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Earlier AD diagnosis creating demand for early-stage support groups

Many people are being diagnosed earlier in the course of Alzheimer's disease (AD) because of improving sensitivity and specificity of diagnostic techniques and increased awareness of the disease. Health care professionals, the Alzheimer's Association, and other organizations are responding by offering a broader range of support services to ease the emotional and social strains of people with early-stage AD and their families. As these support programs expand, new research is finding that people with early-stage AD retain more cognitive capacity than previously thought.

People with early-stage AD often have preserved personality and coping skills and remarkable awareness of themselves and their symptoms. However, they may experience considerable distress, embarrassment, and isolation because of perceived stigma of the disease. Thus, they are seeking, along with their family members, new coping strategies, meaningful activity, and mental stimulation. They are eager to educate themselves, to share common experiences, and to break potential barriers and isolation imposed by the early diagnosis and symptoms of AD.

(see Early-Stage Support Groups, page 2)

NIA adds 2 ADCs to research network

The National Institute on Aging (NIA) is pleased to announce the addition of two Alzheimer's Disease Centers (ADCs) serving the southeastern U.S.: the University of South Florida (USF), headquartered in Tampa, and Emory University in Atlanta, Georgia. More than 10 percent of the Nation's AD patients—an estimated 600,000—live in these two States. Emory University was fully funded as an ADC from 1991 until 2000 and has been an Affiliate Center under the NIA program since 2000. USF's staff and facilities are new to the NIA research network.

The NIA has worked with local scientists and officials in the southeastern U.S. for some time to expand the ADC network. "Not only are we now able to extend much-needed diagnostic, treatment, and education services to

(see New ADCs, page 6)

New booklet from ADEAR

Can Alzheimer's disease be prevented?

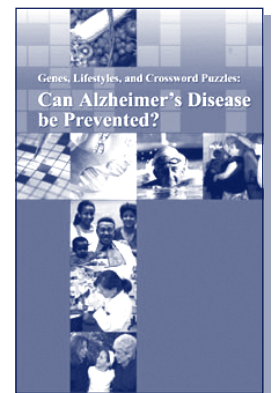
A new free 28-page booklet from the Alzheimer's Disease Education and Referral (ADEAR) Center—*Can Alzheimer's Disease be Prevented?*

—provides the latest research findings on risk factors for AD. It

describes the ongoing search for prevention strategies and how heart disease, high blood pressure, diabetes and insulin resistance, and inflammation may affect development of AD.

The booklet discusses intriguing new research from observational studies and discusses thought-provoking theories

(see New Booklet, page 5)



Early-Stage Support Groups

(from page 1)

What exactly is a support group?

The Alzheimer's Disease Education and Referral (ADEAR) Center receives thousands of calls and e-mails a year from families, professionals, and people living with AD who need help in addition to medical care. They may be seeking respite, a safe place to express concerns, tips for care, resources, or just reassurance that they are not alone. ADEAR information specialists often refer the caller to a local office of the Alzheimer's Association, whose services include a variety of support groups led by a caring, compassionate group of health care professionals and/or trained volunteers.

Although support groups vary in structure, format, membership, and leadership, all offer a forum for education and learning as well as a positive, safe, and nonjudgmental place to discuss concerns for people with AD and their family members, together or separately. Many diagnosed people and their family members acknowledge the need to connect with others who are facing similar challenges, loss, anxiety, confusion, depression, isolation, and grief, and specialized support groups may offer the right help at the right time.

Early-stage support groups

Within the last decade, a number of support groups specific to the unique needs of people with early-stage AD and their families have been established. With greater public awareness, earlier diagnosis, and advocacy to reduce the social stigma of AD, there is greater demand for this early-stage support.

Generally, most support groups offer participants an opportunity to share common personal experiences with

others in similar situations. Early-stage support groups are usually facilitated or led by a professional and/or a trained volunteer and commonly meet once a week for 6, 8, or 10 weeks. Participants can expect to share common experiences, and learn tips from the insights and materials prepared by the professional or trained facilitators. Some sessions are for both care partners, and others are mainly for people living with the diagnosis of AD. When people with AD talk with each other, common themes come up, such as dealing with loss of independence and driving, money management, self-esteem, how to tell others about the diagnosis, and how to reduce embarrassment or fear of making mistakes in social situations.

Detecting AD early

Researchers and experienced clinicians agree that diagnosing AD in its earliest stages can be highly beneficial: the patient can seek optimal early treatment, participate in clinical trials, deal with emotional and practical issues, and make decisions with his/her family that reflect long-held values and beliefs. However, knowing the diagnosis earlier can take a significant emotional and psychological toll on the person with AD. Lisa Gwyther, MSW, CCSW, Associate Clinical Professor, Department of Psychiatry and Behavioral Sciences at the Duke University Alzheimer's Disease Center in North Carolina, says that "people with early-stage AD must address questions of how much to tell, to whom, and when, long before their disability may be recognized by others. It is extremely important that people with early-stage AD and their families get timely, consistent, open-ended support in learning to cope effectively and even thrive over time.



People with AD retain a capacity for pleasure and take joy in nourishing and sustaining relationships."

