Penny Marshall
Talks About Her Mom and Her New Book

A Second Opinion
When It's Time to Get One

A New Approach to Caregiving

The latest news on Alzheimer’s research and treatment
ALZinfo.org
Continuing To Set The Standard In User Experience For Those In The Alzheimer’s Community

Snap a photo of this QR code* to get more information about Alzheimer’s disease!

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Resource Locator
Find a doctor, facility, long-term care information, and more Alzheimer’s and dementia resources in your area by zip code. Listings include phone numbers and directions.

Ask The Experts
Our experts are here to give you a personal answer to your dementia and Alzheimer’s questions. No question is too big or too small.

Preserving Your Memory
Readers can download these pages online and find out the latest research on Alzheimer’s, caregiving tips, and strategies for healthy living.

Social Networking
You are not alone. We have over 380,000 Facebook friends and the online social network ALZTalk.org to help you stay connected when it’s convenient for you.

Caregivers Corner
Tips for caregivers, including: what you need to know for traveling with your loved one, what to ask an elder law attorney, the Clinical Stages of Alzheimer’s disease, and more.

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A Breath of Fresh Air

The days are getting longer, and the weather is just starting to warm up a bit. We hope this issue of Preserving Your Memory has arrived in time to help you celebrate spring.

Our cover story is a chat with writer/director/actor Penny Marshall about her mom and her new book (page 18). We also talked with Maura O’Malley of Lifetime Arts about the innovative MetLife Foundation Creative Aging Libraries Project, which entered its second phase in December 2012 (page 14).

Tom and Karen Brenner have authored a new book detailing their work with Alzheimer’s and dementia patients, and it’s full of ideas for caregivers seeking to reach their loved ones (page 12). And for those whose loved ones have received an Alzheimer’s diagnosis, we look at the importance of getting a second opinion when called for (page 27).

On the research front, we talk to Fisher Center scientist Jean-Pierre Roussarie about his work in Alzheimer’s research (page 11). And we learn about current directions in the search for better Alzheimer’s drug treatments (page 30).

We hope this issue of Preserving Your Memory is a breath of fresh air for you.

Betsey Odell
Editor in Chief

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

U.S. Lagging Behind in Alzheimer’s Support

A report from the U.S. Senate Special Committee on Aging found that among five nations, the U.S. is falling behind in supporting the growing number of people with Alzheimer’s disease and other forms of dementia.

Notable among the five nations—France, Japan, Australia, Great Britain and the U.S.—France is now implementing its third plan to address Alzheimer’s as a nation. The U.S. issued its first plan in May 2012.

The report examines trends that are currently under way in all five countries. These trends include coordinating research more effectively, diagnosing Alzheimer’s more reliably and improving training in dementia care by medical practitioners. Among the issues examined is the degree to which home-care services are available to people with Alzheimer’s or other forms of dementia.

The U.S. lags behind the others in paid long-term care support for people over age 65; home-based care provided for people over age 65; and the amount of hours of unpaid care provided by family caregivers.

Alzheimer’s Drug to Be Studied Again

An experimental drug from pharmaceutical company Eli Lilly that had mixed results in previous trials will be studied anew, according to a company spokesperson.

The drug, solanezumab, was targeted at people with mild to moderate Alzheimer’s disease, but failed to significantly improve cognition or daily functioning of people with mild to moderate Alzheimer’s in previous research. But the drug did show promise in improving the cognition of people with mild Alzheimer’s when they were separated out from the larger study results.

The new study, which will begin in the third quarter of 2013, will look more closely at how the drug affects people with mild Alzheimer’s. The drug targets beta amyloid, a protein found in the brain of people with Alzheimer’s. The study will focus on 1,000 people age 70 to 85 who have varying levels of beta amyloid in their brains.

“We remain encouraged and excited by the solanezumab data,” David Ricks, a senior vice president at Lilly and president of Lilly Bio-Medicines, said in a statement. “We are committed to working with the F.D.A. and other regulatory authorities to bring solanezumab to the millions of patients and caregivers suffering from this devastating disease who urgently need this potential treatment.”

Dr. Reisa Sperling, professor of neurology at Harvard University, is leading the trial. She says her team hopes to find that solanezumab will slow memory decline by as much as 30 percent.

