



PATHWAYS

Moving Toward a Cure

Spring 2008

Choosing to Care for Alzheimer's Patients at Home

By Thomas Baumgartner Jr.,
MPH, MSW, LSW

The decision to care for patients with Alzheimer's disease (AD) in the home is influenced by various factors. Some caregivers report feeling guilty when thinking about placing a family member in an assisted living or nursing facility. Reasons may include the belief that they are abandoning their loved one in an unfamiliar environment or breaking a promise to keep the patient in the comfort and safety of his or her own home. Cost is another factor that may make a placement in a care facility a less viable option. A caregiver's life savings may become rapidly depleted if the monthly cost for an assisted living or nursing facility is several thousand dollars.

The type of in-home care needed for AD patients varies depending on their level of impairment. There may be little need for in-home services for more mildly impaired individuals. However, as the disease progresses, caregivers may require additional support in caring for their loved ones. Following are several recommendations as to where caregivers

may find services to help care for patients with AD or other types of dementia in the home.

For those living in the Pittsburgh area, the Allegheny County Area Agency on Aging (AAA) is one option that caregivers may wish to consider when pursuing in-home assistance. The agency's services include care management, home-delivered meals, adult day care services, home health aides, personal care, and respite care. By contacting AAA, caregivers also may learn more about the Pennsylvania Department of Aging (PDA) Waiver program or the Long-Term Care Capitated Assistance Program. Both share the common goal of helping elderly Pennsylvanians to remain in their own homes rather than being placed in care facilities. Each program has various criteria for eligibility. To learn more about these criteria or other AAA services, please call 412-350-5460 or 1-800-344-4319. Those living outside Allegheny County should contact their county's local agency on aging to determine whether it offers services comparable to those of AAA.

Lastly, caregivers may need to seek periods of respite from their caregiving obligations. In addition to the services mentioned above, caregivers in Allegheny County may want to contact the Allegheny County Respite Care Coalition, whose mission is to provide caregivers with access to respite services. Interested individuals may call 1-800-876-7607 to obtain more information.

To learn more about caregiving resources in the Pittsburgh area, contact Thomas Baumgartner Jr. at 412-692-2716 or baumgartnertc@upmc.edu.

Klunk and Mathis Win Prestigious Award

The Alzheimer Disease Research Center (ADRC) is pleased to announce that two University of Pittsburgh researchers—William Klunk, MD, PhD, and Chet Mathis, PhD—received the 2008 Potamkin Prize for Research in Pick's, Alzheimer's and Related Diseases at the annual meeting of the American Academy of Neurology in Chicago, Ill., on April 16.

Klunk and Mathis received the Potamkin Prize in recognition of their development of the amyloid plaque imaging compound Pittsburgh Compound B (PIB), which enables the visualization of amyloid plaques in the brains of living humans, a long-sought goal. Such methodology, when available for wide use, will enable more accurate diagnosis and also will be used to follow individuals to determine if anti-amyloid medications are effective in removing amyloid from the brain or in slowing its accumulation.

Klunk and Mathis spent more than eight years developing the compound and published their initial results in *Annals of Neurology* in 2004. It was collaborators in Sweden who nicknamed the ligand Pittsburgh Compound B; there also was a Pittsburgh Compound A, but PIB worked better.

In 1988, the Potamkin Foundation established the award, in honor and memory of Luba Potamkin, to be given to researchers who have made outstanding



