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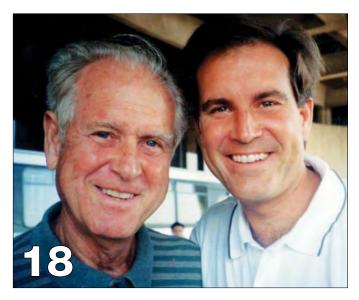








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Fall Forward

es, we usually think "fall back" if we live in an area that observes daylight-saving time. But with this issue of *Preserving Your Memory*, we are taking a hopeful look ahead to better treatments and, we hope, a cure for Alzheimer's disease.

Our cover feature is an in-depth talk with sports commentator Jim Nantz, who lost his father to Alzheimer's but has focused his energy on raising awareness of the disease (page 18). Nantz is a familiar voice to many of us, and his advocacy on behalf of the cause is inspiring.



Betsey Odell

Writer Greg O'Brien has been featured all over the media thanks to his new memoir,

On Pluto: Inside the Mind of Alzheimer's. We talked with Greg about being a caregiver himself to his mother, and his own battle with Alzheimer's—and we talked to his family about it, too (page 12).

There's a new movie, *Glen Campbell: I'll Be Me*, an intimate portrait of the man and musician during his farewell tour of the U.S. and beyond. We spoke with director James Keach about the making of this important and unique film (page 28).

What exactly is a clinical trial? Who enrolls in one? How is it conducted? We take a closer look at these critical research studies (page 24) and the important role they serve in learning about Alzheimer's and pointing the way to better treatments.

We hope you find this issue of *Preserving Your Memory* to be a stimulating way to welcome the cooler months.

Betsey Odell

Editor in Chief

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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 one of the world's largest research teams 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. Oprah's O Magazine listed us as the top charity to give to for Alzheimer's. The Fisher Center Foundation has earned Charity Navigator's highest 4-Star rating for fiscal management and commitment to accountability and transparency. For more information or to make a donation, go to www.ALZinfo.org.

The Latest News on Alzheimer's Disease and Brain Health

New Therapeutic Target Identified

South Korean researchers have identified a new potential target for Alzheimer's disease therapy, according to a study published in the *Journal of Experimental Medicine*. The target, an enzyme called acid sphingomyelinase (ASM), breaks down cell membrane lipids in the myelin sheath that coats nerve endings.

Researchers linked ASM to the process cells use to clean themselves, called autophagy. In people with Alzheimer's, the autophagy process is disrupted, which causes beta-amyloid to accumulate. Beta-amyloid is linked to the formation of plaques in the brains of people with Alzheimer's.

In experiments with mice that had a condition similar to Alzheimer's disease, scientists found that higher levels of ASM caused the autophagy process to clog up, which in turn caused cellular waste to accumulate. On the other hand, mice with lower levels of ASM had a cleaner autophagy process, and better memory and cognitive ability.

ASM has been known to be present at higher levels in people with Alzheimer's, although whether it's a cause of Alzheimer's disease has not been established.

Researchers are hopeful that breaking up this accumulation of beta-amyloid may help preserve memory in people with Alzheimer's.



One study found that an eye test detected the presence of Alzheimer's disease with 100 percent sensitivity.

UCLA Researchers Reverse Memory Loss with Metabolic Program

In a small trial of 10 patients—some with scan-confirmed patterns of Alzheimer's disease—UCLA researchers report that they were able to reverse memory loss using a novel therapeutic program that included a restricted diet and exercise, according to a study published in the Sept. 27 edition of *Aging*.

In the study's protocol, the 10 patients avoided eating simple carbs, gluten, or processed foods. They are more fish and took vitamin B-12, vitamin

D-3, and fish oil supplements. They participated in yoga and meditation, took melatonin, and got adequate sleep.

Nine of the 10 patients reported improvement in cognitive abilities within 3 to 6 months, according to researchers. Six of the patients, who had to stop working because of memory impairment, were able to return to their jobs.

Researchers report that the memory improvements remained for some of the patients for the 2½-year period following the study. Plans are now being made for larger studies to further explore these promising results.

Eye, Smell Tests to Detect Alzheimer's?

Newly presented research points to the possibility of using simple smell and eye tests to identify developing Alzheimer's disease before other symptoms become apparent. The four studies indicate that the tests, which are much more affordable than the more elaborate PET scans typically used to identify the presence of beta-amyloid proteins in the brain—a telltale sign of Alzheimer's development—could be used far more widely, particularly in regions where PET scan equipment might not be available.

The eye test scans the retina for the presence of beta-amyloid. One study found that the eye test detected the presence of Alzheimer's disease with 100 percent sensitivity in 40 patients.

The smell test works on the notion that as Alzheimer's destroys neurons, the sense of smell is impacted at an early stage. "Our research suggests that there may be a role for smell identification testing in clinically normal, older individuals who are at risk for Alzheimer's disease," said Matthew E. Growdon, leader of one of the studies.

Transplanted Brain Cells in Mice Helps Reverse Memory Loss

Researchers at the Gladstone Institutes found that transplanting new brain cells into mice with a condition similar to Alzheimer's disease can help reverse the characteristic loss of memory, according to a study published in the *Journal of Neuroscience*.

The technique proved effective in treating the condition in mice that had been bred to have the human apoE4 gene, which has been closely linked with the development of Alzheimer's. That gene is present in 25 percent of the population at large, and it is involved in 60 percent to 75 percent of all Alzheimer's cases.



A recent study found that transplanting new brain cells into mice afflicted with a condition similar to Alzheimer's disease can help reverse memory loss.

In the study, mice had either apoE4 or apoE4 with beta-amyloid present. In both cases, researchers were able to replace the neurons lost to apoE4 with the new brain cells called inhibitory neuron progenitors, and in the process were able to improve learning and memory abilities.

"This is the first time transplantation of inhibitory neuron progenitors has been used in aged Alzheimer's disease models," first author Leslie Tong, a graduate student at the Gladstone Institutes and UCSF, said in a press release. "Working with older animals can be challenging from a technical standpoint, and it was amazing to see that the cells not only survived but affected activity and behavior."

Link Found Between Long-Term Use of Anxiety/Sleep Meds, Alzheimer's

A study based on an evaluation of the health insurance program database in

Quebec found that the long-term use of benzodiazepines—a class of medicine used to counter anxiety and to enhance sleep—may be linked to Alzheimer's disease. The study was published in the *British Medical Journal*.

Benzodiazepines are psychoactive drugs frequently prescribed to help people who have problems with anxiety and getting to sleep, and those who are experiencing seizures or withdrawing from alcohol, among other uses.

The analysis revealed that those who had taken benzodiazepines for 3 months or more were up to 51 percent more likely to develop Alzheimer's disease. It also found that longer exposure to the medication increased risk, and the use of long-acting (as opposed to short-acting) medications also further increased risk.

Check the Fisher Center website (www.ALZinfo.org) often for up-to-date and expert-reviewed scientific news.

Petri Dish Breakthrough May Hasten Search for Treatments and a Cure

A team of Boston scientists have discovered a way to grow human brain cells in a petri dish, which will open the door for much faster testing of Alzheimer's drug candidates.

hey're calling it "Alzheimer's in a dish." Lead researcher Dr. Rudolph Tanzi of Massachusetts General Hospital in Boston and member of the Fisher Center for Alzheimer's Research Scientific Advisory Board, on a suggestion from colleague Doo Yeon Kim, and his team have pioneered the growth of human neurons (brain cells) in a petri dish, where Alzheimer's disease treatments can be studied much more quickly than ever before. That's because the human neurons actually develop the telltale plaques and tangles that characterize Alzheimer's when genes that code for Alzheimer's disease are introduced, and they do so in a matter of weeks.

The research was published in the October 12, 2014 issue of *Nature*.

Using this new technique of growing brain cells in a petri dish, researchers will now be able to study treatments much more quickly than they could before, when only mouse brain models were available. "A lot of times when we are coming up with hypotheses for studying this disease, the verification of these hypotheses involves mouse work that can take a year, a year and a half, which is how long it takes the mouse model to develop the disease," says Dr. Jean-Pierre Roussarie, a Senior Research Associate in the laboratory of Dr. Paul Greengard at the Fisher Center for Alzheimer's Research at The Rockefeller University in New York. "This brain cell culture will reduce the delay of waiting for that to happen, so we can study much more in a much shorter period of time."

Dr. Tanzi and his team used human embryonic stem cells and needed chemicals to create neurons in the gel. The team then introduced genes that are linked to the development of Alzheimer's disease, and they witnessed the development of beta amyloid plaques among the neurons. While the neurons do not perfectly mimic their in-brain counterparts in human brain tissue, they do provide a much more accurate model for testing than the mice models used previously. In fact, efforts to reproduce Alzheimer's in mouse brain tissue would yield plaques, but never the accompanying tangles known to occur in human brains with Alzheimer's disease.

"There are technological aspects and advances that this paper introduces, but the paper also presents scientific data per se that confirms the beta amyloid hypothesis. This hypothesis states that the pathology starts with the appearance of the plaques, that then trigger the formation of neurofibrillary tangles (Tau aggregates)," says Dr. Roussarie. "Dr. Tanzi shows that the generation of amyloid plaque is preceding the generation of Tau tangles, and is necessary for it, beautifully demonstrating the amyloid hypothesis. There was data supporting this hypothesis already, but never as convincing as this, in such a simple, controlled model."

The importance of this research is difficult to overstate, according to Dr. Sam Gandy of the Icahn School of Medicine at Mount Sinai in New York. Dr. Gandy completed his post-graduate work under Dr. Greengard at the Fisher Center. He told the *New York Times* that the research is "a real game changer" and "a paradigm shifter."

Nobel Laureate Dr. Paul Greengard, Director of the Fisher Center for Alzheimer's Research, is also very excited about the research and its implications for the future of Alzheimer's research. "I want to extend my warmest congratulations to long-term friend and colleague Dr. Rudy



Tanzi on his publication in *Nature*. He managed to grow neuronal cells in an in vitro system where they recapitulate the two main features seen in patients with Alzheimer's disease: amyloid plaques and neurofibrillary tangles, the two different kinds of protein aggregates that devastate the brain," Dr. Greengard says. "This new fantastic tool will help Alzheimer's research tremendously: It will be an amazing platform for screening new drugs much faster than what was possible before in order to find promising candidates. But it will also help testing hypotheses about the mechanism of the disease much more easily, in order to better understand Alzheimer's. I cannot wait to use this model in future collaborative projects with Dr. Tanzi."