New Research Points to Possible Alzheimer’s Vaccine

A Canadian research team from Université Laval and CHU de Québec, along with pharmaceutical firm GlaxoSmith-
Kline (GSK), has found a way to stimulate the brain's natural defense mechanisms in people with Alzheimer's disease. The breakthrough discovery could lead the way to a treatment for Alzheimer's and even a vaccine to prevent the disease.

The researchers identified a molecule called monophosphoryl lipid A (MPL), which stimulates the activity of the brain's immune cells. When injected into mice with Alzheimer's symptoms over a period of 12 weeks, up to 80% of beta-amyloid plaques in the mice brains were eliminated. Beta amyloid has been closely associated with the development of Alzheimer's disease. When tested over the same period, the MPL-treated mice showed significant cognitive improvement.

“When our team started working on Alzheimer’s disease a decade ago, our goal was to develop better treatment for Alzheimer’s patients,” explained team leader Dr. Serge Rivest, professor at Université Laval’s Faculty of Medicine and researcher at the CHU de Québec research center. “With the discovery announced today, I think we’re close to our objective.”

Space Travel Could Worsen Alzheimer’s, Study Finds

A NASA-funded study of lab mice found that the radiation one is exposed to in space might harm the brain and accelerate the development of Alzheimer's disease.

In the study, lab mice were bombarded with varying doses of radiation equivalent to what they would encounter in space travel, including on a mission to Mars. After exposure, the mice were tested for their ability to recall certain objects or locations. Mice exposed to radiation were far more likely to fail those tasks, researchers found.

NASA is currently planning a mission to an asteroid in 2021 and to Mars in 2035. The agency has been funding research into the effects of cosmic radiation over the past 25 years in order to develop countermeasures and to determine the risks to astronauts of extended space travel.

“Galactic cosmic radiation poses a significant threat to future astronauts,” said Michael O’Banion, a professor at the University of Rochester Medical Center and senior author of the study, which was published in the scientific journal Plos One. “This study shows for the first time that exposure to radiation levels equivalent to a mission to Mars could produce cognitive problems and speed up changes in the brain that are associated with Alzheimer's disease.”

Study: People with MCI Have Trouble Processing Information

It is well known that many people who have mild cognitive impairment (MCI), which can be an early stage of Alzheimer’s disease, have short-term memory problems. A new study focused on people with MCI who have trouble processing semantics and knowledge-based information.

In this study, published in the American Journal of Psychiatry, people with MCI and Alzheimer’s, along with cognitively fit people, were tested on their ability to process semantic information. The tests involved determining which of two objects, such as an ant and a house, was larger. The study found that people with MCI or Alzheimer’s had a harder time telling which of the objects was larger when the two objects were depicted at a similar size.

“This finding suggested that semantic processing was corrupted,” said Dr. Terry Goldberg, Ph.D., a professor of psychiatry and behavioral science at the Hofstra North Shore-LIJ School of Medicine and Director of Neurocognition at the Litwin Zucker Center for Research in Alzheimer’s Disease and Memory Disorders at The Feinstein Institute for Medical Research in Manhasset, N.Y. “MCI and AD (Alzheimer's disease) patients are really affected when they are asked to respond to a task with small size differences.”

Deep-Brain Stimulation Shows Promise

Using deep-brain stimulation via a pacemaker-like device implanted in the brain can help improve the symptoms of Alzheimer’s disease, scientists have learned in a pilot study.

Researchers at Johns Hopkins University found that six patients who were tested showed slight improvement in memory and a slower decline in cognitive function after deep-brain stimulation.

PET scans of the test subjects’ brains showed slightly improved glucose consumption in the brain, which is a positive sign. Glucose consumption decreases in the areas of the brain that Alzheimer's disease affects.

Deep-brain stimulation could open a new door to treating Alzheimer’s disease should further testing with larger numbers of patients show that it is useful.

Check the Fisher Center website (www.ALZinfo.org) often for up-to-date and expert-reviewed scientific news.
Picture a woman who is a serious clotheshorse. She spends a great deal of time building her wardrobe, finding just the right pieces. She then carefully plans out each day’s outfit, matching different looks and colors for optimal stylish impact. These day-to-day experiences with clothing and accessories are positive, even enjoyable for her.