William Klunk (left) and Chet Mathis

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Message from the Director



Steven T. DeKosky, MD

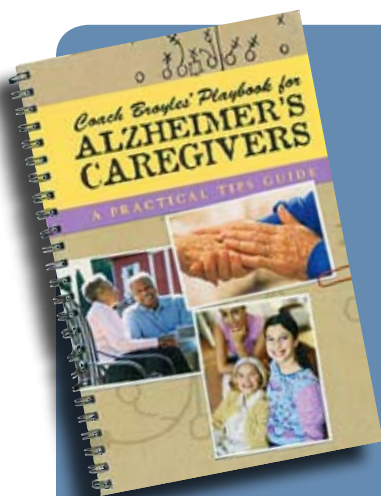
While many theories about the origin and pathological changes in the brain in Alzheimer's disease (AD) are discussed and studied by researchers, alterations in a protein called amyloid precursor protein (APP) are the most widely known and accepted by the greatest number of researchers around the world. Much research has gone into trying to identify ways to stop the altered metabolism of APP, which results in a small protein fragment called beta amyloid. Beta amyloid is toxic to the brain in large amounts; when it binds to itself and forms fibrils, it develops into amyloid plaques that are the hallmark of AD in the brain. Through mechanisms that still are not clearly determined, it appears that the pathological amyloid also induces changes in a normal structural protein in nerve cells called tau. Biochemical alterations to tau result in neurofibrillary tangles—the other protein abnormality, besides plaques, present in every brain afflicted with AD.

Because of the importance of amyloid, there are many drugs that have been directed toward trying to slow its synthesis or speed removal of beta amyloid from the brain before it can form harmful

plaques. A number of such drugs are in development, including one medication called Alzhemed. To the disappointment of many, the first of two clinical trials of Alzhemed (one in the United States and Canada and the other in Europe) did not show an advantage to the medication. The company subsequently halted its trial in Europe and has decided to focus on nutraceuticals as its next step.

A number of results from other studies conducted with anti-amyloid drugs are to be reported at the International Conference on Alzheimer's Disease this summer. One study involves MPC-7869, a drug from Myriad Pharmaceuticals, Inc. This drug affects the amyloid protein in such a way as to make a protein fragment that is smaller than the usual size of one formed in AD. The fragment formed is less sticky and less toxic, is more easily removed from the brain, and does not form plaques. It is hoped that, by shifting the metabolism of amyloid to this benign peptide (protein fragment), the pathological changes of AD can be slowed. We look forward to sharing the results of the studies in an upcoming issue of *Pathways*.

If you have any questions about U.S. Food and Drug Administration-approved experimental drug trials for AD at Pitt's ADRC, please call MaryAnn Oakley at 412-692-2721. As always, the experts at the ADRC are happy to try to answer any questions you may have about the research field or care of your family member.



Free Guide

Tackle the challenges of caregiving with *Coach Broyles' Playbook for Alzheimer's Caregivers: A Practical Tips Guide*, a free football-style playbook by Frank Broyles, former athletic director of the University of Arkansas Razorbacks. Broyles cared for his late wife Barbara, who had Alzheimer's disease, and the book is his personal perspective on caregiving.

To receive your free copy, call 479-313-5079, order it online at www.alz.org, or download it online at www.alzheimersplaybook.com.

Early Onset Alzheimer's Support Group Now Available

The Pittsburgh office of the Greater Pennsylvania Chapter of the Alzheimer's Association is happy to offer a new support group specifically for people who have been diagnosed with early onset Alzheimer's disease (age 65 or younger).

If you, or loved ones, or a friend are interested in joining this support group or would like more information, please call Lois Lutz at the Alzheimer's Association Pittsburgh office at 412-261-5040.

The Greater Pennsylvania Chapter of the Alzheimer's Association has more than 160 support groups in the 59 counties of its service area. Most of these groups aim to educate and help caregivers who have family members or friends with Alzheimer's disease.



The Alzheimer's Association 24-hour helpline

provides reliable information and support to all who need it. Call the toll-free hotline anytime, day or night, at

1-800-272-3900.

alzheimer's  association®

Alzheimer's Disease Cooperative Study

The Alzheimer's Disease Cooperative Study (ADCS) was formed in 1991. Set up as a cooperative agreement between the National Institute on Aging and Alzheimer disease research centers, with coordination by the University of California, San Diego, ADCS was developed in response to the need to advance research in the development of drugs that might be useful for patients with Alzheimer's disease (AD), particularly drugs that might not be developed by industry because they were generic, had a short patent life, or had been developed by a small pharmaceutical or biotechnology company.

