preserving your Memory
The Magazine of Health and Hope

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An interview with the celebrated singer

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Warm Up with Us!

With record low temperatures across the nation, winter has been somewhat harsh for many of us. Here’s hoping the winter issue of *Preserving Your Memory* will bring a little warmth into your day!

In this issue, we talk with the renowned singer Judy Collins about the power of music to heal (page 18). We also talk with author Deborah Shouse about her powerful new book, which chronicles her caregiving experiences with her mother (page 12).

On the research front, we talk with Dr. Sidney Strickland about his team’s research into the vascular connections to Alzheimer’s disease (page 10), and announce a breakthrough at the Fisher Center for Alzheimer’s Research laboratory (page 11). On the fitness front, we look at new research that shows that aerobic exercise is even better for brain health than we thought (page 22).

We also explore ways to manage stress more effectively (page 8) and how to help a loved one who is experiencing the phenomenon known as “sundowning” (page 14). And we examine the process of the Alzheimer’s diagnosis with a leading Mayo Clinic doctor (page 26).

We hope this issue brightens your winter days!

Betsey Odell
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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**

**Familial Alzheimer’s Gene Mechanism Discovered**

Familial Alzheimer’s disease (FAD) is a genetic variant of AD that afflicts a small percentage of the AD population. Researchers at Rensselaer Polytechnic Institute (RPI) have uncovered the process by which two genetic mutations (V44M and V44A) lead to the biochemical changes that have long been associated with FAD.

FAD is marked by the accumulation of high concentrations of a specific form of beta-amyloid, beta-amyloid 42, which forms deposits (plaques) in the brains of FAD patients. The ratio of beta-amyloid 42 (Aβ42) to another form of beta-amyloid, beta-amyloid 40 (Aβ40), is usually about 1 to 9 in a healthy brain. In an FAD brain, however, the ratio is usually much higher. Aβ42 is toxic to neurons and is a critical factor in memory failure in FAD patients.

“The mutations that cause FAD lead to an increased ratio of Aβ42 over Aβ40,” says Chunyu Wang, an associate professor of biological sciences within the School of Science, director of the biochemistry and biophysics graduate program, and member of the Rensselaer Center for Biotechnology and Interdisciplinary Studies. Dr. Wang co-wrote the paper with Wen Chen, who recently earned his doctorate at Rensselaer. “That’s the biochemistry, and that has been observed by many people,” says Dr. Wang. “But the question we asked is: how? How do the mutations lead to this increased ratio?”

Wang’s team explored the process by which enzymes make cuts to a segment of the larger protein, amyloid precursor protein (APP), leading to the shorter chains. One of these chains can become either Aβ42 or Aβ40. They discovered that one particular amino acid involved in the cutting process is affected by V44M and V44A, which can determine where it makes the cut—and whether Aβ42 or Aβ40 results. This could have important clinical implications because one of the goals of Alzheimer’s researchers is to reduce the levels of Aβ42, but not necessarily the amount of Aβ40. Understanding the mechanism of how each is formed could lead to selective inhibitors of Aβ42.

**Researchers ID 14 New Gene Targets**

A set of 14 genes that may be implicated in Alzheimer’s disease (AD) have been identified by a team of scientists at The New York Stem Cell Foundation (NYSCF) Research Institute and the Icahn School of Medicine at Mount Sinai (ISMMS).

Researchers produced stem cells and neural precursor cells (NPCs) from patients with severe early-onset AD that have specific mutations in the Presenilin 1 gene (PSEN1). The NPCs had elevated ratios of beta-amyloid 42 (Aβ42) to beta-amyloid 40 (Aβ40), a hallmark of a brain afflicted with AD. The 14 genes the researchers identified behaved differently in PSEN1 NPCs, as compared to NPCs without the mutations.

One of the genes the researchers studied shows the critical role that inflammation plays in the brains of AD patients.

“The gene expression profile from the familial Alzheimer’s stem cells points to inflammation, which is especially exciting because we would not usually associate inflammation with this particular Alzheimer’s gene,” said Sam Gandy, co-author on the study.

**Vitamin E May Play Role in Slowing Alzheimer’s Progress**

A study of more than 600 older veterans given high doses of vitamin E has shown promise in slowing the progress of AD in mild to moderate stages. In the study, patients showed delays in the decline of daily living skills when given the vitamin E doses.

Researchers said the benefit of the vitamin E regimen was equivalent to keeping one skill that otherwise would have been lost. But vitamin E did not preserve other cognitive abilities.

Scientists do not know why vitamin E may help in these cases. What is known is that vitamin E is an antioxidant, and as such, may play a role in protecting cells from damage that can lead to other diseases.

Researchers cautioned that no one should go out and buy vitamin E expecting to stave off AD. The vitamin has shown no ability to prevent AD, or to help those with mild cognitive impairment (MCI), an early form of dementia linked to the development of AD.

“It’s not a miracle or, obviously, a cure,” says study leader Dr. Maurice Dysken of...
Alzheimer’s disease starts in the entorhinal cortex (yellow). Using fMRI in mouse and human (shown above) brains, CUMC researchers provide evidence that the disease spreads from the entorhinal cortex (yellow) to other cortical regions (red) the perirhinal cortex and posteriorparietal cortex. Image: Usman Khan/lab of Scott A. Small, MD, CUMC

the Minneapolis VA Health Care System.
“The best we can do at this point is slow down the rate of progression.”

Research Unveils Key Alzheimer’s Findings
Columbia University Medical Center (CUMC) researchers have published important findings about where AD starts and how it progresses in the brain. The researchers used functional magnetic resonance imaging (fMRI) in patients with AD and in mouse models of the disease.

The new findings not only advanced knowledge about AD, they could lead to new drug targets in the critical early stages of the disease. The study was published in the Dec. 22 online edition of the journal Nature Neuroscience.

Scientists were able to pinpoint the location of AD’s origin—the lateral entorhinal cortex (LEC). The LEC is regarded as the gateway to the hippocampus, the area of the brain responsible for the consolidation of long-term memory, among other functions.

Researchers also found that beginning in the LEC, the disease spreads to other areas of the cerebral cortex, including the parietal cortex, the area of the brain involved in spatial orientation and navigation. The disease spreads by compromising the function of neurons first in the LEC, and then by doing the same in the adjoining regions.

“Now that we’ve pinpointed where Alzheimer’s starts, and shown that those changes are observable using fMRI, we may be able to detect Alzheimer’s at its earliest preclinical stage, when the disease might be more treatable and before it spreads to other brain regions,” says co-senior author Scott A. Small, MD, Boris and Rose Katz Professor of Neurology, professor of radiology, and director of the Alzheimer’s Disease Research Center.

NCCAM Releases New Study of Alternative Therapies for Brain Health
The National Center for Complementary and Alternative Medicine, part of the National Institutes of Health, released a new study in December addressing five key points regarding the use of alternative therapies for brain health and the prevention or treatment of AD.

The study, titled “5 Things To Know About Complementary Health Practices for Cognitive Function, Dementia, and Alzheimer’s Disease,” recommends talking with your physician about using dietary supplements or vitamins to address cognitive concerns. The five points are:
1. There is no convincing body of evidence that any dietary supplement can slow the progress of AD or dementia.
2. Some preliminary research indicates that some therapeutic approaches, such as music therapy, may have a positive impact on some symptoms of AD and dementia.
3. Therapies that emphasize mindfulness to reduce stress may help reduce stress among caregivers of AD and dementia patients.
4. Using complementary or alternative health practices is no reason to put off seeing your physician about memory loss or other cognitive concerns.
5. Some complementary and alternative therapies can interact with medications and produce serious side effects.

Check the Fisher Center website (www.ALZinfo.org) often for up-to-date and expert-reviewed scientific news.
Let’s face it: Stress is a natural part of life. And it’s not necessarily a bad thing. A little pressure can inspire us to make necessary changes, to try something new, or to take a big next step in a career path, to name only a few examples.

But it doesn’t take much to push stress past “the red line,” to the point at which stress becomes disconcerting or even disabling. In providing care for a person with Alzheimer’s, that point can come quickly. Fortunately, there are ways to prepare for stress and for dealing with stress so it doesn’t become a burden. After all, it’s important to take care of yourself in mind, body, and spirit.

One of the biggest de-stressing techniques can be a very simple one: relaxing. Relaxation is good for everyone, and a necessary part of life in what can be a high-stress environment. Time for relaxation is often the first thing that gets squeezed out of a schedule when we get busy, but it’s important to make time for it.

Relaxation can be as simple as listening to favorite music while sitting in a comfortable chair, or enjoying a cherished hobby. Some people find keeping a journal to be a relaxing pursuit. For others, relaxation exercises, such as tai chi or yoga, are the preferred route.

