical decisions. For example, agents can be given authority to:

- discharge health care providers
- remove the patient from an institution
- choose to refuse or agree to various treatments



- have access to medical records
- make decisions about making anatomical gifts.

The agent should be someone who understands the needs of the patient. Ideally, the agent is a person who can be flexible and stay calm under pressure and the ever-changing dynamics of illness. Depending on what the patient specifies and the legal requirements of the State in which the patient lives, the agent can decide whether the person with AD will end life at home or in a professional facility.

Agents also can be legally empowered to make decisions about starting, continuing, or discontinuing life support if the patient has not specified such wishes in a living will. Life support for an AD patient often involves the question of whether to use a feeding tube. "We generally don't recommend enteral nutrition and hydration at the end of life. It can be uncomfortable for the patient, and there is little if any evidence that it effectively treats common problems such as aspiration, skin breakdown, and infections," said Dr. Karlawish.

Choosing an alternate health care agent is a good idea, in case the primary agent is unavailable. In this connection, the Health Information Portability and Accountability Act

(HIPAA) of 1996 sets rules and limits about who can access private medical information. Each person must state in writing who is allowed to view and obtain medical records in the event that he or she is no longer capable. Without written permission, the agent, alternate agent, family members, or other health professionals will have difficulty obtaining records needed to make informed health care decisions.

The **Do Not Resuscitate** order is a document that instructs health care staff, including emergency medical technicians, not to perform life-saving treatments or other heroic measures (for instance, cardiopulmonary resuscitation) in medical situations where they could be used.

Financial Management and Estate Planning

Planning documents for financial management communicate the financial and estate plan wishes of a person who may be unable to make such decisions. Financial management documents include the **Durable Power of Attorney for Finances**, **Wills**, and **Living Trusts**. Each of these documents must also be prepared and executed when the individual still has legal capacity.

A Durable Power of Attorney for Finances

is a document in which an individual designates an agent, or proxy, to make financial decisions on his/her behalf—again often at a time in the future when the individual is no longer capable of making such decisions. It is durable and is explicitly intended to survive the incapacity of the individual. This document should be carefully drafted to give the agent the necessary powers to carry out the financial affairs of the individual. The Durable Power

of Attorney for Finances can provide patients and families a great deal of flexibility in managing financial matters, and in the right circumstances, it can help them avoid the need for court conservatorship and judicial oversight of financial affairs. They can go into effect upon execution or be springing.

A **Will** is the most familiar financial planning document. It indicates



how a person's assets and estate will be distributed among beneficiaries (heirs) after his/her death. Instructions found in a Will include naming how dependent minors are to be cared for, spelling out specific gifts, creating trusts to manage the estate, and providing funeral or burial instructions. An individual must have "testamentary capacity" (the legal ability to make a Will) in order to create a valid Will. Although testamentary capacity is generally viewed in a liberal way by the courts, it is important that the newly diagnosed patient with AD and his/her family move quickly to make or update a Will and secure his/her estate.

A third financial planning document is the **Living Trust**. In a Living Trust, a "grantor" creates a Trust and designates a person to serve as trustee and follow the Trust's terms after the grantor dies. The trustee manages assets for a

beneficiary (often the grantor) and has a legally enforceable fiduciary duty towards the beneficiary. The Trust is called "Living" because it is created while the grantor is living and not at his/her death. While alive, the grantor usually may serve as a trustee and control the assets even though they belong to the Trust.

The main advantages of a Living Trust are that it can encompass a wide range of property, provide a detailed plan for its disposition after the grantor's death, and avoid the expense and delay of probate for wills. A Living Trust can also state where property should be distributed when the last beneficiary dies or whether the trust continues to exist for the benefit of others. The trustee can also be named as the health care agent through a Durable Power of Attorney for Health Care. Experts advise that extra care should be taken to ensure that the transfer of assets after death will take place, rather than being left in an account after the death of the person creating the trust. They also recommend naming an alternate trustee.

Revisit Plans Over Time

The AD patient and caregivers may need time to consider and sort through the health care team's planning advice. "Because there are so many challenges facing the patient and family, we need to recognize that one conversation about advance planning may not be enough. We should revisit the issue from time to time with the family and with the patient, if feasible, and reiterate to them that advance plans can and should evolve as situations change, all the while realizing that the patient's ability to participate meaningfully in such meetings will decline over time," commented Dr. Knopman.