Now imagine this same woman several decades later. She has Alzheimer’s disease, and opening the door to a closet full of clothing—an activity she once found pleasurable—fills her with anxiety. The vast number of choices makes selecting an outfit overwhelming. And once she does manage to stumble upon a suitable article or two, dressing presents an entirely new set of challenges. Her daughter, who is also her caregiver, is equally exasperated by the experience.

This hypothetical scenario represents what many Alzheimer’s caregivers and their loved ones go through on a daily basis, says Brittany Barnet, a certified dementia care professional, and president of Healthcare Products, LLC. “Dressing poses a series of challenges for someone who has Alzheimer’s disease,” she says. “Obstacles include choosing what to wear, getting clothes on and off easily, and struggling with zippers and buttons. It’s important to minimize these challenges for both the individual and the caregiver.”

Thankfully, there are ways to make the processes of clothing selection and dressing easier on both parties. Here are some tips recommended by eldercare experts:

**Organize Your Loved One’s Closet and Drawers**

Organization is an important first step. If your loved one is still in the early stage of Alzheimer’s disease, you should allow him or her to select daily outfits. This action can promote self-esteem and allow the person with dementia to still feel a sense of control over his or her own life.

As the disease progresses, wardrobe selection can become more overwhelming. You can help reduce the confusion associated with this task with a good spring-cleaning of your loved one’s closet and drawers.

Your first step in the process should be to remove any unnecessary clothing. In the beginning, go ahead and get rid of anything your loved one no longer wears. You can pare down the clothing selection even further by keeping off-season clothing in a different closet.

As you organize, it’s also helpful to categorize items—shirts with shirts, pants with pants, and so on. A helpful way to assist your loved one in remembering which drawers to use is to cut out a magazine or catalog picture of certain categories of clothing and then tape those pictures to the corresponding drawers. For example, tape a picture of a nightgown to a drawer containing sleepwear.

Once the Alzheimer’s disease has reached a moderate stage, you will want to limit your loved one’s choices even further, and eventually get more involved in helping him or her select clothing. Perhaps at this point, you can lay out two outfits for your loved one each day, and then let him or her choose what to wear from that small selection. According to Barnet, this will still allow your loved one some autonomy, while making the decision process easier and less stressful.

When it comes to advanced Alzheimer’s disease, it might be wise to limit your loved one’s clothing choices altogether. Removing most or all of the stored clothing from the dressers and closets in his or her immediate living area may be a necessary step to prevent confusion and distress.
Select Alzheimer’s-Friendly Clothing
Making sure your loved one has appropriate clothing may mean getting rid of some of his or her existing wardrobe. It might also require buying new clothing. Here are some tips that will help you make the right selections:

• Opt for tops that fasten in the front rather than pull over the head.

• Look for shirts, sweaters and jackets with Velcro fasteners. If you are unable to find any, you can add the fasteners to existing clothing items (or have a tailor or seamstress do so).

• Choose clothing that is loose-fitting and stretchable.

• Ensure that socks are snug, but not tight, and of the “no-skid” variety.

• Buy non-slip shoes that don’t have laces.

• Stock up on duplicates of wardrobe items your loved one likes to wear repeatedly.

• Lean toward durable fabrics, and avoid clothing with special washing requirements.

• Consider clothing that fastens in the back if your loved one has a problem with repeated disrobing.

• Don’t forget other specific doctor-recommended clothing—such as circulation-enhancing socks or diabetic shoes—your loved one may need.

Hygiene Matters
Because dressing is often such a challenging event, it may be tempting at times to let your loved one go a day or two without changing clothes. Avoid this if at all possible. Changing is necessary for optimal personal hygiene. Where undergarments are concerned, frequent changing helps prevent urinary tract and other infections.

Looking for Clothing Designed Specifically for People with Dementia?
Visit The Alzheimer’s Store at: www.alzstore.com

Bath capes and non-slip shoes can be helpful for Alzheimer’s patients.

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• Don’t forget other specific doctor-recommended clothing—such as circulation-enhancing socks or diabetic shoes—your loved one may need.