Kent Karosen, President of the Fisher Center for Alzheimer's Research Foundation, heralded the results of the study as a major breakthrough in the search for better treatments and a cure for Alzheimer's disease. "This vital development means that the beta amyloid hypothesis, which has been the focal point of our efforts in the Fisher Center laboratory, is the correct approach in Alzheimer's research, as it clearly marks the connection between plaques and tangles," he says. "This level of scientific innovation is why funding for Alzheimer's research is critical. Our next step is to focus on creating and testing drugs in this new system to help Alzheimer's patients."

"A lot of times when we are coming up with hypotheses for studying this disease, the verification of these hypotheses involves mouse work that can take a year, a year and a half, which is how long it takes the mouse model to develop the disease. This brain cell culture will reduce the delay of waiting for that to happen, so we can study much more in a much shorter period of time."

—Dr. Jean-Pierre Roussarie, a Senior Research Associate in the laboratory of Dr. Paul Greengard at the Fisher Center for Alzheimer's Research at The Rockefeller University in New York

Therapy Dogs:

Making a Connection with Alzheimer's Patients

Therapy dogs serve in all sorts of health care environments to bring comfort and a friendly (and furry) face to patients living with a broad variety of conditions—including Alzheimer's disease.

"We went once to a rest home, to the

Alzheimer's unit, and a lady held out her hands to Eva and put her in her lap. We found out later from a nurse that she had not spoken to anyone in five years, but she spoke to Eva," recalls Juli Hauser, therapy dog parent to four dogs—two now deceased (Eva and Foxie)—and resident of Burlington, N.C. "I visited another Alzheimer's patient for three years with Foxie, Eva, and Polly. She never responded at all—didn't even look at us. Her daughter told me that she didn't recognize her any more. The first time I took Luc to see her, she raised her head, looked at him, and said, 'That's a dog.' The next visit she talked to him a while although I couldn't understand her words. It's amazing what dogs can do that we can't."

What Hauser is describing is the impact therapy dogs can have with even late-stage Alzheimer's patients who are having difficulty remembering or communicating with loved ones. Hauser, whose dogs are registered with the national organization Therapy Dogs International (TDI), still regularly visits Alzheimer's and hospice patients with Polly and Luc.

But what exactly is a therapy dog? Simply, it's a dog that, along with his or her parent(s), has successfully completed extensive training and received all relevant vaccinations and testing to be certified as capable of rendering therapeutic benefits to patients of hospitals, elder-care facilities, or other health care settings.

Diane Greytak, a therapy dog parent in Arlington, Texas, routinely takes her dogs Huey (6 years old) and Elwood (5 years old), both Labrador retrievers and both registered with TDI, to visit Alzheimer's patients near her home. She says the training and preparation for a therapy dog and its human companion is rigorous, indeed. "The testing

required by TDI is a good place to start. A therapy dog needs to have a sound temperament and be able to deal with and accept different situations presented at a facility," she says. "They are constantly accommodating and learning but the handler is always exposing the dogs to new and different situations. Then when something unexpected might occur, the dog is able to respond appropriately. They must have good behavior around people and the use of service equipment (wheelchairs, walkers, etc.) and respond to basic commands given by the handler."

There's one further requirement, as well. "And they must love their job!" Greytak adds.

Therapy Dogs and Alzheimer's Patients

For Greytak, getting Huey and Elwood used to being around Alzheimer's patients was a matter of time and patience. "I started out slowly, letting my dogs become familiar with the sights, sounds, and smells of the facility," she says. "I have built on the TDI requirements for certification as a therapy dog, continuing to expose them to new situations so they will feel comfortable and confident when encountering something different. My job is to make sure that my dogs are responding appropriately and enjoy what they are doing."

Hauser points out that it's a give-and-take process. "They have to enjoy being petted and handled by a variety of people. They have to be able to tolerate the loud noises and movements of patients. Parents have to commit to a regular schedule at the facilities they visit," she says. "You have to realize it's a working situation, so discipline is a must. You have to keep the dogs' health up to date—they need more vaccinations and fecal checks than typical dogs do. You







also have to keep them carefully groomed and clean. And you have to keep up their training. Dogs can get a little lax if they don't get regular training. It's hard to visit at Hospice because patients die, but it's also so rewarding."

When interacting with Alzheimer's patients, Greytak says, the dogs take their cues from the patients themselves. "Some patients interact with the dogs by having physical contact with or petting them. Others respond by watching what the dogs are doing with the other people in the room. Many will sit and talk about the dogs they had when they were younger. The patients enjoy watching the dogs respond to commands. Some just like to have the dog sit at their feet."

Hauser agrees. "You learn to read their body language. If they put their hand out towards Polly, they want to interact with her. If their head is down and they don't look at her, you don't go to that patient. Sometimes they want to talk about a dog they had when they were younger. Sometimes the interaction is completely nonverbal."

Both Greytak and Hauser see the clear benefits to patients that being a therapy dog parent can bring. "Good therapy dog parents must also love what they are doing because we understand the benefits of what our dogs can do for people," says Greytak. "All in all you have good-hearted people with good-hearted dogs, all reaching out to make a difference."

A Report from the Interior

Poignant new book offers an honest firsthand perspective of Alzheimer's disease

reg O'Brien knows what memory loss looks like, having cared for his mother during her bout with Alzheimer's disease prior to her death in 2008. But, unlike most caregivers, he also knows what memory loss feels like, having received his own diagnosis of early-onset Alzheimer's disease in 2009 at the age of 59.

Rather than hide behind his illness, Greg decided to face it head-on in the only way he knew how: by chronicling it. Using his decades of experience

as a writer and journalist, he began to take notes detailing his ongoing journey through cognitive decline. The result is a newly released book titled *On Pluto: Inside the Mind of Alzheimer's*, which Greg describes as a document written by an investigative reporter embedded inside his own brain—a brain capable of taking him "out to Pluto, where no one can see you or hear what is said." (A glimpse into Greg's life and the impact Alzheimer's disease is having on his family is also captured in a touching short documentary by award-winning filmmaker Steve James called *A Place Called Pluto*.)

Doctors have told Greg that a head injury from a serious 2004 bicycle accident likely "unmasked" symptoms of dementia that might otherwise have remained hidden for longer. Tests have also confirmed that he carries the marker gene for Alzheimer's disease, which afflicted his maternal grandfather as well as his mother. Now, with worsening short-term memory issues, occasional trouble recognizing long-time friends, and bothersome hallucinations, Greg has good days and bad days. His goal is to share as many of his insights as possible before his ability to do so is irreparably altered.



Greg O'Brien

Candid, illuminating, and occasionally even light-hearted, *On Pluto* provides a firsthand perspective of cognitive impairment and its rippling effects. While it tells Greg O'Brien's personal tale, it will resonate with anyone dealing with or suffering from any form of dementia.

We spoke with Greg; his wife, Mary Catherine; and the eldest of their three adult children, Brendan, about the book and the story it so frankly tells.

The inside perspective.

Preserving Your Memory: What was your primary goal in documenting your experience through On Pluto?

Greg O'Brien: I felt the overriding need to write a book about living with Alzheimer's, not dying with it, and doing so with faith and humor and hope. I want to dispel the myth that Alzheimer's is only about the end stage by helping people understand the early and mid stages. Because this thing is often a 20-year roller coaster ride that has its ups and downs.

PYM: What do you want caregivers to know about what it's like to experience Alzheimer's that they can only learn from someone who has the disease?

GO: Caregivers are the unsung heroes in this war on Alzheimer's. They deal with a tremendous assault that those

with Alzheimer's are not aware of when they get to the end stages because the memory of a caregiver never wanes. Even though you sometimes feel totally alone with this disease, you want to know instinctively that there's someone there

next to you who has your back. It's not going to make you well, but there's comfort in knowing that someone loves you because there are times in Alzheimer's when you don't love yourself. Caregivers do an extraordinary job. Without caregivers in this fight against Alzheimer's, we would all lose.

PYM: You write about serving as a caregiver to your parents, including during your mother's cognitive decline. Would you have cared for her differently knowing what you know now as an Alzheimer's patient yourself?

GO: I know it's difficult to understand, but for me Alzheimer's is a blessing. I saw what my mother (and her father before her) went through. They taught me how to live with Alzheimer's; how to fight; how never to give in.

PYM: Does your book tell a universal story of memory loss, or just your individual story?

GO: It applies to all forms. Yes, there are different labels for slightly different forms of dementia, but it all gets back to a loss of self. When you lose your memory, you lose yourself.

PYM: You have been able to retain your ability to communicate even as your disease progresses. As a writer, you must be very grateful for that.

GO: My cognitive decline is on a similar track as my mother's. I believe if you've been blessed with a good brain

and a good IQ, some of my doctors have called that a "cognitive reserve" that allows me to fight hard to preserve some things ... for a while, anyway. I have less capacity than I used to, so I have to pick and choose. If I wake

up some day and I can't write or can't communicate, that idea really scares me. So I am desperately holding onto that for as long as I can.

PYM: Do you think there will ever be a time when people with cognitive impairment won't feel they have to hide their symptoms from the public?

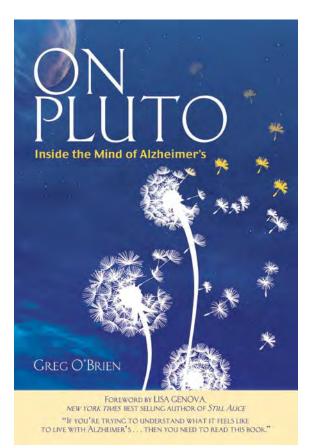
GO: I'm hoping that we find a way to make Alzheimer's "popular," even though that's a strange word to use in this context. If we start to talk about it and start to understand the early and mid stages, people will start realizing that this is affecting many more millions of people than we thought.

PYM: Is it correct that you have also been diagnosed with cancer?

GO: Yes, I have prostate cancer and I monitor it, but I'm choosing not to treat it. My family is a bit upset about that, but they understand. We're a ways from finding a cure for Alzheimer's and you can't just remove a brain like you can with a cancerous organ. I don't want to go to a nursing home, so if I need an exit strategy, that's it.

