

Advances

The Alzheimer's Association Newsletter

Published quarterly for caregivers and individuals affected by Alzheimer's disease.

Progress in Alzheimer Research and Care

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For Families with Alzheimer's, Planning for the Future Starts Now

Alzheimer's is an equal opportunity disease. It is not bound by race, ethnicity, religion, geography, gender, or age. Its devastating toll does not discriminate; it pervades the lives of those affected and everyone around them. Alzheimer's victims face many decisions and legal and medical experts agree that families should begin planning for financial, legal, and medical contingencies as soon as a diagnosis is made. No decision is more important than planning for the future.

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CATIE:

Federal Study Targets Challenging Alzheimer Symptoms

“Few things are more distressing than coping with a loved one’s irrational anger, physical aggression, or unfounded suspicions and accusations.”

For many families, the hardest time in the long Alzheimer journey comes when serious disruptions in an individual’s thinking and behavior emerge. Recognizing how deeply these symptoms affect quality of life, the U.S. National Institute of Mental Health (NIMH) launched the CATIE Alzheimer’s disease trial to investigate therapies. CATIE (Clinical Antipsychotic Trials of Intervention Effectiveness) will enroll 450 participants to compare the benefits of four different medications in treating delusions (firmly held beliefs unfounded in reality), agitation (being restless or easily upset), hallucinations (hearing or seeing things that are not actually there), and physical or verbal aggression.

The heavy burden of these symptoms, which most individuals with Alzheimer’s disease experience at some time, is documented in research and in the clinical experience of experts such as Hillel Grossman, MD, director, division of geriatric psychiatry, Mount Sinai Medical Center, New York City.

“My practice reflects very closely what the research suggests—that disruptions in behavior and distortions in thinking are far more troubling to caregivers than memory loss or the gradual decline in ability to do customary activities. Few things are more distressing than coping with a loved one’s irrational anger,

physical aggression, or unfounded suspicions and accusations,” says Grossman.

According to Lon S. Schneider, MD, professor of psychiatry, neurology, and gerontology at the University of Southern California and a principal investigator for CATIE, “The trial is the first study that will directly compare the relative benefit in Alzheimer’s disease of four drugs already approved by the U.S. Food and Drug Administration (FDA) to treat symptoms of major mental illness: olanzapine (Zyprexa®); quetiapine (Seroquel®); risperidone (Risperdal®); and citalopram (Celexa®).”

Answering Real-World Questions

“In addition to comparing effectiveness, CATIE is designed to answer such real-world questions as how long treatment should last, whether an individual who gains no benefit from one medication may respond to another, and how user-friendly these drugs are for Alzheimer families,” says Schneider.

CATIE is structured so that participants can try other medications if the first one does not help. Enrollees initially are randomly assigned to take one of the study drugs or a placebo (inactive treatment). After two weeks, those assigned to the placebo can switch to one of the active treatments if they have not improved, and enrollees who have not improved on one active drug



may switch to another. As the trial progresses, participants who improve on a study medication may stay on it, and those who do not benefit will be offered another active treatment.

Participants Share Experiences

One CATIE participant who has completed the trial is Rose, who lives in a major Northeast city in the same apartment building as her daughter Jody. After Rose's husband lost his battle with cancer in 1994, her own health declined. When Rose first developed memory problems, her family suspected depression resulting from her recent loss and her own illnesses. Her family doctor, however, diagnosed Alzheimer's.

Jody learned about CATIE from her local Alzheimer's Association chapter and decided to enroll her mother about a year ago. "We needed help. Right after her diagnosis, Mom tended to be quieter than usual. Then one day she started talking and she just didn't stop. She got very agitated and talked constantly, usually not making much sense, except when she got really angry."

Rose tried all the study medications, but side effects prevented her from continuing to take the one that helped her most. After she completed the study, the medical team put together a combination of nonstudy medications

for her. Although she continues her nonstop talking when awake, she sleeps soundly for seven hours each night and gets along well in her day care program and with her two home health aides. "We'd participate in another study in a heartbeat," says Jody.

Emily and her mother Dora, who live in the Southeast, are still enrolled in CATIE. Dora's family also suspected depression when she first developed symptoms because her best friend from high school and her oldest brother had just died. But a psychiatrist at a local memory clinic diagnosed Alzheimer's disease.