(continued on page 38)
A Moment in Time

I have a sister whom I love with all my heart and I have a best friend whose mother, whom I love with all my heart, are both suffering with the insidious disease that has a few different labels. Whether you call it Alzheimer’s or dementia, as you all know it steals your memory, and you feel that you lose those precious people in your life long before you lose them to death. I wrote this poem in their honor, and in honor of all the brave families out there who are losing their loved ones to this horrible disease. I am sure you will recognize in it a “moment” that you have had.

A Moment
You called me by my name today
Your eyes were clear as a star-filled sky
My heart was filled with dismay
What made today different from all the days gone by
You said, “I love you” today
The joy I felt was sublime
“Mamma,” I replied, once again you are mine
What made today different from all the days gone by
Today I caught a glimpse of all your yesteryears
When everyone knew your name
And were addicted to your fame
When you were sought after
For your special brand of laughter
What made today different from all the days gone by
As I look eagerly into your face
Wanting more and more of your good grace
I see the clouds begin again
The blankness that has become familiar
Swooping down in fear and anger
Robbing you of you
Robbing me of you
Robbing the world
Of all your splendor
What made today different from all the days gone by
Today, I received a gift
And that gift was a moment, just a whisper of a moment
With my mamma!

I would like to say to all of my nieces and nephews up in Newfoundland, who are tirelessly caring for my big sister, “thank you” from the bottom of my heart and please “stay the course”—I know how much you all love her and she is so special. To my friend Lina I would like to say, you are such an incredible daughter to your mom. So few people in life give to a parent as you do, “stay the course”—she is so special. And for anyone out there who is caring for a loved one with this illness or any other, “stay the course,” as I am sure your loved one is special!
News from the Fisher Center for Alzheimer’s Research

Preserving Your Memory talked to Dr. Jean-Pierre Roussarie, postdoctoral associate at the Fisher Center for Alzheimer’s Disease Research Laboratory, about the work they are doing there now.

Preserving Your Memory: Please tell me about the research you’re currently doing in Dr. Greengard’s lab. What is the nature of the research? What are you targeting?

Dr. Jean-Pierre Roussarie: My approach is slightly different from the usual ones. I am trying to understand why certain brain regions are hit harder than others by Alzheimer’s disease (AD). In other words, what makes the brain region that controls the formation of recent memories more vulnerable than other brain regions in Alzheimer’s disease, and how can we protect these vulnerable brain regions from the ravages of this disease?

PYM: If you had to sum up your work in a few sentences, what would you say?

Dr. Roussarie: It is clearly not the whole brain that is affected by AD. At early stages, only regions involved in the formation of new memories stop functioning while the rest of the brain remains normal. To understand why these regions are particularly vulnerable, we are comparing all the proteins present in vulnerable regions to those present in resistant regions so that we can pinpoint proteins that cause the vulnerability and proteins that cause resistance.

PYM: What have you learned thus far from your research?

Dr. Roussarie: We have made a lot of progress. We were able to identify a very small number of proteins that are present only in vulnerable regions and not in resistant regions, as well as proteins present in resistant regions but not in vulnerable regions. We are now investigating whether these proteins indeed play a major role in causing vulnerability or resistance. We have two approaches. The genetic approach, for which we are collaborating with the renowned Alzheimer’s geneticist Rudy Tanzi, is to learn if Alzheimer’s patients have mutations in any of the proteins we have identified. If such mutations were associated with increased risk for developing Alzheimer’s disease, this information would make us more confident that the mutated protein causes the brain cells in that region to be more vulnerable to Alzheimer’s disease. We already have one promising candidate protein that is present at much higher levels in resistant brain regions. We recently discovered that certain mutations in this protein are associated with the risk of getting AD.

Our other approach is to use animal models. We use the really great tools that the Greengard lab has been developing for many years. They allow us to manipulate the quantity of proteins in the brain of an animal model in any region we want to study. We plan to change the levels of proteins we have associated with vulnerability to see if brain cells become more or less protected in different animal models of AD. These two approaches will tell us which proteins are the most important for protecting or harming brain cells in AD. The proteins are likely to become very promising new therapeutic targets.

PYM: What impact might your work have on Alzheimer’s diagnosis or treatment in the future?