PYM: What else do you want people to know about your story?

GO: I don't want to proselytize, but one of the most important things to me as I travel down this road is having faith. I have had the "what's the deal" talk with God and what I heard back is, "Pal, I've been trying to get your attention all your life. Maybe now we can start to do some things together."



Greg's book, On Pluto: Inside the Mind of Alzheimer's

The family perspective.

PYM: How is it for you to have your family's personal experience with Alzheimer's disease portrayed so publicly through this book?

Mary Catherine O'Brien: It's hard, mostly because I'm not a very public person so I hadn't really talked about it with very many people before this. However, the book makes this discussion a bit more comfortable. Having it finally acknowledged and not having to avoid talking about it has been helpful.

Brendan O'Brien: Yes, it's been tough. In our family, we're used to keeping our emotions inside so it's a little different to be so out in the open with everything. At the same time, all of us—my parents; my sister, Colleen; and my brother, Conor—see the long-term benefit of telling our story to get the word out as much as possible. So for us, it's a bit of a blessing.

PYM: Do you think On Pluto will help destigmatize memory loss?

MCO: For whatever reason, people are embarrassed to talk about anything having to do with the mind, whether it's depression or memory loss. I do think that's changing ... slowly. I think Greg's book will contribute to that change in attitude.

BO: Part of the stigma of Alzheimer's is that it's embarrassing to admit that you're losing your mind and some of your faculties. But it makes things a lot easier when your friends and family know what's going on because they can begin to accept it and learn how to approach it.

PYM: What advice would you give other family members who are caring for individuals in various stages of Alzheimer's disease?

MCO: The financial concerns are a big part of it. For me, it was making sure that my kids are going to be protected. We did meet with an elder attorney, which was helpful and I think is important. You need to make sure that whatever happens down the road everyone's going to get taken care of. And I need to keep working, so that's a big issue. I'm not yet retired, and we don't have the finances that allow us to have me stay home and take care of him, so that's a big question in my mind. Because we just don't know the timing of what's to come.

BO: One of the best things you can do is embrace the reality rather than push back. When I see my dad get confused, rather than try to correct him, it's better just to go with it (unless it involves a safety issue). If he thinks the sky's purple on a particular day, I don't care; the sky can be purple. If he mixes up my brother's name with mine, there's no advantage in correcting him because it will just put him in a deeper hole or embarrass him.

PYM: Are you conflicted about Greg's choice not to treat his prostate cancer?

MCO: No, I totally agree with him. We watched his mother go through what she went through in the final stage of her Alzheimer's, and he doesn't want his kids to see him like that, or anybody to see him like that, so I understand his choice.

PYM: Are there any silver linings related to what your family is going through?

MCO: One of the positive things, even though it's been very emotional, is that it's really brought us all together. We've always been a close family, but this has made a big difference. The kids have gotten involved, both with our family's situation as well as with Alzheimer's advocacy.

PYM: How do you feel about Greg being diagnosed so early?

BO: An early diagnosis is an advantage for everyone involved. I can't even explain how happy I am that we found out about this when we did. Too many people find out at the very end and they look back and think of all the things they could have done with their loved ones before things got too far along. Also, when you know early on what's going on, it helps explain the confusion that can be so frustrating if you don't know that there's something going on in the brain.

MCO: When you get diagnosed later, you're more focused on the end. We're not there yet, so we're less focused on what's to come. It's more of a day-to-day thing for us right now. We don't spend a lot of time agonizing over what's going to happen, because you don't know what's ahead. We're just enjoying the time we have together now.

Writer Mary Adam Thomas is a frequent contributor to Preserving Your Memory.



The O'Brien family

"All too often, those with the disease have become voiceless, locked in their own insecurities and symptoms, and misunderstood by those who just don't want to go there. Like every man and woman, these time travelers in disease need guidance, acceptance, trust, and love. So, go there with them at times to Pluto, try to fathom their journey. It's not such a bad place. We can all get to Pluto; it's just that some of us are not coming back."

-Greg O'Brien

On Pluto: Inside the Mind of Alzheimer's

A Helping Hand

When is it time for professional in-home care?

eople with Alzheimer's disease go through a lot of changes—something that you, as a caregiver, know all too well. Sometimes those changes are overwhelming. How do you know when it's time to seek the help of a professional caregiver?

Karen Carnes, BSN, RN, MSN, Chief Clinical Officer, Interim HealthCare, offers some insight and advice on making this difficult decision.

Preserving Your Memory: What are some of the reasons why caregivers seek professional inhome care for people with Alzheimer's disease?

Karen Carnes: Caregivers have a difficult time understanding and coping with the changes they're

experiencing with their loved one who has a diagnosis of Alzheimer's. They know something is different. They have the intellectual explanation of what's going on, but now they're actually beginning to live with the changes in their loved one and they don't always know how to handle it.

It could be that changes are just beginning or that the changes are not so pronounced that the individual needs to be in a medical facility. Often these individuals are perfectly capable of being at home, but the caregiver doesn't know

Under the appropriate circumstances, professional in-home care may be the right solution for your loved one.

how to provide the care that's now needed.

PYM: Are there signs to look for that signal when it might be time to seek in-home care?

KC: When that caregiver begins to have feelings of frustration or even anger over the challenges they face, it's time to seek

help. It's perfectly normal to have these emotions; but when that caregiver begins to have these feelings of frustration, it is wise to get help certainly before they get overwhelmed.

PYM: What is involved in in-home care?

KC: Home care can provide a variety of services depending on the specific needs of the individual. Care runs the gamut from a once-weekly visit to a professional caregiver in the home 24/7; services can be provided by home care aides, nurses, therapists, or social workers.

Services can begin with a home-care aide providing basic personal care and assistance with activities of daily living like bathing and dressing. This is necessary because often the family is no longer able to or comfortable with

providing these tasks. They have become tired or overwhelmed or they are just not comfortable doing this for their mother or father, someone who's traditionally been their own caregiver.

If it's a fairly new diagnosis or the individual is starting on new medications or different combinations of new medications, it's very helpful to have a nurse visit in the home. A nurse is trained to provide medication monitoring. Medication monitoring requires the nurse to observe, document and report to the individual's physician the individual's response to the

Trained in-home caregivers can also help family members deal with the new habits, moods, and behaviors by teaching specific care techniques both for these emotional outbursts as well as wandering behaviors and other habits that are quite common for individuals with AD.



medications, including any side effects. The nurse also counsels the individual or their caregivers regarding potential side effects.

When the individual begins to have a physical decline and can't bathe, dress or get around, physical and occupational therapists work with the family. It's not always the individual with AD, but often the family that needs to learn how to assist the individual out of bed, with bathing and even techniques to assist the individual with eating.

A social worker can also play an important role in teaching coping skills to family caregivers. New challenges with a loved one require new emotional skills that family caregivers may have never previously acquired.

PYM: How is in-home care paid for?

KC: Well, it depends and people should always confirm their own coverage. Generally, there are some Medicare benefits available to individuals if there's

a short-term need for a nurse or a physical or occupational therapist and the individual is homebound.

There may be Medicaid coverage for individuals who qualify, depending on the state and county in which the individual resides. Of course, paying privately is always an option. Many families find that hiring a home care agency to send an aide to provide personal care and support services is quite affordable and well worth the expense.

PYM: What are some things to keep in mind when seeking an in-home care provider? Are there certain things to ask when interviewing caregivers?

KC: The community reputation of the home care provider should always be researched. Other questions include how long they've been in business, are they accredited by an outside accrediting body, and has the home care agency provided special training for the caregivers to work with patients with Alzheimer's or other dementia. If the family wants to be able to take advantage of the Medicare benefit, that home care agency must be Medicare certified.

When interviewing for a caregiver, individuals should ask about the kind of training the caregivers have, how often a supervisor checks on the caregiver (in person and by phone) and how will the home care agency bill them. It's also very



Karen Carnes, BSN, RN, MSN, Chief Clinical Officer, Interim HealthCare

good to know in advance what kind of system the agency has for successfully covering the agreed-upon shifts or visits when the assigned caregiver is not able to make it that day due to illness or vacation. A final important discussion is the agency's process for handling situations where the family or individual doesn't get along with the aide.

PYM: How does the person with AD adjust to having inhome care? What can help make the adjustment easier?

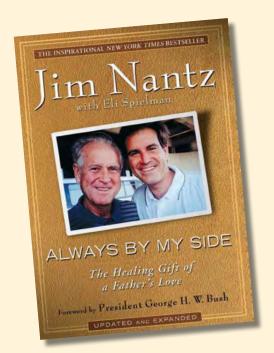
KC: Not everyone with Alzheimer's or dementia reacts positively to a stranger in their home. The earlier in the disease that a stranger is introduced, the easier it is and the first contact is extremely important. The adjustment is always easier in a nice, calm atmosphere with

loved ones present to introduce the new person into the environment. Often individuals with Alzheimer's disease don't remember names, but if they have a calm, positive experience in a safe environment with their usual caregivers (family, loved ones) present, it's much easier to begin that relationship and continue it positively on an ongoing basis.

PYM: Any tips for having a positive relationship with the in-home care provider?

KC: There should be frequent communication and contact by supervisors, either onsite observing interactions or with phone calls to both the in-home caregivers as well as to the family members. Through this constant contact, the supervisors can assess if the case continues to be within the scope of an individual caregiver's expertise or if it is advancing more quickly than anticipated.

The individual is our primary concern. But the individual is also part of a family unit and AD affects that entire family unit. Certainly Interim HealthCare isn't on site full time—at least initially. So we have to monitor how the family is handling the situation. Through frequent communication, we become partners in handling the disease; we teach them about medication management and daily living skills for themselves and for their loved one with Alzheimer's.



Jim Nantz: A Son's Calling

ou may not recognize his face, but if you're a sports fan, you'll likely recognize his voice. Jim Nantz, a sports commentator for CBS for almost 30 years, calls some of the biggest events in sports. From the Super Bowl to the Masters to the NCAA Final Four Men's Basketball Championship, Nantz has covered it all. He is a two-time Emmy award winner and a five-time National Sportscaster of the Year recipient. He's also the son of a parent who was afflicted with Alzheimer's. His father, Jim Nantz II (this Jim is the third), had Alzheimer's for 13 years before passing. We talked with Jim about his father's illness and why he's made it a mission to raise awareness and help defeat Alzheimer's.

