

InSight Light offers quick-reading features related to Alzheimer's disease and healthy brain aging, and efforts to bring the vital knowledge we seek in those areas ever closer *in sight*.

# inSight *light*

Fall 2009

## Alzheimer's Disease and Dementia — What's the difference?



**Overheard at lunch:**  
*"Does Jen's mom have Alzheimer's, or is it dementia?"*

**T**

hat question reflects a common misunderstanding about what Alzheimer's disease and dementia are, and aren't. Here's a quick review of the facts.

"Dementia" means progressive and debilitating loss of cognitive capabilities, including thinking, reasoning, and memory. Far beyond "forgetful," dementia describes a collection of cognitive problems that significantly impair a person's ability to carry out normal daily activities.

Many different problems can cause dementia, including head trauma, vascular disease, stroke, alcohol or drug abuse, frontotemporal disorders, Parkinson's, or HIV/Aids. But in the United States, Alzheimer's disease

About **70%** of cases of dementia in older people in the US are caused by **ALZHEIMER'S DISEASE.**

About **30%** of cases of dementia in older people in the US have **OTHER CAUSES**, which may include head trauma, stroke, vascular problems, frontotemporal disorders, Parkinson's disease, or HIV/Aids.

**WHAT CAUSES DEMENTIA?**

is by far the most common cause. Here, the vast majority of cases of dementia in older people — more than 70% of cases by most estimates — result from Alzheimer's disease.

So, the question is not whether Jen's mother has Alzheimer's disease *or* dementia. If a progressive loss of cognitive abilities makes it difficult for her to perform day-to-day functions, she has dementia. The question is, does her dementia result from Alzheimer's — the most likely cause among persons over age 65 in the US, or from another condition or disease?

Specific types of brain imaging, laboratory, and cognitive testing would be used to make a diagnosis.

### I · N · S · I · D · E

Today, as many as 30 million people across the US and in 14 foreign countries read a story about **Alzheimer's disease** in their newspaper this morning.



And they'll do the same thing tomorrow morning, and the next day, and for many weeks to come, as the story they're following unfolds.

For some of these people, this story *may be the only thing they've ever read about Alzheimer's.*

Want to see what's got their attention? Pick up almost any major newspaper. Ignore the World News and Local News sections. Skip Science and Health.

Go directly to the comics

### A · L · S · O



● Studies, Outreach and Honors, More

# Comic strips

today cover topics far edgier than in yesteryear. Still, I was surprised — and gratified — that morning this summer when I opened the *Philadelphia Inquirer* to the funnies and saw “Alzheimer’s” in one of the page’s longest running, most widely syndicated features, *Rex Morgan, M.D.*

**M**uch of my work for the Penn Memory Center is about making people aware of issues related to this disease, a growing public health catastrophe that many of us just want to ignore. So any time and any way Alzheimer’s disease is brought to the attention of the public, I’m for it.

Days later, when I realized that Alzheimer’s was key in the unfolding story, I wrote to the strip’s author, Woody Wilson. I thanked him for covering the topic, asked if he’d consider an interview for this

**Q: Why did you decide to bring Alzheimer’s into Rex Morgan’s world? Do you have personal experience with the disease?**

**WW:** We routinely go at tough issues in the strip. And beyond that, my mother-in-law, Mae, has Alzheimer’s. She was widowed and living on her own, but several years ago, she began to have problems with day-to-day things. She was forgetting. She had trouble keeping up with her bowling league and other interests. But it was the driving that really tipped us off. A couple of times she headed out on a routine trip and ended up in the sticks, in the Arizona desert. She gave her bank account number to a telephone scam artist. My wife, Carol, who is also my editor, especially worked hard for years to help her stay as inde-



photo: Carol Edwards

Big response to AD storyline, says strip’s author

newsletter, and offered him a DVD of the Emmy-award winning documentary on PBS which I co-wrote and -produced, entitled *Alzheimer’s Disease: Facing the Facts*, for his research.

I grew even more gratified when he wrote back, saying he’d watched our “superbly done” show on PBS in preparing to cover this topic; and that he would be happy to do an interview to share some background on the genesis of this storyline with our readers.

And so here it is.

pendent as she wanted to be, but it wasn’t effective anymore. Three years ago, with Mae fighting it all the way, we moved her to an independent living facility. She kept losing ground. About nine months ago, she entered a memory care unit.