Advance Planning Regarding Funeral Arrangements

The family of a person with AD also may want to consider advance planning for the funeral. As difficult as these topics may be for everyone—including the health care professional—to discuss, and although it may be several years until end-stage AD, experts say that advance planning for death can provide a sense of peace and help reduce anxiety or a sense of urgency.

Resources for Low-Income Families

Low-income families who cannot afford the services of a private lawyer can still do some advance planning, particularly in the area of health documents. The basic health planning documents, though they may vary from State to State, use terminology and instructions that are fairly consistent. Document templates can often be downloaded from State government Web sites, and legal advice or help may be available from local Area Agency on Aging officials. Other sources of legal assistance for low income families include State legal aid bureaus, the State Bar Association, local nonprofit agencies, foundations, or social service agencies that provide umbrella services and may be able to provide referrals to organizations that offer reduced-fee or free services.



Legal & Financial Planning Documents



Medical Document	How It is Used
Durable Power of Attorney for Health Care	Gives a designated person the authority to make health care decisions on behalf of the patient.
Living Will	Describes and instructs health care staff how the patient wants end-of-life health care managed.
Do Not Resuscitate Form	Instructs health care staff not to perform specified life-saving or other heroic measures.
Legal/Financial Document	
Will	Indicates how a person's assets and estate will be distributed among beneficiaries after his/her death.
Durable Power of Attorney for Finances	Gives a designated person the authority to make legal/financial decisions on behalf of the patient.
Living Trust	Describes how the patient wants to allocate funds and settlements.

Ethical Wills

An increasingly popular, but not legally binding, document is the Ethical Will. Ethical Wills are written statements by people who are dying. The Ethical Will imparts end-of-life wisdom about what the person has gleaned from life. The Ethical Will often completes "unfinished business" and ties up loose ends. These documents thus serve as a testament to the person's philosophy of life. To an early-stage AD patient, an Ethical Will provides the opportunity to reflect on life, share values, restate principles, convey hopes, impart lessons learned, and provide details on family culture and background.

Summary

Facing AD is difficult and can be emotionally wrenching for all concerned. At some point soon after the diagnosis, the health care team can help the patient and family begin thinking about and addressing many end-of-life issues. Facilitating health care and financial planning can help families

confront tough questions about future treatment, caregiving, and legal arrangements, and can help increase patient and family empowerment and closure.

Resources

The **ADEAR Center** provides a *Legal and Financial Issues* reading list, which can be downloaded online at www.nia.nih.gov/Alzheimers/Publications/legal.htm. Or, you can call the ADEAR Center at 1-800-438-4380 for a copy. The resources have been selected from the ADEAR Center's AD Lib searchable library database at www.nia.nih.gov/Alzheimers/Resources/SearchHealthLiterature. The Center also offers *So Far Away: Twenty Questions for Long-Distance Caregivers*, which discusses legal and financial concerns and outlines many of the issues facing families when a patient lives far away. Also available is the *Age Page: Getting Your Affairs in Order*, which summarizes the steps older people can take to prepare for legal and financial planning in later life.

Additional resources:

AARP

Legal Counsel for the Elderly
601 E Street, NW
Washington, DC 20049
1-888-OUR-AARP (1-888-687-2277)
www.aarp.org/lce

Aging with Dignity

5 Wishes
1-888-5WISHES (1-888-594-7437)
www.agingwithdignity.org

Alzheimer's Association

225 North Michigan Avenue, Fl. 17
Chicago, IL 60601-7633
1-800-272-3900
www.alz.org

American Bar Association

Commission on Law and Aging
740 15th Street, NW
Washington, DC 20005-1019
Phone: 202-662-1000
www.abanet.org/aging
The American Bar Association and the American Psychological Association have co-written a handbook entitled *Assessment of Older Adults with Diminished Capacity: A Handbook for*

(continued next page)

Attorneys. This handbook is designed to help lawyers become familiar with clinical indicators and appropriate assessment tests and resources for assessing diminished legal capacity in older clients. It is available online at www.apa.org/pi/aging.