"Mother progressed very rapidly from having some memory problems to severe impairment," says Emily. "We began to consider assisted living for safety reasons and then she started having seriously paranoid thinking. Her psychiatrist suggested the CATIE trial. Her first study appointment fell on the day after she moved into assisted living."

Emily says that Dora has been on the same drug from the beginning and has done well. She is no longer paranoid, seems fairly content, and sleeps well most nights. She still experiences some delusions and misperceptions, such as thinking that she has just been out for a drive when she hasn't left the facility. But Emily and her family cope with these

situations as experts recommend. They "go with the flow" and don't attempt to correct them as long as Dora's misperceptions are harmless.

Emily echoes Jody's positive assessment of the trial and says, "We really liked not being locked into taking one drug or a placebo for the duration. Whoever designed CATIE really understood Alzheimer's and caregiving."

For more information about CATIE as well as other clinical studies:

800.272.3900 / www.alz.org
www.catie.unc.edu/home.htm

What Helps You Alleviate Caregiver Stress?

For nearly 19 years, Paula Rizzo has been dutifully caring for her best friend and mother, Iva Yarbrough, 83, through her long, painful journey with Alzheimer's disease. She has found comfort and stress relief by sharing her experiences with others.

Paula, the youngest of six children, lost her father to cancer when she was a child, and Iva worked in the school cafeteria to support her family. "She started making mistakes on the job, forgetting how to make a salad," says Paula, now 41. "Her boss sent her to the doctor, who ran many tests that confirmed she had Alzheimer's disease. The diagnosis rocked our world; few knew what Alzheimer's was back in 1984. My sobbing mother made me promise to never put her in a nursing home. I promised, and I've been taking care of her ever since."

At times, Paula thought she was going to burn out from the stress. She had difficulty eating and sleeping and didn't go out much because of the huge responsibility on her young shoulders. The Midland, Texas, resident found support early on by attending meetings of the Alzheimer's Association Greater West Texas Chapter (now the STAR Chapter). With her mother now in the advanced stages of Alzheimer's, Paula's anxiety and stress are rising. She plans to return to Alzheimer support group meetings soon.

"My biggest concern is whether I'll really be able to let go. I know it sounds crazy, but I don't know what I'll do after she dies," she writes.

"I haven't been able to live a normal life, and I may have forgotten how."

Paula's concerns are echoed by the thousands who call the Alzheimer's Association's national 1-800 Contact Center, which last May celebrated its first anniversary of providing around-the-clock concern, care, and connection to those touched by Alzheimer's disease.

Around-the-Clock Concern

"People need to get help, whether it's by calling our toll-free helpline or connecting with their local Association chapter," stresses Beth Kallmyer, LCSW, associate director, Contact Center. "We're here 24/7. Nobody should endure this devastating disease alone. Our job is to listen, provide practical suggestions, and to link callers to appropriate services."

Last year, trained Association staff fielded 157,406 calls from stressed-out care partners. Warning signs of stress include anger toward the person with the disease, social withdrawal from friends or activities that once brought pleasure, anxiety, depression, exhaustion, sleeplessness, irritability, lack of concentration, and health problems.

And high degrees of stress can kill you. Sixty-three percent of elderly stressed caregivers experience a higher mortality rate than do non-stressed

caregivers, according to a 2000 report of the *Journal of the American Medical Association*.

"Alzheimer's disease is unlike cancer, heart disease, or any major chronic illness," says Contact Center Care Consultant Mark Debus, LCSW. "It stresses people physically and emotionally as they deal with progressive, severe memory loss over seven to 10 years or longer. People call and say, 'My Mom is paranoid that I'm stealing her money,' or 'My husband shouts obscenities at me for no reason.' I remind them that these attacks are not personal. It's not their loved one, but the disease talking."

Reducing Caregiver Stress

- Call the Alzheimer's Association anytime, day or night, at 800.272.3900.
- Educate yourself about the disease and caregiving techniques at each stage of the disease's progression.
- Know what resources are available—for yourself and for your loved one.
- Seek help and support from friends and family and tap into community resources.
- Do legal and financial planning to prepare for the future.
- Give yourself credit, not guilt—it's okay to make mistakes and to sometimes lose patience.

Some *Advances* readers alleviate their caregiver stress by enrolling their loved one in adult day care, reading, gardening, singing, or having respite care for a few hours in the evening. Some, like Paula Fulco, find regular physical exercise key to relaxation.

