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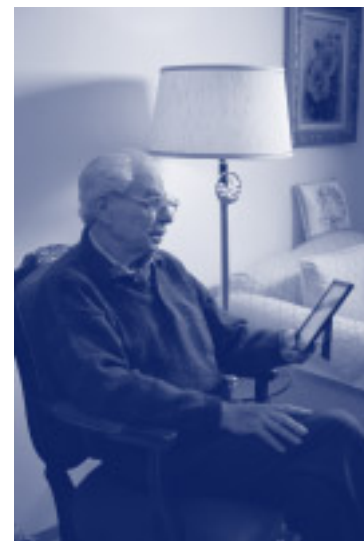
New Neuroimaging and Biomarkers in MCI and AD Initiative

A new National Institute on Aging (NIA) initiative will launch a multi-year neuroimaging study using serial magnetic resonance imaging (MRI) and positron emission tomography (PET) scans to examine how brains change as mild cognitive impairment (MCI) and Alzheimer's disease (AD) progress. Scientists will correlate the imaging information with clinical, neuropsychological, and biological markers from blood, cerebrospinal fluid (CSF), and urine samples. Potential markers include levels of amyloid and *tau*, components of the plaques and tangles considered to be the hallmarks of AD; indicators of inflammation such as C-reactive protein and alpha-antichymotrypsin; and measures of oxidative stress such as oxysterols and isoprostanes. Markers for disease on brain scans and from these fluids can aid in early diagnosis and in the evaluation of response to treatment. "We hope that the AD Neuroimaging Initiative will help create rigorous imaging and biomarker standards that will provide the yardstick by which the success of future treatments can be measured," said Susan Molchan, M.D., Program Director for AD Clinical Trials, Dementias of Aging Branch, Neuroscience and Neuropsychology of Aging
(see *Neuroimaging*, page 2)

Alzheimer's Disease and End-of-Life Issues

Despite our best research efforts, Alzheimer's disease remains incurable. Researchers are using sophisticated technologies to pinpoint how AD progressively steals memories and destroys personality; and yet, AD remains irreversible. Although one does not die of Alzheimer's disease, during the course of the disease, the body's defense mechanisms ultimately weaken, increasing susceptibility to catastrophic infection and other causes of death related to frailty. At some point after the mind has been lost to this devastating disease, the body will be lost as well.

Families and caregivers of people with AD face many challenges as they cope with the steady loss of their loved one's mental and physical skills. As the disease moves to its end stages, certain steps can provide measures of comfort—both to the caregiver and to the person with AD. Healthcare professionals can
(see *End-of-Life*, page 3)



Progress Report on Alzheimer's Disease Now Available



The National Institute on Aging is pleased to announce that the *2001-2002 Alzheimer's Disease Progress Report* is now available. Designed as both a companion piece to the popular *Alzheimer's Disease—Unraveling the Mystery* published late
(see *Progress Report*, page 6)

Menopausal Hormone Therapy and Dementia

Can estrogen after menopause preserve mental abilities and protect the brain from dementia? Laboratory research and observational studies involving small groups of women suggest it can. However, in May 2003, scientists taking part in a large clinical trial reported that, in women 65 and older, taking a combination of estrogen and progesterin every day did not seem to prevent dementia or slow its progression over time. In fact, the older women on this estrogen plus progesterin were at twice the risk of developing dementia as those taking the placebo. This combination also did not prevent general cognitive
(see *Hormone Therapy*, page 6)



News From the Alzheimer's Disease Education and Referral (ADEAR) Center
A Service of the National Institute on Aging
National Institutes of Health
U.S. Department of Health and Human Services

Neuroimaging

(from page 1)

Program at NIA. The initiative is being planned as a partnership among the NIA/NIH, university investigators, the pharmaceutical and the imaging equipment industries, the Food and Drug Administration, and the NIH Foundation, with participation from the Alzheimer's Association and the Institute for the Study of Aging. Like the Alzheimer's Disease Genetics Initiative, an important aspect of this initiative is that the clinical, imaging, and biological data collected will be made available to all qualified scientific investigators promptly.

Researchers will be conducting a longitudinal, multi-site study that will include approximately 150 cognitively normal individuals to be followed for 3 years, 350 people with MCI to be followed for 3 years, and 150 people with early AD to be followed for 2 years. Using MRI and PET scans at regularly scheduled intervals, investigators hope to learn when and where in the brain degeneration occurs as memory problems develop.

A Coordinating Center for the initiative will manage the tracking of subject recruitment and visits, including clinical/neuropsychological assessment, MRI and PET scans, blood/CSF collection, genotyping, data quality assurance/quality control, and transmission, storage, and assurance of confidentiality of data. A Neuroimaging Center will establish imaging protocols, assess and control the quality of scans, and process, store, and distribute the brain scans. Approximately 25 clinical sites throughout the country will evaluate potential participants for the initiative, collect the clinical and neuropsychological data, perform the MRI and PET scans, and collect blood, urine, and from some subjects, cerebrospinal fluid samples, for shipment to central storage facilities.

Brain Shrinkage and Metabolism

As MCI and AD progress, areas of the brain involved with memory, such as

the hippocampus, shrink. Using the high resolution images produced by MRI, researchers will be evaluating the best ways of measuring this volume loss in the hippocampus and other structures. PET scans assess brain function by measuring the rate of metabolism of glucose, the brain's fuel. PET scans of people with AD show that glucose in certain parts of the brain is metabolized at lower levels than in healthy people. Previous studies have shown that low glucose metabolism can be seen in some people even before memory loss symptoms become prominent.