There’s plenty you can do to help yourself use your relaxation time more effectively. Consider these steps:

• **Exercise.** Of course, exercise is great for your health in general, but it’s also an effective way to help you release stress. Before starting an exercise program, talk with your doctor about what exercises would be best for you. In general, you want to get a total of 150 minutes of moderate-intensity exercise every week. A brisk walk is great exercise.

• **Eat healthy.** Given the stress of caregiving, it’s all the more important that you eat a healthy diet. In general, you want to limit high-fat meats (choose lean meats or other sources of protein instead); eat plenty of vegetables and fruits; choose whole-grain foods; and prefer low-fat dairy products.

Yoga can be an effective stress reducer.

• **Get plenty of rest.** Sufficient sleep is vital to staying healthy and keeping stress at bay. Go to bed and awaken at the same times every day, and you’ll help your body get the rest it needs.

**It’s important to take care of yourself in mind, body, and spirit.**
• **Create a caregiving team.** We all need a break once in a while, and in caregiving it’s even more important to make time for yourself. That means having your own support system. Consult with family members and friends who can step in from time to time and offer a helping hand. Many people want to help, but often don’t know how or feel awkward asking if you need help. Remember, no one goes this journey alone.

• **Consider getting outside help.** Alzheimer’s support groups are available in many areas and provide a wonderful resource for caregivers. If you prefer private sessions, some therapists and counselors specialize in helping caregivers cope. There are other community resources that may be available in your locale, as well.

• **Learn as much as you can about Alzheimer’s.** Knowing what to expect with your loved one’s condition can help you understand how you (and others) can best help with caregiving.

• **Accept change.** Alzheimer’s is a progressive disease, and your loved one will go through many changes as the condition progresses. Understand that change is part of the process. To the extent possible, anticipate changes and have a plan for dealing with them as they occur.

• **Plan ahead.** Take care of long-term plans as soon as you can, so you can eliminate worry about the future as much as possible. Preparing the necessary legal documents should be part of your planning, and mapping out a course for long-term care should be part of the discussion, too.

• **Pat yourself on the back.** There is nothing easy about caregiving, and you’re an extraordinary person for providing care to your loved one. Give yourself some credit! A healthy reward once in a while is a good way to keep thinking positive.

Exercise is another great way to keep stress at a minimum.
News from the Fisher Center for Alzheimer’s Research

*Preserving Your Memory* talked to Dr. Sidney Strickland, head of the Laboratory of Neurobiology and Genetics and dean of graduate and postgraduate studies at the Fisher Center for Alzheimer’s Research Laboratory at The Rockefeller University, about the work they are doing there now.

Dr. Sidney Strickland is a recognized leader in the study of vascular factors and their effects on Alzheimer’s disease. A colleague of Dr. Paul Greengard, Director of the Fisher Center for Alzheimer’s Disease Research laboratory at The Rockefeller University, Dr. Strickland is head of the Laboratory of Neurobiology and Genetics and dean of graduate and postgraduate studies there.

Dr. Strickland and his team study the molecular mechanisms of nerve cell death and regeneration, with a special focus on Alzheimer’s disease. *Preserving Your Memory* spoke with Dr. Strickland about his research work.

**PYM: Why is inflammation such an important consideration in brain health?**

Dr. Sidney Strickland: Inflammation is a good process in most circumstances. It’s what the body uses to fight infection and tissue damage. But if it’s chronic and goes unchecked, it can be very deleterious. What we’ve uncovered is a process in Alzheimer’s disease that can lead to chronic inflammation, which can kill neurons and cause damage in the brain.

**PYM: How do the beta-amyloid peptide and fibrinogen interact with each other?**

SS: They have a physical interaction. Fibrinogen is the major protein component of blood clots. When the Alzheimer’s disease beta-amyloid peptide binds to fibrinogen, the clot that is formed is abnormal and hard to degrade. This persistent clot can promote the chronic inflammation that I mentioned earlier.

**PYM: How does the beta-amyloid peptide affect the brain?**

SS: It’s not exactly known how it affects the brain. That’s what everyone is looking for. Our results show that the beta-amyloid peptide can interact with clotting components and lead to persistent blood clots. In addition to persistent clots leading to chronic inflammation, they can lead to less blood flow to critical areas of the brain. If you don’t have blood flow to those areas, the tissues die. So persistent clots can create less blood flow and inflammation, and both those processes can end up killing cells.

**PYM: What are the prospects for new Alzheimer’s disease treatments or therapies coming out of your research?**

SS: This is one exciting aspect for us because there are new therapeutic strategies that evolve from our study. We don’t think there will be just one therapy for Alzheimer’s disease; there will probably be many therapies that attack various aspects of the disease. So if we could block the interaction of the beta-amyloid peptide with fibrinogen, it would prevent the formation of persistent clots, but it wouldn’t affect normal clotting. In this case, a person would have bleeding tendencies, but would not have formation of the beta-amyloid peptide-induced abnormal clots that can cause damage. We predict in this case that there would be beneficial effects on the cognitive dysfunction that characterizes Alzheimer’s disease.
Two years ago, Fisher Center scientists discovered that nerve cells use a process called autophagy to rid themselves of beta-amyloid, the protein associated with Alzheimer’s disease. Autophagy works by transporting proteins to cell structures called lysosomes, which then digest the proteins. The team also demonstrated that Smer28, an experimental drug-like molecule, helped cells get rid of beta-amyloid by stimulating autophagy.

The result of these groundbreaking findings was a worldwide effort to find drugs that stimulate autophagy to treat Alzheimer’s.

The same team of Fisher scientists recently discovered a cellular pathway that takes the proteins that form beta-amyloid to sites within the cell where they are digested through autophagy. A protein called AP2 recognizes the beta-amyloid-forming protein and forces it to be wrapped up in what is called a cargo vesicle, a structure that is essentially a tiny molecular cage, that then carries the proteins into the autophagy system for digestion.

These new findings will give scientists even more targets for drug development to treat Alzheimer’s. By tweaking the system that regulates cargo vesicles, future drugs should be able to reduce beta-amyloid levels in the brain.
One Caregiver’s Story

Author Deborah Shouse helped care for her mom throughout her journey with Alzheimer’s disease. She recounts the times they shared in a powerful new book.

The caregiver’s journey is fraught with challenges and difficulties, particularly when Alzheimer’s disease is in the picture. How fortunate, then, that some caregivers feel led to write down their experiences so we all may benefit from what they learned along the way.

A new book does this in a particularly potent way. Prolific author Deborah Shouse is an accomplished speaker and workshop presenter who captured the breathtaking expanse of experiences with her mom in *Love in the Land of Dementia: Finding Hope in the Caregiver’s Journey*. Throughout these pages, we accompany Shouse as she experiences the ups and downs of her mother’s battle with Alzheimer’s.

*Preserving Your Memory* talked with Deborah about her book, her mom, and the difficult, yet rewarding voyage through her mom’s Alzheimer’s. At turns funny, poignant, and heart-rending, *Love in the Land of Dementia* is a great read for the caregiver in your life.

*Preserving Your Memory*: The book’s broken into many short chapters, which are almost like vignettes. Did you intend this as you wrote it?

Deborah Shouse: My first writing was really journaling: I was writing to express my grief and confusion around my mother’s Alzheimer’s. The journaling helped me to make sense of my feelings. Later on, it helped me appreciate what was going on in the whole experience.

*PYM*: What sorts of transitions in your thinking and attitudes did you have to go through to get to the “land of dementia” with your mom?

DS: One of the first transitions was slowing down, because my mom was moving and thinking more slowly. I noticed my usual racing pace did not work with her anymore. I had to teach myself to be quieter, calmer, and more patient when I was around her. That slowing down was beneficial to me, and I actually began to look forward to it.

Another transition was letting go of the mom I had known and my expectations of how I would act and how she would act, and embracing the mom I had at each stage of her journey. That was an ongoing process.

Another transition was trying to be in the present. When I was with my mom, I practiced being appreciative of what was going on in the moment. I tried to let go of expectations and just enjoy the moment. When I could be right in the present, I was much happier.

*PYM*: What surprised you most about how you changed in response to your mom’s advancing Alzheimer’s?

DS: I learned I could keep my relationship with my mom even when her words were gone. It was an important life lesson, knowing Mom and I could still connect on so many levels—a spiritual level, a physical level, an emotional level—with touch, with eye contact, with just being together.

*PYM*: How did your changing relationship with your mother affect your relationship with your daughters?

