

preserving your

Spring 2009

# Memory

The Magazine of Health and Hope

## Leeza Speaks

About Her New Book on Alzheimer's, Caregiving, and Family

## Silver Alerts:

Finding the Wanderers

## Clinical Trials and Your Loved One:

A Good Match?

"Pocket" Alzheimer's Films:  
Spreading the Word



FISHER CENTER FOR  
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**Imagine not being able to recognize your best friend.**

Today millions of people with Alzheimer's can no longer remember the ones they love. That number is expected to increase dramatically in the next 20 years. And it's one more reason MetLife Foundation continues to support research to find a cure. This year the Foundation honors the outstanding work of Takeshi Iwatsubo, MD, University of Tokyo, Japan, and Michael S. Wolfe, PhD, Brigham and Women's Hospital and Harvard Medical School, Boston, with the MetLife Foundation Award for Medical Research.

**MetLife Foundation**  
A leader in finding an Alzheimer's cure

# Features

## Is a Clinical Trial Right for Your Loved One?

Clinical trials are a critical phase of drug testing that involve human subjects. Your loved one may benefit from an Alzheimer's trial. Here's what to consider first.



## Silver Alert Finding Its Way Home

Finding the wandering Alzheimer's patient is the goal of Silver Alerts, a program that is proving successful in many states—with more on the way.



## Small Package, Big Gift

Writer David Shenk has created four short films that explain Alzheimer's disease in a nutshell. They're free to download and distribute—in fact, that's his goal.



## Leeza's Place

The star talks with us about caregiving, her new book, and her tireless advocacy.



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# preserving your Memory

The Magazine of Health and Hope



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# Looking Back, Looking Ahead

Spring always seems to bring refreshment and renewal after the chilly winter months. We think our new issue is doing the same thing.

For our Spring 2009 issue, *Preserving Your Memory* magazine is taking a look at the difference dedicated professionals are making for Alzheimer's patients and their caregivers. Leeza Gibbons, our cover feature, gives us an interview on her new book, *Take Your Oxygen First*, an exploration of her years of caregiving for her mother, as well as an easy-to-follow presentation of the basics of Alzheimer's and caregiving from her co-authors.

In our article on Silver Alerts, we see how an important government program is helping locate wandering patients. We also talk with Kimberly R. Kelly, one of the nation's leading authorities on search and rescue of Alzheimer's patients, in our Ask the Experts column this month. And then we take a closer look at clinical trials—do they make sense for your loved one?

Technology touches all our lives, and it's making a difference for Alzheimer's patients and caregivers, too. Of course there's the vitally important research taking place at the Fisher Center and elsewhere (which we report on in every issue). Plus, writer David Shenk has applied his communications talents to a series of four short, "pocket" films (available free for download) that explain Alzheimer's disease in an easy-to-understand way, on page 15.

We hope this spring brings you refreshment and renewal!



Betsey Odell

Please send your tips, stories, or questions to the Fisher Center for Alzheimer's Research Foundation, West 46th St. & 12th Ave., New York, NY 10036, or by e-mail to [betsey@alzinfo.org](mailto:betsey@alzinfo.org)

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## About the Fisher Center for Alzheimer's Research Foundation

Since 1995, the Fisher Center Foundation, a 501(c)(3) nonprofit organization, has been providing hope and help to the public by funding research into the cause, care, and cure of Alzheimer's disease and creating much needed educational programs. We are the world's largest research team leading the battle against Alzheimer's disease. Our team of internationally renowned scientists, under the direction of Nobel laureate Dr. Paul Greengard, has been at the forefront of research that has provided a conceptual framework for modern-day investigations into Alzheimer's disease. Of every dollar we raise, 94 cents goes directly to research programs. Oprah's O Magazine lists us as the top charity to give to for Alzheimer's. For more information or to make a donation, go to [www.ALZinfo.org](http://www.ALZinfo.org).

# The Latest News on Alzheimer's Disease and Brain Health



Insulin continues to show promise as a potential Alzheimer's medicine.

## Insulin Shows Promise as Alzheimer's Shield

Insulin may provide a protective barrier against the proteins that are associated with Alzheimer's disease, slowing the loss of memory associated with the disease, according to new research from Northwestern's Cognitive Neurology and Alzheimer's Disease Center.

Insulin appears to block amyloid beta-derived diffusible ligands (ADDLs), proteins that block memory-forming synapses in the brain's memory centers. As we age, our bodies become less sensitive to the effects of insulin.

William L. Klein, a researcher at the center and senior author of the study, said in a news release issued by the

school that the new research strengthens a possible connection between Alzheimer's and diabetes. "Therapeutics designed to increase insulin sensitivity in the brain could provide new avenues for treating Alzheimer's disease," said Klein. "Sensitivity to insulin can decline with aging, which presents a novel risk factor for Alzheimer's disease. Our results demonstrate that bolstering insulin signaling can protect neurons from harm."

The report was published online Feb. 2 in *Proceedings of the National Academy of Sciences*.

## Nutritional Deficiencies Increase Beta-Amyloid, Study Finds

Laboratory mice that are deficient in key brain nutrients tend to develop beta-amyloid in the brain more quickly. But a recent study published in the January 2009 *Journal of Alzheimer's Disease* found that these mice showed improvement in maze testing when the nutrients were replaced via apple juice.

Thomas B. Shea, who co-authored the study, said the study points to the importance of long-term nutrition to prevent changes related to aging, such as those seen in Alzheimer's patients.

Shea and his colleague, Amy Chan, compared the impact of better nutrition via apple juice on two groups of mice: one normal, one bred to lack the gene for apolipoprotein E, which helps protect cells from the damage caused by oxidative stress.

In a previous study, Shea and his colleagues gave laboratory mice apple juice

prior to maze tests and found that their performance improved, and that the juice decreased production of amyloid-beta in the mice brains.

Shea cautioned that the results of the study should only point to the benefits of good nutrition in brain health; drinking large amounts of apple juice has no known benefit.



More good news about coffee: lower dementia risk.

## Moderate Coffee Consumption May Reduce Dementia Risk

Enjoy your morning cup of "joe"? New research points to an additional benefit to moderate coffee consumption for middle-aged adults: lowered risk for dementia later in life.

The Finnish study looked at the effects of coffee on 1,400 adults over 20 years. It found that those who drank three to five cups per day had a 65% lower risk for developing dementia,

including Alzheimer's disease, as they aged. It was published in the January 2009 *Journal of Alzheimer's Disease*.

Researchers caution that the study is preliminary. More study is needed to determine what chemical or combination of chemicals in coffee has the benefit in fighting dementia. Coffee is associated with a lower risk of diabetes, a condition that has been associated with higher risks of dementia. But coffee also has plant compounds that act as antioxidants, which may also help preserve cells over time.

### **University of Miami Researchers Identify Nine Genes That May Have Alzheimer's Role**

In a development that could open new doors in Alzheimer's disease research, nine genes were identified that may have a role in Alzheimer's development, said Margaret Pericak-Vance, director of the Miami Institute for Human Genomics at the University of Miami Medical School.

Because earlier interventions are expected to work more effectively in delaying and slowing the progression of Alzheimer's, Pericak-Vance said, these newly identified genes could open up new possibilities for more effective treatments in the next decade. Further research is needed to determine what interactions between the nine genes might take place, and how they affect Alzheimer's development.

"We need to create a genetic landscape that lets us see how the genes interact," Pericak-Vance said. "The problem is not just a single gene; these nine are probably interacting with each other."

"If you have a gene that favors Alzheimer's, you're in a gray zone. You know you have increased risk. You may or may not get the disease depending on how the genes interact with each other, and how the genes interact with the environment."

### **Common Gene Variant Linked to Alzheimer's Development in Women**

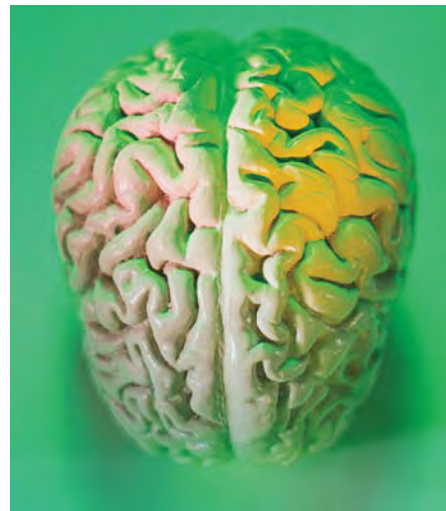
Women who have two copies of a common gene variant on their X chromosomes are at a greater risk of developing late-onset Alzheimer's than those who don't have both copies, according to a study published by Mayo Clinic researchers in *Nature Genetics*.

Researchers cautioned that these results don't show why women develop Alzheimer's disease more often than men. Rather, it points to one genetic variant that requires more research to determine what role it may play in the progression of the disease.



**Women with two copies of a common gene variant are at greater risk for late-onset Alzheimer's.**

"This is a very common genetic variant, and many women who have two copies of it don't get Alzheimer's. But, overall, the odds were substantially greater that female patients with the disease did have two copies," said the Mayo Clinic's Steven Younkin, M.D., Ph.D., the study's senior investigator at the Florida campus, and George M. Eisenberg, professor of Neuroscience in the College of Medicine.



**Sugar glucose may be a key to slowing the development of Alzheimer's.**

### **Lack of Glucose Energy Starves Brain, Study Finds**

One of the keys to slowing the development of Alzheimer's disease may be making sure that the brain is getting enough of the sugar glucose, researchers at Northwestern University's Feinberg School of Medicine have found.

The study's lead author, Robert Vassar, said that an important protein in the brain is modified when the brain doesn't get enough energy in the form of glucose. That "starvation" causes an enzyme in the brain to stimulate production of the sticky protein clumps that are associated with Alzheimer's.

"This finding is significant because it suggests that improving blood flow to the brain might be an effective therapeutic approach to prevent or treat Alzheimer's," said Vassar, a professor of cell and molecular biology at the Feinberg School.

Vassar said that people can improve blood flow to the brain by getting exercise, reducing cholesterol and managing hypertension (high blood pressure). ■

*Check the Fisher Center website ([www.ALZinfo.org](http://www.ALZinfo.org)) often for up-to-date and expert-reviewed scientific news.*

# Is a Clinical Trial Right For Your Loved One?

**A**mong the many decisions you will face as a patient (or caregiver) dealing with Alzheimer's disease (AD) is whether or not to participate in a clinical trial. Clinical trials help scientists understand how AD affects the brain and facilitate the testing of breakthroughs in treatment and prevention. Before joining a clinical trial, patients and their caregivers should understand as much as possible about the specific study and its potential impact.

## Making a Difference

A devastating neurological disorder, AD affects more than 30 million people worldwide and results in more than \$100 billion in annual patient care costs, said Michael S. Rafii, MD, PhD, director of the Memory Disorders Clinic at the University of California, San Diego (UCSD). Yet treatment and preventive measures approved for the disease are limited. "Current FDA-approved drugs for AD do not prevent or reverse the disease, and provide only modest symptomatic benefits," said Dr. Rafii, who is also assistant professor of neurosciences at UCSD and associate medical director of the Alzheimer's Disease Cooperative Study, a national research consortium between the National Institute on Aging and UCSD.