**Q: Alzheimer’s is a real change from the last topic, illegal immigration, where Rex, his wife, and daughter take a cruise and find a child stow-away.**

**WW:** Well, it was time to get off that ship! And if you’re looking for compelling health and social issues, which are what we cover, it’s hard to find one that will have more impact on more people in the very near future than Alzheimer’s. Researching the topic, I was stunned to learn what this disease costs, keeping people in nursing



An early segment from the Alzheimer’s storyline in *Rex Morgan, M.D.*

Courtesy King Features Syndicate ©2009

homes or families losing work to take care of a parent. And it's frightening to realize how many baby boomers are projected to get it. It's like a tragedy time bomb.

**Q:** In the strip, Becka, a nurse, takes a temporary job on a memory unit. She's met uninterested staff, patients who fall in love and run away, and a son who faithfully visits the mother who no longer recognizes him. What's next?

**WW:** Bits and pieces of our experience on the memory unit do figure in. But it's really an Alzheimer's love story. Not just about the two patients who believe they are each other's spouse, but about learning how to love someone who has Alzheimer's in ways they can still appreciate.



Woody Wilson,  
author,  
*Rex Morgan, M.D.*

Bits and pieces of our experiences at the memory unit are in the storyline. **But it's really an Alzheimer's love story.** Not just about the two patients who believe they are each other's spouse, but about learning to love someone with Alzheimer's in ways they can still appreciate.

**Q:** How did you come to these insights?

**WW:** Early on, my response to my mother-in-law's problems was to try to 'fix' them. A man's first response is usually to try to fix it. I tried 'talking sense' to her, having her "see reason." Nothing improved, of course. And my response to my wife as she dealt with those problems was not the support she needed.

On a fishing trip, I shared my frustration with a friend who is a former dean of the University of Tennessee Health Sciences Center College of Nursing. He suggested *Playbook for Alzheimer's Caregivers, a Practical Tips Guide*, by retired Arkansas football coach Frank Broyles.\* It's a little gem of a book, particularly for men. You learn there's no 'fixing' the problems of Alzheimer's. But if you love someone with Alzheimer's, or someone who cares for a person with the disease, you can learn to be patient and loving in ways each of them will best respond to.

**Q:** You write *Rex Morgan, M.D.*, and another strip, *Judge Parker*, and work with artists who draw them?

**WW:** Yes. My two strips have the best artists in the business. Graham Nolan came to *Rex Morgan* in 1982. I'm assured that what I write will appear the way I envision it. In this story, for instance, look at the character Henry, who'd been a golf pro. The de-

termination on his face when he was figuring out how to escape from the locked courtyard. Graham drew that guy just perfectly.

**Q:** Some scenes reminded me so much of the Alzheimer's unit where my mother was for three years before she died, and how sad I often felt there, I cried looking at them. Tough stuff for the "funnies." What reactions have you had to the segments so far?

**WW:** We've received quite a lot of mail already, heartrending stories, many from people telling us how this disease stole their parents. Those are tragic to read. And we've heard from a few nursing homes complaining about our depictions of some staff watching TV rather than attending to resi-

dents. But most people who write are telling us we're right on, and to keep at it. The story is the good and bad of what I've seen, and what those in the field know can happen, even in the best places. We don't do 'painless dentistry' in our stories. I write it the way it is.

**Q:** *Rex Morgan, M.D.* reaches 30 million readers in the US and 14 foreign countries. There are documented cases of people diagnosing illnesses from info in the strip. It's been used to teach at Harvard. Do you have particular hopes for the impact of this storyline about Alzheimer's?

**WW:** We cover issues, but we're still a story about characters. But by involving our characters in those issues, we build awareness. Our strips on epilepsy, pediatric asthma, and others were used in various national educational campaigns.

I hope that happens with this storyline. I want to show how Alzheimer's affects the people who have it, and those who care about them, and what we're *all* in for if the predictions hold up about how many people will eventually get this disease. Plus, I want people to know there's solid data out there about what you can do to cut your chances of getting Alzheimer's. That kind of information isn't getting the attention it deserves.



## Outreach, Appearances, Achievements & Honors



### Emmy Award

**In** May, *Alzheimer's Disease: Facing the Facts* received the Emmy® for Documentary Program at the Boston/New England awards ceremony of the National Academy of Television Arts & Sciences. The film was previously awarded a CINE-Golden Eagle.