DS: My two daughters got to see me being very vulnerable, particularly at the beginning of my mom’s journey, when I was grieving a lot. They were able to reach out to me and help me, and I felt lucky to be receiving such support from them.
**PYM:** Did your understanding of your dad change in light of your mom’s illness? How?

**DS:** One of the big gifts in my mom’s illness was my relationship with my dad. Traditionally, in my family, my mom was the emotional conduit, and my dad did not like to get involved in anything emotional. Through my mother’s dementia process, though, my dad and I connected emotionally. Seeing the depths of my dad’s love for my mom was inspiring. Even though he was grieving, he always honored and included Mom in every conversation and he helped show me ways to notice and appreciate my mom.

**PYM:** How did you separate the empathy you naturally felt toward your mother with the need to have enough distance to provide care?

**DS:** In the beginning, I almost couldn’t do that. That was the period of my most intensive grieving. Journaling helped me get my feelings out on paper, so I could be present with my mom. I also have a wonderful life partner, Ron, who helped me a lot through all of this.

**PYM:** What was grieving the gradual loss of your mom like for you? How did you manage it?

**DS:** There are a lot of losses along the path in the Alzheimer’s journey. Each one I had to sit with a while. One big loss is when your parent no longer knows your name. First I was devastated. Then one day, Mom said, “I’m sorry I can’t remember your names.” I felt such a wave of tenderness and empathy towards her; her comment took me out of myself and let me really try to imagine what all this was like for her. Even when she didn’t know my name, she usually smiled at me: she knew I was a nice person and welcomed me.

For me, the grieving process included feeling the feelings, then looking for the blessings.

**PYM:** Did it surprise you that you were able to find “in the moment” connections with your mom, even at the end of her life?

**DS:** It surprised and delighted me that that happened. I feel really lucky that I was able to see and appreciate those connections. The eye gazing was really something, and to do that with my mom was especially meaningful. My friends who have early-onset Alzheimer’s say—“We want people to know we’re still here.” My mom was still there; I was glad I worked through my grief so I could really see and appreciate her just as she was. That was really an important part of my journey.

**PYM:** At one point you write, “In the end, only love is left.” Did your ideas of love change after going on this journey of Alzheimer’s with your mom?

**DS:** Yes, this experience expanded my idea of love. Again, my father led the way for me. At one point, we were sitting in a private dining area of the memory care unit where Mom was living, and Dad said, “Isn’t your mom beautiful?” At that time, Mom was resistant to bathing, and her hair was greasy and she wore an old sweatshirt. At first, I didn’t think she looked very good. But then I began to see what my dad already knew: her inner beauty was so strong. I saw how loving she was, how elegantly she handled the loss of her memory, and how she kept her sense of humor. I was able to follow in my dad’s footsteps and even feel more love for her because we connected on a level that was beyond the rational.

I also want to mention two things that were really important to me. Early on, I made a vow that I was going to look for the gifts and blessings in the Alzheimer’s journey and that I was going to stay connected to my mom throughout the experience. That was my guiding principle all along, and it really helped me focus on what was good rather than grieve over what was lost.

I also believe in the importance of sharing our stories. The more we can talk about this disease that impacts so many of us, the more we share our personal stories of hope, humor and challenges, the more we can get the proper care for the person who has Alzheimer’s, the support and care for the family and professional caregivers, and the funding for programs and research.

*Love in the Land of Dementia: Finding Hope in the Caregiver’s Journey* is available through Amazon.com, Barnes & Noble (bn.com), and through booksellers everywhere.
“Sundowning”
Alzheimer’s Challenges at the End of the Day

People with dementia often have certain problems when it gets dark at the end of the day and stays dark through the night. This problem is called “sundowning.” The problems that get worse include increased confusion, anxiety, agitation, and not being able to get to sleep and stay asleep.

“Sundowning is a very common problem for Alzheimer’s patients and, of course, for caregivers,” says Jeff D. Williamson, M.D., chief of gerontology and geriatric medicine at Wake Forest Baptist Medical Center in Winston-Salem, N.C. “It’s very challenging to manage.”

Sundowning Symptoms
As anyone who has cared for someone with Alzheimer’s disease (AD) knows, the patient will have good days and bad days. According to the National Institute on Aging (NIA), some of the personality changes that may intensify with sundowning late in the day or during the night include the following:

- Getting upset, worried, and angry more easily
- Acting depressed or not interested in things
- Hiding things or believing other people are hiding things
- Imagining things that aren’t there
- Wandering away from home
- Pacing a lot of the time
- Showing unusual sexual behavior
- Hitting you or other people
- Misunderstanding what he or she sees or hears

Health-related problems other than AD can contribute to behavioral changes:

- Illness or pain
- New medications
- Lack of sleep
- Infections, constipation, hunger, or thirst

- Poor eyesight or hearing
- Alcohol abuse
- Too much caffeine

Problems in their surroundings are also contributors for the caregiver to consider:

- Being in a place he or she doesn’t know well.
- Too much noise, such as TV, radio, or many people talking at once. Noise can cause confusion or frustration.
- Stepping from one type of flooring to another. The change in texture or the way the floor looks may make the person think he or she needs to take a step down.
- Misunderstanding signs. Some signs may cause confusion. For example, one person with AD thought a sign reading “Wet Floor” meant he should urinate on the floor.
- Mirrors. Someone with AD may think that a mirror image is another person in the room.

Treatments
Almost all Alzheimer’s patients will have some manifestation of sundowning, notes Dr. Williamson. “So, it’s important that caregivers understand that sundowning is not caused by something they did or didn’t do,” he says. “But there are some strategies to get through this.”
According to Dr. Williamson and NIA research, there are certain behavioral strategies that can help caregivers with sundowning:

- Having a daily routine may help. Calmly reassuring and giving cues to orient the person who has dementia is also helpful in the evening and closer to bedtime. Try to keep them going to bed at the same time every night.
- Doing calm activities at the end of the day and before bedtime may help the person with dementia sleep better at night. If they are active during the day, these calm activities can make them tired and more able to sleep.
- Avoid loud noises and activity in the home at night, so the person does not wake up once they are asleep.
- Do NOT restrain a person with dementia when they are in bed. If you are using a hospital bed that has guardrails in the home, putting the rails up may help keep the person from wandering at night.
- Always talk with your healthcare provider before giving the patient store-bought sleep medicines. Many sleep aids can make confusion worse.

Take the person to places where they can move around and exercise during the day, such as shopping malls. If the person who has dementia has an angry outburst, try not to touch or restrain them. Touch or restrain them only if you need to for safety. Instead, try to stay calm and distract them during outbursts. Do not take their behavior personally.

**When to Call the Doctor**

In addition to behavioral steps that can help with sundowning, there are medication issues that can be a factor, according to Dr. Williamson.

“Depression is often an under-recognized part of sundowning,” he says, “And the patient may not be able to articulate it. There are antidepressants and anti-anxiety medicines that a physician may recommend. So, it’s important that you talk to your healthcare provider, especially when you have questions about medications.”

On the other hand, sometimes currently prescribed medicines or over-the-counter products may be creating or contributing to sundowning symptoms. Talk to the patient’s doctor any time you think that medicines may be the cause of changes in the behavior of someone who has dementia, Dr. Williamson recommends.

**When Caregivers Need Help**

Children of an Alzheimer’s patient often wonder how they can help the primary caregiver—especially when the caregiver is a mother or father. This is especially important when an Alzheimer’s patient is showing signs of sundowning, which is even more stressful on caregivers.

“I find a lot of caregivers are embarrassed to ask for help,” says Dr. Williamson. “It’s a fork in the road for some families. Children can offer to help by volunteering to stay with the patient for short periods while the primary caregiver gets a break. Church members and social club members who know the patient can do that, as well.

“And there are times when a person can be a better caregiver with the person they love by regularly taking the patient to an Alzheimer’s care center while they take a break,” says Dr. Williamson. “Families shouldn’t feel guilty about these things. Caregivers should realize that this is a good thing.”
Handling Difficult Emotions
Coping with emotional outbursts in Alzheimer’s patients

Caring for a person with Alzheimer’s can be difficult. And when the person you’re caring for gets upset and has an emotional outburst, it’s even harder.

“It’s very hard for well-intentioned family members not to take attacks or outbursts personally,” says Lisa P. Gwyther, MSW, LCSW, Associate Professor, Department of Psychiatry and Behavioral Sciences, at Duke University in Durham, N.C. “Families feel misunderstood and unappreciated by the person they are trying to help or protect.”