Several types of support groups meet at Duke University Medical Center. Gwyther believes that people with AD need to find a comfortable level of familiar routines and social opportunities in their daily lives. Sometimes, because of geographic isolation or other constraints, this can best be achieved in a dependable weekly or monthly support group. She finds that people with early-stage AD are willing and quite open, in most cases, to discuss their concerns with other support group members who become friends over time.

A recent NIA-supported study conducted by the Rush University Medical Center in Chicago found that while people with early-stage AD had identifiable characteristics and memory problems, they did not have the more serious cognitive problems found in mid-stage AD. These problems include confusion and disorientation, performance issues in social or work settings, or inability to plan ahead. This research suggests that, although hampered by memory deficits, people with early-stage AD can participate in many daily activities, including active involvement in a support group.

Support group structure

Generally, there are two major types of early-stage AD support groups.

One model is the structured, time-limited, 6- to 10-week group of about 20 to 30 people (including both caregivers and the person with AD) attending for one to two hours at a time. The participants are provided with a list of topics to be discussed, by whom, and in which session(s). Guest speakers share expertise in particular subjects, such as the legal or financial burdens facing a family caring for a person with AD. In some programs, caregivers and care partners meet in separate but concurrent groups. In other programs, the person with AD and his or her caregivers are usually together for half of each session and then separated for the second half. Experts say this can encourage freedom to discuss issues or express concerns without the presence of the respective caregiver or diagnosed person.

At the end of the time-limited early-stage AD support group model, participants are encouraged to take advantage of existing community resources for more help, or to attend, if available, support groups that cater to the needs of mild-to-moderate AD. Some time-limited groups offer monthly "graduate groups" that afford participants the opportunity to continue meeting or to develop social networks. Sometimes these graduate groups focus on providing social activities and the social framework for leading a normal and healthy life (within the context of the limitations of early AD).

Researchers have found that, in many cases, AD families may withdraw or be gradually excluded from their usual social groups, friendship circles, or network of former work colleagues. An Alzheimer's Association chapter may sponsor multigenerational pot luck dinners or trips to an outdoor concert or a bowling alley. Because of their non-demanding social nature, these activities would be appropriate for people in the moderate stages of AD. Sue Stone, of the Family Day Center in Fairfax, Virginia, says, "Alzheimer's patients need compan-

ionship and laughter through social situations almost as much as they need to learn what they should expect in the upcoming months and years ahead. We are focused on getting through today rather than what's going to happen tomorrow."

The second main type of early-stage support group is the "ongoing" model. It is less structured and gives participants the opportunity to initiate topic discussion and process complex issues over an extended period of time. Participants with AD may be in the group anywhere from many months to a number of years, depending on the rate of decline and their continued ability to participate meaningfully in group discussion. These weekly ongoing groups can also give families the opportunity to build long-term relationships.

There are many other types of support groups that are organized to help meet some of the needs of people with early-stage AD. They feature programs offering participants volunteer work, art, writing, and vocational pursuits.

Where are groups emerging?

In many areas of the country, the Alzheimer's Association, NIA-funded Alzheimer's Disease Centers (ADCs), and other organizations have created early-stage support groups. As health professionals gain experience and fine tune their approaches, they are also now offering more specialized, culturally diverse programs. But there are still many places where lack of resources and skilled medical services results in fewer early-stage diagnoses. That means less awareness, less demand for local

services, less education, and more potential social stigma of AD.

Who can participate?

To participate in an early-stage support group, people with AD and their care partners are usually screened by a clinical professional or a social worker. A comprehensive assessment or an interview will establish if the person with AD has the emotional, cognitive, and behavioral skills to function successfully in a group. Participation also may be based on whether the person with AD has a willing and able partner to escort to and, in most cases, participate in the sessions.

Robyn Yale, a social worker in San Francisco who pioneered the first early-stage support group in 1986 and consults for the Alzheimer's Association and other organizations, says, "It's important to screen people to select those who will be comfortable and do well in the group. We seek people with AD who have insight into their condition, the ability to articulate their feelings and concerns, and the desire to have the support group experience." Yale notes that while having a care partner to escort the person with AD and attend a concurrent support group is ideal, it is not a mandatory prerequisite.

Yale's book, *Developing Support Groups for Individuals with Early-Stage Alzheimer's Disease*, has been used as a guide for creating groups
(continued next page)





nationally and internationally. In it, she discusses planning, implementing, and evaluating group sessions. She identifies topics that are likely to arise and encourages group members to raise issues that are important to them. Suggested topics include questions and concerns about memory loss, relationships with family and friends, adjusting to new situations, and wellness and optimism. Yale's model has evolved from time-limited to ongoing groups, with individuals transitioning out of a group when they can no longer participate.

Group leaders vary in how long they permit participants to remain in the group as their cognitive abilities decline. Clear guidelines and ongoing communication are essential so that group facilitators and people with AD and their families have a sense of how and when transitioning out may happen. While challenging, this is a necessary part of the process for individuals and the group as a whole, and, according to Yale, it can be managed successfully. Yale raises another concern: "The fact that there are few regions of the country with an appropriate program as a 'next step' for this population is also difficult, as they may not yet be ready for day care," she says. At the very least, group leaders hope they have instilled a spirit of camaraderie, coping skills, and emotional support that will continue to help people with AD and caregivers when the sessions end. An important point, many group leaders say, is that early-stage support groups are not for all people with early-stage AD and their family

members. While most participants report positive outcomes, such as a greater sense of control over their lives and feeling that they are not alone, others may not participate due to family conflict,

denial, significant cognitive impairment, or discomfort with the intimacy of a group experience.