“I started out with brisk walking, then graduated to running three or four miles a few times a week,” says Paula, who cared for her mother, Jane, for four-and-a-half years until her death last May.

More Knowledge, Less Stress

Arming herself with information about Alzheimer’s disease helped MaryLou Dunsford increase her caregiving knowledge and decrease her stress. She recommends the following books: *The 36-Hour Day* (by Nancy Mace and Peter Rabins); *A Caregiver’s Survival Guide: How to Stay Healthy When Your Loved One is Sick* (by Kay Marshall Strom); *Quiet Moments for Caregivers* (by Betty Free); and *Aging Parents: When Mom and Dad Can’t Live Alone Anymore* (by Eldon Weisheit).

And Pat Krider, of Louisville, Kentucky, finds volunteering curtails the stress of caring for her husband, a Navy career man who was “tops in his field” until Alzheimer’s disease struck.

“The man I love and married 47 years ago isn’t the one who sleeps next to me now, but we remember who he was, and try to help him be all he can be,” writes Pat, who volunteers with a community ministry and as a court

appointed special advocate working with abused or neglected children.

“I volunteer for me; I feel it’s healthier to help others, many with problems far greater than mine,” concludes Pat. “I jokingly say I will be volunteering when I die because I believe a positive attitude and helping others can keep us trying when the going is rougher than we ever envisioned.”

For More Information:
800.272.3900 / www.alz.org

Caregiver Stress: Signs to Watch for, Steps to Take (PR200Z)

Respite Care Guide: How to Find What’s Right for You (PF112Z)

Steps to Success: Decisions About Help at Home for Alzheimer’s Caregivers (published in cooperation with the American Association of Retired Persons in 2002)

First copy, free.



Have Racial and Ethnic Differences Impacted Your Care or Decision Making?

Researchers find the risk of dementia is higher among African Americans, Blacks, and Asian Americans than Caucasians. Yet studies show these populations and other under-represented minorities may be reluctant to seek a diagnosis and may delay placement in care facilities.

Everyone should have access to good dementia care and services. Individuals from diverse ethnic communities and rural areas, however, may face barriers to diagnosis, treatment, research, and care. Such barriers may include language and cultural differences, and economic inequalities.

We Want to Hear from You!

As a Black or African American, Native American, Asian American, Latino, or other underrepresented minority, have you faced challenges in getting information from your health care provider? Do your cultural traditions play a role in nursing home placement decisions? Do you participate in an Alzheimer-related clinical research trial? Please share your experiences.

Your experiences could be incorporated into a “Dialogue” article in the summer 2003 *Advances*. Please send your stories to us no later than April 3.

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Treating the Whole Person: Managing Coexisting Medical Conditions

Most people with dementia are likely to have other medical conditions. They may take medication for arthritis or diabetes. They may develop a sinus infection or a more serious long-term condition. These circumstances raise several questions for families. What should we treat? Which health care professional should we see? Is this problem serious?

Addressing these questions with one physician is the best strategy. Laura Mosqueda, MD, director of geriatrics at the University of California at Irvine College of Medicine, notes that her job as a primary care provider for an individual with dementia is to focus on the whole person, not just on the dementia or other coexisting conditions the person may have.

In most cases, the primary care provider will be a physician in family medicine, internal medicine, or geriatrics. In some communities, families may depend on a nurse practitioner or physician assistant to fulfill this role. Lisa Gwyther, MSW, director of Duke University Alzheimer's Family Support Program, recommends that families be very direct in asking a doctor if he or she is willing to be a primary care physician for a person with dementia and to be the main communicator with specialists as needed. "If your physician is not doing that for you, find another one," says Gwyther.

What are the Goals of Care?

When there is a good relationship between the primary care physician, the person with dementia, and the care partner, then all treatment decisions can begin with a single question: What are our goals of care?

A primary goal is to control pain and discomfort. But other goals need to be considered and prioritized. Is the goal to be alert, to maintain certain activities, to prolong life? The overall care goal may change over time, depending on the progression of dementia symptoms, the severity of other medical conditions, individual and family values, and care decisions made in advance by the person with dementia.

Treatment decisions also depend on assessing the problem. As dementia symptoms worsen, the care partner's role in assessment increases. Eric Tangalos, MD, an internist at the Mayo Clinic in Rochester, Minnesota, states, "The caregiver is the eyes of the physician and voice of the patient." To fulfill this dual role effectively, care partners need to learn what to look for and how to talk about what they see.