The most common causes for emotional outbursts, says Gwyther, include:

• Miscommunication, misperceptions, or misunderstanding of what is being said or requested
• Feeling rushed, discounted, left out, or abandoned
• Feeling threatened or lost in a world that isn’t making sense
• Untreated pain, discomfort, or illness
• Reminders of their lost capacity

“Caregivers should expect the person to respond best if he or she is treated with respect and dignity, and not marginalized or excluded,” says Gwyther. “The person needs more time, more visual or other sensory cues or reminders, more reassurance and more attention to maintaining predictable routines with less to remember.”

Gwyther adds that people living with progressive dementia can have a good quality of life. Caregivers should try to balance the person’s continuing need for both stimulation and retreat. “The person will tire easily from thinking and responding, not just physical exertion,” she says. “Individuals with dementia will have more difficulty starting new activities or remembering where they are in a task.”

What triggers an emotional outburst? Often loud, confusing environments with lots of distractions or many simultaneous conversations can upset someone with Alzheimer’s, says Gwyther. A change in environment or routine (like travel or a hospital stay) can also be upsetting, as can situations that test the person’s memory. “Loud popping sounds to veterans with PTSD, who may now have dementia, can be especially threatening,” she adds.

“Each person is different,” says Gwyther. “Certain places or activities will upset one person and comfort another.”

When it comes to handling these emotional outbursts, Gwyther advises first calming yourself. “The person is probably sensitive to your mood and non-verbal tension or anger more so than the content of what you say,” she says. Gwyther offers these additional tips to help with emotional outbursts:

• Make efforts to normalize the situation—deflect, distract, and reassure.
• Acknowledge that the person is upset and assure them you will help them feel better and stand by them until they calm down.
• You don’t have to agree with the person’s delusions, but do validate their feelings of loss or fear.
• Try to reduce fears of abandonment in a world that, to them, seems scary or confusing.
• Help the person do as much as possible for himself and find ways to acknowledge and reward contributions.

If the triggers of the emotional outbursts aren’t addressed, says Gwyther, the outbursts will escalate. “Wise families learn how to change their communication, the environment, activities or demands, to minimize disruptive outbursts,” she says.

“Families are well-advised to take time for themselves and to seek activities they can continue to enjoy both on their own and with the person,” she says. “It helps to become less task-centered, less type-A,” she adds. “Jump off the fast lane and enjoy shared moments of pleasant activities.”

And it’s important that caregivers not neglect their own well-being. “Caregivers need restorative sleep, healthy diets, exercise, respite options, social and intellectual engagement,” says Gwyther. “[They need] opportunities to share and learn from the experience of others in a similar situation—support groups, online support, and dependable listening and support of family and friends.”

“Caregivers should expect the person to respond best if he or she is treated with respect and dignity, and not marginalized or excluded.”

—Lisa P. Gwyther, MSW, LCSW, Associate Professor, Department of Psychiatry and Behavioral Sciences, Duke University
Judy Collins: The Power of Music

By Tamekia Reece
For more than fifty years, Judy Collins has wooed the world with hits such as “Both Sides Now” and “Send in the Clowns.” Now age 74, the Grammy award-winning singer shows no signs of slowing down. She is the author of several books, founder and CEO of a record label, Wildflower Records, and she’s an activist, speaking around the country about mental health and suicide prevention. Collins also still tours heavily. Recently, she was the featured performer at the 13th Annual Music Has Power Awards by the Institute for Music and Neurologic Function. Preserving Your Memory talked with Collins about the performance, her long career, and why she believes music can soothe the body and soul.

**Preserving Your Memory: How was the performance at the Music Has Power Awards?**

**Judy Collins:** Oh my goodness, it was just wonderful. It was so interesting because just as I was leaving to go [to the event], I received a letter from my neighbor’s daughter. I’d given him a copy of *Over the Rainbow*, my book and audio CD, for his grandchildren. His daughter was writing to say they had played the songs for his wife, who is suffering from dementia. His daughter said when they played the songs her mother became very animated and danced around, and for the length of the song, regained herself. I read the letter to the audience during my concert. I thought it was such a very interesting and synchronistic thing that went along with the power of music to be healing.

**PYM:** Has music helped you through the struggles [alcoholism, depression, panic attacks, grief, and bulimia] you’ve had throughout your life?

**JC:** Absolutely. For me, art and music—the practice of music, the listening to music, the attention to art in general—are all things that help our mental health. They encourage us to be mentally healthy and to be involved with our lives in a very direct and active way. I have always been involved with the verbal and the visual arts. These are the things I’ve depended on for my mental and physical health, my enjoyment, and my education.

**PYM:** One tragic situation you faced was your son’s suicide. [Her only child, Clark, battled addiction and depression for many years. He committed suicide in 1992.] Do you have advice for people struggling with grief, loss of a loved one, or mental illness in the family?

**JC:** The things I suggest to survivors and people who are witnesses to dementia and the loss of presence in their loved one is to get your life in order. Put the oxygen mask on yourself and make sure you get the help you need. Get therapy if you need it. Look for groups of people that can help you. You have to take care of yourself. Go to concerts or other places for entertainment, get a massage or facial, and take care of your feet. All of these things are important for laughter, therapy, and staying on top of your own mental health.
PYM: In your book *Sanity and Grace* (Tarcher, 2003), you mention some of the people who helped you cope after Clark’s death. When dealing with mental health issues of a family member, how important is it for people, especially caregivers, to have a support system?

JC: It’s essential. You cannot have a healthy life without a support system. Reach out to people you can talk to—spouses, friends, therapists, people in your spiritual group, anyone who can be on the same wavelength and listen to you. One of the most important things we can find in life is somebody to listen to us. My old friend Ed Schneidman wrote books about suicide and was considered to be the father of the suicide prevention movement. He felt talk therapy was instrumental in healing and that people could get through anything and live past midnight if they were in talk therapy. It’s an extreme point of view, but having done this and been in talk therapy for most of my adult life, I totally agree with him. I very much believe in human contact as a healing force.

PYM: Some reports say your mother had Alzheimer’s. Is that true?

JC: No, she didn’t have Alzheimer’s. She died of a stroke. She had a number of mini-strokes, which obviously is different from dementia, but the result is similar because the brain shuts down in certain areas, and the person disappears on you and doesn’t remember names and other things. So it’s the same kind of result, and of course it’s very upsetting.

PYM: What about your own health? You still do a lot of performing. How do you keep yourself physically and mentally healthy?

JC: I do a number of things in my regular daily life to ensure my health. For me, exercise is the most dramatic mood-altering activity I can do, so I exercise on a regular basis and I’ve been doing a form of meditation for about 35 years. I also watch what I eat and stay away from junk foods. I try to do activities like crossword puzzles, practicing piano, and making music to increase my brain health. I take vitamins, and I don’t take any mind-altering drugs or drink. I also laugh a lot. I think laughter is something that is very healing and important in terms of mental health.

Music as Medicine

A number of studies show music therapy can be beneficial to people with dementia. The Institute for Music and Neurologic Function (IMNF), in Bronx, N.Y., strives to expand the growing pool of knowledge. Its staff studies the link between neuroscience and music therapy, educates and trains future music therapists, and provides music therapy services to a broad range of people, says Concetta Tomaino, DA, MT-BC LCAT, the co-founder and executive director at the IMNF.

Music Has Power Awards

Started in 2000, the Music Has Power Awards recognizes people who have contributed to advancing knowledge about music and the brain or have otherwise helped advance the IMNF’s mission. Selecting Judy Collins as the featured performer for this year’s ceremony was an easy choice. “We like to have an artist that resonates with our mission,” Dr. Tomaino says. “Judy’s music has deep meanings for many of the people we knew would be in attendance, and Judy herself speaks about the transformative power of music and how important it has been in her and her family’s lives.”

Music and Alzheimer’s

Research and clinical practice show people with dementia still recognize music that was personally important to them, says Dr. Tomaino. “The music tends to have historical connections that are emotionally charged and representative of a certain time, person or place,” she explains. With music therapy, those particular songs can act as a gateway to seemingly lost memories.

In addition, during early dementia, use of melodies may help patients recall names of people, addresses, phone numbers, and things they need to do. Music may also influence mood, reduce agitation, decrease wandering, and help manage other behavioral issues.

Although music therapy won’t cure Alzheimer’s, it goes a long way in helping to improve the lives of dementia patients, caregivers, and their families.
Pym: You recently taped a special in Ireland for PBS?

JC: Oh, yes. We did a wonderful show at the Dromoland Castle in County Clare, Ireland. I had three guests. Ellen Ellis, a wonderful six-year-old step dancer, danced to one of my songs. Mary Black, a wonderful Irish singer, did a duet with me, and I did another duet with Ari Hest, a very fine up-and-coming American singer-songwriter. Then I sang a lot of the old wonderful Irish songs like “Danny Boy,” plus some new songs of mine like “New Moon Over the Hudson,” which is about Ireland. We had a wonderful band with pipers, guitarists, and drummers, and it was just a magical night. The special will air on WGBH (in Boston) and around the country on PBS in March.