How does the early-stage support group impact quality of life?

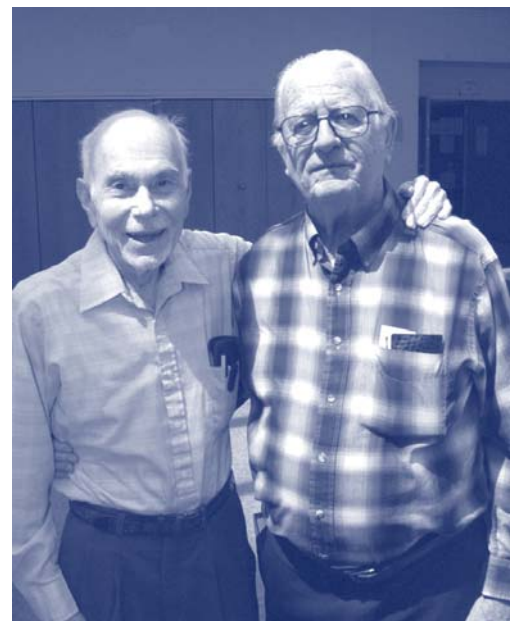
Rebecca Logsdon, a Research Associate Professor of Psychosocial and Community Health at the University of Washington Alzheimer's Disease Research Center, is collaborating with the Western and Central Washington State Alzheimer's Association Chapter to evaluate early-stage groups conducted by the chapter. "Early-stage groups are becoming more and more popular, but there is a wide range of practices among Alzheimer's Association chapters regarding who may participate and what type of group is offered," says Logsdon.

"The goal of our 3-year study, funded by the Alzheimer's Association, is to evaluate quality of life outcomes of early-stage group participants compared to a control group. We are evaluating specific benefits that were identified in discussions with early-stage participants and facilitators, including overall quality of life, depression, perceived stress, sense of control, communication between participants and caregivers, and decision making regarding legal, financial, and medical planning, says Logsdon. She believes her research ultimately "will allow us to provide the most appropriate and effective

interventions and resources for individuals and families dealing with early-stage Alzheimer's disease."

Veteran social worker Lisa Snyder, of the University of California, San Diego, firmly believes that the criteria for participating in an early-stage support group should be strict. She believes that participants must be high functioning within the group and dedicated to participating in order to maximize the experience for everyone. Snyder has adopted an ongoing group model to keep the patient-caregiver pair as long as they are able. In *Coping with Alzheimer's Disease and Related Disorders: An Educational Support Group for Early-Stage Individuals and Their Families*, a manual created by Snyder for conducting an early-stage AD support group, an 8-week structured course highlights issues such as self-esteem, legal and financial concerns, health maintenance, and daily living.

Kathleen O'Brien, Senior Vice President of Program & Community Services for the Alzheimer's Association, notes that the Association has more than 91 early-stage support programs offered across the country. Most adopt the time-limited model. O'Brien notes also that the Association is working hard to create more specialized AD caregiver support groups, particularly those serving minority and bilingual populations such as African-American, Hispanics, and Chinese-Americans, as



well as groups designed specifically for male caregivers.

While the level of resources for support group options may be uneven throughout the country, O'Brien encourages people to consider their options. "Practical and emerging alternatives to classroom-based support groups can be found in some locations via telephone or e-mail," she says. More and more people with AD and their families are finding that the Internet and telephone "help lines" are proving viable alternatives to classroom-based support groups. "These choices are especially helpful for those who cannot travel to a nearby support group or who do not have the resources in their area. The most important thing is to get help if they need it and to do that by any means possible, whether that's on the phone, on the Web, or in class," she emphasized.

Health professionals can help

Some AD caregiver advocates believe that health professionals are slowly becoming aware that support groups are positive options for families who are initially frightened and depressed by the Alzheimer's diagnosis. But more work is needed to inform health care professionals about the benefits of support groups for their early-stage AD patients. UCSD's Snyder says, "If health care professionals campaign for early-diagnosis for dementia patients, then they should also advocate for support groups and other services to help families in the early stages of the disease."

While support group models differ from one another significantly, each is intended to help people living with AD and ease the family's burden. Although formal studies of their effectiveness are ongoing, experience so far suggests that early-stage support groups allow those with AD and their caregivers to build the emotional structure they need to cope with the significant demands of the disease.


For more information

To find out if an early-stage AD support group is operating in your area, contact the Alzheimer's Association at 1-800-272-3900 or visit www.alz.org. Some ADCs also organize support groups. Call the ADEAR Center at 1-800-438-4380 to receive a print directory of the ADCs or visit www.alzheimers.org/adcdir.htm. Other resources include:

- Family Caregiving Alliance (FCA) at 1-800-445-8106 or www.fca.org
- Children of Aging Parents (CAPS) at 1-800-227-7294 or www.caps4caregivers.org

Suggested reading:


Yale, R. (1995). *Developing Support Groups for Individuals With Early-Stage Alzheimer's Disease: Planning, Implementation, and Evaluation*. Available from Health Professions Press, Inc. P.O. Box 10624, Baltimore, MD 21285-0624. 1-888-337-8808; 410-337-9585; FAX: 410-337-8539. PRICE: \$32.50.