When a person has dementia, the physician's normal approach for assessing a particular complaint is hampered. Physicians are trained to take good histories and to ask the right questions of a patient in order to understand what is happening. A

physician may not know if a history is accurate if the person with dementia cannot find the right words to describe how he or she feels. Also, by the time of a doctor's appointment, the individual may not be able to recall having a particular problem.

Mosqueda advises care partners to pay particular attention to what the individual says at the time a problem occurs. If a person with dementia complains of feeling dizzy, for example, the care partner should ask for details right away when the person can provide a clearer explanation. The care partner should record this information as well as details about what time of day and how often the problem occurs.

Tuning in to Changes

Gwyther suggests the care partner ask the physician two questions when they are concerned about a particular symptom or condition: (1) What should I watch for? and (2) When should I call? Care partners should also be aware that sudden changes in behavior or dementia symptoms may be the only sign of a medical problem. For example, an older adult with pneumonia may experience confusion but have no fever or cough. The golden rule, according to Mosqueda: "Any sudden change in behavior is a medical problem until proven otherwise."

“Decisions about treating multiple conditions are often not medical questions, but family questions. We can’t look these answers up in a book.”

Weighing Diagnostic Tests with Overall Treatment Goals

In some cases, the primary care physician or a specialist may order a diagnostic test. When these are recommended, it is always appropriate to talk about these options in light of overall treatment goals. What will we do with the information from a laboratory test? Will the results change the treatment strategy? If not, is the test necessary? Will the test itself cause distress or discomfort?

Mosqueda notes that to a specialist a test may be a routine procedure that requires an overnight stay in the hospital. Her job is to consider what impact an overnight stay may have on her patient with Alzheimer’s disease and to discuss this with the family. For a person with dementia, some examinations may be more likely to result in harm than in a benefit for the patient.

Having a primary care physician who can moderate these conversations for families is, of course, ideal. However, some families will be faced with less than ideal circumstances requiring them to help manage the process involving more than one physician. Care partners should be proactive by (1) asking specialists to send all records to the primary care physician, (2) asking specialists to talk to the physician, (3) asking

for copies of all lab reports, and (4) bringing these copies to all appointments.

How Does the Treatment Affect Dementia and Quality of Life?

Subsequent treatment decisions for other medical conditions must also follow this same model of caring for the whole person. The care partner and patient should ask about the benefits and risks of pursuing a course of treatment. How do the treatment options align with our overall goals? How might the treatment affect the dementia symptoms and general quality of life?

Neurologist Victor Henderson, MD, of the University of Arkansas, often consults with families and physicians who are considering treatments for other medical conditions. The perspective he offers about the current state and probable course of dementia for a patient is often valuable in treatment decisions. Henderson says, “Decisions about treating multiple conditions are often not medical questions, but family questions. We can’t look these answers up in a book.”

The summer issue of Advances will continue this discussion with a focus on medication management.



Finding a primary care physician to serve as the main communicator with specialists is key to managing dementia and other medical conditions, such as arthritis or diabetes.

“The caregiver is the eyes of the physician and voice of the patient.”

Q:

What Is Mild Cognitive Impairment?

A:

Mild cognitive impairment (MCI) is a general term most commonly defined as a subtle but measurable memory disorder. A person with MCI experiences memory problems greater than normally expected with aging, but he or she does not show other symptoms of dementia, such as impaired judgment or reasoning.

Compared with the large body of information about Alzheimer's disease, research about MCI is still relatively small. Because scientists are still answering basic questions about this disorder, it is important to note that the definition of MCI is itself a "work in progress."

In 2001, the American Academy of Neurology (AAN) published practice guidelines for the early detection of memory problems. The AAN workgroup of specialists identified the following criteria for an MCI diagnosis:

- an individual's report of his or her own memory problems, preferably confirmed by another person
- measurable memory impairment detected with standard assessment tests
- normal general thinking and reasoning skills
- ability to perform normal daily activities

One of the current challenges in defining MCI concerns the second factor on this list. There is not yet a consensus on key questions: (1) How much memory impairment is too much to be considered

more than normal? (2) How much memory impairment is significant enough to be considered a symptom of mild dementia? (3) How hard should one look for subtle abnormalities in other areas of thinking, and how do we know if these changes are normal aging or worse?