A number of studies in MCI and AD have demonstrated that imaging may provide more sensitive and consistent measures of disease progression than memory assessment. "The information collected during the Neuroimaging Initiative may allow for early identification of people with MCI and AD who may benefit from emerging preventive and treatment medications. The data also could determine whether neuroimaging measures, such as the size of the hippocampus, may serve as indicators of benefit from drug treatment in clinical trials," said Dr. Molchan. A slowed rate of shrinkage in a brain structure known to be affected by AD together with neuropsychological test data indicating that memory function was stabilizing or improving, would be strong evidence that a drug is slowing or stopping degeneration in the brain. The drugs currently available for AD temporarily relieve some symptoms for some people, but are not thought to actually slow degeneration.

Advances in the understanding of the pathophysiology and genetics of AD are providing opportunities for developing drugs that slow or stop the progression of disease. Early in drug development, imaging measures and other biological markers may help to rapidly identify appropriate doses, assess safety, and compare drugs. This may help to increase the safety and efficiency of clinical trials and may decrease the cost and time of developing drug treatments for this disease that robs people of their memories. ✨

Updates: AD Genetics Initiative

Recruitment for the AD Genetics Initiative is off to a good start following the Alzheimer's Association's Education Conference in July. Chapter directors throughout the country were asked to spread the word about the new Initiative. As a result, 100 families are being enrolled in the study.

Researchers are searching for risk factor genes for late-onset AD. They are recruiting families with two or (preferably) more living members who have late-onset AD. Blood samples from affected and unaffected family members will be collected to create and maintain cell lines for DNA analysis. A national case-control sample set, in which the genes of individuals with AD (case) are compared to those who have no symptoms of the disease (control) is planned.

Families interested in participating can contact the National Cell Repository for Alzheimer's Disease at 1-800-526-2839.

Valproate Clinical Trial

A new trial underway during the summer of 2003 will examine whether valproate, an anticonvulsant/antipsychotic drug, is effective in treating or preventing agitation and psychosis in people with probable AD. A secondary aim is to see if continuous valproate therapy slows cognitive decline.

Principal Investigator for the AD Cooperative Study, which directs this 4-year trial, "A Randomized, Double-Blind, Placebo-Controlled Trial of Valproate to Attenuate the Progression of Alzheimer's Disease," is Leon Thal, MD, University of California at San Diego Alzheimer's Disease Center (858-534-4606, lthal@ucsd.edu). The Project Director is Pierre Tariot, MD, University of Rochester Alzheimer's Disease Center (585-760-6572, pierre_tariot@urmc.rochester.edu). ✨

End-of-Life

(from page 1)

help caregivers fill the last days with love and tenderness even through the wrenching turmoil of letting go.

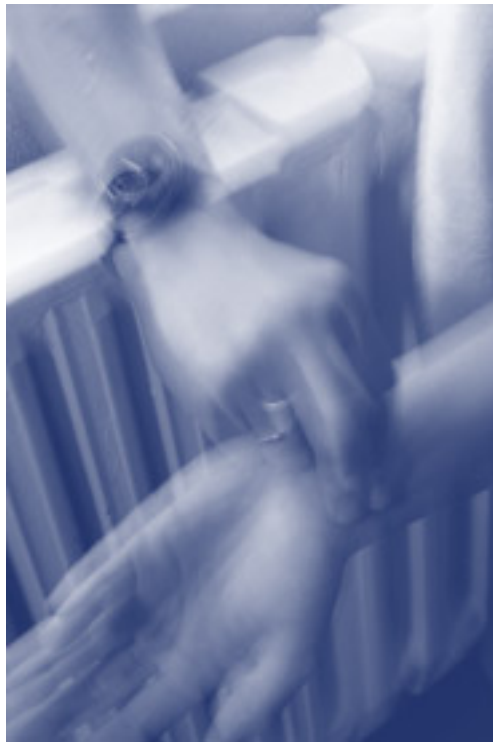
Many caregivers are unaware that resources and healthcare professionals are available to provide comfort and help each AD patient end life with dignity. They face emotional conflict and unnecessary guilt.

"A lot of what we think about death and dying is based on the cancer model," says Dr. Stephen Post, professor in the department of bioethics at Case Western University School of Medicine. "Alzheimer's is a complicated and difficult disease." Late-stage AD is characterized by the inability to communicate by speech or recognize family members, the inability to move about without assistance, incontinence, loss of appetite, and loss of the ability to swallow, with death usually resulting from aspiration pneumonia, infection, or coronary arrest. On the average, the advanced stage of AD lasts 1.5 to 2 years, according to Dr. Post, though 20-30% of patients will "linger" 4, 5, 6, or even as long as 10 years, he says.

Doctors, nurses, social workers, and other healthcare professionals can help caregivers understand the dying process and the role of palliative care for the AD patient. This is the purpose of palliative care—to provide comfort and symptom relief, without the use of aggressive treatments, such as tube feeding, mechanical respiration, dialysis, and cardiopulmonary resuscitation, which often only prolong the suffering of the patient. Community programs, such as hospice, can be of great service to family members and healthcare professionals by assisting with medications, patient physical care, and counseling. The objective in managing the advanced stages of Alzheimer's disease should be to maximize comfort while preserving patient dignity and respect.