Carol Edwards is the Executive Producer of the film, which she co-wrote and -produced with long time colleague Glenn Orkin of Motion, Inc. Narrated by Emmy and Tony award-winning actor Edward Herrmann, the arresting one-hour documentary, still airing on PBS affiliates nationwide, features appearances by Dr. John Trojanowski and other prominent AD researchers from Penn and across the country. Penn Memory Center research participants and families also appear.

- See clips and learn more at [www.alzheimersfacingthefacts.org](http://www.alzheimersfacingthefacts.org)



photo: Glenn Schreiber



Glenn Orkin and Carol Edwards, co-writers and producers of *Alzheimer's Disease: Facing the Facts*, and Dr. John Trojanowski at the ceremony where the film was honored with the 2009 Emmy Award for Documentary Program.



### Trojanowski, Lee honored in Japan



photo: claudmey | sxc

In June, Drs. John Trojanowski and Virginia Lee were honored at the 50th Anniversary and Annual Meeting of the Japanese Society of Neuropathy. Dr.

Trojanowski gave the keynote talk, "Pathological TDP-43 defines a novel class of Neurodegenerative Disorders." They also lectured on ADNI, AD biomarkers, and tau-focused Alzheimer drug discovery at related events in Tokyo, Kyoto, and Osaka.

### Research Collaboration in Puerto Rico



photo: coopgreg, for sxc

Dr. Steven Arnold, Penn Memory Center Director, Latino outreach coordinator Mirna Negròn, and Research Coordinator Jessica Nunez-López traveled to Puerto Rico

in June, to strengthen our collaboration with Alzheimer's researchers there, and to explore establishment of recruitment efforts for clinical and biomarker research. The team also toured a hospital's Neuroscience Institute and met local physicians. Dr. Arnold spoke on "Ethno-racial aspects of Alzheimer's Disease" at a large public meeting of the San Juan Alzheimer's Association.

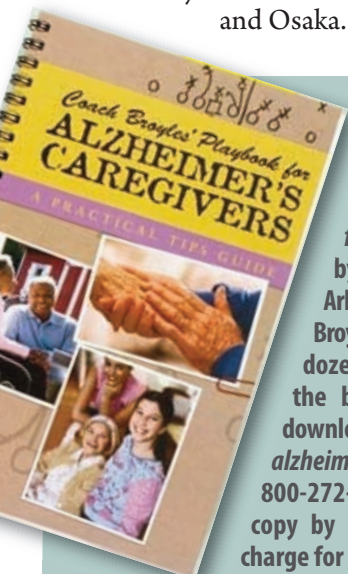
### Lecture at University of Pittsburgh



photo: xptakis | sxc

In June, Dr. Jason Karlawish spoke at the 2009 Jay L. Foster Memorial Lecture on "The Making and Un-making of Alzheimer's Disease," covering the chal-

lenges facing society, patients, and families about treatment and quality of life. The talk was sponsored by the University of Pittsburgh's Graduate School of Public Health.



\* The "little gem of a book" Woody Wilson found helpful, *Playbook for Alzheimer's Caregivers*, by retired University of Arkansas football coach Frank Broyles, is available in over a dozen languages. You can see the book page-by-page and download a free .pdf at [www.alzheimersplaybook.com](http://www.alzheimersplaybook.com). Or call 800-272-3900 to order a print copy by mail (there is a \$9.00 charge for shipping and handling).

## Two views on antipsychotic Dementia treatment



photo: personalfx | sxc

Dr. Jason Karlawish was quoted in a *Philadelphia Inquirer* story, “Elderly Patients Boost Sales of Dangerous Antipsychotics,” (7/9/09) by Miriam Hill. She reports on two

women, Kathy Wiggins, a PMC patient, and Helen Marciniszyn, who used powerful antipsychotic medication with extremely different results: Mrs. Wiggins’ husband, Bill, believes the medicine saved his wife. Mrs. Marciniszyn’s daughter, Helen, believes the medication contributed to her mother’s death.

● [www.philly.com/philly/news/homepage/50111882](http://www.philly.com/philly/news/homepage/50111882)

## International Conference on Alzheimer’s



Virginia M.-Y. Lee, Ph.D., MBA, Director of the Center for Neurodegenerative Disease Research, was honored with the Khalid Iqbal Lifetime Achievement Award at the International Conference on Alzheimer’s Disease (ICAD) in

July in Vienna, Austria. Drs. Chris Clark and Jason Karlawish also spoke there. Dr. Karlawish’s talks focused on economic and social burdens of Alzheimer’s worldwide, and attitudes on MCI. Dr. Clark spoke on findings from a PET imaging study of relationships between amyloid levels and cognitive performance.