Pym: Anything else in the works?

JC: I do 120 shows a year around the world. We usually list all the concerts on my website, judycollins.com.

Pym: Wow! How do you do it? To what do you attribute your success and longevity?

JC: Many things have contributed to my being able to sustain a career in music for 54 years and be working more and better, I think, than I’ve ever worked in my life. First, I’ve always had a positive attitude about life. I’ve had a lot of illnesses. I’ve had polio, tuberculosis, alcoholism, hepatitis, eating disorders—you name it. I’m always hopeful. I always know I’m going to live through whatever it is, somehow. I’ve also always reached out for the help I needed. I’ve gotten therapy since I was around age 23; I went to treatment and stopped drinking 35 years ago; I’ve read books on mental health; and I’ve read and listened to nutritionists and healers. I believe the discipline of my life, having a positive attitude, being willing to seek help, and having music in my life are all things have contributed to my being able to have a full and healthy lifestyle.

Pym: Any final words for the readers?

JC: Just stay in touch with the arts and music, and keep your brain and heart happy!

Music at Home

Use these tips to incorporate music into your loved one’s daily life.

• Start with songs from his youth or songs you know he once enjoyed. However, don’t be afraid to try different things. Coming up with a good playlist may take some trial and error.

• Watch the response. If your loved one seems upset or otherwise negatively affected by a particular song or type of music, remove it from the playlist. On the other hand, if she seems to enjoy a song, play it more often and try out similar music.

• Don’t overstimulate. Refrain from playing music too loudly and avoid programs or stations with commercial interruptions. Also, eliminate other distractions like the television and background conversations, noises, and movements.

• Use faster-paced music to boost mood. To induce relaxation, say, during mealtime or before bed, play or sing slower-paced, soothing songs.

• Encourage toe tapping, hand clapping, or even dancing. Music provides a good opportunity to get in some physical activity.
Aerobic Exercise: Even Better for the Brain Than We Thought

By now, most of us know that aerobic exercise is really good for the body. According to the Mayo Clinic, aerobic exercise:

- Helps you with weight management
- Helps you manage chronic conditions, such as high blood pressure and diabetes
- Activates the immune system to help you ward off viral illnesses, such as colds and the flu
- Strengthens your heart
- Boosts your “good” (HDL) cholesterol to help keep your arteries clear
- Boosts your mood
- Helps you age in a healthy way, so you can stay active and independent
- May help you live longer

Before the exercise regimen began, midway through (at the 6-week point), and after training, at 12 weeks.

The result? Researchers identified increased brain blood flow, particularly to the anterior cingulate region and the hippocampus, as well as gains in memory performance, among the participants. “By measuring brain blood flow non-invasively using arterial spin labeling (ASL) MRI, we can now begin to detect brain changes much earlier than before,” says Sina Aslan, Ph.D., founder and president of Advance MRI and a collaborator in the research. Dr. Aslan points out that increased brain blood flow in the anterior cingulate region “has been linked to superior cognition in late life.”

“I was surprised by the significant gain in both immediate and delayed memory with aerobic exercise.”
—Sandra Bond Chapman, Ph.D.

“I was surprised by the significant gain in both immediate and delayed memory with aerobic exercise,” says Sandra Bond Chapman, Ph.D., founder and chief director of The University of Texas at Dallas Center for BrainHealth, and the lead author of the research paper. “We know the brain changes by how it is used and that cognitive gains increase with practice. But our research showing that significant memory gains emerge without memory training and with aerobic exercise alone should increase our commitment to get moving.”

Among the team’s findings, Dr. Chapman took particular note of one. “One of the earliest cognitive losses that herald later emerging Alzheimer’s disease is delayed memory, so this evidence that aerobic exercise improves not only immediate but remarkably also delayed memory is very promising,” she says.

Dr. Chapman also pointed to two further insights from the research. “In addition to the meaningful gains in regional and global gains in cerebral blood flow, we found two other brain gains: (1) increased white matter integrity, (i.e., the cables connecting different brain regions allowing information to travel between brain cells) and (2) increased speed of neural response across important brain networks (i.e., a capacity that allows thoughts to be integrated more rapidly).”

It’s vital that we keep going, too, once we’ve started an aerobic exercise regimen. “What we do know is that physical exercise must be a regular practice because the brain and cognitive benefits are not lasting, just like the benefits to our physical health that are...
not maintained if we stop exercising,” says Dr. Chapman. “It is also important to point out is that the aerobic exercise must elevate your heart rate.”

So what about strength training? Also worth doing, Dr. Chapman notes. “There is little evidence documenting that strength training leads to brain and cognitive improvement; it does, however, build a stronger body, which is beneficial to our overall wellness. Strength training is also beneficial in building muscle strength, core strength, and bone density that can help prevent falls in older adults. Traumatic brain injuries from falls in older adults are one of the major causes of cognitive loss as we age.”

To further compound the positive effects of aerobic exercise, Dr. Chapman says that brain training is invaluable. “Our scientific evidence suggests that mental exercise trumps aerobic activity. Yes, the ability of aerobic activity to quickly enhance memory and potentially stave off Alzheimer’s disease is impressive and needs to be wildly practiced; to achieve even greater brain and cognitive gains requires changing the way you think. In another recent study published in Cerebral Cortex, study participants ages 56 to 71 years of age experienced significant cognitive changes and improvements in overall brain health after only 12 hours of directed brain training.”

The imperative for all of us is to get moving, says Dr. Chapman. “This study provides some of the first evidence that aerobic exercise can cause regenerative brain and cognitive gains to emerge earlier and more rapidly than previously thought possible. Since our brain is our most valuable asset at any age, we must remain committed to healthy lifestyle habits across the lifespan.”

New research shows that aerobic exercise is great for brain health.
Food for Thought
What to eat—and avoid—for brain health

It’s often said that fish is brain food … and it may not be far from the truth. But what foods should people eat—or avoid—for brain health?

“We know that midlife obesity and high saturated fat diets—the more typical Western diet—are associated with an increased risk of developing dementia,” says Valerie Wilson, MD, geriatrician and Clinic Director, Sticht Center on Aging, Wake Forest Baptist Medical Center, in Winston-Salem, N.C. “However, once people have Alzheimer’s dementia, it is less clear that a healthy, low saturated fat, low glycemic index diet is beneficial.”

Dr. Wilson explains that sugar and fatty acids are metabolized differently in the brains of people with Alzheimer’s. “There is data to suggest that eating a low-fat diet may actually worsen cognitive performance in people with memory impairment because they are dependent on these fatty acids for their brain’s metabolism,” she says.

“While I don’t recommend limiting fat, unless there is some other compelling reason, I do recommend trying to eat fruits and vegetables because of the potential benefit antioxidants have on the brain.”

Dr. Wilson also recommends eating fatty fish such as salmon, because of its omega-3 fatty acids and vitamin D.

“However,” adds Dr. Wilson, “there’s not a lot of data available looking at dietary interventions to treat dementia, and studies looking at specific vitamin supplements have not consistently proven to be beneficial.”

One thing that Dr. Wilson recommends that people with Alzheimer’s limit or avoid is alcohol, as it tends to make memory symptoms worse.

People taking medication are often advised to avoid certain foods. Dr. Wilson says. However, there are no known food interactions with the traditional medications used to treat Alzheimer’s disease.

So … what foods are good for your brain? Fatty fish, fruits and vegetables, says Dr. Wilson, particularly green leafy or colorful vegetables, because of their higher concentration of antioxidants.

“The Mediterranean diet, which focuses on eating primarily fruits, vegetables, whole grains and beans, and includes olive oil as a major source of fat,” Dr. Wilson adds, “has been shown to be beneficial in preventing or slowing down the rate of cognitive decline.”

Fatty fish, such as salmon, and brightly colored vegetables are good for your brain health.

Antioxidant foods
If you’re looking for good sources of antioxidants, try eating more fruits and vegetables. The U.S. Department of Agriculture (USDA) says the best foods are cranberries, blueberries, Russet potatoes, pecans, red beans and red kidney beans, pinto beans, cooked artichokes, and apples. The spices cinnamon and cloves also contain antioxidants, the USDA says.

Brain food
The following fish and plant sources contain healthful omega-3 fatty acids, which may help keep your brain healthy.