Eldercare Locator

1-800-677-1116
www.eldercare.gov

Family Caregiver Alliance

180 Montgomery Street, Suite 1100
San Francisco, CA 94104
1-800-445-8106
www.caregiver.org

National Library of Medicine

MedlinePlus
Search for:
"Advance Directives"
"End-of-Life Issues"
www.medlineplus.gov

National Academy of Elder Law Attorneys

1604 North Country Club Road
Tucson, AZ 85716
520-881-4005
www.naela.com

National Association of Professional Geriatric Care Managers

1604 North Country Club Road
Tucson, AZ 85716-3102
520-881-8008
www.caremanager.org 

ADNI (from page 1)

standards for tracking the progression of memory decline.

An important feature of ADNI is that data will be available to all qualified researchers via password-protected databases on the Web. To date, more than 200 qualified researchers have signed up for database access.

Preliminary results were reported by scientists in June at the Alzheimer's Disease Prevention Conference in

Washington, DC. Among the findings:

► **Predicting Alzheimer's**—A University of California, San Diego, study found that analyses of MRI and PET images could detect early changes in cerebral cortex thickness in brains of people with MCI over a 6-month period. Further research is needed to see if the changes, with other brain measures, could predict conversion from MCI to AD.

► **Validating PET Scans**—A study reported by scientists at the Banner Alzheimer's Institute in Phoenix and colleagues compared changes over time in PET scans of glucose metabolism in people with normal cognition, MCI, and AD. The study found that scans correlated with clinical symptoms of each condition and that images from different study sites were comparable (or consistent). This study suggests the validity of PET scans for use in future clinical trials.

► **MRI Reliability**—Mayo Clinic scientists found that a standard physical model can be used successfully to monitor performance of MRI scanners at many different clinical sites. This will help ensure accuracy of the MRI images produced from 80 MRI scanners from scores of sites over 5 years.

► **Biomarker Analysis**—University of Pennsylvania scientists and colleagues compared analyses of cerebrospinal fluid samples among seven laboratories. The study evaluated differences within and among the labs' performance. This will help ensure that methods for

measuring biomarkers are accurate and comparable across laboratories.

Enrollment Goals for ADNI Met Early


Significant progress was made in enrolling ADNI participants. Goals were met months ahead of schedule, and enrollment is now complete with a full 798 qualified participants. Of those, 229 have no memory problems, 386 have MCI, and 183 have AD. Investigators recruited participants at 58 local study sites across the U.S. and Canada.

Add-on to ADNI Begins

Earlier this year an optional "add-on" component of ADNI was launched, funded by the

Alzheimer's Association and General Electric. The project will utilize Pittsburgh Compound B, or "PIB," which is a PET tracer for amyloid imaging, to detect beta-amyloid in the

brain. The ability to pinpoint amyloid deposits in the living brain can advance the study of AD and could aid in early, perhaps even preclinical, diagnosis.

The \$60 million, 5-year ADNI study is supported primarily by the NIH, with private-sector support from pharmaceutical companies and other private organizations through the Foundation for NIH. In addition to NIA, other Federal partners are the National Institute of Biomedical Imaging and Bioengineering, also part of NIH, and the U.S. Food and Drug Administration. For more information on ADNI, go to www.adni.org. 

An important feature of ADNI is that data will be available to all qualified researchers via password-protected databases on the Web.

AD Library Highlights

These highlights describe materials recently added to the Alzheimer's Disease Library Health Information Database (AD Lib). The items selected represent topics and formats of general interest to readers of *Connections* and ADEAR Center users or their clients. Please order directly from the source listed for each item. Journal articles are available in many university and medical school libraries. Ad Lib is accessible on the Internet at www.nia.nih.gov/Alzheimers/Resources/SearchHealthLiterature/.

Toolkit on Memory Loss for Physicians

Memory Loss Tool Kit. 2006

Robinson, B.E.; Barry, P.P.

Available from the Practicing Physician Education Project (PPEP), American Geriatrics Society, The Empire State Building, 350 Fifth Avenue, Suite 801, New York, NY 10118. Telephone: 1-800-563-4916; Website: www.gericareonline.net/tools/index.html. PRICE: free online access.