● more information on ICAD at [www.alz.org](http://www.alz.org)

## Did You Miss this in the News?

### “Alzheimer’s Breakthrough” in Washington

In July, US Senator Barbara Mikulski (D-MD) and 28 co-sponsors introduced SB 1492. Known as “The Alzheimer’s Breakthrough Act of 2009.” It would double National Institute of Health spending on Alzheimer’s research, and fund other initiatives supporting healthy brain aging, early diagnosis, and caregiving. Read about the bill at

● [www.govtrack.us/congress/bill.xpd?bill=s111-1492](http://www.govtrack.us/congress/bill.xpd?bill=s111-1492)

The Alzheimer’s Association offers a web site where you may petition your legislators to support the bill.

● [www.thepetitionsite.com/takeaction/691214949](http://www.thepetitionsite.com/takeaction/691214949)



## Treating Dementia: Do We Have A Pill For It?

Dr. Jason Karlawish co-edited the recently released book, *Treating Dementia: Do We Have A Pill for It?*, from Johns Hopkins University Press.

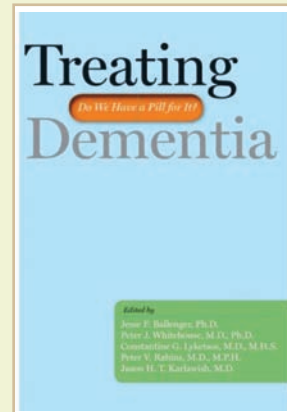
An excerpt from the book jacket reads, “Treatments for age-related dementia and the growing reliance on pharmaceuticals to alleviate its worst symptoms raise a number of questions about attitudes toward aging and cognition, the relationship between growing older and getting sick, and the conflicting interests of patients, caregivers, physicians, and

scientists and business. This volume aims to foster a constructive debate about the future of dementia treatment by providing multiple perspectives on these

tangled issues” from noted clinicians, researchers, and scholars from a broad range of disciplines.

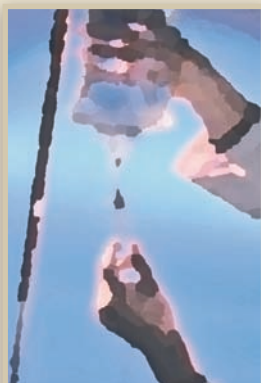
Dr. Karlawish added, “Alzheimer’s disease is as real as the Earth we live on. I have patients who repeat the same question over and over and cannot manage their checkbook. But the way we talk about the disease is in flux. We are transforming it from a set of symptoms, such as memory loss, into a risk of future decline, a risk we will measure using a variety of ‘biomarkers.’ As we do, we are changing the contours that divide the normal from the abnormal, and the ways we decide a treatment is beneficial and worth its costs and risks. It’s a provocative and accessible book that helps to make sense of our collective futures.”

● more at [www.amazon.com/Treating-Dementia-Do-We-Have-A-Pill](http://www.amazon.com/Treating-Dementia-Do-We-Have-A-Pill)



# OPEN

## Investigational drug trials are important offerings of the Penn Memory Center



INFUSION STUDIES

### ● ELAN Also called the "ICARA" study

#### Overview

This Phase III, double blind, placebo controlled randomized study tests safety and effectiveness of Bapineuzumab, a humanized monoclonal antibody, in slowing the progression of Alzheimer's disease. Bapineuzumab is designed to provide anti-

bodies to amyloid beta (A $\beta$ ) directly to the patient, which bind to and clear A $\beta$  plaques characteristic of the disease.

### ● Immune Globulin Intravenous Study (IgIV)

#### Overview

Immune Globulin Intravenous (IgIV) has been approved and used successfully for more than 20 years to treat various autoimmune and immunodeficiency diseases. Now, Increasing evidence suggests that immunotherapy targeting amyloid beta (A $\beta$ ) peptide can be used to treat Alzheimer's disease. Because it contains anti-amyloid properties, IgIV is being tested in a Phase III, double blind, randomized placebo controlled study as a treatment for mild to moderate Alzheimer's.