As such, the mandate of ADCS is to:

- develop trials for promising agents designed to ameliorate behavioral symptoms, improve cognition, slow the rate of decline, or delay the appearance of AD;
- develop surveys and other measurement instruments for use in clinical trials, including cognitive, behavioral, and other efficacy measures;
- expand the range of patients studied in AD trials;
- enhance the recruitment of minority groups into AD trials; and
- develop novel and innovative approaches to the design and analysis of AD clinical trials.

Since its inception, ADCS has initiated 21 protocols (18 drug trials and three assessment tools). These protocols have each enrolled between eight and 790 subjects and have ranged from Phase I to Phase III studies. The University of Pittsburgh ADRC was a charter clinical site of ADCS in 1991 and maintains an active partnership with it. Pitt's ADRC participates in many new ADCS clinical trials. More information about ADCS can be found at adcs.ucsd.edu.

Lingler Awarded Brookdale Fellowship

Jennifer Lingler, PhD, CRNP, of the Alzheimer Disease Research Center Education and Information Core, has been awarded a Brookdale Leadership in Aging Fellowship by the Brookdale Foundation. The fellowship is a highly competitive national award given to emerging leaders in the field of research on aging.



Lingler's research focuses on the role that family caregivers play in mediating communication between people with Alzheimer's disease and their health care providers. She will use the award to develop an intervention that teaches family caregivers how to maximize their effectiveness when communicating with health care providers.

Planning Your Gift to the Alzheimer Disease Research Center

James Olsen, major gifts officer at the University of Pittsburgh and UPMC Medical and Health Sciences Foundation, answers your questions about planned gifts.

Q. What is a planned gift?

A. The term "planned gift" can be misleading, as it implies that all other gifts are unplanned, which is not true. The term generally refers to any gift that requires the assistance of a professional or trained volunteer. Perhaps we should refer to them as professionally planned gifts.

Q. What is a bequest?

A. A charitable bequest, the most common type of planned gift, is a distribution from your estate to a charitable organization through your last will and testament.

Q. I am not a wealthy person. Do I have an estate?

A. Yes. Your estate is the sum of all that you own, including property, insurance policies, retirement accounts, and cash. Wealthy people have larger estates, but almost everyone has the resources to make a charitable bequest. If every adult in America made a charitable bequest of just \$100, charities would receive billions of dollars in additional funds every year.

Q. How can I learn more?

A. I welcome the chance to visit with you about planned gift opportunities that would benefit the Alzheimer Disease Research Center. Please call me at 412-647-7781 or send me an e-mail at ojim@pmhsf.org.



In Memoriam



The University of Pittsburgh Alzheimer Disease Research Center thanks the following individuals and companies for their generous donations received July 1, 2007–January 31, 2008.

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*Bernard & Ethel Lazar Alzheimer
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Bernice Friedland

Your contributions are greatly appreciated and help to support research and education in the area of Alzheimer's disease. You can remember or honor a loved one by using the envelope enclosed in this newsletter to send in your donation.

Klunk and Mathis Win Prestigious Award

(Continued from page 1)

contributions to the understanding of Alzheimer's disease and related dementias. Over the years, this award has been given to some of the most outstanding scientists in the field and has become known as the "Nobel Prize of neurology."

Please join the ADRC in congratulating these gentlemen for the superb research they have done, and continue to do, to support the mission of the ADRC.

Topics at Noon Series

Thursday, May 1, 2008

Noon-1 p.m.

Classroom B

4 West UPMC Montefiore

200 Lothrop Street

Pittsburgh, PA 15213

"The Future of Therapy in
Alzheimer's Disease"

Steven T. DeKosky, MD
Professor and Chair, Department
of Neurology
Director, Alzheimer Disease
Research Center
University of Pittsburgh

*Light refreshments will be served.
Registration is not required. For more
information, call 412-692-2700.*

Jay L. Foster Memorial Lecture Series in Alzheimer's Disease

Friday, May 16, 2008, 1-2 p.m.