This toolkit from the American Geriatrics Society can be used by practicing physicians to evaluate and care for patients with cognitive problems and suspected dementia. It includes both professional tools and patient education materials. The professional tools include memory loss evaluation forms that capture medical history and the patient's and informant's "Story of the Memory Problem." The toolkit also contains a copy of the Geriatric Depression Scale (short form), and family report forms on patient behaviors, memory problems, medical history, and caregiving issues. Educational materials include handouts on:

- Memory and Aging
- Medical Evaluation of Memory Loss
- Brain Imaging in Memory Loss
- Specialists in Memory Loss
- Treatments for Alzheimer's Disease
- Driving and Memory Loss
- Advance Directives in Memory Loss

Toolkit on Caregiver Needs for Physicians

Caregivers Count Too! A Toolkit to Help Practitioners Assess the Needs of Family Caregivers. 2006

Available from the National Center on Caregiving at Family Caregiver Alliance, 180 Montgomery Street, Suite 1100, San Francisco, CA 94104. Telephone: 1-800-445-8106; Website: www.caregiver.org. PRICE: free online access.

Developed by the Family Caregiver Alliance, this toolkit is designed for health care practitioners to help caregivers, who often have health problems because of their caregiving responsibilities. This toolkit can be used by any health care professional who works with older people and adults with disabilities or disorders such as dementia. It explains who family caregivers are, what they do, and why it is important to assess their needs. It includes a list of online resources for more information, and offers basic guidelines for conducting caregiver assessment, including the recommended areas to cover and questions to ask. The toolkit explains:

- who should be assessed,
- who should conduct the assessment,
- when the assessment should happen, and
- where it should take place.

The toolkit provides six sample caregiver assessment tools, an annotated list of Family Caregiver Alliance publications relating

to caregiver assessment, and an annotated bibliography of caregiver assessment materials and journal articles.

Toolkit on Long-Term Care for American Indians

Native American Map for Elder Services (NAMES): A Long Term Care Planning Tool Kit. 2005

McDonald, F.; Ludtke, R.; McDonald, L.; Allery, A.

Available from the National Resource Center on Native American Aging, Center for Rural Health, University of North Dakota School of Medicine and Health Sciences, P.O. Box 9037, Grand Forks, ND 58202. Telephone: 1-800-896-7628; Website: <http://medicine.nodak.edu/crh/>. PRICE: free online access.

According to the National Resource Center on Native American Aging, "American Indian and Alaska Native elders in Indian Country have fewer options for long-term care services when compared with other seniors." To address the special long-term care planning needs of these populations, the Center has developed a toolkit called "The Native American Map for Elder Services (NAMES)," which includes a chart listing the services and personnel needed for elders who are at different levels of functional limitations and a booklet summarizing the needs assessment and planning process. The main planning toolkit describes community needs

assessments, health promotion and preventive care services, and home- and community-based services. The toolkit also lists funding and general resources available to help tribes plan and implement long-term care services for their elders.

State-by-State Transportation Guide

State-by-State Guide to Transportation Assistance. 2006

Gearon, C.J.

AARP Bulletin

Available free online from AARP at www.aarp.org/bulletin/yourlife/state_by_state_transportation.html.

This Web page provides a State-by-State guide to transportation assistance for older people (and their caregivers) who do not drive and cannot use public transportation to obtain rides for essential trips, such as medical appointments and shopping. Transportation services vary among communities and may be 'fixed route' (similar to a bus route, with scheduled routes and stops) or 'demand response' (like a taxi service, with on-demand, door-to-door service). The services may be provided by urban and rural transit systems, human service organizations, churches, and other providers. For each State, the Web pages provide links to and details about transportation assistance options, and, where available, selected counties.

New Edition: the 36-Hour Day

36-hour Day: A Family Guide to Caring for People With Alzheimer's Disease, Other

Dementias, and Memory Loss in Later Life. 4th edition. 2006

Mace, N.L.; Rabins, P.V.