To learn more about the ICARA or IgIV studies, contact Deb Rooney, RN, CCRC  
 ■ 215-662-7057 ■ deb.rooney@uphs.upenn.edu

### ● L ZAM Lilly LY2062430

#### Overview

Because Alzheimer's disease is thought to be caused by an excess of amyloid beta peptide (A $\beta$ ) in the brain, a sticky protein that forms the pathological amyloid plaque characteristic of the disease, treatments to slow the build-up of A $\beta$ , or increase its clearance from the brain, might be expected to slow the progression of the disease.

This Phase III, double blind, randomized placebo controlled study tests if L-ZAM, an anti-A $\beta$  humanized monoclonal antibody, can slow functional decline in persons with mild to moderate Alzheimer's.

To learn more about the L-ZAM Study, contact Staci Hoops  
 ■ 215-615-3082  
 ■ staci.hoops@uphs.upenn.edu

### ● S-connect



MEDICAL FOOD STUDY

#### Overview

This study tests if dietary management of nutrient deficiencies with a once-a-day nutritional drink with Souvenaid® (containing FortasynTM Connect, a specific proprietary combination of nutrients) has a positive effect on cognition in patients with mild to moderate Alzheimer's disease.

■ patricia.martinez@uphs.upenn.edu

To learn more, contact Patricia Martinez  
 ■ 215-746-2557

### Did You Know?

People with **NORMAL COGNITION** are very important to our research

**S**tudying people in their 70s, 80s, and beyond with normal memory and thinking helps science better learn what goes wrong in the brains of those with age-related cognitive problems. These valued research partners are known as "normal controls." The basics of being a normal control are simple. Once a year,

you'll come to the Penn Memory Center for cognitive testing, a brief neurological exam, and blood and urine samples — about a 2-hour visit. You'll leave knowing you've accomplished something — helping find the answers we need about AD.

To learn more contact Marianne Watson, RN ■ 215-662-4373  
 ■ marianne.watson@uphs.upenn.edu



What's on my Facebook page? I enjoy travel, jewelry making, and of course, being a normal control at the Penn Memory Center . . .

## Win a Brain Game

**T**here's yet no solid evidence that the "brain games" proliferating in today's market can improve day-to-day overall cognitive functioning or stave off decline. But some of them are fun, and "since research shows a happy mind tends to be a healthier mind, why not play them if you like?" said PMC neurologist David Wolk, M.D.

In that spirit, we tell you of a contest from game maker Dakim, Inc. and *Alzheimers Weekly.com*; in which five people age 65+ can win a \$2,500 BrainFitness system, free.

## Obesity: A Heavy Toll on Brain Health

**B**rain cells of obese older adults are smaller than those of slimmer seniors, especially those areas of the brain vital to learning and memory, a recent study showed. Researchers say it's the first established link between excess body weight and "severe brain degeneration."

Using high resolution brain mapping, Paul Thompson, a professor of neurology at UCLA, and colleagues, looked at scans of people in their 70s as part of a larger study on the causes of brain damage. Comparing scans based on body

## of interest on Heathy Brain Aging

touching the screen — no keyboard or mouse is used. Games are designed for a range of users, from those with normal brain function, through mild to moderate dementia. Difficulty levels go up or down automatically based on a user's performance. Games are updated online every few days.

Contestants will write a paragraph or two on why they or someone they care about would benefit from the game.

You can download an entry form, and try sample games on their website. **Deadline is November 5, 2009.**

● [www.dakim.com/thanksgivingcontest](http://www.dakim.com/thanksgivingcontest)

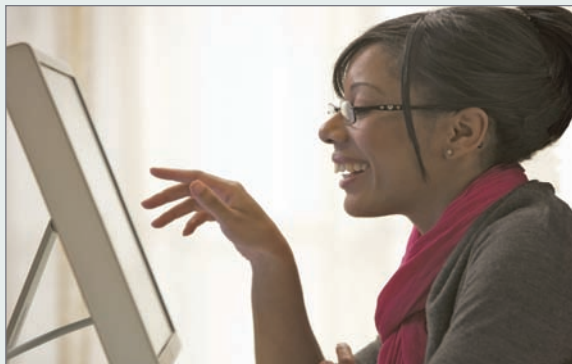


photo: edward bock | dreamstime

I bet Aunt Helen would enjoy this . . .