As scientists continue to make advances and explore new approaches for AD, the demand for study participants has increased. By participating in a clinical study, patients have the opportunity to help some of these new treatments, preventive strategies and diagnostic tools become a reality.



Getting involved with a clinical trial may help speed the development of new Alzheimer's treatments.



## Study or Trial?

Not sure what the difference is in the two terms? A clinical study is a broad category used to describe any medical research project that uses human volunteers. A clinical trial is a specific type of study in which one group of participants receives an experimental treatment, while another group receives a placebo (an inactive, look-alike) treatment. The success of the trial is determined by comparing the outcomes of the two groups.

Many of the people who participate in clinical trials are motivated by their desire to help others and the hope of eventually curing the disease. “It’s about taking a proactive stance versus helplessness and hopelessness—it’s about altruism and concern for your children and grandchildren,” said Lisa P. Gwyther, MSW, LCSW, education director at the Bryan Alzheimer’s Disease Research Center at Duke Medical Center. “It’s also about access to the best and brightest experts who are genuinely interested in your condition and your response. And it’s a chance to make a difference and be part of an ‘answer’ and not just part of ‘the problem,’” added Gwyther, co-author of *The Alzheimer’s Action Plan* (2008).

The reasons for joining an AD study are as unique as the participants themselves. “An individual’s decision to enter a clinical trial is a very personal one and there are a variety of reasons for considering taking part in a study,” said Dr. Rafii. “Having hope for a future cure, feeling better, and contributing to research and society are some personal reasons participants enter trials. Participants who enter clinical trials also receive access to cutting-edge treatments before they are readily available to the general public.”

## How Do Trials Work?

Each clinical trial is unique, and its process depends on the research being tested. The research team often includes doctors, nurses, social workers and other health care professionals. Clinical trials are sponsored by health care institutions, government agencies, pharmaceutical companies, individual physicians, and medical device companies. Studies take place in hospitals, universities, doctors’ offices and community clinics. As you evaluate a study, be sure to find out the location of the study site and how frequently your attendance will be needed.

All clinical trials are based on their own protocol. This set of rules defines what types of people are sought to participate in the trial; the schedule of tests, procedures,

## Words to Know

Making an informed decision about study participation starts with understanding important terms such as these:

### Control/Control-Group

Researchers refer to the standard, or group by which experimental observations are evaluated, as the control or control group. Often, one group of patients in a clinical trial will be given an experimental drug or treatment and then compared to another group (the control) that is given either a standard treatment for the illness or a placebo.

### Blinded Study/Masked Study

In a blinded or masked study, participants do not know whether they are in the experimental group (the one receiving the treatment being tested) or the control group (the one receiving a standard treatment or no treatment).

### Double-Blind Study/Double-Masked Study

When neither the staff nor the study participants know which participants are part of the experimental group and which are part of the control group, it’s called a double-blind or double-masked study. These types of studies are conducted to eliminate the influence of any expectations on the part of doctors and participants.

### Informed Consent

Informed consent is the process the patient (or their caregiver) goes through to learn important facts about a clinical trial before deciding on their participation.

### Placebo

A placebo is an inactive pill or look-alike treatment that has no real value. In clinical trials, participants in a control group are often given a placebo and their outcomes are compared to the participants in the experimental group receiving the treatment being tested. Study participants are usually randomly assigned to either the control group or the placebo group.

### Protocol

Each clinical trial is based on a set of rules—called a protocol—outlining the types of people who may participate and specifics about the schedule of tests, procedures, medications and dosages, and the length of the study.



Participating in a clinical trial can give a patient access to the latest treatments.

medications and dosages; and the length of the study. If you participate in a clinical study, you will likely be seen regularly by the research staff to monitor your health and to determine the safety and effectiveness of the treatment. Some clinical trials involve more tests and doctor visits than you would normally have for your illness or condition.

In many AD trials, the patient is essentially a passive bystander and the processing of information about the trial and decision-making are the responsibility of the caregiver, spouse, next-of-kin or person designated with power of attorney. This elevates the role and responsibilities of the caregiver and should be considered before joining a trial.

“The caregiver usually accompanies the subject to all visits for the duration of the study and provides a wealth of information with regards to how a patient is doing while on a study drug,” explained Dr. Rafii. “Alzheimer’s disease affects a patient’s memory such that the caregiver’s account of how things are going helps clinical researchers understand the effects of the drug, and any benefits derived, in addition to those measured as part of the clinical trial protocol.”

Some clinical trials will pay participants, while others do not. In some programs, researchers will reimburse you for expenses associated with participating in the research, such as transportation costs, child care, meals and accommodations. You are ultimately in control of your participation and you can leave a clinical trial at any time. If you plan to stop participating, let the research team know your reasons.

### Risks vs. Benefits

As you consider participating in a study, evaluate the benefits and risks specific to your participation. Benefits include taking an active role in your health care, gaining access to the most advanced treatments available, receiving exceptional medical care at top facilities, and helping others by contributing to research advancement.

### Weighing the Decision

When evaluating the potential risks a clinical trial poses to you or your loved one, consider there may be side effects or adverse reactions to medications or treatments; the



Clinical trials help researchers understand the effectiveness of new medicines.

treatment may not be effective for you; and the study's protocol may require a lot of time for trips to the study site, treatments, hospital stays or complex dosage requirements.

Informed consent is the critical process of learning key facts about a study before deciding whether to volunteer. The government has strict guidelines and safeguards to protect people who choose to participate in clinical trials and requires potential participants to be given complete information about a study in writing. You should also ask the research team to explain all the risks and possible benefits and answer any of your questions before you make a decision.

Informed consent is a process that continues throughout the study. Participants should feel free to ask the research team questions before, during and after the study. If the patient suffering from AD is not mentally capable of giving consent, the informed consent process must be conducted by next-of-kin or the person granted power of attorney. ■

## Questions to Ask

Michael S. Rafii, MD, PhD, director of the Memory Disorders Clinic at the University of California San Diego, suggests asking the following questions to determine if participating in a clinical trial is right for you or your patient:

1. Why is this research being done?
2. What is the purpose of the study?
3. Why does the research team think the treatment will work?
4. Where is the study site?
5. What kinds of therapies, procedures, and/or tests will I (or my patient) have during the trial?
6. How long will the study last?
7. How often will I (or my patient) have to go to the study site?
8. Will I (or my patient) be able to take my regular medications during the trial?
9. What medications, procedures or treatments must I (or my patient) avoid while in the study?
10. What are my (or my patient's) responsibilities during the study?
11. Will I (or my patient) have to be in the hospital during the study?
12. Will I (or my patient) be able to find out the results of the trial?

## Finding a Study

To find out if there is an Alzheimer's disease research study in your area, contact one of these resources:

- Go to [www.clinicaltrials.gov](http://www.clinicaltrials.gov)
- Call the Alzheimer's Association's 24/7 Helpline at 1-800-272-3900
- Contact an Alzheimer's disease center near you directly. To find a center in your area, go to [www.alzinfo.org](http://www.alzinfo.org) and use the *Resource Locator* tool.

## Want to Know More?

Read more about participating in clinical trials in *The Alzheimer's Action Plan: The Experts' Guide to the Best Diagnosis and Treatment for Memory Problems* by P. Murali Doraiswamy, Lisa P. Gwyther and Tina Adler; St. Martin's Press, 2008.

# Silver Alert Finding Its Way Home

Emergency System for Missing Seniors Gaining Ground One State at a Time

Silver Alerts aim to locate wandering Alzheimer's patients.

**T**heir names and hometowns are different, but their unsettling stories are all too similar. Mary Zeltzer, 86, from Largo, Fla. Mildred Rogers, 76, from Raleigh, N.C. George Brelsford, 82, from Warsaw, Ind.

Victims of Alzheimer's disease (or other forms of dementia), they have wandered away from their homes or residential facilities and have become lost. Statistics show that if they are not located within the first 24 hours of their disappearance, half of them could suffer serious injury or even death.

With an estimated 5.5 million Americans currently living with Alzheimer's, 60 percent of whom typically wander, there are more than 3 million adults whose safety and security is threatened every time they leave their familiar surroundings. As Alzheimer's populations grow, so do the numbers of those who roam unsupervised.

Concerned family members, caregivers, elected officials and law enforcement agencies throughout the country have banded together to help protect these vulnerable adults. A growing number of states have implemented "Silver Alert" systems to locate and safely return individuals with Alzheimer's or other forms of dementia or cognitive impairment.

### How the Silver Alert Works

Silver Alert is modeled after the Amber Alert program, which quickly disseminates key information about lost or abducted children in order to raise public awareness and activate necessary law enforcement responses.

When a family member or caregiver reports a lost adult with the hopes of distributing a Silver Alert, local law enforcement must first confirm whether the individual suffers from some form of dementia and is a potential danger to self or others. Upon confirmation of these factors, the agency immediately issues a Silver Alert through a statewide emergency communications network and to local media outlets. If the missing person is thought to be driving, the alert is also issued via electronic highway signs.

Currently, around 14 states have instituted formal Silver Alert programs and more than a dozen others are considering similar legislation.

### Saving Lives

Silver Alert will come as a relief to anyone who cares for someone with Alzheimer's, said Dr. Marc Agronin, a board-certified geriatric psychiatrist and the director of mental health services at the Miami Jewish Home and Hospital for the Aged, Florida's largest long-term care facility. "The risk of someone with moderate to severe Alzheimer's wandering off and getting lost or injured is a concern that a lot of caregivers have," he said. "When it happens, it has

the potential to be a life-threatening situation. Having systems in place to help safeguard individuals and assist the caregivers is important."

Dr. Agronin, who also serves as the medical editor for *Geriatric Psychiatry News*, the official publication of the American Association for Geriatric Psychiatry, speaks to the wisdom of using the existing Amber Alert infrastructure. "It makes sense if you already have an alert system in place for missing children to apply the same principles to vulnerable or missing adults," he said.

### Benefits of Silver Alerts

However, in pointing out the differences between the two population groups in missing-person situations, Dr. Agronin gets to the heart of why Silver Alert can be so crucial. "It's important to note that someone with moderate to severe dementia can easily become disoriented and get lost, but they won't raise the same suspicions that a young child would," he explained. "If anyone saw a young child wandering alone, we would know it's a problem. But we wouldn't necessarily know that with an adult. Someone casually encountering an Alzheimer's patient might not think there's anything out of the ordinary if they're not familiar with the signs of dementia. So the risks associated with wandering might be increased without a comprehensive system in place."

In addition, Dr. Agronin believes that the benefits of such a program would surpass any associated downsides. "As long as the program is done in a way that helps find the person without compromising privacy and confidentiality, it's appropriate," he noted. "The urgency of finding the person outweighs other considerations."

While current Silver Alert programs vary slightly from state to state, efforts are underway to ensure that the entire nation is covered by some variation of the system.

### Inspiration and Legislation

U.S. Rep. Gus Bilirakis, from Florida's Ninth District, is one of several lawmakers leading the legislative charge, crediting one family's experience last February as his motivation. When Mary Zeltzer, an 86-year-old Florida woman with dementia who lived in a Largo assisted living facility, did not return from a quick trip to the grocery store, her daughter became worried and notified the authorities. But without an organized system in place, the search and rescue efforts were hampered. Several days later, divers retrieved the remains of Mrs. Zeltzer, who had apparently become disoriented, mistakenly driving off a ramp into the Intracoastal Waterway.