The Palliative Course

Experts agree that palliative care is the most appropriate course of action for advanced Alzheimer's disease. Use of aggressive medical interventions in the advanced stage, such as CPR, feeding tubes, intravenous antibiotics, even dialysis, is considered by experts to be of little benefit, and may impose a further burden of suffering on the patient. "The Alzheimer's Association firmly recommends palliative care and hospice approach in the advanced stages of the disease," says Dr. Post.



"Family members should never be made to feel guilty in making a decision to allow a person with AD to die naturally."

"Healthcare professionals are duty-bound to do more than simply present technological options like items on a laundry list, without clarifying the burdens that these technologies create for people with advanced dementia," Dr. Post says. Healthcare teams in these circumstances must be nonjudgmental and listen attentively to family wishes, while providing accurate facts on the adverse implications of prolonging end-of-life treatments.

Artificial Feeding and Hydration

Family members should be warned about the potential medical problems associated with artificial feeding and hydration. These include, in the case of nasogastric tubes, pain and discomfort related to the forceful introduction of physical devices in the esophagus, needed sedation, and infections often resulting from the procedure. "Many family members are not aware that no longer eating and drinking is part of the dying process, and it is normal," says Dr. Post.

"Our modern culture tends to treat dying as unnatural. Our technology allows us to forestall death, yet cannot prevent it. Family members need to be informed, with great compassion, sensitivity, and patience, about the dying process and how natural and inevitable it truly is. The body is shutting down. The natural process of dying means that the body no longer wants or needs food or fluids. This is often viewed as unnatural by caregivers, and even some healthcare professionals. However, we need to explore our own feelings and attitudes toward death and dying before we can help families through this transitional process, this time of loss and change," comments Darby Morhardt, MSW, Social Worker, Northwestern University Alzheimer's Disease Center.

Cessation of food intake results in the release of endorphins, which reduce pain. Feeding tubes and hydration block the release of endorphins and can result in weeks of "unnecessary suffering" Dr. Post said, with patients "uremic and bloated and unable to clear mucus from their lungs." Percutaneous endoscopic gastrostomy (PEG) feeding can result in back-up to the esophagus, increasing the risk of aspiration pneumonia, while lack of ambulation—PEG feeding often requires physical restraint to prevent patients from pulling out their feeding tubes—increases the risk for bed ulcers and skin infections.

(continued next page)

Artificial feeding also deprives a patient of taste, says Dr. Ladislav Volicer, clinical director of the Geriatric Research, Education and Clinical Center (GRECC) at the E.N.R.M. Veterans Hospital in Bedford, Massachusetts. "Alzheimer's patients love sweets," Dr. Volicer says, "even in the later stages—things like milk shakes and ice cream." Artificial feeding also deprives patients and caregivers of personal contact, which is a meaningful activity.

"We haven't had any tube feeding in the last 10 years," says Dr. Volicer, who often converts patients back to assisted feeding on arrival. "They can always eat to some degree," he says, "except during the actual dying process." Patients in the dying phase do not experience hunger and thirst, he adds.

Problems with choking can be addressed by substituting thick liquids, such as yogurt instead of milk, and by using commercial thickeners. "What we are trying to do is switch the emphasis of care from high tech to high touch," he says. "That also includes very aggressive management of pain. We use a lot of narcotics in the management of late-stage dementia."

Antibiotics may be useful for urinary tract infections, but they are not reliable against chest infections, because of increasing resistance, says Dr. Post. Some physicians prefer to recommend acetaminophen (like Tylenol) for fever.

Hospital transfers should also be discouraged. "There is published evidence," says Dr. Volicer, "that the 3-month mortality rate is lower if patients are treated in a nursing home than if they are transferred to the hospital."

The End Draws Near

It's difficult to predict when an AD patient is going to die. "The average clinicians are not as good at this as they would be for cancer," says Dr. Jason Karlawish, of the University of Pennsylvania's Institute of Aging,

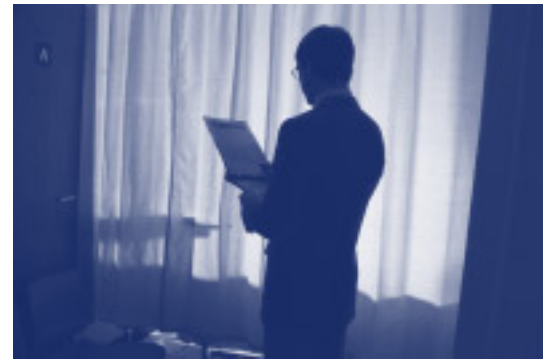
"because there is a lack of clear understanding of this stage of AD." Dying for the Alzheimer's patient is marked by little if any verbal output, complete dependency in all aspects of daily living, and the complications of brain failure, which include episodes of aspiration, urinary tract infections, fevers, skin breakdowns, and more than 10% loss of body weight. "This is the typical profile of a patient who I would expect could die within a year," says Dr. Karlawish.

Working with Family Members

In the absence of advance directives (see page 5, the healthcare team should work with family members to arrive at a consensus of care and abide by final decisions. There are often conflicts over the use of heroic efforts to prolong life. At odds are everything from the philosophies of individual providers and institutional caregivers to issues of patient competence in the absence of legal instruments. The solution: arrival at a plan by way of a narrative consensus. Healthcare workers can guide this effort by creating an environment of "equal standing," Dr. Karlawish says, in which all family members are encouraged to discuss how they perceive the patient's illness and arrive at a consensus that will provide the patient with the most comfort and the highest quality of remaining life. "You should be hearing yourself talking about half the time in the beginning," Dr. Karlawish says, "but if you've done it right, the caregiver should wind up doing most of the talking." Physicians should not be hesitant to recommend hospice as an option, he says.