**Rodef Shalom Congregation
4905 Fifth Avenue**

"'We Need to Do Something': Family
Decisions in Alzheimer's Disease"

Lisa P. Gwyther, MSW
Associate Clinical Professor
Department of Psychiatry and
Behavioral Sciences
Duke University School of Medicine

ADRC Mission

The overall objective of the ADRC is to study the pathophysiology (changes in the brain) of Alzheimer's disease (AD) with the aim of improving the reliability of diagnosis of AD and developing effective treatment strategies. The ADRC is funded by the National Institute on Aging and, as part of its research program, provides a comprehensive outpatient evaluation, including medical, neurological, psychiatric, social, and cognitive assessments. A major focus of the ADRC is a commitment by individuals to participate in additional ADRC research studies. Individuals enrolled at the ADRC are encouraged to participate in additional studies in order to be followed by the center.

Volunteers Needed for Clinical Trials

Pittsburgh Compound B (PIB)

Description

This study will use PET imaging to determine how amyloid changes across stages of severity in Alzheimer's disease (AD) and whether amyloid is present in elderly individuals without memory problems.

Study Length

Varies

Study Requirements

- 30 years of age or older
- Healthy individuals or diagnosis of probable AD or
- Diagnosis of mild cognitive impairment

Compensation

Up to \$200 per year

Tolcapone COMT - Inhibition and Cognitive Enhancement in AD

Description

In this 6-week study, we will test whether a drug called tolcapone can improve the attention and memory of patients with mild to moderate Alzheimer's disease. Participants will undergo repeated cognitive and behavioral testing and have blood analysis to determine tolerability.

Study Length

Six weeks

Study Requirements

- 50–90 years of age
- Diagnosis of probable AD
- Have a reliable study partner

Optional Phase

Patients may continue to take tolcapone following study termination.

Glaucoma Study

Description

Glaucoma is an eye disease that leads to loss of vision. Previous studies have shown a risk of peripheral (side) and central vision problems in patients with Alzheimer's disease (AD). This study aims to investigate the structures inside the eye that are involved with peripheral and central vision problems in patients with AD to identify any possible links to glaucoma. Studying this disease and noting the prevalence of glaucoma in AD populations could shed some light on the mechanism and possible treatment modalities for glaucoma.

Study Length

One 60-minute visit (approximate)

Study Requirements

- 60 years of age or older
- Diagnosis of AD

For information about the PIB study, contact Claire McConaha at 412-692-2727 or cwm15@pitt.edu; and for the Tolcapone COMT study, contact Patricia A. Wilkosz, MD, PhD, at 412-692-2700 or pawst19@pitt.edu; and for the Glaucoma study, contact MaryAnn Oakley at 412-692-2721 or oakleym@upmc.edu.

Volunteer Studies for Caregivers

Making Sense of MCI: Patient and Family Perspectives

Description

The purpose of this study is to learn how those diagnosed with mild cognitive impairment (MCI) and their family members make sense of—or come to terms with—their symptoms and diagnosis.

Study Length

A one-time interview lasting approximately 45 minutes

Study Requirements

Diagnosis of MCI and a family member willing to answer questions about the individual with MCI

CEAD Project: Characterizing the Experience of Alzheimer's Disease

Description

The purpose of this research study is to learn more about suffering in patients with Alzheimer's disease and related dementias (ADRD) and the impact of patient suffering on family caregivers. The study uses one-on-one interviews with people who have ADRD and their family members.

Study Length

Initial interviews and follow-up interviews one year later

Study Requirements

Spouse, partner, or family member of an individual diagnosed with Alzheimer's disease or a related dementia

Self-Management and Resource Training (SMART) Study

Description

This study is designed to determine if a self-management (educational) program strengthens the personal resources (physical and/or mental) of men and women living with a family member who has cognitive impairment (MCI or dementia).

Study Length

13 months

Study Requirements

Spouse or living partner of an individual diagnosed with mild cognitive impairment (MCI), Alzheimer's disease, or a related dementia

(See article on the next page.)