Preserving Your Memory: Tell me about your dad's first experience with Alzheimer's.

Jim Nantz: That really comes down to a single day in May of 1995. I was covering a golf tournament in Fort Worth, Texas. My dad was tagging along for the weekend, which was something we did quite often and I loved having him be a part of it. My dad had been out watching some of the action by foot. He came back to my tower just before we

were going on air. He appeared very overheated and stressed. I knew something was amiss. I encouraged him to go into the clubhouse and cool off. He walked down the stairs of my tower and we began our broadcast live. Little did I know, my dad collapsed at the base of the tower and was taken to a local hospital. It turns out he had suffered a mini-stroke. That became really the trigger point, if you will, where life was never going to be the same for him again.

PYM: Did he have any issues with his memory before then?

JN: The reality is there were some moments of confusion for him for perhaps two years prior. He never lost his keys or anything, but at times, he had an inability to get people's names out correctly. He would mix their first name with their last name. We of course were clueless that this was actually a medical condition and one day my dad would be suffering from Alzheimer's. We just thought it was an absent-minded moment when occasionally he'd get a name upside down. We laughed it off, he laughed along with us, and it was life back to normal, or so we thought.



Jim Nantz with his dad on one of their many road trips

PYM: How did the Alzheimer's diagnosis come about, and what was your initial reaction?

JN: Well, he recovered from that mini-stroke after a couple days in the hospital. Then we noticed during the next couple of years that, again, the ability to say names correctly and his recollection of things that happened was slipping. It became more frequent. I was living in Connecticut at the time and took him to a doctor near my home. The doctor told me, "I think your dad might have Alzheimer's." I refused to believe it. I decided to call Dr. Stan Appel at Houston Methodist Hospital. We'd interviewed him for a story on CBS 10 years before. He's a remarkable man who has done so much for Alzheimer's and the other neurodegenerative diseases. So when it came time for a second opinion, I called Dr. Appel. We booked an appointment and went in to see him. He did a series of tests with my father, and then he so gently handled that watershed moment. He called for a social worker to come in and take my mother into another room to comfort her. He pulled me aside as the man of the household to tell me, "Your dad does have Alzheimer's. Your family faces a very long and tough battle ahead. We're going to do the best we can to try to find answers, make your dad comfortable, and slow down the progression of the disease, but you need to be strong for your mom and sister."

PYM: After the diagnosis, you still took your dad to a few broadcast events. How did that go?



Jim with his beloved family: Jim, Doris, and sister Nancy Hockaday

JN: We wanted my dad to still be able to live, to try to be able to blend in with society and lead as normal a life as possible. However, having said that, we knew we needed to watch over him because there were times he could get downright silly and even embarrassing in certain situations. We did find out that the loud noises and all that uproar seemed to be taking a toll on him. He was hypersensitive to too much hubbub. We began to dial back on those kinds of events for him.

PYM: So once he was no longer able to attend the events, how did you maintain contact since you were traveling for work?

JN: I've always been a steady phone caller to my parents. I check in every day, always have, at least once a day. We tried to do everything we could to have constant communication. And I was very good about coming to Houston once a month. But I was not there on the caregiving side like my mom, my sister Nancy and my brother-in-law Don. They lived it every day. They gave so much of themselves for years to make sure Dad was looked after. They were so beautifully selfless about it. And I'll never forget it.

PYM: In 2008, you published your bestseller Always By My Side: The Healing Gift of a Father's Love. What made you write the book?

JN: In 2007, I was going on a 63-day stretch that included calling the Super Bowl, the Final Four, and then the Masters.

A writer for the *Los Angeles Times* interviewed me and wrote the article in the context that no one in the history of sports television had ever been the play-by-play voice on all three of those events in the same year. That spawned some interest from the book community that wanted a day-by-day sports book about the experiences. Even though those events are entertaining, I didn't really think anybody would care about a detailed account of my life on the road. Then someone suggested the idea of somehow incorporating my father in the book. Now *that* had my interest. So it morphed into my writing about the three-championship journey and finding my father, since he wasn't physically able to be on the trip. It became a wistful nine-week journey of a father-son trip that I only wish could have happened for real.

PYM: The book got a strong reaction and was an immediate bestseller.

JN: I could have never expected the reaction. To this day, people still approach me and say, "My mother suffers from Alzheimer's." "My father died of it." I've become, in a way, an ambassador for the cause. The book became one of the single most important things I'll ever do in my life because the reaction was the impetus for me to go back to Dr. Appel and tell him we needed to do something together to make a difference. That's how we came up with the Nantz National Alzheimer Center (NNAC).

PYM: In your book, you write about how difficult it was to place your dad in an assisted care facility. Any advice to families struggling with that decision?

JN: There's a tremendous sense of guilt that you'll always feel. The fear of turning around, walking out that door and leaving your loved one behind, while not knowing exactly what kind of care he is getting when you're not there. That's something that never escapes you. You have to have faith and believe in the people you're entrusting with your loved one. It is also really important to think about the caregiver. Long before we made the decision to move my dad, Dr. Appel had been advising me to make sure my mom was okay and received the support she needed. The concern was we didn't want to lose my mom too.

PYM: As you mention in the book, it's common for people to feel despondent or "lost" when a loved one is ill. Do you have any words of encouragement?



"Now it's time that I spend the rest of my life letting people know the real Jim Nantz, my dad."

JN: It's so deflating it is easy to look at the world in a very bleak way. But you have to treasure each day because some day you're going to want those days back. My dad died in 2008. In 2007 and 2006, I remember wishing I could have him back like he was in 2005, when there was some recognition in his eyes. In 2005, I remember wishing for 2003 when he could still talk a little. Back in 2003, I remember thinking back to 2000 when we were able to take walks together. What I realized is that every day you have them, there's a reason to be grateful. I know it's hard when you're seeing your loved one as a fraction of the person they used to be, but they're still here. Once my dad was gone, I just longed to still have him.

PYM: In addition to the NNAC, you also have a wine label?

JN: Yes, it's called "The Calling," which takes on many different meanings. One of which is I am there for the calling of the sporting events. But more than that, it's meant to inspire people to follow their calling. That's what I feel I've done with my whole life. I followed the calling of a young boy who wanted to broadcast sporting events. It is my calling to link arms with Dr. Appel and Houston Methodist to take

on Alzheimer's and neurodegenerative diseases. The wine label also gives me a platform to talk about what we're doing in the fight against Alzheimer's and raise money throughout the year to give back to our cause.

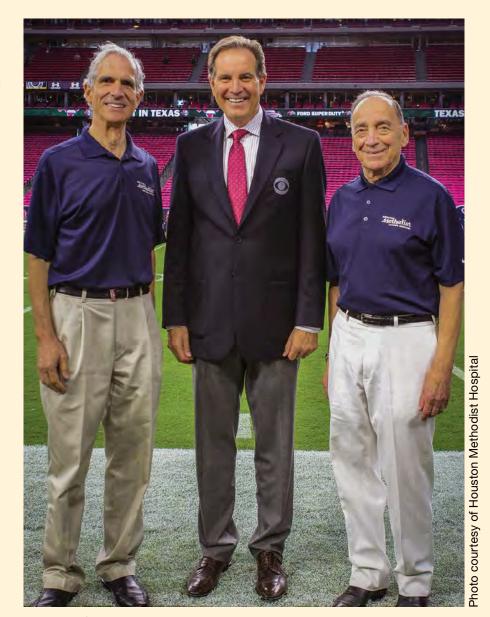
PYM: With the book, the NNAC and the wine label, it definitely seems you're helping your father's memory to live on.

JN: My father wasn't interviewed once in his life. He was never on national television. He worked hard, provided for his family, went away to college, and moved a young family around the nation as he climbed the corporate ladder. He was an everyman, a loving man. I've been blessed with every little dream that I ever strove for as a kid. Now it's time that I spend the rest of my life letting people know the real Jim Nantz, my dad. Through me, he is trying to create change to help make a difference in other people's lives. I'm just thankful I've been given the strength, vision, encouragement and support to use my voice to take on this mission, with my wife, Courtney, to help generations to come.

The Nantz National Alzheimer Center

In 2011, Jim Nantz partnered with the Houston Methodist Neurological Institute to open the Nantz National Alzheimer Center (NNAC). Jim and his wife, Courtney, work tirelessly to increase funding for research

and generate awareness of dementia and Alzheimer's disease, as well as the possible effects that concussions have on these diseases. Under the leadership of Dr. Appel and Dr. Joseph Masdeu, the NNAC has become a world-renowned center with a focus on improving care and treatment for patients through the advancement of scientific research, the investigation of the causes of this debilitating disease, and provision of effective tools, guidance and support for patients' families and caregivers.



From left: Dr. Joseph Masdeu, director, Nantz National Alzheimer Center, Houston Methodist Neurological Institute; Jim Nantz; Dr. Stanley Appel, chairman of neurology, Houston Methodist Hospital; director, Houston Methodist Neurological Institute

A Human Touch

Stanley Appel, M.D., chairman of neurology and director of the Houston Methodist Neurological Institute, says the NNAC not only delivers great diagnostic care and research, it delivers hope with humanism. "Jim Nantz is one of the nicest guys in the world and that's an approach we like to follow for our patients," he says. Staff members are honest and direct yet also kind and supportive. The positive interaction helps build trust and hopefulness for patients and their families at a time it's needed most.

Food By Jason Schneider

A Drink to Your Health?

Weighing the risks and benefits of alcohol use

aving a beer or glass of wine with friends is something many of us have done at some point, sometimes even on a regular basis. News stories often tout the benefits of certain types of alcohol—usually on cardiovascular health. But when it comes to mild or moderate alcohol consumption, do the benefits outweigh the risks? And how does alcohol affect the health of your brain?

"Whereas it is well-known that high levels of alcohol consumption are associated with a variety of brain disturbances, including balance problems, judgment and planning problems, and even dementia, the effects of mild/moderate consumption are less clear, and results are even conflicting," says James C. Garbutt, MD, Professor; Medical Director, Alcohol/Substance Abuse Program, University of North Carolina School of Medicine.