- Mackerel
- Lake trout
- Herring
- Sardines
- Albacore tuna
- Salmon
- Tofu
- Soybeans
- Canola
- Walnuts
- Flaxseeds
Mediterranean Vegetable Strata

Ingredients
1 small zucchini
1 small Vidalia onion
1 red or green bell pepper
½ cup sliced mushrooms
1 large whole-wheat roll
6 large eggs
¼ cup reduced-fat sour cream
4 ounces reduced-fat cream cheese, softened
4 ounces garlic and herb feta cheese

Directions
• Preheat oven to 425°F.

• Lightly oil or spray a cookie pan with olive oil. Slice vegetables and roast for about 20 minutes, turning once. Onions and peppers will take longer than mushrooms, which can be added when you turn the vegetables.

• While vegetables are roasting, cut roll into small cubes (less than an inch). Spread cubes evenly over the bottom of a two-quart baking dish. Layer vegetables on top of bread. Spread crumbled feta cheese evenly over vegetables. Beat eggs with sour cream and cream cheese. Pour egg mixture over vegetables.

• Bake at 350 degrees for 45 minutes. Let sit for 10 minutes before serving.

Serves 8. Each serving contains about 178 calories, 11 g protein, 10 g fat, 90 mg cholesterol, 9 g carbohydrates, 1 g fiber, and 326 mg sodium.
When Arizona resident Susan Christianson’s memory lapses went from annoying to concerning, she and her husband decided to raise the issue with their primary care physician. The doctor examined Ms. Christianson, then 73, and referred her to a neurologist. Following a series of in-office examinations and two MRIs, the neurologist determined that Ms. Christianson had suffered a series of what were described as “mini strokes,” which were the probable cause of her worsening cognitive issues. The official diagnosis at that point was vascular dementia. Upon her passing several years later, her family arranged an autopsy that defined Ms. Christianson’s condition as likely Alzheimer’s disease (AD) with some vascular features.

Martin Bassett, a retired writer from Michigan, began to notice minor cognitive issues when he was in his mid-60s. His physician assured him that his symptoms were just normal signs of aging. Still, Mr. Bassett decided at the age of 67 to apply for long-term care insurance as a way of covering his bases. When he failed the memory test given over the phone during the application process, he returned to his doctor with serious concerns. The doctor sent him to a psychologist specializing in neurocognitive testing. The initial diagnosis: mild cognitive impairment likely caused by hypertension. Eighteen months later, Mr. Bassett returned to the same clinician for follow-up tests. This time, the psychologist noted a dramatic decrease in function. With additional input from a neurologist, Mr. Bassett received an updated diagnosis of dementia, likely caused by blows to the head sustained on the football field and in the boxing ring during his years as a student athlete.

Floridian Angela Morrison was 73 when she asked her doctor to recommend a specialist who might be able to find the cause of what she perceived as increasing forgetfulness. As Ms. Morrison feared, a geriatrician felt that her MRI pointed to the likelihood that she was experiencing the early stages of AD. She and her husband were devastated, but they quickly put their legal and financial affairs in order, discussed future plans and joined a local support group. Five years later, when Ms. Morrison’s symptoms
had not changed, she saw a neurologist. This time, after undergoing extensive neurocognitive screening, she was told that her memory issues were nothing more than typical age-related lapses exacerbated by medication side effects; her earlier AD diagnosis had been incorrect.

Seeking a diagnosis for memory impairment can be a lot like memory impairment itself: confusing and potentially frightening. Doctors’ approaches can differ, answers can vary and the proper way forward can be unclear. However, for many individuals and loved ones living with cognitive issues, pursuing a diagnosis is the first step toward gaining a sense of control over what often feels like an uncontrollable situation.

According to neurologist Ronald Petersen, MD, PhD, director of the Mayo Clinic Alzheimer’s Disease Research Center and an active member of the American Academy of Neurology, there are many important reasons to seek a diagnosis. For example, medical exams can rule out perfectly treatable medical conditions that affect memory but have nothing to do with degenerative brain disease. And in cases where AD or other forms of dementia are definitively diagnosed, it can give patients and their families the opportunity to discuss options. Dr. Petersen addresses some of the most common questions people have about how and why to pursue a diagnosis for memory loss.

**What is the best way to start the diagnostic process?**

If you or a loved one is worried about memory loss, start your quest for information close to home. Survey family members, friends and co-workers to see if they have noticed you becoming more forgetful. If they have, then the next step is to make an appointment with your general practitioner. “Your personal physician knows you well and is familiar with your other medical issues,” says Dr. Petersen. “It’s quite possible that your memory lapses might be related to another condition, like high blood pressure, diabetes, breathing problems, or even anxiety or depression. Or you may be taking a medication that is known to alter memory.” In many cases, people’s memory is impaired by fixable conditions.

**Which doctors diagnose Alzheimer’s disease?**

If your general practitioner rules out other causes and recommends that you see a specialist for your memory issues, you will likely be referred to a psychiatrist, a neurologist, and/or a geriatrician. (In some cases, PhD psychologists also participate in the assessment and therapeutic care of individuals with memory loss but they are not licensed to dispense medications.) The ideal care team mix depends on each patient’s particular case.

**What tests are used to diagnose?**

Typically, a mix of tests are conducted to identify the precise nature of a person’s memory issues. In addition to in-office exams (where thorough medical histories should be reviewed), people will receive some combination of cognitive and neuropsychological tests, neurological...
To identify the cause(s) of memory issues, doctors perform a variety of tests. Each exam depends on the patient’s symptoms and the clinician’s preferences, but most cognitive assessments include some combination of the following:

- Patient history
- Physical exam
- Neurological evaluations
- Cognitive and neuropsychological tests
- Brain scans (MRI, CT, PET)
- Electroencephalograph (EEG)
- Lab tests
- Psychiatric evaluations
- Symptomatic testing

Tests are designed to rule out:

- Anemia
- Brain tumor
- Chronic infection
- Intoxication from medications
- Severe depression
- Thyroid disease
- Vitamin deficiency
- Stroke
- Hydrocephalus

Tests and procedures are ordered to measure:

- B12 level
- Blood ammonia level
- Blood chemistry (chem-20)
- Blood gas
- Cerebrospinal fluid (CSF)
- Drug or alcohol levels (toxicology screen)
- Thyroid function
- Thyroid-stimulating hormone level

Brain may be the next step. An MRI can provide critical information, including things to be ruled out as well as additional information about the suspected causes of the problem. By looking at a picture of what Dr. Petersen refers to as “the organ of interest,” doctors can make sure that the problems are not being caused by a brain tumor, hydrocephalus, or stroke.

How long does the typical diagnostic process take?

If a medical exam or test reveals an obvious cause of memory impairment, then the diagnostic process can be quick and clear. However, if AD or another neurodegenerative cognitive condition is suspected, then multiple appointments and follow-ups are necessary, which can take a matter of months. “If a diagnosis of some type of cognitive impairment is made, then the interval of follow-up depends on the specific diagnosis and its causes,” says Dr. Petersen. “If it’s a degenerative disease, then we’ll want to see you again in six months or a year. If it’s sleep apnea or a medication side effect, then we’ll want to see you sooner.”

Is getting diagnosed always preferable?

Some people living with the realities of memory loss might wonder whether it’s even worth pursuing a diagnosis; whether knowing the clinical name for their condition really makes any difference. According to Dr. Petersen, this is an understandable concern. However, even though getting a diagnosis might be frightening or threatening, he feels it’s always better to have the information. “First of all, it’s worth getting evaluated because you may be told you’re really okay; that your memory issues are perfectly normal symptoms of age or caused by something that’s treatable,” he notes. “On the other hand, if testing points to something in the Alzheimer’s ballpark, there are medications that can help.” In addition, he explains, if a person learns that his or her condition is degenerative before symptoms become too severe, that individual can still participate in family discussions regarding short- and long-term care strategies. “It’s always better to know than put your head in the sand,” he says.

Nobody wants a diagnosis of Alzheimer’s disease. But information can be very powerful—and empowering. With a diagnosis in hand, patients and loved ones can make more informed plans for the future while making the most of the present.

*Names and locations changed to protect privacy.
Living with Alzheimer’s Disease

Products That Make Life Easier, Simpler, and Safer

Every 69 seconds, someone in the United States is diagnosed with Alzheimer’s disease. There are now more than 5 million Americans living with the disease. What is not widely known—even by some physicians—is that there are products available that are made especially to help make Alzheimer’s patients’ lives better with the disease, and, in some cases, to help them remain living at home longer and safer.

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

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

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

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

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

For more information and many more helpful products, go to www.alzstore.com or call (800) 752-3238.
Managing a Difficult Hospital Stay

By Kevin Gault

For many people, a visit to the hospital is stressful. For someone with Alzheimer's disease, it can be frightening. It's important that families know how they can make hospital stays less daunting for loved ones who have the illness.