Sparing a Lifetime of Guilt

Doctors can educate themselves to make knowledgeable recommendations. "Nothing should be left to surrogate decision-making without clear data and recommendations," Dr. Post says. "Family members need to be spared a lifetime of guilt."



Social workers make good moderators at consensus meetings. Clergy can also play an important role for both family and the patient, says Dr. Post, who views the AD patient as still having an emotional, recreational, and symbolic self. "Pastoral care involves symbols," he says. "Oftentimes, we underestimate the importance of pastoral care for reconnecting these people with some aspect of themselves that is otherwise ignored."


Healthcare professionals also can help families understand that all feelings—anger, sadness, guilt, relief, conflict, fear—are normal as they witness the patient going through the dying process.

A Healing Death

If there is a kind point in the progression of AD, Dr. Post suggests, it is the point at which the patient begins to forget what they have forgotten, where they no longer have insight into their behavior.

But for family members with memories intact, there is no such kind point. There is only a series of losses at each stage of the disease, as their loved one slips away. "So many of the healing aspects of death and dying are lost with Alzheimer's disease," says Dr. Post. Much of the understanding family members have of the dying process is what the healthcare team brings to them. In the absence of advanced directives, the healthcare team must provide the means by which family members can arrive at a consensus that will preserve patient dignity and quality of life, and the best chance for healing for those left behind.

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- Family Caregiver Alliance
1-800-445-8106
www.caregiver.org
- National Hospice Foundation
1-800-338-8619
www.hospiceinfo.org
- National Hospice and Palliative Care Organization
703-837-1500
www.nhpc.org 

End-of-Life Legal Instruments

What sets Alzheimer's disease apart from many other terminal diseases is the progressive, irreversible loss of cognitive abilities, which begins early and becomes increasingly worse. The majority of patients arrive at the later stages of Alzheimer's without advance directives. "In the mild stage, many patients are able to make decisions, but a substantial number, perhaps even 50%, will have difficulty with complex decisions, like planning for the future," says Dr. Jason Karlawish, of the University of Pennsylvania's Institute of Aging.

By the advanced stage, the patient is no longer able to communicate pain or certain needs. "Once someone loses language," Dr. Karlawish says, "cognition becomes an interpretive act on the part of others." Pain is often related to immobility, as well as constipation, osteoarthritis, and osteoporosis. The challenge to the physician "is to interpret the meaning of grunts, groans, and agitation, which are often misinterpreted by family members and the physician, and determine what the need is that is not being met."

Advance Directives: Durable Power of Attorney

Ideally, the healthcare team should initiate discussion of an end-of-life care plan while the patient is able to participate. The team should also be sensitive to the patient's and family's ability to tackle these issues head-on. Some families will be quite capable of making orderly decisions about an impending death, but others may feel uncomfortable even thinking about what is going to happen to their loved one.

It may help family members to consult with a social worker. During this difficult period, social workers can counsel families, and provide key information to other members of the healthcare team about the family's dynamics, history, and emotional make up.

The durable power of attorney for health care, also referred to as the medical power of attorney, empowers

one designated individual to make all medical decisions (if the patient lacks capacity), unless limited by other directives. The living will, in some States called "instructions," "directive to physicians," or "declaration," states the patient's desires regarding life-sustaining or life-prolonging medical treatments.

The durable power of attorney for health care is superior to a living will, Dr. Post says, because it has "absolute legal clout" (not all States regard the living will as legally binding), and because of the prognostic uncertainty of the disease—"It's impossible to anticipate the incredible number of situations that might occur," he says. The living will can be a useful adjunct to a durable power of attorney for health care because it can serve as a guide to the proxy. It can also serve as a springboard for initiating discussions of end-of-life care. Diagnostic honesty is critical to the adoption of advance directives, but their legal limitations must be recognized.

Do Not Resuscitate Orders

Experts agree that there is no question that Do Not Resuscitate (DNR) orders should be standard procedure for advanced Alzheimer's patients. "Resuscitation is a horrendous experience for someone with Alzheimer's disease," says Dr. Post. "Only 10% will survive the CPR effort, and almost all who do can be so severely injured by the application that they will not recover. And they will be even more compromised cognitively. Physicians should argue vehemently against any resuscitative efforts for advanced AD patients."

RESOURCES

- Family Caregiver Alliance. *Fact Sheet: End-of-Life Decision-Making*.
- Family Caregiver Alliance, *Fact Sheet: End-of-Life Choices—CPR and DNR*.
- Kass-Bartelmes, B.L. *Advance Care Planning: Preferences for Care at the End of Life*. Research in Action, March 2003; Agency for Healthcare Research and Quality.

Hormone Therapy

(from page 1)

decline. They recommended that women not take menopausal hormone therapy to prevent dementia or to preserve their mental abilities.

Menopausal hormone therapy, once called hormone replacement therapy (HRT), is used to treat the symptoms of menopause such as hot flashes and to prevent bone loss after menopause. Women with a uterus take a combination of the hormones estrogen and progesterone or its synthetic form, progestin, to prevent a thickening of the endometrium (the lining of the uterus) and a slightly increased risk of endometrial cancer. Women without a uterus take estrogen alone.

The investigators are part of the Women's Health Initiative Memory Study (WHIMS), a substudy of the Women's Health Initiative (WHI). They found that each year there would be 22 cases of dementia in every 10,000 older women taking placebo and 45 cases of dementia in every 10,000 women taking this combination of estrogen plus progestin. That is an increase of 23 cases of dementia. Most of the dementia found in women in the study was diagnosed as probable Alzheimer's disease, and vascular dementia ranked second. There was no significant difference in the risk of being diagnosed with mild cognitive impairment when the placebo and combination therapy groups were compared.