Because researchers are still investigating these questions, other details about MCI remain unclear. For example, some research suggests that essentially all cases of MCI progress to Alzheimer's disease or another form of dementia. This would mean that MCI is simply a very early sign of dementia. Other studies suggest evidence that some people with MCI may not develop dementia, but that many are at a very high risk of developing the disorder. Still other studies indicate that people diagnosed with MCI may "revert" to normal.

Differing MCI Definitions

The differences in these conclusions are the result, at least in part, of significant inconsistencies in definitions of MCI. The different findings also point to the need for long-term studies that follow the progression of symptoms in people with differently defined MCI and studies that look at the biological changes associated with normal aging, MCI, and Alzheimer's and other dementias.

In the December 2001 issue of *Archives of Neurology*, a team of specialists

recommended further research to define subcategories of MCI. For example, a problem with language rather than memory may be considered a mild cognitive impairment that is an early sign of dementia other than Alzheimer's.

A better understanding of MCI and early detection of people with this disorder is important. If a person is diagnosed with MCI, the physician can monitor changes and prescribe appropriate drugs if changes in symptoms indicate the development of mild dementia.

A clearer picture of MCI is also relevant in efforts to prevent or delay the onset of Alzheimer's disease. Current clinical trials are testing potential preventive therapies, including vitamin E, non-steroidal anti-inflammatory drugs, and *Ginkgo biloba*. Other clinical trials are testing compounds that may interfere with key pathological changes in the Alzheimer brain. When and if these trials demonstrate a preventive benefit, our ability to identify people with MCI and those most at risk for developing dementia will be critical to early intervention.

Our consultant for this column was neurologist Steven T. DeKosky, MD, chairman of the department of neurology and director of the Alzheimer's Disease Research Center at the University of Pittsburgh. DeKosky has chaired the Alzheimer's Association Medical and Scientific Advisory Council and chairs the Clinical Issues and Interventions Work Group for the Association.

Art Therapy Helps Alzheimer Patients Paint Vivid Memories

Henry Leininger paints a simple picture of a home with a blue roof and then sketches a circle next to it. Hazel, his wife, immediately connects the images to Henry's memory of the house where they met 48 years earlier—which had a blue slate roof and stood beside a gravel pit.

A wall in Hazel's living room is covered with such visual memories from her husband, who has Alzheimer's and lives at Life Care Center in Longmont, Colorado. She draws great comfort from his paintings, particularly the one showing an owl perched on a picket fence. "At that moment," recalls Hazel, "Henry remembered that I collect owls."

Such is the power of art and the notion that art therapy can help people with Alzheimer's feel good about themselves and communicate with others. For example, researchers in England reported that half of the people with Alzheimer's who took part in a 10-week art therapy course exhibited significant improvement in their symptoms of depression.

According to the Mundelein, Illinois-based American Art Therapy Association, art therapy is the therapeutic use of art making, within a professional relationship, by people who experience illness, trauma, or challenges in living, and by people who seek personal development. While goals differ according to participants' needs as determined by therapists, the following are general benefits art therapy may provide to people with Alzheimer's:

- Encourage decision-making and independence
- Counteract social isolation
- Improve communication, social skills, motor coordination, and manual dexterity
- Improve mental alertness through problem-solving, visual memory, concentration, and imagination
- Vent emotions, providing an acceptable alternative for unacceptable behavior

The Alzheimer's Association offers the opportunity for such self-expression through art via its national *Memories in the Making* initiative, created over a decade ago in the Orange County Chapter and now existing nationwide in 22 Association chapters. As program director for *Memories in the Making*, Jean Boylan supports chapters when they begin or enhance their art therapy efforts, which are conducted at local assisted living facilities, adult day care programs, nursing homes, and senior centers. Jean, of the Rocky Mountain Chapter, credits the art therapists, the many professional artists who volunteer, and Alzheimer patients for the program's success.

"The goal is to offer an emotionally safe environment with positive messages," Jean says. "It's designed to be fun, but it's also a communication tool for families and professional care partners to learn more about their loved ones' perspective as it changes with dementia.