"This was such a terrible experience for that family. The local police just didn't have the ability to find her," Bilirakis

said. “It reminded me of when I was growing up, and my great-grandmother would wander. But there was always someone in that community who would find her and direct her back home. So I decided to file a bill because I knew there was a need for this. Mrs. Zeltzer’s story inspired me.”

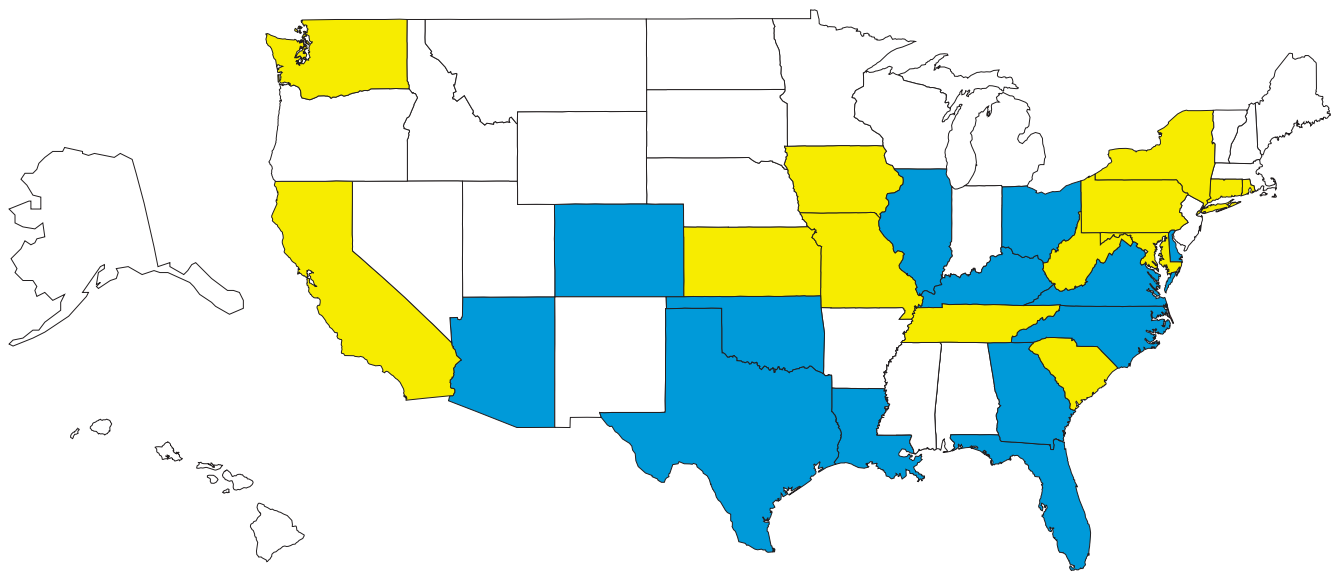
When Bilirakis initiated his statewide efforts, there were Silver Alert programs in place in several states but none in Florida. With strong public support, as well as the active participation of Mrs. Zeltzer’s daughter, Mary Lallucci, Bilirakis steered the Silver Alert toward the Florida legislature. (Ultimately, Governor Charlie Christ signed an executive order, so no bill was necessary.)

### Rolling It Out Nationwide

From there, Bilirakis focused his attention on broadening the scope of Silver Alert, extending its reach on a national scale. His Silver Alert Grant Notification Act (H.R. 5898)

called for a national grant program overseen by the Department of Justice that would allow states to obtain federal funding to create new or improve upon existing Silver Alert systems. It was one of several eldercare legislative proposals brought to the House in July 2008. Another was Texas Rep. Lloyd Doggett’s H.R. 6064, a bill with similar characteristics. Soon, the congressional representatives joined forces, combining their bills into what is now known as the National Silver Alert Act, which was unanimously approved by the House in September but initially rejected by the Senate.

“Lloyd and I will address the Senate’s concerns, and re-file for approval. Our goal is to have the Silver Alert in all 50 states and six territories,” said Bilirakis. “I would encourage every American citizen to call their elected representatives and get them on board with this, because it is so important. I won’t rest until I get that bill.” ■



#### States with Silver Alert or similar systems currently in place (blue)

- Arizona
- Colorado
- Delaware
- Florida
- Georgia
- Illinois
- Kentucky
- Louisiana
- North Carolina
- Ohio
- Oklahoma
- Texas
- Virginia

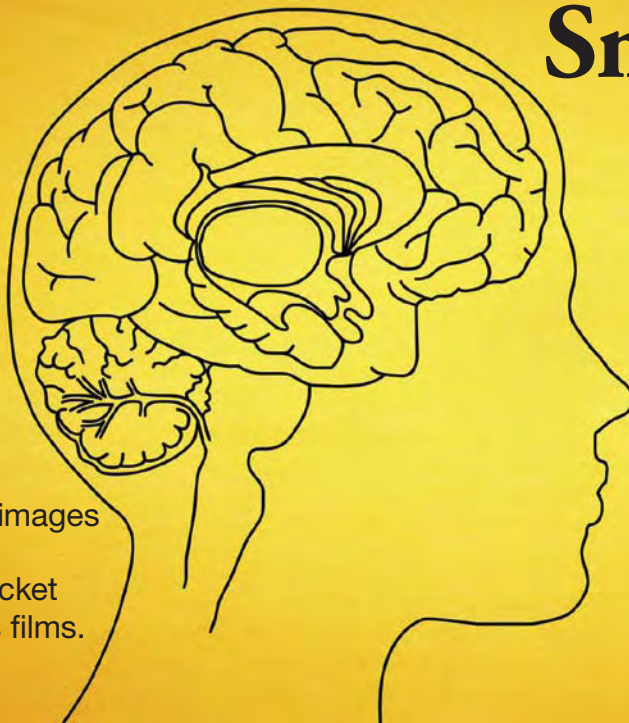
#### States considering alert programs or legislation for a system (yellow)

- California
- Connecticut
- Iowa
- Kansas
- Maryland
- Missouri
- New York
- Pennsylvania
- Rhode Island
- South Carolina
- Tennessee
- Washington
- West Virginia

# Small Package, Big Gift

Author David Shenk delivers a broad message about Alzheimer's in four tiny films.

One of the images from David Shenk's pocket Alzheimer's films.



**A** diagnosis of Alzheimer's disease overwhelms its victims and their families. The disease eventually attacks every corner of your brain, burdens family members, can span a decade or more, costs an ever-growing amount in health care, and affects an ever-expanding segment of our society. Even the healthiest brain would struggle to process all of this information.

David Shenk, author of *The Forgetting*, recognized the need for a better method of message delivery. His four new so-called "pocket films," titled "A Quick Look at Alzheimer's," seek to and succeed at boiling down such a torrent of facts into easily digestible bits of information.

Shenk, who frequently lectures on the topic and whose book became a 90-minute PBS film, realized he could reach more people with a shorter, more portable medium. "It takes many hours to read a book," Shenk said. "I can only give lectures in so many places, and not everybody has 90 minutes to watch a film." Alternatively, these pocket films, viewable at [aboutalz.org](http://aboutalz.org), total less than 8 minutes, cut straight to the point, and can be accessed by anyone with an Internet connection. Shenk developed the pocket films in partnership with the Alliance for Aging Research, through a grant from the MetLife Foundation.

Shenk also made sure to package the films in every conceivable format. One click, and you can download them to iTunes, e-mail them, upload them to your Website, or add

them to Facebook, Digg, Stumble or Delicious. Doctors can pop in a DVD for patients and their families. Lecturers can put them in a PowerPoint presentation, while advocates can use an iPhone to flash them in front of members of Congress.

"Ultimately, it's a viral thing," Shenk says, "and nothing can spread stuff like the Web can."

## Spreading Awareness

As the films point out, the urgency to spread awareness couldn't be greater. Today, approximately 5.1 million Americans suffer from Alzheimer's. By 2050, as our population ages, that number is expected to grow to more than 16 million. Costs will soar, and the strain could cripple our healthcare system.

Today, scientists are optimistic about a cure and better treatments, but research is expensive and takes a long time. While the goal for annual funding hovers around \$1 billion, the actual funding from Congress topped off at several hundred million dollars and has begun to fall with the souring economy. Every year that funding falls short, the distance to a cure lengthens. Meanwhile the impact of the disease is growing, and scientists are watching so many of their gains wither on the vine.

Two stated goals of the film are to "reduce stigma" and "to help strengthen the public fight against the disease." Shenk explained that one of the reasons funding has



Eye-popping animation makes pocket films easy to follow.

stagnated is that people, including members of Congress, are afraid to address Alzheimer's. "It's not like they don't know it exists," Shenk said. "It's just that they don't want to spend a lot of time thinking about something that is so existentially frightening as something that erases your brain." Forty years ago, people whispered the word cancer. Twenty years ago, AIDS was taboo. "Now, Alzheimer's is the big disease that needs to be demystified," says Shenk.

### Improving Care

Shenk's other goal was to improve care now. Medication, which currently only treats Alzheimer's symptoms such as mood disorders, plays only a small role in overall care. "Improving care is about families understanding the disease; preparing for the course of the disease; getting emotionally, physically and financially ready for the disease; and getting the right care in the home or outside the home," Shenk said.

To that end, Shenk's films break down the course of the disease. Shenk introduces families to the Alzheimer's community and lists the basic resources available to them. He also outlines a family's initial course of action: to address estate planning, power of attorney, and long-term care insurance. Additionally, [aboutalz.org](http://aboutalz.org), masterfully built by Jefferson Raab, provides links to many more resources.

Shenk assembled a team of superlative talent: Tony and Emmy Award-winning actor and Alzheimer's spokesperson David Hyde Pierce as the narrator and award-winning animator Jossie Malis. Malis's animation matches the script's simplicity as Hyde Pierce, who performed pro bono, matches its comforting tone.

### Helping Us All Understand

Shenk, who has no personal experience with Alzheimer's, dove down the rabbit hole of Alzheimer's 11 years ago when he overheard a conversation in a restaurant. His curiosity led to the book, the PBS film, his lectures and now this. "I've found that in my 11 years in the community, the most important thing I can do is to help people understand the disease better, to help people become more comfortable thinking about it and talking about it," he says.