In 1992 the National Institutes of Health began the WHI hoping to learn how to protect postmenopausal women from heart disease, breast and colorectal (colon and rectum) cancer, and osteoporosis. The WHI includes a randomized clinical trial to determine the benefits and risks of using menopausal hormone therapy. The WHIMS substudy involves women from the WHI 65 and older to

study whether menopausal hormone therapy will keep older women from getting dementia and losing the mental abilities that help them perform daily tasks.

In the WHI more than 27,000 women, ages 50-79, took estrogen (Premarin™), estrogen plus progestin (Prempro™), or a placebo. Premarin™ contains 0.625 mg of conjugated equine estrogens only, and Prempro™, taken daily, is a combination of 0.625 mg of conjugated equine estrogens and 2.5 mg of a synthetic progesterone known as medroxyprogesterone acetate. These were the hormones most commonly used for menopausal hormone therapy at the time the study was planned.

In July 2002 the part of the WHI involving estrogen plus progestin was stopped early when scientists found that women taking this combination were at increased risk for certain health problems, including heart attacks, breast cancer, strokes, and blood clots. This combination was beneficial in some ways also—fewer hip fractures and less chance of colorectal cancer. Even so, the scientists believed the risks were greater than the benefits. So, all women taking estrogen plus progestin in the WHI study, including the WHIMS substudy, were told to stop their study pills. Women taking estrogen alone were allowed to keep taking their pills.

The WHIMS investigators reported their results in the *Journal of the American Medical Association*, May 28, 2003. Wyeth Pharmaceuticals, manufacturer of both Premarin™ and Prempro™, funded the WHIMS study. The WHI is sponsored by the National Heart, Lung, and Blood Institute, along with the National Cancer Institute, National Institute of Arthritis and Musculoskeletal and Skin Diseases, Office of Research on Women's Health, and National Institute on Aging. 🦋

Progress Report

(from page 1)

last year, and as a stand-alone publication, the *Progress Report* summarizes research advances by NIA and other Institutes of the National Institutes of Health. While *Unraveling the Mystery* provides more background information on AD, the *Progress Report* focuses on recent research activities on these key themes:

- What causes the transformation from healthy aging to AD?
- Can certain factors increase the risk of or protect against AD?
- What can be done to halt AD, slow its progress, or lessen its effects?

The *Progress Report* examines mild cognitive impairment (MCI) and describes current thinking about early AD. Recent studies indicating that neuropsychological tests can predict AD to some extent are discussed. Scientific advances in neuroimaging and brain scanning technology are presented, along with descriptions of the continuing work to refine our understanding of the role of beta amyloid and *tau* proteins in AD development.

Risk factors for AD, including summaries of epidemiologic studies of unique populations are summarized in the *Progress Report*. A discussion of the role of genetics and the search for genes that may contribute to late-onset AD is presented. Summaries of clinical studies recently completed or now underway, including the Memory Impairment Study, the Women's Health Initiative, and the effects of cholesterol-lowering and non-steroidal anti-inflammatory drugs are provided.

The 2001-2002 *Progress Report on Alzheimer's Disease* can be viewed online at www.alzheimers.org/pr01-02/index.htm. Copies can be ordered via the ADEAR Center's new online ordering system, or by calling 1-800-438-4380 or by using the order form on the back page of this newsletter. 🦋

Hospitalization Brochure Now FREE

Hospitalization Happens: A Guide to Hospital Visits for Loved Ones with Memory Disorders is now free from ADEAR. This brochure can help you prepare for hospital visits for people with AD. In it you will find advice on:

- working with and communicating with hospital staff
 - packing an "emergency bag" with essentials, I.D. cards, and medicines
 - how to plan for a scheduled or unscheduled hospital stay
- Order copies from www.alzheimers.org/eshop, or call 1-800-438-4380, or use the form on the back page. 🦋

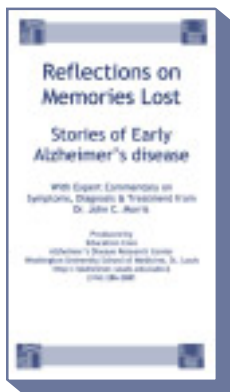


This brochure was originally produced by the North Carolina Division of Aging in conjunction with the Joseph and Kathleen Bryan Alzheimer's Disease Research Center.

New Educational Video Combines Personal Stories and Science

The ADEAR Center is pleased to add a new video, *Reflections on Memories Lost: Stories of Early Alzheimer's Disease*, to our catalog. Produced by the Alzheimer's Disease Research Center at Washington University in collaboration with the St. Louis Black Repertory Theater Company, this 33-minute program combines poignant dramatized scenes with expert commentary on the symptoms, diagnosis, and treatment of early AD. The vignettes are adapted from Lisa Snyder's book, *Speaking Our Minds: Personal Reflections from Individuals with Alzheimer's*, and feature two African American characters with AD and their caregivers. Dr. John C. Morris of the Washington University ADRC, provides medical commentary pertinent to the scenes portrayed. The video is available from the ADEAR Center for \$7.50 and can be previewed and ordered through the ADEAR Web site at www.alzheimers.org/eshop or by using the order form on the back page of this newsletter.