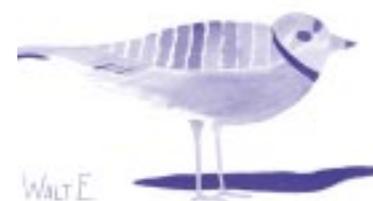
"It doesn't matter what the art is," she adds. "What matters is that Alzheimer patients are able to reach a place outside of their dementia and extract some part of who they once were and, more important, who they still are."

After the program has been running in a chapter's community for about a year, there is generally a body of work worthy of a public art show. In addition, many chapters now include a *Memories in the Making* art auction as part of annual fund-raising activities. For example, the Rocky Mountain Chapter hosts four auctions statewide that raise over \$250,000 a year.

"The power of art for the families and the participants is amazing," says Val Dean, former board member, Rocky Mountain Chapter. "It also provides an avenue for the Association to reach into the community through the media to let people know that help is available."

For More Information:

Jean.Boylan@alz.org
www.arttherapy.org



Alzheimer patient Walt created this bird painting through *Memories in the Making*.

around the association



Join Us in July at the Premier Forum in Alzheimer Care

The Alzheimer's Association is proud to host its 11th national education conference July 20–23 in Chicago, Illinois. This year's theme is Bridging Research and Care, reflecting the translation of quality research outcomes into quality care practices.

The conference features plenary speakers Dan Kuhn, MSW, who will host a panel of early-stage individuals and their families; Steven T. DeKosky, MD, who will discuss future treatments for Alzheimer's; and William H. Thomas, MD, the creator of The Eden Alternative™, will explore the role of aging in shaping human life.

For More Information www.alz.org, e-mail info@alz.org, or call 312.335.5790.

Two On-Line Resources for Caregivers and Employers

The Association worked with the Centers for Medicare & Medicaid Services (CMS) on two new on-line Medicare resources for caregivers and employers.

Medicare Basics: A Guide for Caregivers, a step-by-step guide through eight critical decision points, provides caregivers with guidance on how to make health care decisions on behalf of their loved ones.

When Employees Become Caregivers: A Manager's Workbook includes an outline of issues that affect employees, educational tips, and cost solutions for businesses.

For More Information www.medicare.gov to download a PDF

Our Address is Changing; But Not Our Mission

Effective April 28, the Alzheimer's Association's national office will be moving to 225 North Michigan Avenue, Suite 1700, Chicago, Illinois 60601. Our phone number will stay the same: 800.272.3900. Our Public Policy office will remain in the nation's capital. Phone number is 202.393.2109.

Through its 81-member chapter network and more than 250 service delivery areas, the Association's mission remains steadfast: to eliminate Alzheimer's disease through the advancement of research and to enhance care and support for individuals, their families, and care partners.

Updated Brochure on Alzheimer's Available from the NIA

The National Institute of Aging (NIA) has updated its brochure, *Alzheimer's Disease: Unraveling the Mystery*. It explains changes in the Alzheimer brain using illustrations, investigates factors in disease development, and provides information about the search for new treatments.

For more information, call Alzheimer's Disease and Education Referral Center (ADEAR) at 800.438.4380, e-mail adear@alzheimers.org, or www.alzheimers.org, to download a PDF.

in the news

Among the Best

For the second consecutive year, the Alzheimer's Association is listed among the top charities in America in an annual special report published by *Worth* magazine. In *Worth's* list of "100 Best Charities," the Association is among 13 organizations in the "Best Health Charity" category and is the only Alzheimer's disease-related charity mentioned. "Choosing among charities is never easy," said *Worth* Editor Reshma Memon Yaqub. "We are confident that the charities on this list will spend your money wisely and will do their best to change some of the grim facts of today's world that we all face."

Carol's Story

The *Washington Post Magazine's* Jan. 12 cover story featured an article by *Post* Staff Writer Michael Leahy about his mother Carol's Alzheimer's disease and the current state of research and public policy on Alzheimer's. Marilyn Albert, PhD, chair of the Association's Medical and Scientific Advisory Council, was interviewed. The number of people with Alzheimer's is expected to rise from 4 million to 14 million Americans by mid-century, financially straining businesses and Medicare and Medicaid. Albert added that federal research funding for Alzheimer's needs to be increased to \$1 billion from its current annual level of nearly \$600 million.