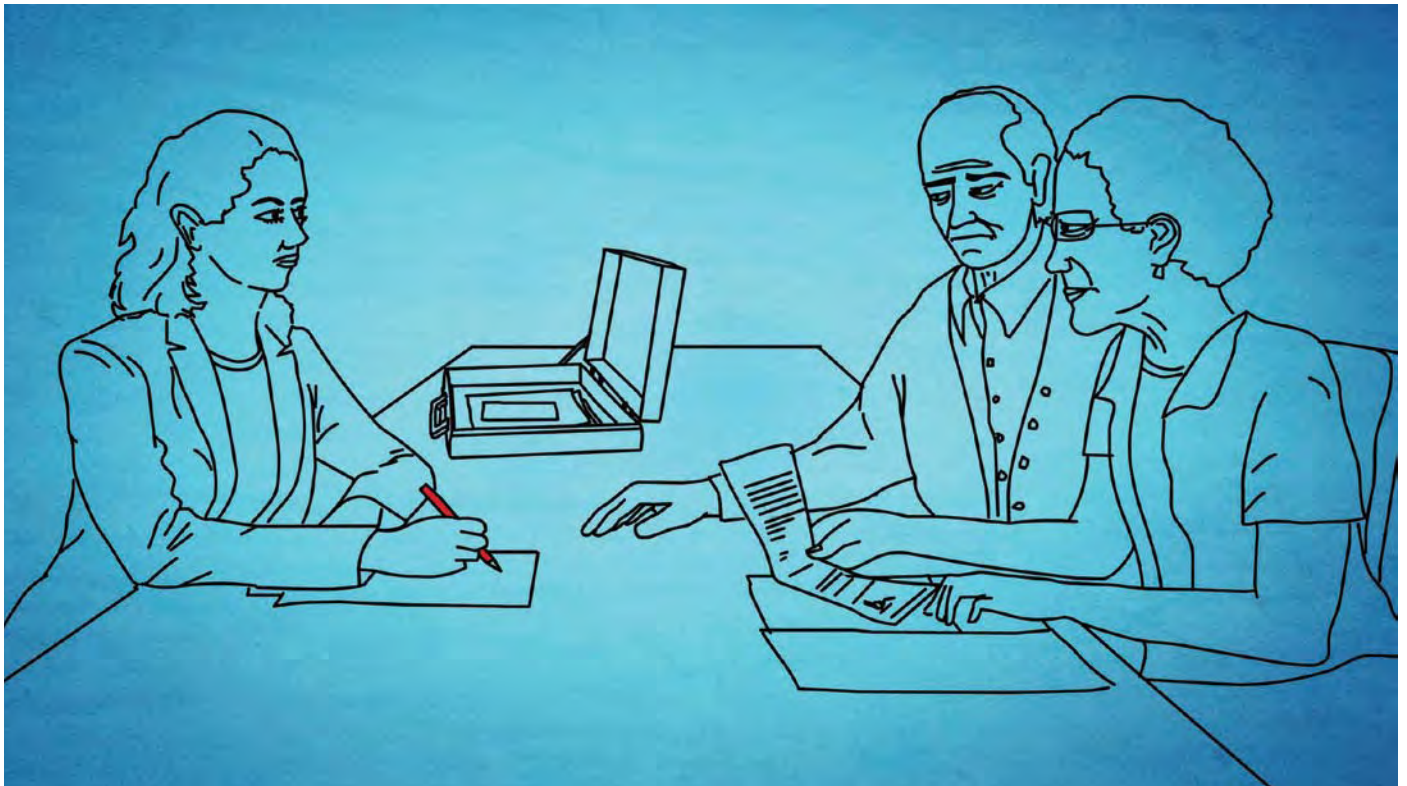
And certainly, he's achieved that once again with these films. They place victims and their families in a broader, and therefore more comforting context. They also draw in those of us who are blissfully unaffected by and unaware of the ravages of Alzheimer's. Shenk's films provide a great service by informing us and encouraging us that if society works together, Alzheimer's is not only manageable, but also conquerable. ■





The pocket films cover all aspects of Alzheimer's treatment and research.

The importance of legal preparation is also discussed.



# Leeza Speaks to Caregivers

**L**eeza Gibbons needs no introduction. To every American with a television, she's one of the most recognizable voices and faces. To Alzheimer's patients and their caregivers, she's a powerful advocate for research, treatment, and especially caregiving. It's a role she knows well, as one of the caregivers of her beloved mother, the late Jean Gibbons.

Leeza's advocacy led to the Leeza Gibbons Memory Foundation, from which was launched Leeza's Place. Both a website for caregivers to learn and share, and a growing nationwide presence of welcoming places for caregivers, Leeza's Place has become the primary stop for Alzheimer's caregivers.

In May 2009, Leeza's new book, *Take Your Oxygen First* (LaChance Publishing), will debut. Both a collection of memoirs and reflections of Leeza's family regarding Jean and the entire Gibbons family during the time of caregiving for Jean, as well as an authoritative guide to Alzheimer's, the new book gives both the science and the personal experiences from Leeza and her extended family that every Alzheimer's caregiver will benefit from. Leeza coauthored the book with longtime medical collaborators James Huysman, PsyD, LCSW, and Rosemary DeAngelis Laird, MD.

*Preserving Your Memory* magazine talked to Leeza about her new book and her tireless advocacy for Alzheimer's caregivers.

**PYM: Tell me how *Take Your Oxygen First* evolved as a project. How did you come up with the title?**

**LEEZA:** I think the phrase will be familiar to anyone who has traveled by airplane. The flight attendant instructs that in the case of an emergency, before you rush to the aid of others you should first put on your own oxygen mask, because if you don't, chances are that you'll lose consciousness. Then you, along with those you wish to help, will be in danger. That's something my family experienced firsthand when my mom was diagnosed, and as my father and siblings and I dealt with her devastating illness. We found that giving care to someone with memory loss is all-consuming. There are days when you truly feel as if you can't breathe. I watched my Mom disappear behind the veil of Alzheimer's disease and, for a time, I thought we'd lose my Dad, too. That experience is the genesis of *Take Your Oxygen First*. We want to help those who are caught up in the seemingly endless demands of caregiving to understand that they need and deserve to maintain their own well being. It's the only way to not only give proper



Photo courtesy of the Leeza Gibbons Memory Foundation

Leeza and her mom, Jean Gibbons, share a tender moment.

care to your loved one who needs you, but to preserve your own spirit, body, mind and, yes, sometimes even your life.

**PYM: Whom would you say this book is for?**

**LEEZA:** *Take Your Oxygen First* is for anyone who is giving care to a loved one with memory loss, as well as their family and friends. When you find yourself in the caregiving role, or when you know someone who is, it can seem almost impossible to find the information and guidance you need to navigate through your new reality. The sense of being overwhelmed can hit hard. *Take Your Oxygen First* guides you step by step through the process of what to expect so you can take care of yourself while taking care of someone else.

**PYM: The book is unique in that it combines your reflections—and those of your family — in providing care for your mom, with a handy AD caregiver's bible. How did you hit upon the idea of combining the two formats?**

**LEEZA:** It seemed natural, really, because caregiving—especially for a loved one—is such an intensely personal experience. It’s very easy to feel isolated and alone. But there are elements of caregiving that are universal: the deep challenges to mind, body and spirit that caregivers experience; the need for information and support. We wanted to show how our journey with Mom affected every member of our family. We wanted to be honest and real about how lost and helpless we sometimes felt. After all, we are a family like any other, so I think the readers of *Take Your Oxygen First* will find a voice in its pages that echoes their own concerns. But it’s not just a “personal journey”; as you said, it’s also a “caregiver’s bible.” My family’s personal stories are wrapped around authoritative medical, psychological and spiritual information that we think is vital to the well being of every caregiver.

**PYM: From reading your own recollections, it seems your family grew even closer together as you provided care for your Mom. Did it surprise you that this was the case?**

**LEEZA:** We have always been blessed with a warm, close family. What was surprising, though, was how deeply Mom’s AD challenged us as a family and as individuals. My father, Carlos Sr., was nearly overwhelmed physically and almost lost his own health as a consequence. We found that individual strengths emerged as we banded together to give care to Mom. For instance, my sister-in-law, Anne Marie, became the organizer who turned Mom’s evolving needs into a plan for care. My sister, Cammy, rescued my father from a poor diet and from the grip of loneliness and depression. It’s sad that there are so many caregivers who don’t have a family support system. *Take Your Oxygen First* fills that void by providing a roadmap through the experience.

**PYM: Take Your Oxygen First is unique also for the contributions your family members make to the book. At what point did this become a “family” project?**

**LEEZA:** That’s easy: from the very beginning, when Mom got her diagnosis of Alzheimer’s disease. She gathered us all together, sat us down, and told us to tackle the challenges head-on. She gave us our marching orders; *Take Your Oxygen First* represents further steps on that march. We are incredibly blessed that each of us, right down to the grandkids, feels strongly about sharing our story and lighting the path for someone else.

**PYM: I wasn’t aware that your grandmother also suffered from AD, with your mom as her caregiver. How do you think your mom’s experience as your grandmother’s caregiver affected your experiences as one of your mom’s caregivers?**

**LEEZA:** It gave us a bit of a head start because in some ways we knew what we would be up against, but we still fell into

the trap of denial and waiting too long to begin the process. Looking back, I’m surprised at how much we covered up and kept silent when we knew something was wrong. I imagine Mom’s own experience with her mother was what prompted her to have that family meeting; she’d been there, so she knew what we would be up against. I remember my Mom have so much guilt over her mother’s care. She and her sister had argued and disagreed about what was best. That’s why Mom insisted that we each know what she wanted. It was a beautiful gift. We didn’t ever second-guess ... we knew.

**PYM: Leeza’s Place has become a major online destination for caregivers, and the Leeza’s Place locations are growing in number as well. Did you foresee this idea catching on so quickly when you co-founded the Leeza Gibbons Memory Foundation?**

**LEEZA:** We knew we had created something that was missing; we basically created what we wished we had while dealing with Mom. The fact that it has caught on so quickly speaks to the great need and the lack of a voice for caregivers. These are the family first responders and they need education, empowerment and energy to deal with a very demanding situation. At Leeza’s Place you can *Take Your Oxygen First* and breathe, knowing that someone understands; someone who has been there. All caregivers need information and support to help them through their important work. Everyone at Leeza’s Place and the Leeza Gibbons Memory Foundation is proud to be a part of that. ■

## Sharing Your Story

LaChance Publishing is a unique firm in that it specializes in books about caregivers and survivors. Where do these stories come from? From people like you. LaChance published *Voices of Alzheimer’s* in 2007, which is still available through the company’s bookstore (lpstore.lachancepublishing.com/index.aspx).

The publisher is still seeking submissions on several other topics, too. You can share your story at LaChance’s website: [www.lachancepublishing.com/submissions.html](http://www.lachancepublishing.com/submissions.html). Be sure to read the guidelines before submitting.

## Visit Leeza’s Place

Want to find out more? A great place to start is Leeza’s Place ([www.leezasplace.org](http://www.leezasplace.org)), which hosts an exhaustive collection of Alzheimer’s and caregiving information materials, as well as a vibrant online community where you can get answers to your questions from staff members and caregivers just like you.

Leeza also has a personal website: [www.leezagibbons.com](http://www.leezagibbons.com). There you’ll find her blog, updates on her many charitable activities and a large gallery of photos of her family.





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*Kimberly R. Kelly is one of the nation's leading search-and-rescue authorities on locating and returning wandering Alzheimer's patients. Preserving Your Memory talks to Kimberly about the challenges of retrieving wanderers, where we stand now as a nation in helping Alzheimer's patients get back home, and what the future holds for wandering Alzheimer's patients and the search for the missing.*

# Finding the Wanderers

By Sam Gaines

If you need to understand the issue of wandering Alzheimer's patients and the ongoing effort to find them, Kimberly R. Kelly is the person to talk to. Kimberly is founder and director of Project Far From Home, an educational program designed to teach law enforcement, fire, EMS, and search and rescue (SAR) teams about missing and at-risk Alzheimer's subjects. She is also the Commander of 1SRG, 1ST Special Response Group, an international, non-profit, non-governmental organization that specializes in rescuing or recovering missing persons in extreme situations or climates.