The primary benefit reported with alcohol consumption, says Dr. Garbutt, has been a reduced risk for heart attack or ischemic stroke. The cardiovascular benefit, he adds, seems to come from ethanol, whether in beer, wine, or liquor.

"This benefit may underlie the overall improvement in lifespan for those with 'safe' drinking patterns, compared to abstainers," he says. "However, a number of illnesses such as high blood pressure, cirrhosis, breast cancer, pancreatitis, and gastric ulcer are more likely to occur with any level of alcohol consumption."

He adds that it's important for individuals to determine whether using alcohol is in their best interest. "A woman with a family history of breast cancer may decide not to drink because any increase in risk is unacceptable," he says. "Additionally, those with a personal or family history of alcohol problems may decide not drinking is the safest path to follow."

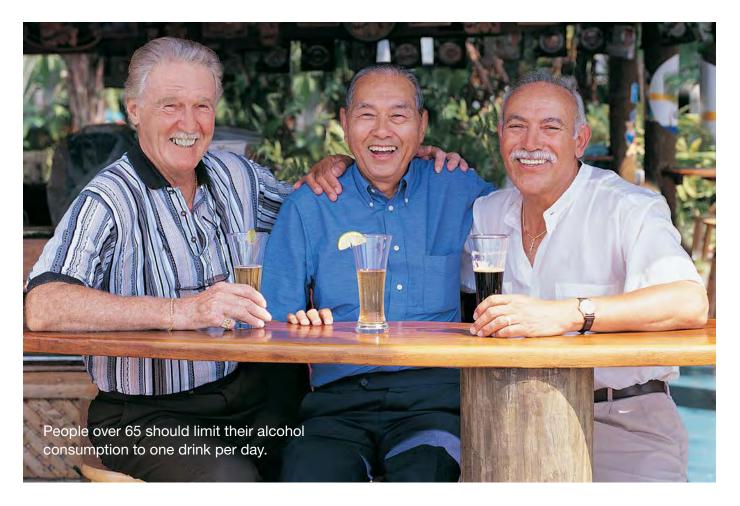
Some Medicines and Alcohol Don't Mix

Dozens of medicines interact with alcohol and can be harmful. Here are some examples.

- Taking aspirin or arthritis medications and drinking alcohol can increase the risk of bleeding in the stomach.
- Taking the painkiller acetaminophen (Tylenol) and drinking alcohol can increase the chances of liver damage.
- Cold and allergy medicines that contain antihistamines often make people sleepy. Drinking alcohol can make this drowsiness worse and impair coordination.
- Drinking alcohol and taking some medicines that aid sleep, reduce pain, or relieve anxiety or depression can cause a range of problems, including sleepiness and poor coordination as well as difficulty breathing, rapid heartbeat, and memory problems.
- Drinking alcohol and taking medications for high blood pressure, diabetes, ulcers, gout, and heart failure can make those conditions worse.

Medications stay in the body for at least several hours. So, there can still be a problem if you drink alcohol hours after taking a pill. Read the labels on all medications and follow the directions. Some medication labels warn people not to drink alcohol when taking the medicine. Ask a doctor, pharmacist, or other health care provider whether it's okay to drink alcohol while taking a certain medicine.

Source: NIH Senior Health, "Alcohol Use and Older Adults"



Defining "Mild" and "Moderate"

So what amount is considered "mild" or "moderate" with regard to alcohol? "There are no clear definitions for mild vs. moderate," says Dr. Garbutt. "There are recommendations for 'safe' levels of consumption, which are no more than two standard drinks per day for a man and one standard drink per day for a woman, without heavy drinking days (five or more drinks in several hours for a man, four or more drinks for a woman)."

Dr. Garbutt says a standard drink is considered 12 oz. of beer, 5 oz. of wine, or 1.5 oz. of hard liquor.

Alcohol and Brain Health

When it comes to alcohol use and its effect on brain health, the picture is not so clear. "The direct long-term effects of alcohol consumption on brain function are difficult to sort out," says Daniel I. Kaufer, MD, Associate Professor, Neurology & Psychiatry; Director, UNC Memory Disorders Program, University of North Carolina School of Medicine. "Chronic excessive alcohol can cause problems with balance and coordination due to toxic effects on the cerebellum, but effects on higher cognitive functions (i.e., dementia) is complicated by a number of secondary factors."

These factors, he says, include liver damage, which can impair brain function due to metabolic disturbances, and a poor diet, which causes a deficiency of vitamin B1 (thiamine). "Chronic thiamine deficiency can cause a severe memory disorder referred to as Korsakoff's syndrome, which can look like Alzheimer's but is not a progressive disorder," says Dr. Kaufer. "Individuals

who abuse alcohol are also at a higher risk for having traumatic brain injuries and hemorrhagic strokes, which makes it difficult to isolate the specific longterm consequences of alcohol toxicity on cognition and behavior."

Alcohol use is particularly detrimental to younger people, says Dr. Garbutt, as it negatively affects the developing brain. "Ideally, alcohol consumption would not begin before 18 years, and of course in the United States, it is illegal to consume alcohol in most states before age 21," he says.

"Overall," he adds, "older individuals are more susceptible to some of the detrimental effects of alcohol, including motor and balance problems and blackouts. Individuals over 65 years of age should avoid consumption of more than one drink per day."

Taking Part in the Search for the Cure

Getting involved in **clinical trials** is an effective way to advance the pursuit for better treatments and even a cure for Alzheimer's disease.

s we learn more about Alzheimer's, the facts and figures are alarming. It's estimated that more than 5 million people in the United States are living with the disease, and as many as 41.8 percent of assisted living and other residential care residents have Alzheimer's or other dementias. By the year 2050, the number of Americans with Alzheimer's is expected to reach 16 million.

For every person with Alzheimer's, there are many family members, caregivers, and friends whose lives are also affected. While we haven't yet found a cure, there's still hope.

Investing in Alzheimer's research has yielded many exciting breakthroughs. In 2010, scientists at the Fisher Center for Alzheimer's Research laboratory discovered a gamma-secretase activating protein (gSAP) that's central to creating beta-amyloid, which can kill brain cells and cause Alzheimer's when in overabundance. Clues like these help us to better understand Alzheimer's and can influence how we treat the disease.

Scientific discoveries advance Alzheimer's research, and clinical trials are another important piece of the puzzle. Before a patient can even receive an Alzheimer's medication, it must be tested in a clinical trial. In the search to find a cure, clinical trials bring us one step closer.

The Importance of Clinical Trials

A clinical trial is a research study of how certain interventions (a medication, procedure or behavior) affect the biomedical or health outcomes in human volunteers or patients. It's also a fast track to finding Alzheimer's treatments that will work.

"Without clinical trials, we can't prove if a drug is helpful," says John M. Ringman, M.D., M.S., Clinical Professor at the Department of Neurology at University of California, Los Angeles and the Easton Center for Alzheimer's Disease Research. "In order to do so, you need to perform appropriately controlled blinded randomized studies."

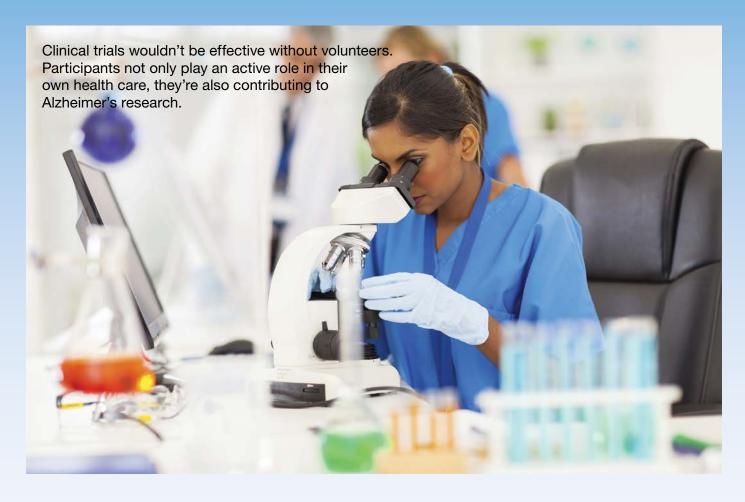
Sometimes, clinical trials turn up surprising results. Lately, we've been hearing a lot about estrogen and its effects on Alzheimer's. Early studies were hopeful that estrogen-containing therapy would protect the brain from Alzheimer's, but clinical trials challenged that thought.

"In fact, all the clinical trials suggested that it's not effective and may actually be damaging," says Gary Gibson, Ph.D., Director for the Laboratory for Mitochondrial Biology and Metabolic Dysfunction in Neurodegeneration at Burke Medical Research Institute and a professor of neuroscience at Weill Cornell Medical College. "In Alzheimer's disease, you want to delay the degeneration and if you find one way to do that, then maybe you can improve it with additional therapy or changing dosages." When clinical trials fail, they provide us with insight for future research.

The Latest in Alzheimer's Clinical Studies

Currently, we don't have an Alzheimer's drug that will prevent or reverse or even stop the disease from worsening but with every clinical trial, even those that fail, we inch toward an answer.





"Now there is increasing emphasis on intervening earlier in the course of the disease, or even before symptoms appear, to prevent the disease from manifesting symptoms in those who are either genetically predisposed or have some biomarker evidence that the pathology of the disease is already in progress," says Dr. Ringman.

At UCLA, Dr. Ringman is studying a rare gene that causes Alzheimer's at a young age (late 30s to late 50s). In families where this gene has been identified, each child is at a 50 percent risk for inheriting that gene and developing the disease. "Because the age of onset is pretty consistent, you can not only predict who in the family is going to get the disease, but also about what age," adds Dr. Ringman.

Meanwhile, Burke Medical Research Institute researchers are studying the brain's reduced ability to use glucose and how that contributes to Alzheimer's disease. "We found that some critical proteins involved in the brain using glucose are reduced, and these proteins require vitamin B1, or Thiamine, in order to work," says Dr. Gibson. "If we can get the brain to use the glucose better, we think we'll be able to delay degeneration." This hasn't been tested in humans, but researchers are planning a clinical trial.

How to Further Alzheimer's Research

Clinical trials wouldn't be effective without volunteers. Participants not only play an active role in their own health care, they're also contributing to Alzheimer's research.