Available from the Johns Hopkins University Press, 2715 North Charles Street, Baltimore, MD 21218. Telephone: 1-800-537-5487; Website: www.press.jhu.edu. PRICE: \$45.00 hardcover; \$16.95 paperback

This widely-used book for AD caregivers has been recently updated and is now in its fourth edition. It offers guidance and comfort for families caring for loved ones with AD, other dementias, and memory loss in later life. This edition includes new information on diagnostic evaluation, resources for families and adult children caregivers, updated legal and financial information, current information on nursing homes and other communal living arrangements, and updates on research, medications, and the biological causes and effects of dementia. Its chapters provide an overview of dementia, information on getting medical help, the characteristic behavioral symptoms of dementia and problems arising in daily care, getting outside help, care for the caregiver, and dealing with children and teenagers.

Lewy Body Dementia Brochure

Lewy Body Dementia: Lewy Body Disease (LBD), Dementia with Lewy Bodies (DLB), Diffuse Lewy Body Disease (DLBD), Parkinson's Disease with Dementia (PDD). 2006

Available from the Lewy Body Dementia Association, P.O. Box 451429, Atlanta, GA 31145-9429. Telephone: 1-800-539-9767; Website: www.lewybodydementia.org. PRICE: free print copy and free online access.

This brief, but helpful, brochure from the Lewy Body Dementia Association explains the basics of dementia with Lewy bodies (DLB). Symptoms of this progressive brain disease include cognitive decline with deficits in executive functioning, fluctuating cognitive abilities, recurrent visual hallucinations, and parkinsonism. The brochure explains that about 20 percent of all dementia cases are DLB affecting about 800,000 people in the U.S. It discusses the importance of early diagnosis and evaluation, risk factors, primary symptoms, and treatments. The brochure also emphasizes that medical management of DLB is complex because of increased sensitivity to many drugs.

Early-Stage AD Movement Program

Movement With Meaning: A Multisensory Program for Individuals With Early-Stage Alzheimer's Disease. 2006

Larsen, B.

Available from Health Professions Press, P.O. Box 10624, Baltimore, MD 21285-0624. Telephone: 410-337-9585; Website: www.healthpropress.com. PRICE: \$29.95

This book is a guide to a multisensory movement program (called Movement with Meaning), for people with early-stage AD. The book recommends and describes breathing exercises to reinforce relaxation and concentration, memorization of a poem or song, exercises for balance and coordination, simple yoga postures, music and rhythm activities, and sensory stimulation activities. Step-by-step instructions are provided for each activity.

Clinical Trials and Studies Update

Effects of Omega-3 Fatty Acids To Be Tested

The Alzheimer's Disease Cooperative Study (ADCS) has launched a major clinical trial to test whether omega-3 fatty acids (known as DHA, or docosahexaenoic acid), found in the oil of certain fish, may also benefit the brain by lowering the risk of AD. The ADCS is a Federally-established consortium conducting clinical trials on AD, coordinated by the University of California, San Diego and at sites in the United States and Canada.

The DHA trial, which will take place at 51 sites, seeks 400 participants age 50 and older who have mild to moderate AD.

Researchers will be evaluating primarily whether the omega-3 fatty acid, taken over many months, slows the progression of both cognitive and functional decline in people with mild to moderate AD. During the 18-month clinical trial, investigators will measure the progress of the disease using standard tests for functional and cognitive change.

Participants will receive either two grams of DHA per day or an inactive placebo pill. About 60 percent of participants will receive DHA, and 40 percent will get the placebo. Researchers will also evaluate whether taking DHA supplements has a positive effect on possible physical and biological markers of AD, such as brain atrophy and proteins in blood and spinal fluid.

This project joins ongoing ADCS trials testing whether huperzine and statins can slow AD, as well as a study of valproate to determine whether it can either slow decline or help delay the agitation and psychosis that often emerge in AD patients.

Recruitment Planning Underway for...

Home-Based Assessment—Older individuals, particularly the very elderly, may have physical, social, and health limitations that make it difficult for them to take part in research. This study, to be conducted among people aged 75 and older, will examine the use of mail-in questionnaires, automated telephone technology,

"We are deeply indebted to all clinical trial participants for their commitment to advancing our understanding of this terrible disease. Without these unselfish people, we could not conduct this essential research. All of us are very grateful to each and every one of you."