"*Reflections on Memories Lost* is an exceptional, quality video that is both novel and user-friendly. Congratulations to the actors and to Dr. Morris for capturing the essence of each important message. This could be an excellent minority recruitment and retention tool for use in clinics or with small groups," says Lisa Gwyther, Bryan Alzheimer's Disease Research Center, Duke University.



Publications Ordering added to NIA Websites

Ordering a publication from the National Institute on Aging is now easier than ever before. The NIA's website – www.nia.nih.gov and the NIA's Alzheimer's Disease Education and Referral (ADEAR) Center's website – www.alzheimers.org now offer online ordering systems. Materials can be purchased using a secure, online credit card processing system.

Web users can search publications by key word, browse by category, or view all materials in one continuous list, in each online system. Publications can be viewed and added to the user's shopping cart, or can be viewed and printed directly from the online versions available. Many publications are in online (html) and portable document file (PDF) formats.

You can order multiple copies of publications based on each publication's assigned quantity limit. Generally, you can order up to 50 free fact sheets and *Age Pages* and up to 25 free booklets.

Anyone interested in bulk orders of ADEAR publications in quantities beyond the ordering system's limits



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can e-mail the ADEAR Center: adear@alzheimers.org, or call the Center's toll-free line, 1-800-438-4380. For bulk orders of publications offered on the NIA online ordering system, contact the NIA Information Center: niaic@jbs1.com, or toll-free, 1-800-222-2225. Users should allow about 2-4 weeks for delivery.

Specialists at each center are available to help users navigate the online ordering system, and can assist with information requests. Each center also continues to accept checks or money orders (in US funds) as payment.

Payment by credit card is processed by PayPal, an industry leader in secure online credit card purchasing. Once an order has been placed for a cost item and the user is ready to complete the transaction, the user is transported to the PayPal website. Major credit cards and electronic checks are accepted for payment.

Security of information is protected by a number of rigorous firewalls, and user privacy is ensured. See each system's online Privacy Statement for more information.

The direct online address for the ADEAR publications ordering system is: www.alzheimers.org/eshop.

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.

End-of-Life Issues

Improving Care for the End of Life: A Sourcebook for Health Care Managers and Clinicians. 2000.

Lynn, J.; Kabcenell, A.; Schuster, J.L.

Available from Oxford University Press. 2001 Evans Road, Cary, NC 27513. 1-800-445-9715. Website: www.oup-usa.org. PRICE: \$55.00

This book is designed to help healthcare professionals and families improve care for patients during the last stages of life, including people with Alzheimer's disease. The examples are taken from research involving more than four dozen healthcare organizations committed to improving end-of-life palliative care. Each chapter provides stories of their successful efforts to provide good end-of-life care. Part 1 suggests quality improvement projects most organizations can implement right away. Part 2 focuses on changes patients and families often demand or would most benefit from. Part 3 describes environments that encourage better practice. Part 4 discusses opportunities for change in caring for patients with specific diseases. The last chapter gives specific tips on getting started. Content-specific resources are listed at the end of each chapter. Issues covered throughout the book related to patients with AD and other dementias include advance care planning, ethical issues, family caregiver support, nursing facility improvement, palliative care, terminal stage determination, depression, pain management, and final phases of care.

Living With Grief: Loss in Later Life. 2002.

Doka, K.J., ed.

Available from the Hospice Foundation of America. 2001 S Street, NW, Suite 300. Washington, DC 20009. 1-800-854-3402. Website: www.hospicefoundation.org. PRICE: \$24.95

This book explores how older people are affected by grief and loss. It features writings from renowned experts and professionals in the aging field as well as personal accounts of grief and loss from older individuals. Part 1 looks at death as a fact of older life. Part 2 addresses the fundamental losses and realities of growing old and dying. Part 3 discusses the many and particular losses experienced by older people, including the loss of a spouse, parent, and grandchild. It also examines the effects of loss on the survivor's health, suicide in older people, traumatic loss, cultural aspects of loss, and counseling strategies. A chapter focuses on the losses that accompany AD, the psychological impact of those losses, and the strategies caregivers can use to help the person with AD. Other chapters discuss the spectrum of long-term care options for older people and the concept of 'disenfranchised' or unvalidated grief among older persons.

Who Cares: A Loving Guide for Caregivers. 2002.

Marrella, D.

Available from DC Press. 2445 River Tree Circle, Sanford, FL 32771. 1-866-602-1476. Website: www.focusonethics.com/whocares.html. PRICE: \$14.95

This book is designed to let future caregivers know the wishes and preferences of an aging person who can no longer convey the necessary information. It is to be completed by the individual for whom future care is intended and then given to the future caregivers. It allows the future care recipient to document such information as likes and dislikes, personal beliefs, physical problems, medications and allergies, family medical history, favorite brands of personal products, wishes for medical treatment and life support, preferred healthcare providers, daily routine, favorite foods, hobbies, clothing sizes and preferences, favorite forms of entertainment, religious affiliation and practices, important family names, financial and business affairs, and favorite places to visit.

Religious Perspectives: Tissue Donation and Postmortem Human Brain Research. 2000.

Available from the Harvard Brain Tissue Resource Center. McLean Hospital, 115 Mill Street, Belmont, MA 02478-9106. 1-800-272-4622. Website: www.brainbank.mclean.org. PRICE: free

This brochure presents selected religious perspectives on tissue donation and postmortem human brain research. Although positions vary from one denomination to another, the majority of religions appear to support postmortem brain tissue donation and research. While some faiths have very particular laws governing the circumstances of donation, the mandate to heal and the call to compassion are recognized as fundamental to all religions. This brochure summarizes the perspectives of Protestant Christianity,

Catholicism, Judaism, Greek Orthodox, Islam, Buddhism, Hinduism, Jehovah's Witness, and Christian Scientists.