Copies of Lisa Snyder's manual, *Coping with Alzheimer's Disease and Related Disorders: An Educational Support Group for Early-Stage Individuals and Their Families*, and a manual by Lisa Gwyther designed to help families in North Carolina, *Working with Family Caregivers of People with Memory Disorders*, can be requested from ADEAR at 1-800-438-4380. 

New Booklet

(from page 1)
about the possible origins and development of AD. These findings and NIA's continuing research programs are renewing hope that someday we will be able to delay the onset of AD, slow its progress, or even prevent it altogether.

The booklet can be previewed and ordered on the ADEAR website at: www.alzheimers.org/pubs/PreventingAD/TOC.htm.

- You can also order copies by:
- calling the ADEAR Center at 1-800-438-4380.
 - using the order form on the back page of the newsletter. 

Clinical trials update

Two large national AD clinical studies sponsored in part by NIA are seeking volunteers. Contact the ADEAR Center at 1-800-438-4380, or www.alzheimers.org/trials for more information on:

- **ADNI**—The Alzheimer's Disease Neuroimaging Initiative will use imaging techniques, such as magnetic resonance imaging (MRI) and positron emission tomography (PET) to measure brain structure and function. ADNI is an NIA public-private partnership that also will study biological markers to see if they can be used to identify early AD changes and progression. Researchers are looking for participants between age 55 and 90 who have been diagnosed with MCI or early AD, and also are seeking participants who are in good general health. ADNI investigators hope to enroll 800 participants. Recruitment is now beginning at some sites.

- The Alzheimer's Disease Genetics Study is about halfway to its goal of enrolling 1,000 families. Funding for the study has been extended as investigators continue recruitment efforts. Eligible families must have at least 2 living siblings (brothers/sisters) who developed AD after age 60 and one other living family member age 50 or older who may have memory loss (or age 60 or older with no memory loss). The study is also seeking volunteers to serve as "controls"—spouses, friends, and other interested people age 60 or older without memory impairment who are *not* biologically related to participating family members. Spanish-speaking staff are available to provide help to potential participating families. The Spanish-language phone line is 1-800-243-5828 or e-mail vcs2103@columbia.edu.

ADCS clinical trials

Several large national studies sponsored by NIA and the Alzheimer's Disease Cooperative Study (ADCS)

(see *Clinical Trials*, page 11)

New ADCs

(from page 1)

a wider geographic area, but we are looking forward to expanding the AD research portfolio with several exciting projects," commented Creighton (Tony) Phelps, Ph.D., Program Director, Alzheimer's Disease Centers, Neurobiology and Neuropsychology of Aging (NNA) Program at the NIA. Florida's population centers—Tampa and Miami—will have access to new services under the USF umbrella, and the new ADC will work closely with the State's 13 Memory Clinics. Based in Atlanta, Emory University will continue expanding its services to Georgia's AD patients and caregivers.

"We are very excited to welcome these two institutions into NIA's national research network. Each team has produced exceptional basic science research, and each is proposing several intriguing projects that will add much to our growing body of knowledge about AD," says Richard J. Hodes, M.D., Director, NIA.

The USF ADC will be led by Huntington Potter, Ph.D. The ADC at Emory will be led by Allan Levey, M.D., Ph.D. Teams of researchers at each institution will examine mild cognitive impairment (MCI) from different scientific perspectives and approaches. At USF, investigators seek to understand the process of transition from normal aging to MCI to AD by determining which combinations of clinical, epidemiologic, imaging, neuropsychological, and biological markers best identify individuals who will experience a rapid rate of cognitive decline. Researchers hypothesize that there is a strong positive correlation between the amount of certain biomarkers and risk factors and the rapid cognitive decline that can be found in preclinical AD patients.

At Emory, one of the ways that ADC staff will explore MCI is by differentiating MCI subgroups through sensitive memory tasks developed in non-human primates at the University's Yerkes National Primate Research Center. The Yerkes Center is



Huntington Potter, Ph.D.

dedicated to biomedical and behavioral research with nonhuman primates, including 3,000 monkeys and apes representing eight species, plus about 2,500 rodents. The Center conducts research on human health disorders such as AIDS, Parkinson's disease, drug addiction, cardiovascular disease, infantile blindness, and adult visual deficits, as well as AD.

"The more we understand the underlying mechanisms of MCI, the better we will be able to understand how and when the disease process begins. Gaining insight into the transformation from healthy aging to MCI and conversion from MCI to AD is crucial to our overall dementia research program," said Marcelle Morrison-Bogorad, Ph.D., Director, NNA program.

University of South Florida

Florida is the fourth largest State in the country in terms of population and the second largest in total number of Alzheimer's disease patients. There are an estimated 430,000 AD patients in Florida, and, as is true across the U.S., the aging population is ethnically diverse and growing rapidly.