—Paul Aisen, M.D., Acting Director, ADCS

and computerized data collection to assess cognitive, functional, and other factors in the home environment to see how home-based assessments might be used in primary prevention trials. Such an approach could significantly reduce the cost and increase the feasibility of participation in these long-term, costly clinical trials. Recruitment is anticipated to begin around September of this year.



Intravenous Immunoglobulin (IVIg)—IVIg contains naturally-occurring antibodies against beta-amyloid, and preliminary studies have shown that immunization with IVIg may improve cognition. In addition, research has

demonstrated that IVIg increased levels of anti-beta amyloid antibodies in plasma and promoted clearance of beta-amyloid from cerebrospinal fluid. Recruitment is anticipated to begin in early 2008.

The ADCS will receive \$52 million over 6 years to conduct these and other trials. The ADCS consortium was first established in 1991 as an infrastructure of leading researchers to carry out clinical trials for promising new therapies for AD.

Participation Info

To learn how you can participate and to get more information on AD clinical trials and studies, call the ADEAR Center at 1-800-438-4380, or visit www.nia.nih.gov/Alzheimers/ResearchInformation/ClinicalTrials.

Calendar of Events

July 11-15

VAS-COG 2007, The International Society for Vascular Behavioural and Cognitive Disorders, San Antonio, TX

Contact:

VAS-COG Secretariat
P O Box 5078
SE-402 22 Göteborg
Sweden
Telephone: +46 (0)31 708 60 22
Fax: +46 (0)31 708 60 25
E-mail: info@vas-cog.org
Website: www.vas-cog.org

July 24-25

Multi-Modal Neuroimaging Training Program Symposium on "Alzheimer's Disease," University of Pittsburgh and Carnegie Mellon University, Pittsburgh, PA

Contact:

McGowan Institute
MNTP - CNBC
3025 E. Carson Street, Room 159.02
Pittsburgh, PA 15203
E-mail: mntp-info@cnbc.cmu.edu
Website: www.cnbc.cmu.edu/OtherTrain/mntp_description.shtml

August 27-29

Alzheimer's Association 15th Annual Dementia Care Conference, Chicago, IL

Contact:

The Alzheimer's Association
Telephone: 312-335-5790
E-mail: careconference@alz.org
Website: www.alz.org/careconference

September 20-21

2007 Alzheimer's Disease Research Conference, Irvine, CA

Contact:

Alzheimer's Association of Orange County
Telephone: 949-757-3703
Website: www.alzoc.org

September 28-29

6th Leonard Berg Symposium "Novel Therapies for Protein Misfolding Disorders," St. Louis, MO

Contact:

Barbie Kuntemeier
University of Washington at St. Louis
Telephone: 314-286-2882
E-mail: kuntemeierb@lists.biostat.wustl.edu
Website: <http://alzheimer.wustl.edu/education/berg/berg2007/>

October 27

Living Our Lives, Planning Our Futures: The Early Memory Loss Forum, Los Angeles, CA

Contact:

The Alzheimer's Association of the California Southland
Telephone: 323-900-3180
E-mail: earlystageforum@alzarsb.org
Website: www.alzla.org

November 8-11

Fifth International Congress on Vascular Dementia, Budapest, Hungary

Contact:

Registration & Accommodation Department
17 rue du Cendrier
PO Box 1726
CH-1211 Geneva 1
Switzerland
Telephone: +41 22 908 0488
Fax: +41 22 732 2850
E-mail: reg_vascular@kenes.com
Website: www.kenes.com/vascular/



New Progress Report on AD Available!

The newest annual report on Federal AD research is now available. The *2005-2006 Progress Report on Alzheimer's Disease: Journey to Discovery* describes recent major developments in NIH-supported AD research. It includes in-depth discussions of NIA-funded AD research as well as significant advances in research supported by other Institutes. To get copies, use the ordering form on the back page, or call the ADEAR Center at 1-800-438-4380, or visit www.nia.nih.gov/Alzheimers.

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- Mourning the Death of a Spouse*—a new *Age Page* from the National Institute on Aging
- Progress Report on Alzheimer's Disease 2005-2006*—the new annual AD research summary from the NIA

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mailing address: _____

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Call our toll-free telephone number: 1-800-438-4380,

or contact us via e-mail: adear@nia.nih.gov



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