The main cause of this problem is the drastic change in environment. Alzheimer's symptoms often worsen with such a change, so when someone with the disease spends time in the hospital—a busy place with monitors, hallway noises, paging systems, electronic alarms, and unfamiliar people—they can become confused, restless, combative, or withdrawn.

"In this situation, you're suddenly taking the person out of a very familiar environment and putting them in a place where almost everything is unfamiliar," says Cindy Barton, RN, MSN, GNP, General Nurse Practitioner at the University of California, San Francisco Memory and Aging Center. "Often the person's sleep becomes disrupted and pain medications may make them more confused than usual. They might not understand what's going on and can't communicate well enough to report their physical symptoms and tell people they're in pain or they're scared."

Family Plays an Essential Role

This situation is also difficult for family members.

"Most families that have a loved one with dementia deal with their symptoms by having consistent routines at home," says Nina Silverberg, Ph.D., Assistant Director of the Alzheimer's Disease Centers Program at the National Institute on Aging. "For example, the person with Alzheimer's usually eats meals, takes walks, and rests at the same times every day. During a hospital stay, all of those routines are disrupted. Many hospital staff members don't have training in how to deal with dementia, so family members have the added responsibility of giving them many details about their loved one's situation. It can be quite a burden on family caregivers."

That burden often continues after a loved one returns home. According to a 2012 study by Harvard researchers, hospital visits can lead to negative outcomes for Alzheimer's patients. The research followed 771 Alzheimer's patients who lived at home and found that being hospitalized increased their chances of moving into a nursing home—or even passing away—within the following year. The risk is even higher if the person with Alzheimer's experiences delirium—an extremely high level of confusion and agitation—during their time in the hospital.

Family members can follow these tips to make their loved one's hospital visit go more smoothly:

- **Ask Questions**—At the hospital, don't be afraid to ask questions for details on the procedures your loved one will be undergoing, the risks and benefits, the expected results, and length of recovery. Ask about how the procedure and hospital stay could affect the patient's thinking and behavior. If anesthesia or new medications will be administered, find out how they will affect the family member's level of awareness.

- **Stay Close By**—"It's important that family members stay with the person as much as possible," says Barton. "Their loved one needs them there because they're probably the only people they recognize and are comfortable with. If possible, create a schedule for family members to spend time with the patient. Try to be in the room when the person wakes up in the morning, when medications are given, when catheters are inserted, and when the doctor stops by."

- **Work with Hospital Staff**—Families should partner with the hospital staff to give them as much information as possible about the patient. Provide a personal information sheet that includes your loved one's typical daily routine, medications, personal care habits, extreme behaviors (and what might trigger them), and their nonverbal signs of pain or discomfort. Tell the staff about hearing difficulties or other communication problems as well as their eating preferences. Ask hospital caregivers to do things that can speed the patient's recovery such as removing IV tubes, adding nutritious items to their diet, and getting them out of bed for walking.

- **Recognize Signs of Discomfort**—"Often, people with Alzheimer's show extreme emotions when they're suffering from a physical problem such as dehydration, a fever, or urinary tract infection," says Silverberg. "These conditions
can cause pain and in many cases, the person with Alzheimer’s can’t express that. It’s important that family members talk with physicians to find out if there is a physical problem causing these emotions.” Keep in mind signs of suffering such as a furrowed brow, labored breathing, moaning, clenched teeth, kicking, or crying. If you’re unable to console your loved one, ask for pain evaluation and treatment every four hours.

**Create a Post-Hospital Plan**—Work with hospital staff to plan long-term care or the person’s return home. Ask these questions: Will the loved one tire more easily as a result of surgery? What medications and dosages should they receive and what are possible side effects? When can the person resume normal activities? Will they be in pain and what can the family do to ease it? If necessary, ask for an in-home nurse, social worker, or care planner for post-hospital care.

**Have Empathy**—Try to put yourself in your loved one’s situation. Remember that with Alzheimer’s, a loss of the ability to communicate verbally doesn’t mean a loss of awareness. Most people who have Alzheimer’s are aware of their situation and might feel distressed about it.

“It’s like being a detective,” says Barton. “Family members should look for clues that tell them why their loved one behaves a certain way and change their environment to make them feel better. The family plays an essential role in effective caregiving. After all, the hospital staff knows how to provide medical treatment, but family members know their loved one better than anyone else.”

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**Get Connected**
The following agencies can provide information about Alzheimer’s disease and connect you with community programs and services:

- **Alzheimer’s Disease Education and Referral (ADEAR) Center**: 1-800-438-4380 (toll-free) www.nia.nih.gov/alzheimers
- **Eldercare Locator**: 1-800-677-1116 (toll-free) www.eldercare.gov
- **Family Caregiver Alliance**: 1-800-445-8106 (toll-free) www.caregiver.org
- **Caregiver Action Network**: 1-800-896-3650 (toll-free) www.caregiveraction.org
- **Fisher Center for Alzheimer’s Research Foundation**: 1-800-ALZ-INFO (toll free) www.ALZinfo.org
What kind of medical care would you want if you were too ill or hurt to express your wishes? If you are an early-stage Alzheimer’s patient or a caregiver for one, this question is even more important to settle earlier rather than later.

Advance directives are legal documents that allow you to spell out your decisions about end-of-life care, financial plans related to your care, and related end-of-life issues ahead of time. They give you a way to tell your wishes to family, friends, and healthcare and financial professionals and to avoid confusion later on.

A living will tells which treatments you want if you are dying or permanently unconscious. You can accept or refuse medical care. You might want to include instructions on:

- The use of dialysis and breathing machines
- If you want to be resuscitated if your breathing or heartbeat stops
- Tube feeding
- Organ or tissue donation

A durable power of attorney for health care is a document that names your healthcare proxy. Your proxy is someone you trust to make health decisions for you if you are unable to do so.

However, these terms and labels may vary from state to state in the U.S., notes Bradley J. Frigon, an attorney in Denver, Colo., who will become president next May of the Board of the National Academy of Elder Law Attorneys (NAELA).

Such terms include healthcare power of attorney, living will, living trust, do-not-resuscitate orders, advanced medical directives, and related labels.

“For that reason, it’s critical to talk to an attorney from the state where the Alzheimer’s patient lives,” says Frigon, “someone who practices estate planning and eldercare and knows the laws that have jurisdiction.

“For people with an early diagnosis or suspicion of Alzheimer’s, it’s very important to get these completed. Later on there may be mental capacity issues or other questions that make it more difficult,” he adds.

Planning for the end of life can be difficult. But by deciding what end-of-life care best suits your needs when you are healthy, you can help those close to you make the right choices when the time comes.

“There are a lot of people out there who just don’t want to talk about it for whatever reasons,” Frigon says. “But I always say to deal with it before there’s a crisis.”

End-of-life planning usually includes making choices about the following:

- The goals of care (for example, whether to use certain medicines during the last days of life)
- Where you want to spend your final days
- Which treatments for end-of-life care you wish to receive
- What type of palliative care and hospice care you wish to receive

Advance care planning is not just about old age. At any age, a medical crisis could leave someone too ill to make his or her own healthcare decisions.

More than one out of four older Americans face questions about medical treatment near the end of life but are not capable of making those decisions. Frigon recommends that patients or caregivers write down such questions before visiting with an estate planning or elder law attorney. Write them down or at least talk about them with someone who would make the decisions for you. Knowing how you would decide might take some of the burden off family and friends.

Advance care planning also involves learning about the types of decisions that might need to be made, considering those decisions ahead of time, and then letting
others know about your preferences, often by putting them into an advance directive. An advance directive is a legal document that goes into effect only if you are incapacitated and unable to speak for yourself. This could be the result of disease or severe injury—no matter how old you are. It helps others know what type of medical care you want. It also allows you to express your values and desires related to end-of-life care. You might think of an advance directive as a living document—one that you can adjust as your situation changes because of new information or a change in your health.

Consulting with an attorney about advance directives is also a very good exercise in thinking through how you and/or the patient want to set things up, notes Frigon.

“For instance, a power of attorney is a very good document, but you don’t hand them out on the street corner,” Frigon says. “Most people wouldn’t know what a good power of attorney looks like or contains. There is a tremendous amount of information that goes into these, so you have to sit down with an attorney who knows the issues and the law.

“To be able to deal with these issues, you have to say, what kind of process are we going to set up and when does that start? When you’re not under a crisis, you can go in and deal with these questions,” he adds.

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.
**Keeping Your Mind Sharp**

**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)

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**MATCH THESE**

Can you identify these unsuccessful U.S. presidential candidates by matching them to their vice presidential running mates?