We don't have an Alzheimer's drug that will prevent or reverse the disease but with every clinical trial, we inch toward an answer.

From systolic blood pressure intervention to dominantly inherited Alzheimer's, there are more than 150 active clinical trials in the U.S. investigating how to diagnose, treat, prevent, and cure Alzheimer's disease. At this very moment, 70,000 volunteers are being sought for this valuable research.

Researchers are looking for a diverse group of people, including healthy individuals who don't have Alzheimer's, those who have already been diagnosed, those who have a family history of Alzheimer's, and people of all ages and races. To be deemed eligible, certain criteria must be met, such as age, gender, stage of disease, other medical conditions, and previous treatment history.

There are many factors to consider before participating in an Alzheimer's clinical study. Keep in mind that participants may receive a placebo, or an inactive substance made to resemble the drug being tested. There's also the risk of side effects from the treatment. When this happens, additional safety monitoring may be recommended or the study may be discontinued.

What to Expect

Every clinical trial is different, but participants typically go through a prescreening and screening process. Prescreening involves being asked about medical history, medications, diagnosis, and the stage of their illness. Screening will involve further questioning and possibly blood tests, cognitive tests or imaging.

If it's a drug trial, the participant may receive a free drug. Other trials may require additional procedures or testing, such as EKGs, lumbar punctures or spinal taps.

The length of a clinical trial can vary from as few as three months to as long as 18 months, but the volunteer will know that up front.

Before enrolling, the patient will be educated on all of the key details about the clinical trial during the informed consent process. Typically, an informed consent document outlining possible benefits and risks is signed before the trial. This is also the perfect time to bring up any and all questions the participant might have.

Questions to Ask

It's important to know as much as possible before joining a clinical trial and participants and caregivers should be armed with plenty of questions before making a decision. This is just a starting point, but questions to ask can include the following:

- How long will the study last?
- What is being studied?
- How often will I have to show up?
- What will I do at the appointments?
- What kinds of tests or procedures will I receive?
- Are hospital stays required?
- What are some of the possible side effects or reactions?
- What kind of follow-up is involved?
- Can I continue other prescribed Alzheimer's treatments?
- Will I have to pay for anything?
- Will transportation or any other accommodations be provided?

Where to Start

There are many ways to find Alzheimer's clinical trials. Trials are being run by doctors in their offices, in clinics, hospitals and universities.

"The best way to do a clinical trial," says Dr. Ringman, "is to meet with someone one on one. Usually, as we see patients, we'll tell them about clinical trials and if they want to know more, we'll give them the details."

ClinicalTrials.gov, managed by the National Library of Medicine at the National Institutes of Health, lists available clinical trials in 50 states and 187 countries.

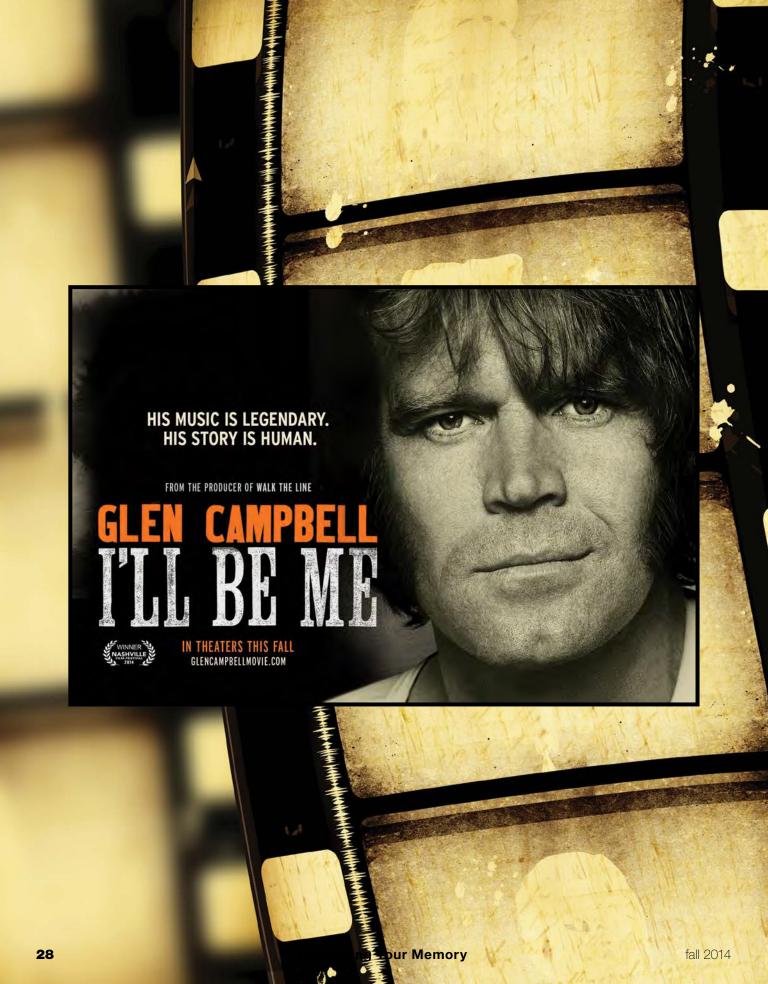
The website for the National Institute on Aging has an Alzheimer's clinical trial search at http://www.nia.nih.gov/alzheimers/clinical-trials.

To get involved with an Alzheimer's clinical trial with Burke Medical Center, visit www.burke.org

For more information on Alzheimer's clinical trials at UCLA, visit

http://www.eastonad.ucla.edu.

Alzheimer's may be a devastating disease, but by participating in clinical trials, we can help find some answers.



Just As I Am

y now it's well known that Glen Campbell, the legendary recording star, is in the fight of his life with Alzheimer's disease. To the credit of him and his family, it's not a battle he's taking lightly. In fact, in spite of the difficulties his condition presents, Campbell and family decided to embark on a 151-date farewell tour over the course of 2011-12. In director James Keach's new documentary feature film, Glen Campbell: I'll Be Me, we travel with Glen, his band, and his family across the country as he plays to sold-out audiences filled with adoring fans. The Campbells also make time for a visit to Washington, D.C., to advocate on behalf of greater investment in Alzheimer's research and care.

So how did he do it? How did a man in the throes of Alzheimer's manage to perform on stage to thousands of people while touring the country? The answer, as the film reveals, is with a lot of love, faith, hope, and support.

Preserving Your Memory: How did you come upon the idea for Glen Campbell: I'll Be Me? What made you want to make this film?

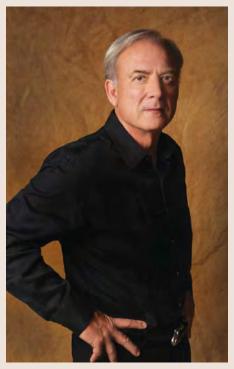
In his powerful new documentary feature, *Glen Campbell: I'll Be Me*, director James Keach chronicles the music legend's farewell tour—and a brave man's battle, with his family at his side, against Alzheimer's disease.

James Keach: Julian Raymond, who produced Glen's last several albums, was producing some music for me and kept saying, "You've got to make this movie. You've got to meet Glen." And I said, I'm not sure that's what I want to do. I'd just made a movie about a singer from Arkansas. And he told me, no, Glen's got Alzheimer's. So I told my partner, Trevor Albert, and we agreed—this sounds like a very tough subject to make a piece of entertainment about. So Julian said, would you please meet him. So over the weekend, Trevor and I watched every movie we could on Alzheimer's. I told Trevor, "These films are so depressing. How can we do this?" But I wanted to be respectful, and meet Glen. Anyway, we met Glen and Kim. He came into the living room, and my son Johnny had his guitar, and Glen looked at Johnny and said, "I play the guitar! You want me to show you something?" Johnny said, sure! Glen said, "This is what my Uncle Boo taught me to play!" And he just shredded it. And then Glen said again, "I play the guitar!" Johnny was a little confused, but soon understood it was the Alzheimer's. So, I was thinking we'd last 5 weeks

at the most, but it lasted 151 shows over 3 years. We fell in love with Glen and Kim and the kids. I knew nothing about Alzheimer's, and now it's become such an important part of my life. I want to make a difference in the lives of millions of us who will encounter this. Glen humanized Alzheimer's, like Magic Johnson humanized AIDS. Glen chose to say, "I'm not afraid of it, this is what God gave me, and I want to show the world. I want you to help me, James."

PYM: Was this film a labor of love from the outset for you, or did it become that along the way?

JK: It was a labor of love. We financed the film ourselves. We thought it was going to be a short run, but after three years of working on it, it became a spiritual journey, really. When you see how the family behaves toward each other, and the way the audience reacted with Glen, you realize how special Glen and his family are. I had the camera on stage, right next to Glen, and saw how he interacted with his daughter and sons—the conversation Glen was having with the audience was so beautiful, they embraced him and lifted him up. They carried him to another place. He knew when he'd forget stuff, and he'd say to the audience, "Does that ever happen to you?" It was just an unbelievable experience as a filmmaker. I think Glen and his family will create an opportunity to change the conversation about this disease. It's the secret in the closet, and now it's time for all of us to join together in a big conversation and embrace each other around this.



Director James Keach

"We fell in love with Glen and Kim and the kids. I knew nothing about Alzheimer's, and now it's become such an important part of my life. I want to make a difference in the lives of millions of us who will encounter this."

—James Keach

PYM: One of the many striking things about Glen Campbell is that he treats the people around him like family, whether he's related to them or not. Did you come to feel like part of the "family" since you were with him so much for so long?

JK: We were totally part of the family. Glen, Kim would say, could remember where "his friend with the beard lived" and would want to come visit. I never knew if Glen knew my name, but he always knew who I was.

PYM: Glen Campbell is notorious for his sense of humor. Obviously, you captured that on film. Did you sense that he was losing that as his disease progressed over the time you were with him?

JK: No, in fact, it was the opposite—he would always look for the laughter. "I've laughed and I've cried, and it's a helluva lot better to laugh," as he says in the film. At one point we were telling his jokes back to him, and he'd get such a kick out of it. One of his jokes was that he was so cold, he was like a chicken with a capon! He'd laugh so hard at that. He's constantly trying to make people laugh. He's a good, good man.