For Families with Alzheimer's, Planning for the Future Starts Now*continued from page 1*

Lynn Bencowitz, JD, an elder-law attorney who works on the regional advisory council for the Houston and Southeast Texas Chapter, suggests that newly diagnosed individuals and care partners immediately take the following steps:

- Seek professional counsel and obtain the necessary legal documents while there is a “window of opportunity” for the affected individual to make decisions.
- If possible, videotape the affected individual signing the documents.
- Prepare a mental health directive to ensure that if the affected individual becomes unable to rationally request medical care, the family can authorize treatment without intercession.
- Designate a legal guardian.

Peace of Mind by Planning

Jim and Linda Fisher followed this practical advice and found peace of mind. Jim, whose wife is a Mid Missouri Chapter board member, began suffering memory loss at age 49. After an MRI disclosed brain atrophy, the Fishers' doctor pointedly asked Jim, “Who do you want making your medical decisions—a stranger or your wife?” The couple wisely met with their attorney and prepared advance medical directives, wills, and durable power of attorney papers. These all proved invaluable when Linda eventually had to make decisions for Jim.

“This has been a long and painful journey for us,” says Linda, nine years into Jim's disease. “By having our plans and paperwork in order, we made the transition from Jim living

at our home to the nursing home as smooth as possible.”

Early Diagnosis Offers “Gift of Time”

Thad Raushi, PhD, a retired college counselor and board member of the Northeastern New York Chapter, was diagnosed nearly five years ago at age 57. In an article recently reprinted in the chapter newsletter, Raushi writes that an early diagnosis can be a “gift of time” for planning. Thad and his wife put this “gift” to use by selecting an experienced elder-law attorney and a financial planner. Besides helping the Raushis prepare vital legal documents, the lawyer also guided Thad through a rigorous process to obtain Social Security disability benefits—twice denied because a psychologist judged that a man of Thad's age and educational level could *not possibly* have Alzheimer's.

Ruth Bischoff, a volunteer with the Delaware Valley Chapter in Philadelphia, says that her late husband William, a former appellate judge, was “in great denial” about the difficulties he had experienced for several years before he was officially diagnosed in 1991 at age 77. With the help of William's former law partners, Ruth worked around her husband's “good” days, when he was lucid enough to discuss matters with her, make decisions, and sign documents. “Without the durable power of attorney, hospitalizing him, placing him in assisted living, or selling our house would have required incompetency hearings, which I would never have wanted to do,” she says. Ruth and William also

amended their wills to ensure care and proper management of her estate had she died first.

Alzheimer's Association chapters and regional offices nationwide offer families an array of resources to help them manage a future with Alzheimer's, including seminars on legal and financial planning, pamphlets and fact sheets, generic legal documents, and referrals to elder-law specialists. Individuals are then empowered to act on finding appropriate support services.

Thad Raushi concludes: “Instead of just floundering with frustrations and fears, I have my affairs in order and can focus on living a quality life with the disease.”

“Who do you want making your medical decisions—a stranger or your wife?”

For More Information:
800.272.3900 / www.alz.org

Steps to Understanding Legal Issues
(ED314Z)

Steps to Understanding Financial Issues—Caregivers (ED315Z)

Steps to Understanding Financial Issues—Individuals with Alzheimer's (ED316Z)

First copy, free.

Rx corner

To obtain Alzheimer's Association fact sheets about memantine or hormone replacement therapy, please call our Contact Center at 800.272.3900, or visit our Web site at www.alz.org.

Memantine: On December 20, 2002, Forest Laboratories, Inc., announced submission of its New Drug Application for memantine to the U.S. Food and Drug Administration (FDA). Memantine is an investigational drug with a different pharmacological action than the drugs currently approved to treat Alzheimer symptoms. The New Drug Application, which includes all the data gained from clinical trials testing memantine's safety and effectiveness, is Forest's formal request that the FDA consider approving memantine for moderate to severe Alzheimer's disease. Memantine has been approved in Germany for about 10 years and won approval for treatment of moderate to severe Alzheimer's in the rest of the European Union in May 2002. Forest announced on January 30, 2003, that the FDA had finished an initial review of the application and accepted it for filing. The FDA now has 10 months to complete its review and decide whether memantine should be approved.

Estrogen: Several trials investigating the possibility that estrogen may help prevent or delay Alzheimer's disease remain ongoing, although some recent studies of estrogen's other health benefits have yielded disappointing results. A new Association fact sheet summarizes the latest data about possible risks and benefits of hormone replacement therapy.



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