In 2002, the Florida Legislature established the Johnnie B. Byrd Sr. Alzheimer's Center and Research Institute on the campus of USF, as a private, non-profit, State-wide institute "dedicated to the cure and preven-

tion of Alzheimer's disease." The Byrd Institute will partner with USF by providing additional expertise and State financial support to the Florida ADC. Headquartered in Tampa, USF will direct two clinical research centers, one in Miami and one in Tampa. In addition, neuropathology services will be provided through the Mayo Clinic in Jacksonville, and the ADC will work with the Suncoast Gerontology Center in Tampa to provide education services. Additional diagnosis and treatment services will be provided at the Wien Center at Mount Sinai Medical Center in Miami. USF will also be working closely with a number of local chapters of the Alzheimer's Association, and the Caregiver Assistance Program, funded by the State of Florida.

Additional research will be conducted at the University of Miami, and the Wien Center has a strong interest in the early detection of dementia for both English and Spanish speakers. The Center will also be involved in the assessment of genetic and environmental risk and protective factors for dementing diseases.

One of the major missions of the Suncoast Gerontology Center is the education of patients, caregivers, physicians, and other health care professionals in the most current knowledge about AD research, diagnosis, treatment, and care. Staff at the Center are developing a network of professionals who will work with minority and underserved populations, conducting outreach programs, and producing Spanish-language material on MCI, AD, and the ADC.

"It is a great honor and responsibility to direct, together with Dr. Ranjan Duara from the University of Miami, the new NIA-designated Florida ADC. This represents the effort of many researchers from all over the State who came together to collaborate on the application. That collaboration was made possible in no small way by the people of Florida, whose representatives established the State-funded Johnnie B. Byrd Sr. Alzheimer's Center and Research Institute. We are very proud that bringing together

many institutions and investigators has led to Florida receiving its first ADC and look forward to working with other researchers across the State and the Nation to more effectively understand and attack Alzheimer's disease," said Dr. Potter.

In addition to USF's research focus on MCI, other major projects will include:

- investigating the use of "cognitive rehabilitation" to intervene in and slow disease progression in MCI and early AD patients. Preliminary evidence indicates that such cognitive rehabilitation can slow cognitive decline in AD patients. Cognitive rehabilitation has been shown to be effective in treating a wide variety of neurological disorders including traumatic brain injury and stroke.
- using mouse models of AD to determine which aspects of environmental enrichment (including cognitive rehabilitation) best slow or reverse cognitive impairment and might be similarly applied to human patients.

The USF ADC is also working on new therapeutic strategies to promote the repair and regeneration of diseased brains. In addition to movement disorders and AD, the Center researches PD, Huntington's disease, ALS, stroke, and Tourette's disorder.

Emory University

Emory University is a private teaching and research institution and was funded as an ADC from 1991 to 2000, and from 2000 until this year, was designated as an affiliate ADC. Emory operates from three principal locations: the Center for Neurodegenerative Disease (housing many research labs), the Wesley Woods Center (a geriatrics center with AD special care units), and Grady Memorial Hospital (a 1000-bed teaching hospital).

Several other specialized research facilities will coordinate research with the ADC, including the Emory Sleep Disorders Center, and the Yerkes National Primate Research Center.



Allan Levey, M.D., Ph.D.

Allan Levey, M.D., Ph.D., ADC Director, stated, "We are delighted to be awarded one of the new ADC grants. The award builds on the spectacular growth in the neurosciences and neurodegenerative disease research at Emory over the past 10 years. The Center brings new strengths and directions in genetics, proteomics (the study of protein structure and function), and cognitive neuroscience to research and clinical care for individuals with MCI, AD, and other dementias, together with a mission to serve a large and diverse community in need."

The Emory ADC maintains an emphasis on the overlap between cognitive and movement disorders, and has a strong outreach program to the large African-American community in urban Atlanta.

Among the special research projects underway at Emory are:

- "Sensitive Memory Tests for Differentiating MCI Subgroups," which will adapt novel, highly sensitive memory tasks developed in non-human primates.
- "Crossed Genetics Risks of Alzheimer's and Parkinson Disease" to examine significantly increased crossed familial risk of AD and PD. This research will test the association of novel candidate genes for AD and PD. Emory has formed a partnership with de CODE Genetics, a genomics company based in Iceland, which has a relatively

homogenous population, to help further this research.

- "Analysis of Proteomic Patterns in Neurodegeneration" which will apply state-of-the-art proteomics technologies to MCI, AD, and PD brains. Emory investigators believe that although AD and PD often represent distinct disorders, significant overlap occurs at genetic, clinical, and pathological levels, suggesting common molecular mechanisms.

The Emory ADC will also address dementia risk factors such as sleep, vascular co-morbidities, and multicultural issues. Researchers believe that sleep-disordered breathing may play an unappreciated role in AD, PD, and other neurodegenerative diseases. Emory's emphasis on dementia in African-Americans will examine how racial and cultural factors influence MCI and that population's commonly occurring co-morbidities such as hypertension, diabetes, and vascular disease.

Other research will concentrate on environmental toxins and their possible role in disease, the cell biology of presenilins and their role in membrane traffic, protein degradation, and hypoxia and oxidative stress.