Kimberly is the author of *Project Far From Home: Understanding the Missing at Risk, Wandering Alzheimer's Subject*, and contributor to *In Search of the Alzheimer's Wanderer: A Workbook to Protect Your Loved One* and *Urban Search: Managing Missing Person Searches in the Urban Environment*.

Kimberly is a retired law enforcement reserve lieutenant, specializing in search and rescue and underwater search and recovery. She was awarded the San Diego County Sheriff's Department Distinguished Service Medal, and was recognized with the President's Volunteer Service Award by President George W. Bush for her efforts in search and rescue.

**Preserving Your Memory:**  
Wandering is a nationwide problem for Alzheimer's patients.



Kimberly R. Kelly

## How widespread a problem is it?

**Kimberly Kelly:** Currently, in the United States, there are an estimated 5.5 million persons with Alzheimer's disease. Research shows that 60 percent, or three in five persons with Alzheimer's disease, will wander away at least once during the course of their disease. Some experts put that percentage as high as 70 percent. Most individuals with Alzheimer's disease wander away multiple times, with anecdotal evidence suggesting an average of 6 to 8 times before family or caregivers recognize wandering behavior or its dangers.

A review of law enforcement and search and rescue records indicate an average of 125,000 search and rescue (SAR) operations each year for missing Alzheimer's subjects. In

most categories, SAR missions are going down, or declining, for a variety of reasons. However, SAR missions for the missing at risk, wandering Alzheimer's patient are increasing dramatically, and that is expected to continue to increase exponentially over the coming years.

**PYM: From your experience and research, what programs or initiatives, if any, are most helpful in locating and returning wandering AD patients?**

**KK:** I highly recommend the Alzheimer's Association's Safe Return program. It was been an invaluable resource to me, in the field, during a mission, when I was working as a law enforcement reserve in search and rescue. I simply called them, notified them of our case, and provided the required information. If the subject was enrolled, Safe Return was often able to provide us with information that had not been discovered during our witness interview. However, if the subject was not enrolled, Safe Return still assisted by entering the information into their system, and coordinating with their own resources.

I also am strongly encouraged by the number of states that have enacted Silver Alerts, or communities that utilize a community notification system, such as UCAN or a Reverse-911, to alert the public when

an Alzheimer's subject goes missing.

In both the Safe Return and Silver Alert systems, we are able to incorporate the public into our search, which increases the probability of early discovery, and thus, reducing mortality rates associated with long elopements.

**PYM: According to your numbers, 46 percent of wandering cases end in fatality. In your view, why is this number so high, and what can be done to improve efforts at locating wanderers?**

**KK:** Actually, the 46 percent mortality rates comes from the 1995 study by Robert Koester and David Stooksbury, in which they analyzed SAR missions in Virginia for missing or wandering subjects with dementia of the Alzheimer's type. They found that Alzheimer's subjects not found within 24 hours, if found at all, had a 46 percent mortality rate.

However, in factoring mortality rates, it is also important to consider weather, terrain, environmental issues, the individual's ability to survive, the community's response to a missing person, and more.

In Nova Scotia, for example, a place with more extreme weather conditions, an Alzheimer's subject not found within 24 hours faces a 70 percent mortality rate.

A 1994 compilation of search records for Rim of the World Search and Rescue team consisted of mission records from 1968 through 1994. In reviewing those missions, it was

discovered that no person aged 60 or over, with Alzheimer's or not, survived beyond 24 hours, if not rescued during



Kelly and her team have won numerous awards for their search-and-rescue efforts on behalf of Alzheimer's patients.

that critical window [100 percent mortality rate after 24 hours, aged 60 or over]. Again, weather and extreme terrain appears to play the biggest factor in this geographic region.

However, mortality rates remain high in urban areas, as well. Contributing factors include wandering subjects not being recognized as in distress by the community, subjects walking into traffic and being struck by vehicles, or other community-based hazards.

The single biggest factor, in my personal and professional opinion, in rescuing (versus recovering) the wandering Alzheimer's subject is early notification and mobilization of law enforcement (LE) and SAR teams who have training and an understanding of Alzheimer's disease, and its related behaviors, particularly in a field setting.

However, because LE often has other conflicting demands, and searchers are few in numbers, it is absolutely critical to notify the public. Personal experience has shown that oftentimes, my subject was "found", or encountered, by multiple members of the community who, unaware that they were speaking with, or assisting, an endangered missing person, long before they were ever found by LE or SAR.

**PYM: In your view, what can we do as a society to reduce wandering and improve the survival rate for those who do wander?**

**KK:** I think it's important to understand that not all wandering is harmful. In fact, it can be quite therapeutic, allowing for exercise, enjoyment of nature, and meaningful exposure to the world and other persons, which in itself may be helpful in reducing the depression commonly associated with Alzheimer's.

Healing gardens, walking paths, nature centers, and such can all provide those explorations in the world, and, under the right conditions, allow for the individual to maintain some independence and autonomy, and still interact with others. Many care facilities and centers are designing such facilities, so they can turn harmful wandering and pacing into a secure, safe, enjoyable place to explore.

However, it is difficult for the average homeowner or caregiver to

provide that type of escape while maintaining such vigilant security.

Further complicating the situation, many caregivers and family members simply do not understand how dangerous unsupervised wandering can be. Issues such as ignorance can be easily remedied, but many families, experiencing denial, simply won't believe that anything bad could happen to their loved one ... "That only happens when someone has a bad caregiver, and I'm not a bad caregiver!"

Many caregivers also have their own health issues, which limit their abilities. "I'm 67 with a heart condition; I can't just go chasing him down if he wants to go for a walk!" Many have said that it takes a village to raise a child. I believe that as a village, we must also support, and many times, save our at-risk elders.

When the missing at-risk person with Alzheimer's has already wandered, time is of the essence. The community must respond, just as it would for a missing child, because the risk of harm or death is simply too great to ignore.

For the community to respond, they must know, and this is why I support programs such as Silver Alert. And for community to care, they must understand. Educating the caregiver, the public, and law enforcement about



Kelly teaches law enforcement and emergency service personnel nationwide.



Kelly with Luke, her search dog.

at-risk wandering is absolutely critical. By proactive, preventative education, we may be able to reduce many of the factors that lead to wandering in the first place.

Wandering is predictable—60 percent to 70 percent will wander at least once. Many wander away multiple times. Unfortunately, the potential for serious harm, even death, is a very real risk for a wandering Alzheimer's subject. It's not enough to say, "Well, maybe it MIGHT happen someday." We must prepare as if it WILL happen. Predictable means preventable, and just by taking a few steps today, to understand and

prepare, we will be able to save the lives of untold at-risk Alzheimer's wanderers.

**PYM: Won't this problem only get bigger as the elderly population grows?**

**KK:** Absolutely. There are about 5.5 million with Alzheimer's in the U.S. right now. It's estimated that by 2050, there will be more than 16 million Americans with Alzheimer's. Researchers estimate that 60 percent will wander, but the real figure is probably closer to 70 percent. ■

*You can learn more from Kimberly about Alzheimer's, dementia and wandering in the DVD Plain Talk About*

*Alzheimer's Disease, available from Vision Video, PO Box 540, Worcester, PA 19490. You can order by phone at (800) 523-0226, or order online at [www.visionvideo.com](http://www.visionvideo.com).*





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Short Term Care	None	Heidi	Oct 8, 2007	1	on Oct 9 by Marc
new to alzheimer's	None	lynn31	Oct 7, 2007	2	on Oct 8 by Heidi
Help for Dementia Caregivers	None	Adus	Oct 5, 2007	2	on Oct 6 by Adus
my moon is driving me crazy	None	yelle	Oct 4, 2007	2	on Oct 5 by Adus
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Her Husband is a Stranger Now, What to do?	None	BalmsMarr	Oct 1, 2007	1	on Oct 2 by Tragic_He
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Any Chats?	None	Tammy9	Sep 21, 2007	2	on Sep 25 by kath
Staying in bed	None	Thornika	Sep 19, 2007	1	on Sep 22 by ahet
Alternative treatment	None	rissar	Sep 15, 2007	1	on Oct 2 by Yae
new to group	None	rissar	Sep 15, 2007	1	on Sep 25 by Marc
Dementia	None	Tammy9	Sep 14, 2007	4	on Sep 14 by Orion
What if you have to leave them alone	None	Heidi	Sep 13, 2007	1	on Sep 30 by curlesto
What if you have to leave them alone	None	Heidi	Sep 13, 2007	1	on Sep 14 by kathry

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All Users

BillyMom says:  
**How's your dad doing today?**

HomerInChicago says:  
**Much better today...I think the meds are finally starting to help**

BillyMom says:  
**How's your mom?**

BillyMom says:  
**Still has her great sense of humor!**

HomerInChicago says:  
**Will you be on same time tomorrow? I have to run...**

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**NP - see you then!**

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# How Do You Keep the Music Playing?

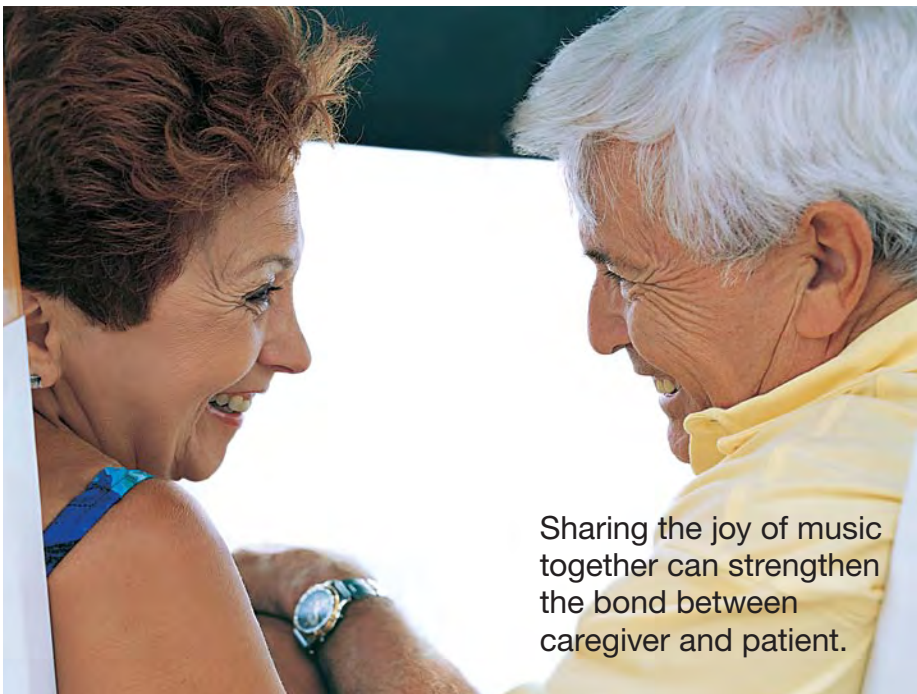
My Dates With My Wife: A Very Different Kind of Dementia Story

**F**eatured in the 1982 movie *Best Friends*, the hauntingly beautiful melody and lyrics of the song “How Do You Keep The Music Playing” has been recorded by many contemporary artists. One line in the song always get to me: “If we can be the best of lovers, yet be the best of friends.” It describes what a relationship between a husband and his wife should be, no matter what.

My wife and I are both 68. We’ve had our ups and downs, like just about every married couple. Yet, through many turbulent years, bringing up children and dealing with what life has dealt us, we have managed to keep the flag flying. It’s worked for nigh on 43 years.