PYM: The Campbells gave you unprecedented access to Glen and the family throughout the tour and beyond. Why was it so important to show how Glen is doing in his day-to-day activities?

JK: Well, I think that if there's going to be any truth, any revelation about the disease, you have to see Glen in his everyday life. We gave Kim a camera and she'd turn the camera on and they'd live. It was always with the understanding that we would show nothing that wasn't dignified or didn't tell the story. We shot 1400 hours of film. We wanted to tell the truth about this disease, so unlike reality TV, this is actually real. None of this was scripted, obviously.

PYM: Throughout the film there are moments of supreme sadness juxtaposed with other moments of unbridled joy. Was that reflective of the journey you took with the Campbells in making this film?

JK: Yes, that was very reflective of the experience with Glen and what he and his family went through. One minute they were very elated and he was brilliant on his stage, and the next minute he didn't know where he was or who you were. As a filmmaker, it was very intentional to balance things so the audience has the experience we had on the journey with him.

PYM: What did you take away from the experience of making this film?

JK: You have to live in the moment and be grateful for every day that you have. You have to learn to accept that things aren't perfect, and to live with the hand you're dealt—to make the best of every day, and never give up. Glen would say so many things, and repeat them because they were very important to him. Glen Campbell

"While facing his own mortality, Glen taught me to live in the moment, to seek laughter, love, spiritual growth and to cherish my family and celebrate the life we share."

-James Keach

"I've laughed and I've cried, and it's a helluva lot better to laugh."

—Glen Campbell

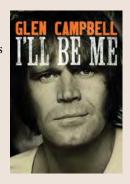
"Together with
the Campbells,
my hope was that
we could change the
way the Alzheimer's
story was depicted
in the media, and
in the world. Glen
was willing to risk
everything in order
to make a difference
in this last musical
chapter of his life."
—James Keach

has taught me to really live in the moment, to be grateful for all the blessings that I have, and not being afraid of showing the gnarly truth. He had a lot of courage to let us see him at his worst, but I would say by seeing him at his worst, we're seeing him at his best.

PYM: How did making this film change your view of Glen? Of Alzheimer's disease?

JK: I knew nothing about Alzheimer's before we started the movie and so it educated me about the tsunami that's facing the world, and unless we find some way to slow it down, we'll be facing something worse than any war. When I started this film, I didn't realize how unbelievably talented this man was, how deep his faith was, and how willing he was to ride the waves of life in a very honest way. He talks so openly about his failures in life, but his failures, in the way he talked about them, became his successes. This is Glen's most noble moment, and he's willing to show the world his faults and his triumphs. He's been amazingly successful and continues to be. He's amazingly human. God willing he's going to inspire millions of people not to give up on life, even if we're facing Alzheimer's, and to love the people with it.

Glen Campbell: I'll Be Me will be playing in theaters nationwide beginning Oct. 24. Check your local theater listings for a date and time near you.



Planning for Future Housing Needs

Be prepared by addressing housing needs sooner rather than later.

t's painful for the families of people with Alzheimer's disease to realize that their loved ones need care that they're not able to provide. At that point, there are difficult decisions to make and endless details to manage, but there are ways to make the situation easier on everyone.

"At that stage, the loved one's disease has progressed," says Shirley Whitenack, President-Elect of the National Academy of Elder Law Attorneys (NAELA) and partner at the law firm Schenck, Price, Smith & King in Florham Park, N.J. "Their memory has deteriorated and they may not always recognize family members. The family can have feelings of panic, sadness, and confusion. In many instances, there is so much to do that caregivers can experience burnout."

For families, choosing the right type of housing for their loved one is critically important. People with mild dementia can receive sufficient care in an assisted-living community, but those with later-stage Alzheimer's need specialized care to ensure their safety and security.

People Who Can Help

Families can get invaluable help from a geriatric care manager. These nurses and social workers evaluate the loved one and help them and their family decide which living situation will be best for them—at home with the help



With the help of an elder-law attorney, a loved one's future housing needs can be planned in advance.

of an aide or in an assisted-living or nursing facility.

There's another ally that the family should enlist in the earliest stages of the illness. "When the loved one is diagnosed with Alzheimer's, family members should contact an elder law attorney," says Whitenack. "This type of attorney can explain their options for long-term care from a financial

perspective, discuss ways to finance that care, and make sure the family has the appropriate documents for power of attorney decision-making."

Power of attorney is a critically important part of this situation. It involves two separate documents that give a family or their attorney permission to make decisions on behalf of the loved one. The power of attorney

for finances allows the family member or attorney to make financial decisions and perform financial transactions. The healthcare power of attorney gives the same permission for medical decisions.

Additional Pointers

Here are some tips from experts on handling this difficult situation:

Huddle Up—"The family should call a family meeting as soon as possible," says Whitenack, "and try to identify ways that each of them can help. It's important to evenly divide the work of caregiving among family members so everyone is taking part and no one feels they're being asked to do too much. If some family members don't get along, it's a good idea to have a third-party mediator to help the family navigate through their issues."

Research Sooner, Not Later-

Don't wait until the last minute to check out the housing options for your loved one. "Start investigating housing sooner than you think you need to," says Michael Kirtland, managing member of the law firm Kirtland & Seal in Colorado Springs, Colo. "If you do research into assisted-living facilities, for example, and you don't have to use it for another year or two, when the time comes you'll be ahead of the game. Often, the family doesn't do this research because they want to help their loved one themselves and they think they can do it. But when the illness progresses and a change of housing is needed, it's a crisis situation and the family isn't as prepared as they could be."

Make Connections—Family members who don't live in the same area as their loved one should determine how connected the person is to their community. "Family members must find out if the person has friends

or relatives nearby who can help the when one they need it," says Catherine Seal, Vice President of NAELA and senior member Kirtland Seal. "They should make a list of those people and make connections with them. The family should get to know the neighbors as well as possible and if they sense they can trust them, give them a key to the loved one's house in case of an emergency."

Keep Everyone in the Loop-

When one of the loved one's children takes the lead role in managing situation, the it's best if that person keeps other family members in the "Sometimes, loop. financial decisions

are made by the child who has the loved one's complete trust and they're made without the knowledge of the other children in the family," says Seal. "That can create conflicts when the other family members find out about it. It's best if the main caregiver keeps their siblings involved and keeps everyone informed every step of the way."

Watch for Burnout—Family members should stay on the lookout for caregiver burnout. If family caregivers need a break, some housing facilities will allow the loved one to stay for



Caregiving works best when it's a team effort.

two weeks to one month. This lets the family try the facility without making a full commitment—and relieves the burden on caregivers for a while. "There can be great fulfillment in caring for a loved one with Alzheimer's," says Whitenack, "but it's also important to get some time away from the stressful aspects of that type of care as well."

Bernard A. Krooks is managing partner of the law firm Littman Krooks LLP (www.littmankrooks.com). A certified elder law attorney, he is a past president of the National Academy of Elder Law Attorneys and past president of the Special Needs Alliance.

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 literary character to his or her occupation? a. Phonetician

- 1. ___ Bob Cratchit, "A Christmas Carol"
- 2. ___ Rhett Butler, "Gone with the Wind"
- 3. ___ Henry Higgins, "Pygmalion"
- 4. ___ Howard Roark, "The Fountainhead"
- 5. ___ Sam Spade, "The Maltese Falcon"
- 6. ___ Tom Joad, "The Grapes of Wrath"
- 7. Meg March, "Little Women"
- 8. ___ Atticus Finch, "To Kill a Mockingbird"
- 9. ___ Catherine Barkley, "A Farewell to Arms"
- 10. ___ Basil Hallward, "The Picture of Dorian Gray" j. Weaver
- 11. ___ Arthur Dimmesdale, "The Scarlet Letter"
- 12. Silas Marner, "Silas Marner"

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 and sweet piece of advice. The black squares are the spaces between words. One letter has been dropped in place to start you off.

G														
Н	Т	Ε				F	Р	Т	Ε	Т	M	S	Ν	N
Ε	Н	L	I	С	С	U	0	G		F		Ε	0	T
W			0		Υ	0		R		Α		R		T
W														

Here's a list of two-word phrases that are all places and social events where people gather. The letters of the two halves are in the correct order, but they overlap. All you have to do to find the place names is separate the letters.

Example: SMAHOLPLPISNG — SHOPPING MALLS

b. Artist

c. Architect

d. Minister

f. Blockade runner

e Nurse

g. Clerk

h. Governess

k. Farm worker

1. Private detective

i. Lawver

- 1. BPALORCTKY 2. FMLAREKEAT 3. STAFATIER 4. BCONACNERDT 5. FSHASOHIOWN
- 6. SDQAUNCAERE
- 7. SOGCACEMRE
- 8. PASGCHEAONOTL
- 9. CRLEUANSIOSN



VISIT US AT KAPPAPUZZLES.COM

BRAIN-BOOSTING CROSSWORDS

(Answers on page 37)

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 entries. The puzzle on the right is a medium-level puzzle and the number of words in the answers haven't been given. The second puzzle is also a thematic puzzle: the title "Put Your Mind to It!" is a hint. Have fun testing your knowledge while doing something that's good for you!

1	2	3	4		5	6	7	8	9	
10					11					12
13					14					
	15			16				17		
			18				19			
	20	21				22				
23					24					
25					26			27	28	
29			30	31			32			33
34							35			
	36						37			

Across

- 1. Show
- amazement
- 5. Track shapes
- 10. Air
- 11. "American
- ____" (Richard
- Gere film)

13. El ___

- 14. Specific item
- 15. HBO offering
- 17. SSW's opp.
- 18. Very long period
- 19. Cribbage pieces
- 20. Hose color
- 22. Jelly containers
- 23. Side of bacon
- 24. Ripken of
- Cooperstown
- 25. "___ So Fine"
- corrections

- 29. Avoided
- 32. Snapple
 - beverages
- 34. Formal
 - argument
- freshener target 35. Parable
 - 36. Titles

 - 37. Director Kazan

 - Down
 - 1. Elephant's
 - party (abbr.)
 - 2. Eden dweller
 - 3. Just

 - okay (hyph.)
 - 4. Adage
 - 5. Utah city
 - 6. Strive
 - 7. CIA
 - employee (abbr.)