1. ___ Robert Dole  
2. ___ Walter Mondale  
3. ___ Mitt Romney  
4. ___ Thomas Dewey  
5. ___ George McGovern  
6. ___ Al Gore  
7. ___ Michael Dukakis  
8. ___ Hubert Humphrey  
9. ___ John McCain  
10. ___ Barry Goldwater  
11. ___ John Kerry  
12. ___ Adlai Stevenson

**DROPLINE**

Take the letters in the top half of each column below and distribute them in the blanks of the bottom half so that the letters spell out a humorous observation.

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

Example: E — ELECTRIC — ELECTRIC MIXER

---

**LEAPFROG**

Here’s a list of kitchen gadgets — one two-word term for each number. Their letters are in the correct order, but they overlap. All you have to do to find the gadgets is separate the letters.

Example: EMLEIXCERIRIC — ELECTRIC MIXER

---

**VISIT US AT KAPPAPUZZLES.COM**

Preserving Your Memory

winter 2014
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 those solving aids are not provided. The second puzzle is also a thematic puzzle: the title "The Light of Day" is a hint. Have fun testing your knowledge while doing something that’s good for you!

**Across**
1. Best on a team (abbr.)
2. Treasury dept.
3. “Healthy" cooking oil
4. Summon a lamp genie
5. Onetime video game leader
6. Zwei follower
7. Metallic rock
8. Joie de vivre
9. 1951 Clift classic, with "A"
10. Mem. of Congress
11. Fred’s twinkle-toed sis
12. They catch rays
13. SEATO’s sphere
14. Caesar’s summation starter
15. British clothespin
16. Clean air gp.
17. Serpent’s tooth
18. Mem. of Amer., in baseball
19. Opposite of Amer., in baseball
20. Where llamas lope
21. They catch rays
22. One, in Berlin
23. In one, in Berlin
24. Class
25. "Venus de ________"
27. Drifted off
28. Spanish "mister"
29. Singer Campbell
30. Fruit Loops bird
31. Gush
32. Spanish hurrahs
33. D-H connection
34. Where llamas lope
35. Italian, in baseball
36. West coast view
37. Pertaining to certain queens and drones
38. Pertaining to certain queens and drones
39. One, in Berlin
40. Archer of "Fatal Attraction"
41. Basis of economic activity
42. Florida nickname
43. AOL, e.g.
44. Peeples of "Fame"
45. And so forth: abbr.
46. Three: prefix
47. Hard-to-find shoe width
48. ________ and sciences
49. Win at musical chairs
50. Shamrock isle
51. Subterfuge
52. Lobbying gp.
53. Fib

**Down**
1. Measure of economic activity
2. Web address: abbr.
3. Spiritual hunger
4. King, in Caen
5. Church coffee pot
6. Daily double, e.g.
7. Feeder filler
8. Alternative indicator
9. Ancient France
10. Archer of "Fatal Attraction"
11. "Aida," for one
12. Hangover headgear
13. Singer Campbell
14. Baby of "Aida"
15. Clift classic, with "A"
16. "The Light of Day" (famed WWI spy)
17. Mata (famed WWII spy)
18. Mad. of "Matlock"
19. "Joie de vivre"
20. Mem. of Congress
21. Friendless fellow
22. Take up again
23. Craze
24. Role models
25. Friendly non-fellow
26. Destined for
27. Intl. pact
28. Writer Wiesel
29. Pastrami parlor
30. Singer Campbell
31. Slippery banana
32. Spanish hurrahs
33. D-H connection
34. Where llamas lope
35. Fresh
37. Expediency initials
38. "Cruella and me!"
39. Linda of "Fame"
40. Fascinated by
41. 49, with "A"
42. Florida nickname
43. AOL, e.g.
44. Peeples of "Fame"
45. And so forth: abbr.
46. Three: prefix
47. Hard-to-find shoe width
48. ________ and sciences
49. Win at musical chairs
50. Shamrock isle
51. Subterfuge
52. Lobbying gp.
53. Fib

**The Light of Day**

1. Guiding rope
2. Florida nickname
3. Spiritual hunger
4. Summon a lamp genie
5. Church coffee pot
6. Daily double, e.g.
7. Feeder filler
8. Alternative indicator
9. Ancient France
10. Archer of "Fatal Attraction"
11. "Aida," for one
12. Hangover headgear
13. Singer Campbell
14. Baby of "Aida"
15. Clift classic, with "A"
16. "The Light of Day" (famed WWI spy)
17. Mata (famed WWII spy)
18. Mad. of "Matlock"
19. "Joie de vivre"
20. Mem. of Congress
21. Friendless fellow
22. Take up again
23. Craze
24. Role models
25. Friendly non-fellow
26. Destined for
27. Intl. pact
28. Writer Wiesel
29. Pastrami parlor
30. Singer Campbell
31. Slippery banana
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41. 49, with "A"
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44. Peeples of "Fame"
45. And so forth: abbr.
46. Three: prefix
47. Hard-to-find shoe width
48. ________ and sciences
49. Win at musical chairs
50. Shamrock isle
51. Subterfuge
52. Lobbying gp.
53. Fib
After you have located and circled in the diagram all of the words in the Word List below, read the leftover (unused) letters from left to right, line by line, to reveal an appropriate message written by Walt Disney. The words from the list are found in the diagram reading forward, backward, up, down, and diagonally, and always in a straight line.

You are looking for a 57-letter phrase.

**Hidden-Message Word-Find**

**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.
Match These


Hidden Message

Fancy being remembered around the world for the invention of a mouse.
Finding Help in Unexpected Places

Linda, a loving daughter from Ray, Mich., can’t help but concede the daily challenges she faced while experiencing the highs and lows of daily care for her aging parents. “It was very scary,” she says. Putting on a brave face may help many caregivers confront these challenges, but tremendous courage is also required to admit we can’t do everything.

Linda may have felt alone in her frustration, but many Americans find themselves in similar situations. With roughly 10,000 seniors turning age 65 every day in the United States, it can be hard to imagine that today’s available resources are able to effectively accommodate this quickly growing segment of the population. For caregivers seeking outside help, recent research shows 59% of families erroneously seek “nursing home” as a care type for a loved one until, after becoming more educated about the process, they realize it may not necessarily meet the senior’s needs.

The encouraging truth, however, is that there are myriad resources that caregivers and family members can use to consistently help meet the challenges of caregiving.

A Place for Mom, the nation’s largest senior care referral service, connects families with a trained, local specialist to provide free assistance in the senior care search process. A nationwide organization, A Place for Mom carries out its mission of being a comprehensive senior living resource through payment from the participating senior communities in their network.

Not sure where to turn, Linda contacted A Place for Mom (toll-free 866-333-0740) for help. Acting as a central hub, the organization aided Linda with her search and pointed her to the available resources that fit her family’s specific needs.

Linda, just one of the tens of thousands of families A Place for Mom helps each month, could not help but gush about her experience. “We are so very grateful for the service you provide. It was comforting to know that there was a person to turn to that seemed to have the answers. Caring for an ailing parent is very scary and you alleviated so much of that fear”.

The numerous benefits of calling A Place for Mom include allowing family members to ask questions that specifically address their loved one’s needs. Advisors provide peace of mind and answers to questions families may not necessarily feel comfortable asking anyone else, taking on the roles of both a senior living specialist and a shoulder to lean on.

Those seeking an opportunity to provide their loved one with services beyond what can be provided at home can determine their needs and budget with the help of an advisor, setting an early tone for the search process. With a focus on specific needs—a recent study showed that pet-friendliness, swimming pool access, on-site medical attention, a working beautician, and in-home meals are the most sought-after amenities—search time is significantly reduced, allowing the senior quicker access to the right type of care.

Diana, a caring daughter-in-law in Newington, Conn., whose experience was similar to that of Linda’s, reinforced the notion that the most educated consumers tend to have the most positive results. “Thank you for your enormous role in my in-laws’ move. You were always so friendly, so calm, so helpful through the process, and I truly believe that they are now in a place where life will be easier and more fun for them.”

Call A Place for Mom today at 866-333-0740 to speak with a trained specialist (Monday-Friday 5:00 AM-9:00 PM and Saturday-Sunday 8:30 AM-5:30 PM Pacific Time).
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.

Visit ALZTalk.org for the most comprehensive Alzheimer’s community resource online. Brought to you by the Fisher Center for Alzheimer’s Research Foundation and ALZinfo.org

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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. Over 5 million people currently suffer from Alzheimer’s disease. The Fisher Center Foundation recognizes a need to increase awareness of the disease as well as educate the public on Alzheimer’s research and patient care.

To subscribe to Preserving Your Memory, please see reverse side, or visit www.alzmag.org