Assessing Pain

Can You Tell Me Where It Hurts?: A Guide to Assessment of Pain in Residents With Dementia. 2001.

Villanueva, M.R.; Smith, T.L.; Lee, A.C.

Available from the Behavioral Assessment Resources, LLC. 955 Town Centre Drive, Suite C, Medford, OR 97504. 1-800-851-958. PRICE: \$24.95 plus \$4.00 shipping and handling for first copy; \$2.00 for each additional copy

This training guide is designed to teach new caregiving staff and family members how to assess pain in residents with dementia. It explains why people with dementia may not be able to tell someone when or where they hurt and why caregivers' instinctive judgments of a resident's pain can be inaccurate. It describes common physical and functional expressions of pain and explains how caregivers can use observations of these indicators to reliably identify pain in their residents. It provides a guideline for assessing pain in residents with different levels of dementia and examples of the visual analogue scale and faces scale that residents with mild to moderate dementia can use to rate their level of pain.

Exercise and AD

Telerounds 64: Effects of Exercise and Cognitive Stimulation on the Progression of Alzheimer's Disease. 2002.

Arkin, S.

Available from the National Center for Neurogenic Communication Disorders, University of Arizona. P.O. Box 210071, Tucson, AZ 85721-0071. 520-621-1472. Website: <http://cnet.shs.arizona.edu/telerounds/past/64.html>. PRICE: \$25.00

This videotape describes a longitudinal study funded by the NIA to evaluate the effects of exercise and cognitive stimulation on the progression of AD. The tape is narrated by Sharon Arkin, clinical psychologist and principal investigator of the Elder Rehab program. Students enrolled at the University of Arizona administered the program. Interventions consisted of twice weekly physical workouts, one supervised by a student and one by a caregiver; 10 to 12 memory and language stimulation activities, administered by the student at one of the weekly workouts; and a weekly student-supervised session of community volunteer work alternating with a recreational activity. The exercise sessions were held at the University Medical Center's Wellness Center. They included aerobic, strength, and flexibility exercises. An evaluation of outcomes revealed significant improvements in physical fitness and mood for program participants. In addition, participants remained stable on measures of language and cognitive function whereas controls declined significantly. The videotape includes a question and answer session.

The AD Patient's View

Person With Alzheimer's Disease: Pathways to Understanding the Experience. 2002.

Harris, P.B.

Available from The Johns Hopkins University Press. 2715 N. Charles Street, Baltimore, MD 21218-4319. 410-516-6900. Website: www.press.jhu.edu. Price: \$48.00 hardcover; \$19.95 paperback

This book explores the subjective experience of living with dementia from the perspective of the patient. Each chapter discusses a different aspect of having dementia, from the initial assessment through nursing home placement. Part I, The Medical Experience, deals with the neuropsychological assessment process, disclosure of the diagnosis, and medical encounters. Part II, The

Impact of the Diagnosis on Everyday Life, explores what it is like to live with the symptoms of dementia, the concept of quality of life, selfhood in AD, the effect of AD on social and family relationships, maintaining meaningful communication, making spiritual connections, and the use of positive coping strategies. Part III, Experiences with Formal Services, discusses patients' experiences with community services, adult day care centers, early stage support groups, art therapy programs, and nursing homes.

Counseling Caregivers

Counseling the Alzheimer's Caregiver: A Resource for Health Care Professionals. 2003.

Mittelman, M.S.; Epstein, C.; Pierzchala, A.

Available from the American Medical Association Press. 515 North State Street, Chicago, IL 60610. 1-800-621-8335. Website: www.AMAPress.com. PRICE: \$45.00; \$35.00 for AMA members

This book is designed to guide health-care professionals in counseling family caregivers of people with AD. Using vignettes and practical suggestions, it covers the spectrum of AD issues and how to help caregivers deal with them effectively. First, it provides an overview of AD, its diagnosis, progression, and effects of caregiving on families. Then, it describes the counseling process, including the assessment, counseling techniques, individual and family counseling, ad hoc (as needed) counseling, and support groups. It also explains how counseling can help caregivers adapt to the caregiving role. Finally, it discusses some of the issues a professional might encounter when working with family caregivers, including relationship issues, medical care for the AD patient, caring for the patient at home, placement in a residential facility, and the end stage of AD.



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

November 1, 2003

Creative Interventions with Alzheimer's Residents: Meeting the Challenge, Miami, FL

Contact:
Geriatric Resources, Inc.
PO Box 239
Radium Springs, NM 88054
800-359-0390 or 505-524-0250
Fax: 505-524-0254
GRI@zianet.com
www.geriatric-resources.com

November 4, 2003

UPenn Center for Neurodegenerative Disease Research Retreat-Symposium, Philadelphia, PA

Contact:
Gayle Viale
Center for Neurodegenerative Disease Research
University of Pennsylvania School of Medicine
3rd Floor Maloney Building
3600 Spruce St.
Philadelphia, PA 19104
215-662-4708
Fax: 215-349-5909
viale@mail.med.upenn.edu
www.ups.upenn.edu-cndr-retreat.html

November 6-7, 2003

4th Neurobiology of Aging Conference, New Orleans, LA

Contact:
Neurobiology of Aging Conference Secretariat
Elsevier
The Boulevard
Langford Lane
Kidlington
Oxford OX5 1GB
UNITED KINGDOM
+44-0-1865-843089
Fax: +44-0-1865-843958
a.williams@elsevier.com