Contact the ADCs:

Emory University

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Website: www.byrdinstitute.org
Director's Tel: 813-866-1600
Director's Fax: 813-866-1601 



NIA introduces new Spanish publications

The NIA is pleased to announce the addition of three new free publications in Spanish. The first, *Conversando con su médico*, is a cultural adaptation of the NIA publication *Talking with Your Doctor*. This new Spanish-language version includes information to help you choose a doctor, communicate effectively with the doctor and other health care providers, work with an interpreter, discuss sensitive issues such as incontinence or sexuality, and find additional health information in Spanish.

Two of NIA's popular *Age Page* series also have been translated into Spanish: *Conductores de la tercera edad* (*Older Drivers*) and *Prevención de caídas y fracturas* (*Preventing Falls and Fractures*).

Conductores de la tercera edad provides information on:

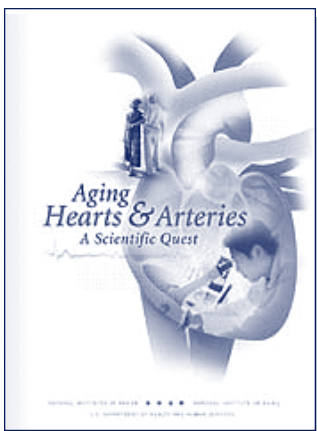
- how age affects driving,
- smart and safe driving for older people,
- when to give up driving, and
- how to maintain mobility after giving up driving.

Prevención de caídas y fracturas discusses:

- ways to adopt exercise programs to build strength and avoid falls and broken bones,
- testing hearing and vision to maintain stability, and
- many tips on making the home a safer environment.

You can order copies in several ways:

- go to www.niapublications.org.
- call the NIA Information Center at 1-800-222-2225.
- use the order form on the back page of the newsletter.



New booklet on aging hearts published

The NIA also recently introduced its newest publication, *Aging Hearts and Arteries: A Scientific Quest*. This free 64-page booklet offers an inside look at the latest cardiac research funded by the National Institutes of Health.

Using easy-to-understand diagrams and illustrations of the heart, *Aging Hearts and Arteries* discusses the link between aging and cardiovascular diseases, such as coronary heart disease and high blood pressure. These illnesses eventually lead to heart attacks and heart failure, and cause more than 40 percent of

deaths of older people every year.

Research is providing us with greater understanding of the intimate relationship between aging and heart health. Use this booklet both as a scientific introduction to the biological processes involved in aging and its effects on the cardiac system, and as your first steps toward a healthier heart.

Topics in *Aging Hearts and Arteries: A Scientific Quest* include:

- anatomy and history of the heart
- characteristics and effects of aging on the normal heart
- clues about when a good heart goes bad
- arteries and their relationship with the heart
- exercise, diet, and metabolism and their connection with heart health

You can order copies in several ways:


- go to www.niapublications.org.
- call the NIA Information Center at 1-800-222-2225.
- use the order form on the back page of the newsletter.

New video in Bosnian language available

A new VHS video in the Bosnian language helps members of that community recognize symptoms of memory

loss and how to get help. Produced by the Washington University at St. Louis ADC, the St. Louis chapter of the Alzheimer's Association, the International Institute of St. Louis, and Bi-Lingual International Assistant Services, the 22-minute video is entitled *Prepoznavanje simptoma gubljenja pamćenja i pristup uslugama: Obrazovni program za Bosansku zajednicu* (*Recognizing Symptoms of Memory Loss and Accessing Services: A Video for the Bosnian Community*).

This video demonstrates the differences between changes in normal aging and those due to AD by observing members of a Bosnian family as they recognize a problem and subsequently seek medical advice and services for a beloved grandmother with memory loss. The video has English subtitles.

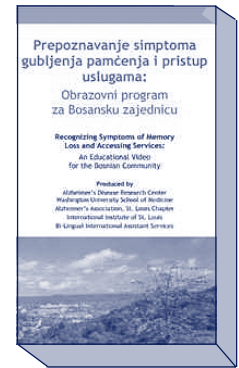
Each video is \$7.50 and can be ordered by credit card on the ADEAR website at www.alzheimers.org. The video can also be ordered by mail by using the order form on the back page of the newsletter. Checks must be in U.S. funds. 

Sign up for NIA E-mail alerts

You can now sign up to receive e-mail alerts from the National Institute on Aging for:

- News and announcements and/or
- New NIA publications.

Simply go to www.niapublications.org/alerts to select your preference. Or, you can use the order form on the back page of the newsletter.



CHID Highlights

CHID Highlights describes materials recently added to the Alzheimer's disease file of the Combined Health Information Database (CHID). 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. CHID is accessible on the Internet at www.chid.nih.gov, by following the link at www.alzheimers.org, or by following the National Library of Medicine's link to CHID at www.nlm.nih.gov/medlineplus/databases.html.

Caregiving Advice

Navigating the Alzheimer's Journey: A Compass for Caregiving. 2004

Sifton, C.B.

Available from the Health Professions Press, P.O. Box 10624, Baltimore, MD 21285-0624. Phone: 410-337-9585; Fax: 410-337-8539. Website: www.healthpropress.com. PRICE: \$32.95

This 650 page monograph uses the author's personal and professional experience dealing with dementia. Sifton has created a guide with practical advice designed to manage the daily struggles and challenges of caring for a loved one who has dementia. The book discusses the balance a caregiver must achieve in order to maintain both the patient's and the caregiver's health. It dispenses advice to avoid caregiver burnout, and, over its 10 chapters, addresses topics such as "living in the moment," and "understanding, preventing, and responding to behavioral symptoms." The author stresses that caregivers should always try to focus on the positive. Useful for the informal caregiver, this book promotes maintaining a positive approach to caregiving and working with the patient's remaining abilities and strengths, rather than dwelling on loss and grief.