9. Arm supports

- 8. Borrower's
- 26. Make opposite

12. Spanish hurrahs

16. Debtor's letters

19. Artist's board

pipers piping

21. Winter melon

22. Traffic snarl

of "Hud"

28. Artist Salvador

31. Paris summer

33. Adriatic, e.g.

30. Aswan landmark

23. Cast off

24. Yields

27. Patricia

20. Number of

Put Your Mind to It!

Across

- 4. Draft letters
- 7. Pt. of speech
- 10. Incentive, informally
- 12. He runs the Springfield Kwik-E-Mart
- 13. Fir fruit
- 15. ____ torch (outdoor party staple)
- 16. Chicago Seven lawver William
- 18. Intellectually provocative article, perhaps 20. It goes with
- tortilla chips 23. Catcher Carlton
- 24. Debar or prevent
- 28. Possessing
- proper opinions 34. Four-time
- Olympic discus champion 35. American petroleum
- company 39. Tom Mix two-reeler
- 40. Conformity
- 44. Ginsberg, Corso, or Ferlinghetti
- 45. Thessaly peak

- 49. "Quills" subject
- 1. Frazier opponent 50. Nintendo product popular with seniors
 - 51. Proceed
 - 52. Lithuania or Latvia, pre-1991: abbr.
 - 53. Near-grads: abbr.
 - 54. Dutch ___ disease

Down

- 1. Like a quick learner
- 2. Pacific neckwear
- 3. Bug
- 4. Satirist Munro's pseudonym
- 5. Took a turn on "Wheel of
- Fortune" 6. Like the
- "Titanic" 7. Height of
- a drama 8. Politicians
- Robert and Elizabeth
- 9. Sweater feature
- 14. Preceding,
- poetically
- 17. No. on a
- Coppertone bottle

- 19. Sentry's order
- 20. Season: abbr.
- 21. Magnate Onassis
- 22. Triangle side
- 25. Actress Hagen 26. "The Rainbow" author's
 - monogram
- 27. Between A and U 29. Sign gas
- 30. Site of a Polish uprising
- 31. "Addams Family" cousin
- 32. Birth name
- indicator 33. Guard
- dog's warning 35. Environs
- 36. Turnpikes
- 37. More buttonlike?
- 38. Against: abbr.
- 40. "Pygmalion" author's
- monogram 41. Pulls a disabled car
- 42. Will beneficiary
- 43. "How Sweet " (James
 - Taylor song)
- 11. Tacky bric-a-brac 46. Visualize
 - 47. Long-running **NBC**
 - comedy show 48. Nav. chief
- 12 15 16 20 22 21 24 28 31 34 36 42 44 46 45 49 50 53

BRAIN-BOOSTING PUZZLES HIDDEN-MESSAGE WORD-FIND™

Modern politics is a contentious and unrelenting struggle. Circle the words below, and the unused letters will spell out an apt quote from Harry S. Truman.

ATTACK AD	PATRONAGE	Р	N	S	S	E	G	Α	N	0	R	Т	Α	Р	I
DIRTY TRICKS	PORK BARREL	Р	0	F	K	0	Y	0	U	W	L	Α	U	F	N
DIKTT TRICKS	FORK BARKEL	T	I	W	Т	С	U	Α	F	Ε	L	0	I	Р	R
FILIBUSTER	POWER	Ν	T	Н	Ε	I	I	N	R	A	R	L	Α	Α	T
IMPEACHMENT	PROTEST	E	С	I	S	R	N	R	D	G	I	R	Ε	Т	A
		M	Ε	N	D	N	Α	N	T	В	T	I	S	T	L
INFIGHTING	SCANDAL	Н	J	N	W	В	Α	s	U	Y	I	Ε	Α	A	K
INNUENDO	SMEAR CAMPAIGN	С	В	S	K	С	Ε	S	L	Ε	Т	Т	Н	С	S
		Α	0	R	S	R	T	I	ı	0	N	R	Ε	K	Н
INTEREST GROUP	SOUND BITE	Ε	0	I	E	Ε	N	N	R	T	G	D	I	Α	0
OBJECTION	TALKING POINT	Р	T	T	R	Ε	0	P	N	G	R	Ε	0	D	W
		M	Ν	G	ı	Α	Р	M	Α	С	R	Α	Ε	M	S
PARTISANSHIP	TALK SHOWS	ı	N	F	1	G	Н	Т	1	N	G	Т	P	Α	D
PARTY LINE		T	N	ı	0	Р	G	N	I	K	L	A	T	0	G

SUDOKU

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

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



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Match These

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

Dropline

When you get something for a song, look out for the accompaniment.

Leapfrog

- 1. Block party; 2. Flea market;
- 3. State fair; 4. Band concert;
- 5. Fashion show; 6. Square dance;
- 7. Soccer game; 8. School pageant;
- 9. Class reunion.

Hidden Message

If you want a friend in Washington, get a dog.

Crossword 1 G A S P O V A L S O D O R G I G O L O P A S O D E T A I L M O V I E N N E E O N P E G S E C R U J A R S S L A B C A L H E S E M E N D E V A D E D T E A S D E B A T E T A L E N A M E S E L I A

WORD-FIND P N S S E G A N O R T A P I P N T P N Y A F E D A P P R N T P N Y A F E D A P P R N T P N Y A F E D A P P R N T P N Y A F E D A P P R N T P N Y A F E D A P P R N T P N Y A F E D A P P R N T P

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

YOU CAN MAKE A DIFFERENCE!

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Using Free Online Resources to Facilitate Family Caregiving Decisions

eeling overwhelmed for stretches of time—some longer than others—is a natural part of living in a household facing the challenges of dementia.

Although some caregivers and families may feel alone in these challenges, the inspiring truth is that there are a number of new resources available for those facing



these same struggles—perhaps more now than ever before.

The nation's largest senior living resource, A Place for Mom (toll-free **866-333-0740** with hours Monday-Friday **5:00 AM-9:00 PM** and Saturday-Sunday **8:30 AM-5:30 PM** Pacific Time), helps caregivers cope with those difficult stretches by meeting the increasing adversity of dementia head-on. Empathetic support, professional advice and centralized tools are some of the ways in which A Place for Mom supports families in the early stages of dementia. However, the later stages of dementia can introduce a new set of challenges. For families in this situation, the increasing unpredictability of the disease often brings about a need for a level of care beyond what can be provided by the typical family—but how does one go about finding the right care?

Research shows that families frequently begin their search for senior living options without a full understanding of what is available. This is understandable, since the senior care industry has been scurrying to meet the rising needs of the growing senior population over the past two decades. As a result, the industry has witnessed the development of many levels of care options. When families begin their search without the safety net of a Senior Living Advisor, they can run into problems. In a recent study conducted by A Place for Mom, 59% of those seeking "nursing home care" ultimately chose an entirely different level of care after they had been educated about the various options by a trusted Senior Living Advisor. It is this advice that can be vital to a family's search.

A Place for Mom's over 240 Senior Living Advisors across the United States help thousands of people each month, providing assistance 7 days a week. These trained professionals perform a thorough consultation, collecting

specific details about the senior's needs and budget in order to identify the appropriate care type. Once the Advisor has a complete profile of the senior, several care options in the area are selected for the family. This invaluable assistance is offered at no charge to families—A Place for Mom carries

out its mission of being a comprehensive senior living resource through payment from the participating senior communities in the A Place for Mom network.

When it comes to selecting a senior living community for a loved one, A Place for Mom also offers families additional resources to find only the best care for their loved one. With over 100,000 senior living communities and care providers across the country, selecting a senior housing option can be daunting. However, SeniorAdvisor. com (toll-free 866-333-0742 with hours Monday-Friday 5:00 AM-9:00 PM and Saturday-Sunday 8:30 AM-5:30 PM Pacific Time)—a ratings and reviews site designed for people engaging in this search process—provides a helping hand to aid in the selection process. With over 25,000 ratings and reviews from real families across the country, SeniorAdvisor.com provides a way for families to get an inside look at the communities in their area, with relevant feedback from other families. Caregivers use the information available on SeniorAdvisor.com to determine which senior living communities they would like to tour or investigate in more detail.

Regardless of the stage of a family's journey, A Place for Mom can offer support and guidance. Caregivers. com, AgingCare.com and Alzheimers.net are examples of three separate online resources providing a sense of community to those involved in the daily ups and downs of caregiving. These resource hubs act as a respite, providing inspirational quotes, valuable tips and smart, poignant advice from healthcare professionals. These online resources can help minimize the stress and fatigue of caregivers. One of the most significant benefits of utilizing these free resources is that families can feel empowered knowing that they are making the best possible decisions for their loved one.

fall 2014



ALZTalk.org, is a free and easy way to make new friends and stay connected with those in the Alzheimer's community. Join today to post messages and share pictures and favorite links. ALZTalk.org gives users a voice and allows them to share tips and stories about coping with loved ones with Alzheimer's. It also offers the ability to ask

our experts questions no matter how large or small.



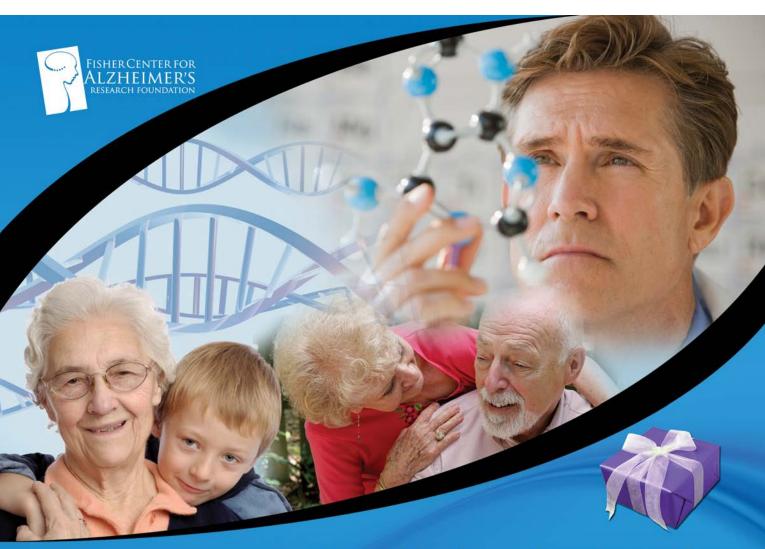


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