Over the past few years, my wife Muriel’s memory has slipped and she lost the ability to perform common daily tasks. She couldn’t remember common information: What day is this? Your phone number? Who is the President? She couldn’t dress herself. She is diabetic, became incontinent and hadn’t been eating well. I was the only caregiver, and I followed the recommendation of keeping myself pleasant and never losing my temper. It worked, at least, most of the time. But with all the medical problems, it became increasingly unmanageable for me to give Muriel proper and safe care at home. A life change had to be made.

She is now a resident in a very fine nursing home, not far from my condo in Boca Raton, Florida. I read recently of a scientist describing a medical condition of some patients as having “pleasant dementia,” as opposed to apathy or anger. This is how Muriel is now. With proper medication, she is stable and



Sharing the joy of music together can strengthen the bond between caregiver and patient.

generally cheerful. She brightens when she sees me come in. She knows who I am and greets me with a big wide smile. She has become well-liked by the more alert patients and staff. She cannot take part in much of a conversation, but she always has a big “hello” and shows a cheery face for everyone.

Let me tell you about our dates. I get to visit Muriel just about every day, between 2 and 3:30 p.m. From my previous caregiver’s chores, these visits have blossomed into enjoyable mini-dates with my wife. On Monday, Wednesday and Friday there are concerts in the main dining room. The facility provides local entertainers who bring their keyboards or guitars, and sing well-known popular songs. Response is varied. Some of the patients just sit and stare. A few move a little and tap their foot. Surprisingly, Muriel

has retained some memory for the old songs we both loved through the years. When the entertainer sings, “Pack up all your cares away, here we go,” Muriel sings along with “Bye-bye blackbird.” I sit next to her wheelchair. She hugs me and holds my hand while keeping time to the music with her other. I’m finding more genuine affection and closeness between us now, which had been missing during the previous difficulties at home. She’s happy being with me, and I with her. We’re like a couple of dating teenagers!

On Tuesday and Thursday, the beat goes on. I bring in my portable CD player, and in the rec room, I play our favorite Sinatra and Tony Bennett tracks. Again, she recalls snatches of the songs and sings along. Saturday and Sunday, bring us to the main dining room where there is bingo. Muriel

can't really play, but I sit next to her to play and Muriel helps by pointing out the bingo numbers on the sheet. We win occasionally, and she is all smiles.

How else do you keep the music playing? I bring in family pictures and remind Muriel who everyone is. I brought in a school composition book and draw pictures of dogs, cats, boats and other

common objects, for her to identify. I write the names of our family. I read to her from books she liked and current magazines. I tell her stories. As much as possible, I keep her busy and involved.

The doctors are right. They say, medication aside, it is the constant warm and loving attention given to dementia patients that can retard worsening of

the condition. All I know is, thus far, it is working with Muriel. And you know, it's a two-way street. I am getting much more than I give. I, too, look forward to my "dates" with my wife. Free of the caregiver's home chores, our relationship has become genuinely wonderful. Like the very last line in the movie song, "The music never ends." ■

## A Rabbit to the Rescue

Written by Sharon Stasney,  
Salt Lake City, Utah

My mother keeps killing the goldfish. She sprinkles the flakes across the top of the water, wanders into the kitchen, rinses her hands in the sink, and then goes to feed the fish again. She tends to overwater the plants also. The more she waters, the more the succulents wither.

This past fall, she kept disappearing into the backyard. She'd come back with the yellow colander full of tomatoes (never mind the tomatoes already sitting on the counter from her previous trips outside). Small piles of prepubescent beans would also appear on the counter two or three times a day.

I live three states away, but hear about my mother's escapades from her caretaker, my 36-year-old brother Randon. When he calls to tell me what my mom's been up to, I remember how she used to slap dough into mounds of bread, snap peas for hours straight and pull the backbone out of a trout in a single rip. For more than twenty years, her hands were busy baking treats for school lunches, buttoning coats and smoothing bangs. Now they flutter. They wander. They often place clean clothes in the washing machine and last week they hid two lovely breaded chicken cordon bleu in the cookie jar. Perhaps mom thought the layered delicacies powdered with bread crumbs were cookies? Perhaps she forgot what the cookie jar was for?



### Getting Mom Ready

If there's one thing my mom loves to do, it's go to church. Unfortunately, her church starts at 9:00 a.m., and getting showered and dressed cannot always be crammed into a matter of hours. Randon shows up around 7:00 a.m. on Sundays to help mom get a jump on things. Last Sunday, she was already in the shower. This was good news.

"Go help mom get out of the shower, will you," Randon asked my dad. "Have her put on the blue suit, the one I put on the bed, so she doesn't have to decide what to wear." My dad nodded and plodded along the narrow hall to the back bedroom, but his hearing is less a matter of biology and more a matter of guesswork, and within a few moments, he was back in the living room, seated in his chair. Randon looked in from the kitchen where he was pulling a carton of eggs from the fridge.

"Dad? Are you helping Mom?"

"What?" Dad asked, unable to hear the question.

"Dad, are you helping mom?" Randon walked in from the kitchen so Dad could see his face.

"Oh yes," Dad nodded his head up and down obediently, "I told her today wasn't Sunday and not to worry about hurrying, just like you said."

Whatever my brother feels in these moments, he usually stuffs it into the morning's omelet and doesn't say a word.

### Bunny Blessings

Today, however, Randon called with good news. My dad had stumbled upon a brilliant solution for my mom's need to be helpful: He bought her a soft black rabbit.

Unlike the dog that used to knock her frail frame down in enthusiastic hellos, Blackie the rabbit sits quietly on my mother's lap. No matter how much water my mother puts in Blackie's bowl, he drinks just as much as he needs. And although she forgets how many trips she's already made to the pantry to fill his food bowl, Blackie doesn't have a tendency to overeat.

Now that the weather is cooling and the remaining tomatoes will need to be pulled from the vines to avoid a freeze, Blackie's arrival is a timely blessing. There's a chance, with Blackie in the house, that the goldfish might live to see the summer. ■

# Fisher Center Scientists Discover Important Brain Chemical Link

Sometimes discoveries made by scientists become part of standard medical practice. However, if a novel idea or finding appears promising for treating a disease such as Alzheimer's, a long process must take place before the discovery can benefit those who are ill. Recently, Fisher Center scientists discovered that a protein called casein kinase one (CK1) controls the production of beta-amyloid in the brain. The abnormal build up of beta-amyloid is believed to lie at the heart of Alzheimer's disease. With that in mind, scientists are very eager to find safe and effective ways of inhibiting beta-amyloid, which otherwise results in amyloid plaques, brain damage, loss of memory and other features of dementia. Could the discovery of CK1's role in the brain's amyloid factory pave the way for an effective anti-amyloid treatment? The answer is—possibly! Here's what's being done to find out.

CK1 is a member of a family of enzymes called "kinases." They work to transmit chemical signals within cells by transferring molecules of a substance called "phosphate" to other molecules within the cell. The molecules that receive phosphate in this manner are mainly proteins. Each kinase generally transfers phosphate to a select group of proteins—its target proteins. These proteins go on to do other things in cells, such as regulate the amount of beta-amyloid made or convert the "tau protein" to a toxic form that may form "tangles" such as those in Alzheimer's disease. In fact, CK1 is not the only kinase implicated in Alzheimer's or



Fisher Center researchers have discovered that the protein CK1 controls the production of beta-amyloid in the brain.

shown to affect beta-amyloid or tau. Several others also play a part.

Within the last year Fisher Center scientists showed that inhibitors of CK1 blocked beta-amyloid production in cells. One of the challenges in this research comes from the fact that most kinase inhibitors block more than one kind of kinase. This can be a problem. Chemists often hope to find compounds that only inhibit a single kinase because they can be used to design drugs with more specific effects. But the scientists at The Fisher Center, their collaborators at the University of Paris, and the Cell Cycle Laboratory at Roscoff (France) see this as an opportunity to discover drugs that work by inhibiting several different kinases at once—kinases

that are known to be important in Alzheimer's disease.

Recently, these researchers made the first step in realizing this goal. They used their skills as chemists and neuroscientists to design several new compounds that not only inhibit CK1, but also two other kinases thought to be important in Alzheimer's disease. In fact one of these (a kinase called CDK5) is known to transfer phosphates to the protein tau, which causes tau to form tangles. If all goes well, the scientists may have the beginnings of a drug that will help correct the defects in both beta-amyloid and tau that result in Alzheimer's disease. This brings us just that much closer to finding effective treatments. ■

# Living with Alzheimer's Disease

## Products That Make Life Easier, Simpler, and Safer

Every 72 seconds, someone in the United States is diagnosed with Alzheimer's disease. There are now more than 5 million Americans living with the disease. What is not widely known—even by some physicians—is that there are products available that are made especially to help make Alzheimer's patients' lives better with the disease, and, in some cases, to help them remain living at home longer and safer.

The Alzheimer's Store is dedicated to providing unique products and information for those caring for someone with Alzheimer's disease. Every product in the store has been carefully selected to make living with Alzheimer's disease as easy as possible. The store also provides a rating system for products that tells potential buyers whether a particular product is for the early, middle, or late stages of the disease. For example:



- ❖ A clock that will automatically remind an Alzheimer's sufferer of the day and date. This easy-to-read, battery-operated wall clock displays the day of the week and date, and automatically changes at midnight.



- ❖ A medication dispenser that prevents accidental double-dosing. This automatic medication dispenser beeps at the right time, provides the right meds, and is lockable so no more pills can be taken until the next dose time. This dispenser should not be used by a person with Alzheimer's without supervision, but it can be very useful for people with milder forms of memory or cognitive impairment.



- ❖ A telephone that allows the user to push the picture of the person they want to call. For those who may be a little forgetful or who have difficulty seeing the numbers, this phone is a blessing.

With over 200 products that address various activities of daily living and caregiver challenges, the Alzheimer's Store is dedicated to finding and providing products for people with Alzheimer's disease and those caring for them.

**For more information and many more helpful products,  
go to [www.alzstore.com](http://www.alzstore.com) or call (800) 752-3238.**

# Pilates and the Mind-Body Connection

**P**ilates is an exercise for all ages. No one illustrated that better than creator Joseph Pilates. He practiced and taught the exercise he developed well into his mid-80s while sporting a physique of a man half his age.

A series of movements performed on special equipment and a padded mat, Pilates is an ideal exercise for seniors because it can improve balance, flexibility and posture. In addition, Pilates goes beyond physical benefits to provide relief from mental stress.

Caring for a loved one with Alzheimer's disease is an emotional task. Often caregivers feel that circumstances are out of their control. Pilates can offer relief by promoting mind-body awareness.

## Better Physical and Mental Control

"Pilates is all about healing a body through movement," says Jamie Sharpe, a Power Pilates and Pilates Method Alliance certified instructor in Cary, N.C. "Pilates is a non-impact form of exercise that really teaches people how to be in better control of their life and health."

Proper breathing, body alignment and precise movements are the principles of Pilates. By emphasizing concentration of breathing with movement, the exercise not only builds awareness of the body but also enhances mental clarity.

"Movement heals the body both physically and mentally," says Sharpe,



Pilates exercises help with balance, flexibility and posture, as well as mental fitness.

who is also a studio coordinator for Triangle Pilates and Cary Yoga Center. "The Pilates method improves stamina, coordination, strength and mobility, and helps to rejuvenate the body."