AD Diagnosis, Treatment

The Dementias: Diagnosis, Treatment, and Research. 3rd ed. 2003

Weiner, M.F., Lipton, A.M., eds.

Available from the American Psychiatric Publishing, Inc., P.O. Box 97250, Washington DC 20090. Phone: 1-800-368-5777; Fax: 703-907-1091. Website: www.appi.org. PRICE: \$90.00 paperback

This third edition, edited by Myron F. Weiner, M.D., and Anne M. Lipton, MD, Ph.D., updates and expands on the previous edition by adding new information on basic and clinical research findings. The book is designed to help medical professionals who have patients with dementia. It serves as an introduction to the pathophysiology of dementia. New to this edition is a section devoted to the possible molecular and genetic sources of AD, an illustrated chapter on contemporary neuroimaging, and a segment focusing on mild cognitive impairment, frontotemporal dementias, and dementias with Lewy bodies. This edition has three major sections discussing the diagnosis of dementia in the clinical and research areas. Many people caring for older people with cognitive impairment, including geriatricians, neurologists, and geriatric psychiatrists, can learn from this book.

Physician Guide: Older Drivers

Physician's Guide to Assessing and Counseling Older Drivers. 2003

Wang, C.C., et al.

Available from Taylor the Older Driver's Project, American Medical Association, 515 North State Street, Chicago, IL 60610. Phone: 312-464-4179; Fax: 312-464-5842.

Website: www.ama-assn.org/go/olderdrivers. PRICE: free

Developed by the American Medical Association and the National Highway Traffic Safety Administration, this guide is a helpful tool for clinicians and medical professionals to decide whether an older person should drive and how to counsel that patient. In its 10 chapters, the following are discussed: safety, whether the patient is at risk, assessing driving-related functions, physician interventions, rehabilitation specialists, clinicians' legal and ethical responsibilities, State-specific licensing requirements, medical conditions and medications that effect driving, and recommendations for safer driving. This guide also is available as a CD-ROM.

AD Activities

The Best Friends Book of Alzheimer's Activities. 2004

Bell, V., et al.

Available from the Health Professions Press, P.O. Box 10624, Baltimore, MD 21285-0624. Phone: 1-888-337-9585; Fax: 410-337-8539. Website: www.healthpropress.com. PRICE: \$29.95

Developed by Best Friends, a trademark of the Health Professions Press, this handbook contains 147 fun and easy activities for caregivers, friends, and families to do with patients with AD and other dementias. The user-friendly format and its simple instructions give ideas on how caregivers and dementia patients can become involved in sensory- and brain-friendly activities. These activities include

everything from decoupage and creating your own wrapping paper, to writing poetry, or using the computer. Along with each formal and informal activity are instructions on how to adapt the activity for people in the early and later stages of the disease. Each activity also has corresponding preventive suggestions to head off potential problems and ways to promote communication and conversation during the event. Best Friends describes the emotional and spiritual benefits of being active and enjoying time with others.

Death and Dying

Talking About Death. 2004

Morris, V.

Available from Workman Publishing, 708 Broadway, New York, NY 10003. Phone: 212-722-7202; 212-254-5900. Website: www.workman.com. PRICE: \$14.95

Author of *How to Care for Aging Parents*, Morris has written this book to help make death "gentler and even meaningful." Her sensitive and surprisingly positive book discusses what caregivers, families members, and friends of the dying should know to prepare for a loved one's death, and even our own. The book contains personal stories combined with practical information about dealing with death. Some issues raised in the book include: how to discuss and bring up the subject of death with a family member; how to make death less upsetting; and what you need to know about end of life issues such as life support, artificial nutrition, pain relief, and hospice care. Morris suggests adopting a proactive philosophy as death approaches and managing its approach with spirituality.

Research and Ethics

Ethics, Law, and Aging Review, Vol 8: Issues in Conducting Research With and About Older Persons. 2002

Kapp, M.B., ed.

Available from the Springer Publishing Company, Inc., 11 West 42nd Street, 15th Floor, New York, NY 10036. Phone: 1-877-687-7476; 212-431-4370. Website: www.springerpub.com. PRICE: \$39.95

This volume is part of a series in issues conducting research with and about older persons. It is designed for clinicians, medical professionals, and anyone who is interested in the legal matters of the elderly. The book is structured in two major parts. The first part is dedicated to ethical and legal issues, such as informed consent, drug testing and approval, and regulating research for those with cognitive impairment. The second part includes several articles discussing surgical intervention in the very old, long-term legal care, and respecting patient's preferences at the end of life.

Therapeutic Strategies

Healing Arts Therapies and Person-Centered Dementia Care. 2002

Innes, A., Hatfield, K., eds.