The SMART Study for Family Caregivers

Studies show that it is stressful to provide care to a loved one with memory and thinking problems. It also can have a negative effect on the caregiver's health, leading to depression, anxiety, and general medical illness. This point was conveyed in an article in the fall 2007 issue of *Pathways*, in which family care managers or caregivers of people with Alzheimer's disease were described as "the forgotten patients."

Because family caregivers are at increased risk for a variety of health concerns, Linda Garand, PhD, assistant professor at the University of Pittsburgh School of Nursing, is conducting a study to learn if a self-management (educational) program strengthens the personal resources (physical and/or mental health) of family caregivers of people with mild cognitive impairment or a new diagnosis of dementia, such as Alzheimer's disease. Specifically, she is interested in learning more about the types and amounts of homemaking and personal care tasks with which caregivers assist family members, how these responsibilities affect the caregivers' general well-being, and if a self-management program has a positive effect on the family caregivers' physical and/or mental health.

This information is important because very little is known about what it is like to live with a family member with mild memory or thinking problems and whether an educational program will help family caregivers to stay healthy.

Family caregivers who take part in the Self-Management and Resource Training (SMART) study are interviewed in their home (or another convenient location) several times throughout a one-year period after they participate in several in-home and telephone-based educational sessions. While the self-management program is designed specifically for family caregivers of people with mild memory or thinking problems, the family member with memory problems will not be excluded from any of the training sessions.

If you want to learn more about Dr. Garand's study, please contact MaryAnn Oakley at 412-692-2721.

Staff Spotlight

Neuropsychology Program Coordinator

Beth Sarles, MPH

Beth Sarles feels that the most rewarding part of her job is seeing the positive, lasting impact that her work can have on people's lives.

Sarles has worked at the Alzheimer Disease Research Center (ADRC) for six years. Currently, she is the coordinator of the Neuropsychology Program.

Sarles coordinates daily with the center's other neuropsychometrists, supervises new ADRC neuropsychometrists, conducts cognitive testing, and helps to implement the center's community outreach and education initiatives. In addition, Sarles manages a new study of an experimental drug that is being tested in people with Alzheimer's disease.

Previously, Sarles worked at Highmark Blue Cross Blue Shield in the outpatient managed behavioral care unit. At the time, the unit was responsible for reviewing and approving outpatient counseling and psychiatric medication management for Highmark members. This work first introduced Sarles to the fields of psychology and psychiatry and enticed her to explore further the opportunities within them. She also worked at UPMC, where she conducted home interviews for a research study, and at WQED Multimedia as a grants researcher.

Sarles earned a bachelor's degree in psychology from the University of Pittsburgh in 2001 and an MPH from Pitt's Graduate School of Public Health in 2007.

Outside the office, Sarles enjoys reading; taking photographs; listening to music; watching movies; traveling; and spending time with family, friends, and her two cats.





University of Pittsburgh

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Ask the Medical Professional

Donna Simpson, CRNP, MPH

Q. How does the Alzheimer Disease Research Center interact with my doctor or primary care physician?

A. The clinical component of the Alzheimer Disease Research Center (ADRC) includes an evaluation for individuals experiencing memory impairment. Accurate diagnoses are established through an interdisciplinary approach, with evaluations by professionals in neurology, psychiatry, neuropsychology, medicine, and social work. There is a significant benefit to be obtained from the accurate diagnosis of Alzheimer's disease (AD) or other specific dementia. Infrequently, other illnesses are discovered through this process.

Throughout the course of their participation at the ADRC, individuals continue to obtain their medical care from the primary health care provider of their choice. The staff members at the ADRC coordinate care with physicians and other providers managing participants' health care. The ADRC also has provisions for communicating medical information to health care providers and making referrals to professionals in the community and/or at the University of Pittsburgh. Participants, their families, and health care providers are always welcome to contact the ADRC for information regarding a specific individual's care (with appropriate privacy rights observed) or for general inquiries.

The ADRC would like to answer your questions about issues regarding AD and related dementias. You may e-mail your questions to oakley@m@upmc.edu. Please specify that it is an Ask the Medical Professional question. One or two questions will be chosen and answered in each edition of Pathways.