## Humble Beginnings

Originally invented by Joseph Pilates during his work with bedridden patients, the exercise has evolved into a popular regimen practiced by dancers, athletes and celebrities. According to the Pilates Method Alliance, an inter-

national association dedicated to certified Pilates instruction, Pilates invented the exercise during World War I.

While under forced internment as a German national in England, Joseph taught fellow internment camp members the movements he had developed from years studying yoga, Zen Buddhism, and ancient Greek and Roman exercises. At this time, he began to develop the system of Pilates movements on the floor known as "mat work."

A few years later, Joseph was transferred to another internment camp, where he became a nurse and caretaker to bedridden detainees suffering from wartime disease and physical injuries. It was here that Joseph started to invent equipment for rehabilitation. He took springs from the beds and fashioned them into resistance exercise machines for bedridden patients.

In 1926, Joseph and his wife Clara emigrated from Germany to New York City, where they opened the first Pilates studio. Joseph taught the Pilates method using the experiences and equipment inspired by his work with internment camp detainees.

## Exercise Equipment

Today, the equipment that Joseph first developed for bedridden internment camp members has not changed much from its original design, although it has evolved.

Two examples of Pilates-based equipment are the reformer and the cadillac. The reformer is designed with pulleys and cables that are pushed or pulled with hands or feet. Handholds, supports and positioning bars are used to stretch the body into positions unreachable on the mat alone.

The cadillac is a raised, horizontal tabletop surrounded by a four-poster frame on which bars, springs, straps and levers are fixed. It challenges the core abdominal muscles, strengthens the back and stretches the entire body.

“I personally think the reformer and the cadillac are amazing for seniors,” says Sharpe. “Each piece of equipment offers assistance and resistance and helps reinforce the mat exercises.”

Mat-based Pilates are movements performed on the floor using gravity and one’s own body weight to provide resistance. Exercise on the mat emphasizes coordinated breathing and is used for conditioning of deep, supporting muscles of the body to improve posture, coordination and balance.

### Gentle Pilates for Seniors

A certified Pilates instructor and rehabilitation specialist based in Encinitas, Calif., Heidi Lerner, M.A., teaches Pilates to seniors ranging in age from 50s to 80s. She offers a modified course called Gentle Pilates that is especially useful for seniors.

“If taught appropriately, each will get what they can handle—not too much toning or too much stretching,” says Lerner. “Gentle Pilates helps with greater range of motion. The tone and flexibility leave my students with a spring in their step.”

Lerner teaches mat classes as well as private or semi-private sessions with equipment. “We work with exercises that strengthen the abdomen, roll and lengthen the spine, and provide circular movement of the limbs to increase flexibility in the shoulders and stability in the hips.”

### How to Get Started

To find a certified Pilates instructor, visit the Pilates Method Alliance online at [www.pmapilatescertified.com](http://www.pmapilatescertified.com) or call 866-573-4945. Lerner advises choosing an instructor who teaches an adaptable style of Pilates that is sensitive to the needs of seniors.

Pilates can be adapted to meet many individual needs, says Sharpe. “Pilates can be modified to work with the client

who has osteoporosis as well as the one with a double hip replacement.”

For loved ones with Alzheimer’s disease, Lerner recommends either private or semi-private instruction to check form and prevent injury. “Ideally, if they could take classes and just learn for home practice some fundamentals such as breathing and pelvic rolling, that would be of tremendous help.” ■



Pilates can be adapted to the needs and objectives of the individual.

# How to Find and Select an Elder Law Attorney

If you have a family member with Alzheimer's disease, there are many issues that need to be addressed. Often, legal issues take a backseat to medical issues, quality of care, caregiver issues, respite and the like. However, properly addressing legal issues in a timely matter can go a long way towards improving the quality of life of your family member with Alzheimer's disease, as well as making things easier for the caregivers.

Selecting an attorney for any purpose can be challenging. Selecting an attorney in a field as specialized as elder law can be overwhelming. After all, an elder law attorney must be knowledgeable in many areas, including Medicare, Medicaid, senior housing, tax law, estate law, trust law and health care decision-making, to name a few. While there is no shortage of attorneys, in general, it may not be so simple to find the right law firm for your needs. Here are some tips:

**1.** Make sure you select an elder law specialist. The legal field has become very specialized in recent years. The law firm you select may impact not only your legal affairs, but also those of your spouse and other family members. You

wouldn't go to a podiatrist if your head hurt, would you? The same specialization guidelines apply to selecting

from other practicing lawyers. Over the years, clients have shared with us that, other than their health and their family, protecting their nest egg for themselves and their loved ones is of paramount importance to them.

**2.** Is your lawyer a Certified Elder Law Attorney? There are currently 444 Certified Elder Law Attorneys in the United States. The National Elder Law Foundation (NELF) is the only organization accredited by the American Bar Association to certify lawyers as elder law attorneys in the United States. It is a nonprofit organization dedicated to the development and improvement of the professional competence of lawyers in the area of elder law. The certification process attempts to identify those lawyers who have the enhanced knowledge, skills, experience and proficiency to be properly identified

to the public as certified elder law attorneys (CELA). There are substantial practice and experience requirements which must be met in order to become certified, including an exam which must be passed. Moreover, CELAs must be re-certified every



Finding the right attorney for your needs can help you make the right decisions.

a lawyer. The elder law field is a very narrow niche within the entire practice of law—so much so, that many lawyers hire an elder law specialist when it comes to their own family's elder law issues. In fact, our office receives about half of its new case referrals



five years. While certification does not necessarily mean that a particular attorney will be more qualified than someone who is not, it is certainly something for you to consider in making your decision. To learn more about NELF, CELAs and the certification process, go to [www.nelf.org](http://www.nelf.org). (See the sidebar for other contact information.)

3. Ask your friends, colleagues and other professionals. Word of mouth and positive feedback are among the best ways to find an attorney, especially one who is likely to have the requisite skills. Don't be afraid to ask; someone who has gone through this process with their own relative can be very helpful to you in terms of what you should be looking for. Also, if you have used an attorney in the past who is not an elder law attorney (real estate, estate planning, litigation, or a matrimonial issue); try asking that attorney for a recommendation to an elder law attorney. Try asking other professionals, such as accountants, financial advisors, hospital discharge planners, geriatric care managers, or others in the aging community. If you hear the same name from several sources, then it is more likely that you have found someone who is well known in their field.

4. Search for the attorney and the law firm on the Internet. While you shouldn't necessarily believe everything you read on the Web, it certainly can be a source of very useful information. If you are not comfortable using the computer, ask someone to

do it for you. It is not uncommon for caregivers or other family members to assist in this process. It is important



Careful planning with a CELA (certified elder law attorney) can take the pressure off your family.

to know if the attorney has held leadership positions in bar associations at the national, state or local level. For example, most, if not all, state bar associations have an elder law section. Also, the National Academy of Elder Law Attorneys (NAELA) is a nationwide group of attorneys who practice elder law. Many states have a state chapter of NAELA. Ask your attorney if he has been active or held leadership positions in NAELA or the state bar elder law section. Attorneys who have held leadership positions in bar associations have the respect of their peers and are often leaders in their field. Has the attorney authored any articles in the elder law field that you can read? This may give you a better sense of what issues you should be thinking about. Does the attorney volunteer his time and give back to the community? Go to the law firm's website to learn more about

their practice areas and how long they have been in business. Does the attorney devote a significant amount of his professional time to elder law matters, or is it just a small component of his practice?

Selecting an attorney for a personal matter such as elder law planning is no easy task. Combine that with the fact that you will likely be dealing with many more pressing non-legal issues at the same time, and it is easy to see why this process can be overwhelming. In a perfect world, the attorney would be selected prior to a crisis and while the family is not under stress. However, that is not always possible. Follow the steps outlined above and you will increase your likelihood of

finding and selecting the right elder law attorney for you. ■

*Bernard A. Krooks, J.D., CPA, LL.M (in taxation), CELA is immediate past president and founding member of the N.Y. chapter of the National Academy of Elder Law Attorneys and a nationally known and widely quoted expert on elder law. For more information, visit the firm's website at [www.littmankrooks.com](http://www.littmankrooks.com).*

### Contacting NELF

NELF staff offices are located at 6336 N. Oracle Rd., Ste. 326, #136, Tucson, AZ 85704, and are open from 8:00 a.m. to 4:30 p.m. MST Monday through Friday, except holidays. The telephone number is (520) 881-1076. The fax number is (520) 881-1076. Voice mail is active 24/7, so leave a message if calling after hours.

# Brain-Boosting Puzzles

“Use it or lose it.” The message is simple. If you don’t use your muscles, they will no longer be as effective as they should be. Of course, the brain is not a muscle; however, it has recently come to light that “mental workouts,” such as solving crosswords and other puzzles, can help ward off Alzheimer’s. In these pages, we offer a variety of different types of puzzles that will work out your various skills involving memory, deduction, and letter manipulation, and, we hope, also provide you with a ton of fun!

(Answers on page 37)

## MATCH THESE

Can you match each famous mountain to its location?

- |                          |                |
|--------------------------|----------------|
| 1. _____ Mt. Kilimanjaro | a. Indonesia   |
| 2. _____ Mt. McKinley    | b. Alaska      |
| 3. _____ Mt. Ararat      | c. Colorado    |
| 4. _____ Mont Blanc      | d. Tanzania    |
| 5. _____ Mauna Kea       | e. Turkey      |
| 6. _____ Mt. Everest     | f. Japan       |
| 7. _____ Krakatoa        | g. Switzerland |
| 8. _____ Mt. Whitney     | h. France      |
| 9. _____ Mt. Vesuvius    | i. Nepal/Tibet |
| 10. _____ The Matterhorn | j. Italy       |
| 11. _____ Pikes Peak     | k. Hawaii      |
| 12. _____ Mt. Fuji       | l. California  |

## DROPLINE

Take the letters in the top half of each column below and distribute them in the blanks of the bottom half so that the letters read from left to right spell out a short witticism. The black squares are the spaces between words. One letter has been dropped in place to start you off.

A	H	A	O	D	I	O	E	A	A	A	E	B	U	E
I	K	E	R	M	N	S	M	B	K	E	L	E		L
	P	R		S	O	T	O	S	K	E	R	P		T
	S	Y		T		W			L	S				
	P													

## LEAPFROG

Here’s a list of common two-word phrases that comically seem to contradict themselves. The letters of the two words are in the correct order, but they overlap. All you have to do to find the terms is separate the letters.