The laptop-sized Dakim game unit is loaded with multimedia games that look, sound, and feel like a TV game show. Answers are given by



photo: carol edwards

Bigger Belly, Smaller Brain?

mass index (BMI) they found obese persons had about 8% less brain tissue than people of a healthy weight. Even those who were just overweight, not obese but with a heavier than normal BMI, had brain sizes about 4% smaller

than people with normal body weight.

Poor blood flow, diabetes, tiny strokes, and other health conditions that accompany obesity may be behind the shrinkage, Thompson said. "These are big losses of tissue that deplete your cognitive reserves, putting you at much greater

risk of AD" and other dementias. By shedding excess pounds, "you're not only saving your waistline, but saving the life of your brain."

● [www.physorg.com/news/170419418.html](http://www.physorg.com/news/170419418.html)

The Penn Memory Center  
relies on YOUR GIFTS  
and BEQUESTS  
to ADVANCE



**As** Alzheimer's disease threatens to become the largest public health crisis in the history of our nation, federal and other funding for our efforts has been reduced. This hard reality makes your gifts and bequests even more vital to help support our operations and nurture our advances.

Donations may be made to ● "Trustees of the University of Pennsylvania" (please write "ADC-PMC" on the subject line) and mailed to ● Faye Silag, Admin. Assistant 3615 Chestnut St. Philadelphia, PA 19104

Or make a gift online at [www.pennadc.org](http://www.pennadc.org). To learn more ways to support the work of the Penn Memory Center, call Irene Lukoff at 215-573-0187. Thank you.

Penn Memory Center  
Ralston House  
3615 Chestnut St.  
Philadelphia, PA 19104

215-662-7810

[www.pennadc.org](http://www.pennadc.org)

## inSight<sup>light</sup>

Jason H. Karlawish, Publisher  
[jason.karlawish@uphs.upenn.edu](mailto:jason.karlawish@uphs.upenn.edu)

Carol Edwards,  
writer, designer, editor  
[carol.edwards@uphs.upenn.edu](mailto:carol.edwards@uphs.upenn.edu)  
voice: 215-573-4634

- inSight-Light is produced by the Penn Memory Center, part of Penn Medicine, of the University of Pennsylvania.

- The Penn Memory Center is a National Institute on Aging-designated Alzheimer's Disease Center (ADC), one of only 28 such centers in the United States, and the only one in our tri-state region.

- Our staff and programs are dedicated to research in Alzheimer's disease and age-related cognitive impairment, and life-long brain health; and to improving the well-being and quality of life of our patients and their families.

- We welcome and encourage your questions, comments, suggestions, requests, and gifts.

- Pre press and printing:  
Ft. Nassau Graphics



photo: carol edwards

Lunch *al fresco* at Ralston House

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photo: drniels | sxc

Short, lighter features of interest

## What is InSight-Light?

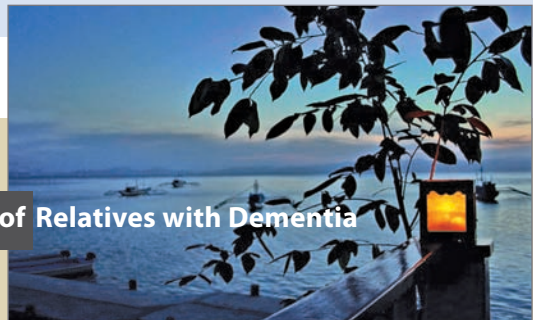


A new, quick-read, "lighter" version of the full-size Penn Memory newsletter *InSight*

debuts here as *InSight-Light*. It will come to you twice a year, *between our two regular InSight issues*. As with the full-size *InSight* newsletter, you can choose to receive either a print version by mail, or an electronic version via email.

*InSight-Light* will allow us to bring you more wide-reaching, lighter features. You'll also get concise answers to common questions about Alzheimer's disease and healthy brain aging, more timely news on activities and offerings at the PMC, and updates from the world of Alzheimer's disease and healthy brain aging research at large. We hope you find *InSight-Light* informative and worthwhile.

- Subscribe to InSight and InSight-Light at [www.pennadc.org](http://www.pennadc.org).



## For Caregivers of Relatives with Dementia



The Penn Memory Center now offers a 6-week series of psychoeducational classes led by qualified mental health professionals to help you learn skills to better care for your loved one and yourself as you move through the changes of Alzheimer's disease and other dementias.

Day and evening sessions are offered. Please call 215-662-7810 to learn more.