November 8-12, 2003

33rd Annual Meeting of the Society for Neuroscience, New Orleans, LA

Contact:
Society for Neuroscience
11 Dupont Circle NW, Suite 500
Washington, DC 20036
202-462-6688
www.sfn.org

November 15, 2003

American Public Health Association's 131st Annual Meeting and Exposition, San Francisco, CA

Contact:
American Public Health Association
800 I Street, NW
Washington, DC 20001
www.apha.org

November 15, 2003

Creative Interventions with Alzheimer's Residents: Meeting the Challenge, Orlando, FL

Contact:
Geriatric Resources, Inc.
PO Box 239
Radium Springs, NM 88054
800-359-0390 or 505-524-0250
Fax: 505-524-0254
GRI@zianet.com
www.geriatric-resources.com

November 18, 2003

Creative Interventions with Alzheimer's Residents: Meeting the Challenge, Fort Myers, FL

Contact:
Geriatric Resources, Inc.
PO Box 239
Radium Springs, NM 88054
800-359-0390 or 505-524-0250
Fax: 505-524-0254
GRI@zianet.com
www.geriatric-resources.com

November 20, 2003

Creative Interventions with Alzheimer's Residents: Meeting the Challenge, Lakeland, FL

Contact:
Geriatric Resources, Inc.
PO Box 239
Radium Springs, NM 88054
800-359-0390 or 505-524-0250
Fax: 505-524-0254
GRI@zianet.com
www.geriatric-resources.com

November 21, 2003

Palliative Care: Current Trends, Issues and Innovations in End-of-Life Care, New York, NY

Contact:
Naim M. Gribaa
The Jewish Home and Hospital
Lifecare System
120 W. 106 Street
New York, NY 10025
212-870-4762
ngribaa@jhha.org
www.jewishhome.org

November 21, 2003

56th Annual Meeting of the Gerontological Society of America, San Diego, CA

Contact:

Gerontological Society of America
1030 15th Street NW, Suite 250
Washington, DC 20005
202-842-1275
Fax: 202-842-1150
geron@geron.org
www.geron.org

November 22, 2003

Creative Interventions with Alzheimer's Residents: Meeting the Challenge, Clearwater, FL

Contact:

Geriatric Resources, Inc.
PO Box 239
Radium Springs, NM 88054
800-359-0390 or 505-524-0250
Fax: 505-524-0254
GRI@zianet.com
www.geriatric-resources.com

December 4, 2003

International Conference on Aging, Disability, and Independence, Washington, DC

Contact:

American Society on Aging
833 Market Street, Suite 511
San Francisco, CA 94103-1824
415-974-9600
Fax: 415-974-0300
info@asaging.org
www.asaging.org-icadi

February 21, 2004

American Association for Geriatric Psychiatry 17th Annual Meeting, Baltimore, MD

Contact:

American Association for Geriatric Psychiatry
7910 Woodmont Avenue, Suite 1050
Bethesda, MD 20814
301-654-7850
Fax: 301-654-4137
www.aagponline.org

February 24, 2004

Restauración Neurológica 2004: Symposium on Brain Aging & AD, Havana, Cuba

Contact:

Head, Basic & Clinic Group BA&AD
CIREN
Ave 25 no. 15805, entre 158 y 160
Cubanacan
Havana City, CUBA
www.ciren.ws-rt2004-restauracion%
20Neurologica%202004.htm

April 14, 2004

2004 Joint Conference of the American Society on Aging and the National Council on the Aging, San Francisco

Contact:

ASA-NCOA Joint Conference
833 Market St, Suite 511
San Francisco, CA 94103-1824
415-974-9600
Fax: 415-495-6509
jc04@asaging.org
www.agingconference.org

May 13, 2004

Alzheimer's Disease: Update on Research, Treatment, and Care, San Diego, CA

Contact:

Sue Johnson
UC San Diego, School of Medicine
Alzheimer's Disease Research Center
858-622-5850
Fax: 858-622-1016
www.adrc.ucsd.edu-events-
up_events.html

May 20, 2004

14th Alzheimer Europe Conference
Prague, Czech Republic

Contact:

CZECH-IN
Conference organiser
Novodvorska 994
142 21 Prague 4
CZECH REPUBLIC
+ 420 239 041 661
Fax: +420 239 041 663
info@alzheimer-conference.org
www.alzheimer-conference.org

July 17, 2004

9th International Conference on Alzheimer's Disease and Related Disorders, Philadelphia, PA

Contact:

Alzheimer's Association
225 North Michigan Ave., 17th floor
Chicago, IL 60601-7633
312-335-5813
internationalconference@alz.org
www.alz.org-internationalconference

October 15-17, 2004

20th International Conference of Alzheimer's Disease International Kyoto, Japan

Contact:

Alzheimer's Association Japan
Conference Secretariat
Kyoto Social Welfare Hall
Horikawa-Marutamachi, Kamigyo-ku
Kyoto 602-8143
JAPAN
+81-75-823-6544
Fax: +81-75-823-6545
adiconference@alzheimer.or.jp
www.alzheimer.or.jp

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- Hospitalization Happens: A Guide to Hospital Visits for Your Loved Ones with Memory Disorders (booklet, Free)*
- Reflections on Memories Lost: Stories of Early Alzheimer's Disease (video, \$7.50, US Funds only, check or money order)*
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