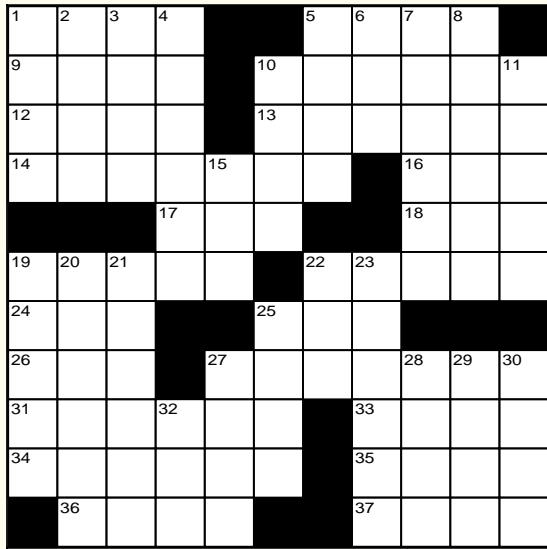
Example: DISFAFERMENECE — SAME DIFFERENCE

- |                    |       |
|--------------------|-------|
| 1. CWIVAIRL        | _____ |
| 2. OHFOFMICEE      | _____ |
| 3. GOGROIEDF       | _____ |
| 4. SOEPCREENT      | _____ |
| 5. SJHRUMIMBOP     | _____ |
| 6. DEMFAINYIBTEE   | _____ |
| 7. SOSWREROEWT     | _____ |
| 8. CCOLNFEUASRELYD | _____ |
| 9. VAWOCRATKINIONG | _____ |

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# BRAIN-BOOSTING CROSSWORDS

We have provided two crosswords here to sharpen your puzzle skills. Start with the one on the left, which is the easier puzzle. In this one we have provided solving aids, such as the number of words in multi-word clues. The puzzle on the right is a medium-level puzzle and the number of words in the answers have been eliminated. The second puzzle is also a thematic puzzle: the title "Mark It on Your Calendar" is a hint. Have fun testing your knowledge while doing something that's good for you!



## Across

1. Parsley or rosemary
5. Attention-getting sound
9. "Roll \_\_\_\_ Beethoven"
10. Mind's-eye representations
12. Dad
13. Spanish woman's title
14. Frosty, e.g.
16. Ailing
17. The present
18. Drunkard
19. Asian metropolis
22. Dillon et al.
24. Onassis, for short
25. Surmount
26. Storage container

27. She might argue the affirmative side
31. Stayed overnight
33. Sheep pen
34. Goodman and Burstyn
35. Rhino's feature
36. Slippery critters
37. Gen. Robert \_\_\_\_ (2 wds.)
10. "I came, \_\_\_\_, I conquered" (2 wds.)
11. Smelling \_\_\_\_
15. Bossy's sound
19. Bistro's four-top, e.g.
20. Camden Yards athlete
21. Ignite
22. Throng
23. Geronimo, for one

## Down

1. Jumps
2. Writer Hunter
3. "\_\_\_\_ Man" (1984 film)
4. Beefy
5. Prayer response
6. Solo of "Star Wars"
7. Conceited one
8. Dark-blue grape
25. Knight and Mack
27. Cub Scout divisions
28. Wrench, e.g.
29. To be (Fr.)
30. "Get Shorty"
32. Toothpaste type

(Answers on page 37)

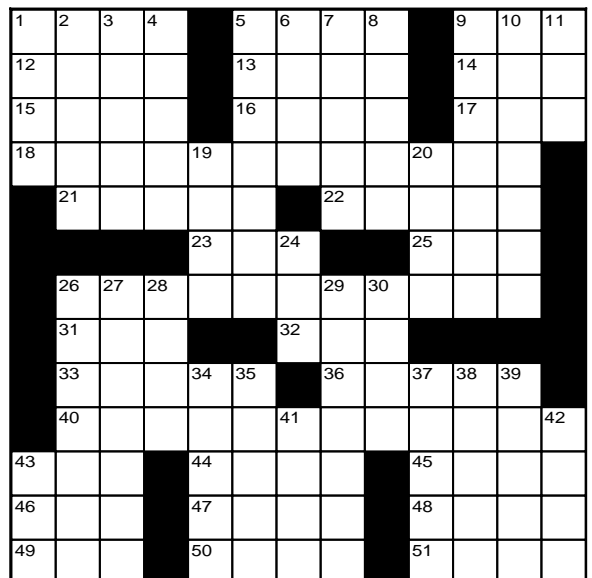
## Mark It on Your Calendar

### Across

1. Gin and tonic garnish
5. Locale of Italy's "Field of Miracles"
9. Federal intelligence org.
12. "Clueless" retort
13. "Odsbodkins!"
14. Dolt
15. Early talk-show host Jack
16. NFL quarterback Tony
17. Blasting substance (abbr.)
18. Hearty bakery treat
21. "The Myth of Sisyphus" author Albert
22. Dual conjunction
23. Blueprint
25. "\_\_\_\_ Sentimental Mood"
26. Evenings with another couple
31. Hospital workers (abbr.)
32. Army privates, usually
33. Enjoyed, slangily
36. Office furniture
40. Testing the age of fossils
43. "Ben-\_\_\_\_" (Wallace)
44. Spoken brothers' surname
46. 2001 Michael Mann film
47. High-water mark
48. Cuts the lawn
49. Government watchdog dept.
50. "The Night \_\_\_\_ Invented Champagne"
51. Attention-getting sound
7. Latin dance
8. Beautiful
9. Nary any
10. Justice O'Connor et al.
11. Evening preceder (abbr.)
19. Ready for drilling
20. Emulate Max Perkins
24. Al Bundy's spouse
26. Horror classic of 1931
27. View from Niagara Falls
28. Internet fan
29. Bo of rock and roll
30. Hopelessly confused
34. Axis sub
35. Paperboy's target
37. Post office purchase
38. Weight units
39. Comes down in flakes
41. Appoint
42. Wind blast
43. Harridan

### Down

1. "Adam 12" org.
2. Abraham's intended sacrifice
3. Sporty Mazda model
4. Actor Zimbalist
5. Scrutiny
6. "Giving You the Best That \_\_\_\_"



# BRAIN-BOOSTING PUZZLES

## HIDDEN-MESSAGE WORD-FIND™

All the words in the list, which are dog breeds, can be found in the letter grid reading across, up and down, and diagonally. When you have found them all, read the leftover letters to discover an apt quote from Josh Billings.

You are looking for a 60-letter phrase.

AIREDALE	FOX TERRIER	A	D	O	G	I	S	T	B	H	E	O	N	L	R
BASENJI	GREAT DANE	Y	T	E	I	L	L	O	C	E	H	I	N	G	E
BEAGLE	GREYHOUND	L	H	A	S	A	A	P	S	O	A	D	O	N	I
BICHON FRISE	LHASA APSO	E	A	R	T	D	D	U	H	T	A	G	H	A	R
BLOODHOUND	POODLE	E	S	I	R	F	N	O	H	C	I	B	L	R	R
BULLDOG	ROTTWEILER	N	H	G	T	G	U	U	H	A	E	L	O	E	E
CHIHUAHUA	SHAR-PEI	A	A	R	O	V	O	S	O	L	U	T	E	L	T
COLLIE	ST. BERNARD	D	R	O	S	Y	H	D	D	H	T	H	A	O	X
CORGI	VIZSLA	T	P	C	U	U	D	O	L	W	Y	D	I	M	O
DACHSHUND		A	E	O	N	R	O	E	E	L	E	E	T	H	F
		E	I	D	H	P	O	I	A	R	U	N	R	Y	C
		R	V	I	Z	S	L	A	I	O	U	B	L	G	O
		G	V	E	Y	E	B	A	S	E	N	J	I	O	U
		R	S	D	R	A	N	R	E	B	T	S	E	L	F

## SUDOKU

To complete the puzzle below, fill in the squares so that each digit 1 through 9 will appear exactly once in each row, in each column, and in each enclosed nine-unit block.

		6		1				4
	8				6	7		
9	1				4			8
	6		9				5	
		5		3		6		
	9				5		1	
2			6				7	3
		8	7				2	
5				9		4		

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# PUZZLE ANSWERS

## Match These

1d, 2b, 3e, 4h, 5k, 6i, 7a, 8l, 9j, 10g, 11c, 12f.

## Droplines

Promises are like snowballs; easy to make, but hard to keep.

## Leapfrog

1. Civil war; 2. Home office; 3. Good grief; 4. Open secret; 5. Jumbo shrimp; 6. Definite maybe; 7. Sweet sorrow; 8. Clearly confused; 9. Working vacation.

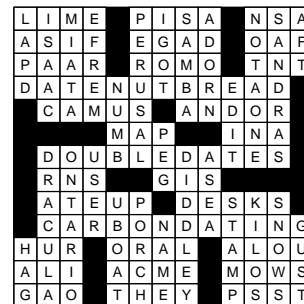
## Hidden Message

A dog is the only thing on earth that loves you more than you love yourself.

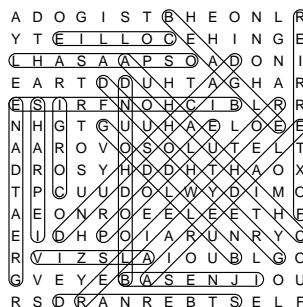
## Crossword 1



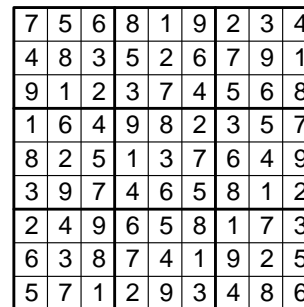
## Crossword 2



## Word-Find™



## Sudoku



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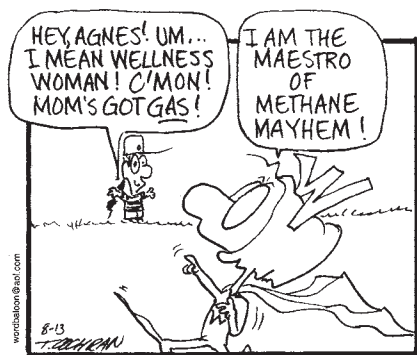
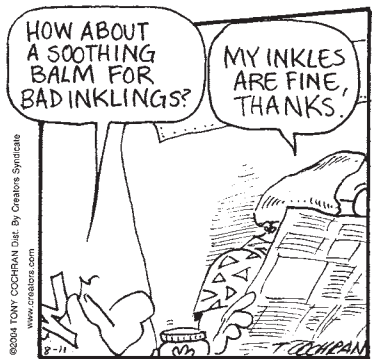
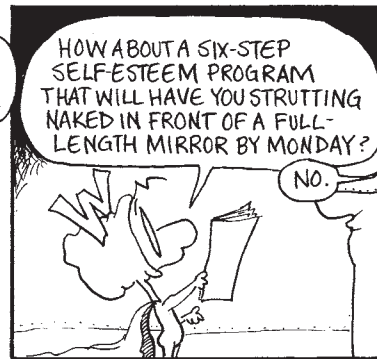
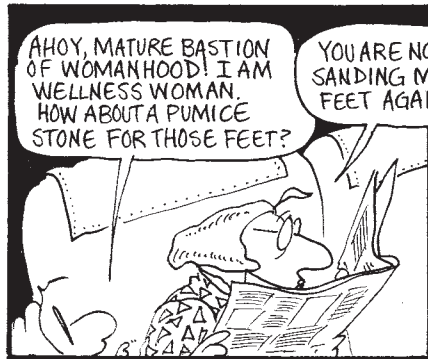
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# Agnes

We are happy to continue to share with you the indomitable Agnes — also sometimes known as “Wellness Woman” — the delightful cartoon creation of artist Tony Cochran. Win, lose, or draw, Agnes faces life’s challenges with spirit, humor, and a never-give-up attitude.





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***Of every dollar raised, 94 cents goes directly to research programs.***

***For more information, visit our website at [www.ALZinfo.org](http://www.ALZinfo.org) or call 1-800-ALZ-INFO.***

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