Available from Taylor and Francis-Routledge Books, Inc., 29 West 35th Street, 10th Floor, New York, NY 10001. Phone: 1-800-797-3803, ext. 7856; 212-216-7856; Fax: 212-244-1563. Website: www.routledge-ny.com. PRICE: \$19.95

This small handbook offers a holistic view on how to deal with dementia using visual arts, music, and dance. Published by the Bradford Dementia Group, the book presents advice to therapists and clinicians and empha-

sizes the human aspect of dementia, rather than the disease itself. Its three major chapters, devoted to (1) art therapy, (2) dance/movement therapy, and (3) music therapy, describe case studies that demonstrate person-centered dementia care. According to the book, this type of personal care promotes successful group interaction, better communication, better self-esteem, and improved memory. Chapters are illustrated with drawings, photos, and charts, and the chapter contributors are all practicing healing arts therapists.

Manual of Geriatrics

The Merck Manual of Geriatrics: A New Generation of Geriatric Care. 3rd ed. 2000

Beers, M.H., Berkow, R., eds.

Available from Merck Publishing Group, Merck and Company, Inc., P.O. Box 2000, RY84-15, Rahway, NJ 01065. Phone: 1-732-594-4600. Website: www.merckbooks.com/mgeri/index.html. PRICE: \$37.50

This reference covers a broad range of health issues affecting the elderly and also discusses typical symptoms, signs, diagnosis, and treatments for many geriatric conditions. It also presents information on nursing care, pharmacy issues, and planning for later life. Other topics include nutrition, geriatric emergencies, home health care, cardiovascular disorders, infectious disease, psychiatric disorders, and legal, ethical, and social issues. One section is of particular interest for readers because it focuses on delirium and dementia. This section's four chapters include: (1) the mental status examination, (2) delirium, (3) AD and other dementias, and (4) behavior disorders in dementia. The book is useful as a medical reference for clinicians or health care professionals who deal with geriatric patients.



For a complete listing of upcoming conferences, please visit:
www.alzheimers.org/calendar

September 25-28, 2005

**American Neurological Association
Annual Meeting, San Diego, CA**

Contact:

American Neurological Association
5841 Cedar Lake Road
Suite 204
Minneapolis, MN 55416
Telephone: 952-545-6284
Fax: 952-545-6073
E-mail: ana@llmsi.com
Website: www.aneuroa.org

September 26-29, 2005

**Autumn Series on Aging, West
Coast, San Francisco, CA**

Contact:

American Society on Aging
833 Market Street, Suite 511
San Francisco, CA 94117
Telephone: 1-800-537-9728, ext. 9675
Website: www.asaging.org/autumn-series

October 7-8, 2005

**5th Leonard Berg Symposium:
Antecedent Biomarkers for Early and
Preclinical Detection of AD,
St. Louis, MO**

Contact:

Tom Meuser, Ph.D.
Washington University
Alzheimer's Disease Research Center
St. Louis, MO
Telephone: 314-286-2882
E-mail: meuser@abraxax.wustl.edu
Website: <http://alzheimer.wustl.edu>

October 9-10, 2005

**"Branch Out Kentucky"
Conference - Uniting to Identify
and Care for African-Americans
with AD, Lexington, KY**

Contact:

Janice Paul
UK Sanders-Brown Center on Aging
800 S. Limestone Street, Room 314
Lexington, KY 40536
Telephone: 859-257-1412, ext. 272
Fax: 859-323-2866

October 20-21, 2005

**UT Southwestern: Genetics of
Alzheimer's Disease & Related
Disorders, Irving, TX**

Contact:

Continuing Education/UT Southwestern
5323 Harry Hines Boulevard
Dallas, Texas 75390-9059
Telephone: 1-800-688-8678 or
214-648-3138
Fax: 214-648-4804
E-mail:
cmeregistrations@utsouthwestern.edu

November 12-16, 2005

**35th Annual Meeting of the
Society for Neuroscience,
Washington, DC**

Contact:


Society for Neuroscience
11 Dupont Circle, NW, Suite 500
Washington, DC 20036
Telephone: 1-202-462-6688
E-mail: info@sfn.org

Clinical Trials

(from page 5)

coordinated by the University of California at San Diego, continue to seek volunteers. Included among these trials are:

- **CLASP**—Cholesterol Lowering Agent to Slow Progression of AD Statin Study, investigating the safety and effectiveness of simvastatin (a cholesterol-lowering drug or statin) to slow the progression of AD.
- **VITAL**—VITamins to slow Alzheimer's (homocysteine study), to determine whether reduction of homocysteine levels with high-dose folate (folic acid), B₆, and B₁₂ supplementation will slow the rate of cognitive decline in people with AD.
- **TAP/DAP**—Treatment of Agitation/Psychosis in Dementia/Parkinsonism, to determine the safety and efficacy of quetiapine for the treatment of psychosis and/or agitation in patients with primary dementia complicated by coexistent parkinsonism, or patients with Parkinson's disease with dementia who have episodes of agitation or psychosis.
- **VALID**—VALproate in Dementia, to demonstrate whether valproate therapy slows the progression of AD or delays the emergence of agitation and/or psychosis in outpatients with probable AD who have not experienced agitation and psychosis in their illness.
- **HUPERZINE A**—to determine whether treatment with *huperzine A*, a natural cholinesterase inhibitor derived from a Chinese herb, improves cognitive function in people with AD.

Visit the ADCS website at <http://adcs.ucsd.edu> for more information. 

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