Dr. Roussarie: The ultimate goal of our work is to be able to prevent vulnerable cells from degenerating. If we find compounds that protect vulnerable cells, we could manage to stop the progression of Alzheimer’s symptoms if we treat patients very early on with these compounds.

PYM: What directions can you see your work taking from here?

Dr. Roussarie: We still need to refine our understanding of the vulnerability of specific brain regions in Alzheimer’s disease. Once we find the proteins responsible for vulnerability, the next step is to find drugs that target these proteins. Given the decades of experience of the Greengard lab and the great expertise of its scientists, I am very hopeful that we will achieve our goals.
Caregiving for a person with dementia or Alzheimer’s disease can be fraught with frustration, but it also can be rewarding in ways that may surprise a caregiver. Getting to those rewarding moments is the subject of You Say Goodbye and We Say Hello, a new book by husband-and-wife team Tom and Karen Brenner. The Brenners—Tom is a gerontologist, trainer, and researcher in the caregiving field, while Karen is an experienced Montessori educator who now works with Tom on Brenner Pathways, the couple’s business—have been featured speakers at conferences on aging for years.

In fact, the book emerged from a frequent request the couple heard at the conferences where they spoke. “Often at these talks, people would come up to ask, ‘Where can we buy your book?’” says Karen. “A few years ago, one of the attendees asked us, ‘Don’t you think you owe it to the aging community to write a book?’ So we were encouraged to write it down.”

What they wrote down is a wealth of real-world experiences where they have been able to reach dementia patients by applying Montessori methods to their work. The Montessori Method refers to the work and philosophy of Maria Montessori, an Italian physician and educator from the late 19th and early to mid-20th centuries whose pioneering work with disadvantaged children opened the door to a more humane, compassionate approach to childhood education. Montessori developed the use of child-sized furniture and child-appropriate educational materials to reach children previously thought unreachable, and her philosophy embraced the encouragement of self-discipline and self-inspired achievement. The results were so successful that her methods have been used around the world in all types of schools (including Montessori schools) to help children succeed in learning.

In their many years of experience working with elder-care facilities and memory enhancement centers, the Brenners came to see that applying Montessori methods could achieve breakthroughs with people with dementia, as well. “Through it all, Karen and I believe that one of the fundamental aspects of this process is that learning never ends,” says Tom. “To a lot of people who have worked in the dementia field, it is an earth-shattering concept when you give them the news that people with dementia can still learn.”

And learn they do. Throughout You Say Goodbye and We Say Hello, the Brenners document astounding instances in which using or adapting a Montessori tool led to a moment of real connection with a person with dementia or Alzheimer’s. In one case, Tom and Karen encountered a man who had been a farmer and who had advanced dementia. He and his brother had both been placed in the memory enhancement center and they could no longer handle farming duties. “So I was thinking, how can I engage people who have this interest?” Tom recalls. He obtained some tractor pictures, had them laminated, and simply asked the gentleman, “Would you like to look at some tractors with me?” The man agreed. They came upon one picture that showed the tractor in high grass. Tom said it looked broken, but the man gently corrected him. “Young man, listen: That tractor ain’t broken. It’s just been parked in high grass. Sometimes you have to look deeper.’ Truly, that has become a core principle of our work.”

Another core principle of the Brenners’ work and the book is to meet people where they are, without expectations. “People with dementia are not the walking dead, being in a relationship with someone who happens to have this condition is not just one long goodbye,” the Brenners write. “We have to find a new way to say hello; it is our job to find a way to be in relationships.” Part of that
process is using positive language in talking with caregivers and people with dementia. “We believe that being a caregiver is an opportunity to be more than we thought we could be,” says Tom. “We fully realize how demanding, exhausting, and heartbreaking this work can be. However, if we can get caregivers to think in a more positive way about the work they’re doing, this can transform their caregiving role and how they feel about what they do.”

Another key point the Brenners make in the book is the importance of what is called “procedural memory,” or “muscle memory,” in connecting with people with dementia. This can be seen when a natural object is placed in the hands of a person with dementia. In one instance, Tom brought some old hubcaps with him to a center, where he invited one man to polish hubcaps with him (using non-toxic polish). “This guy starts telling me war stories from Vietnam, like he’s sitting [on] the footlocker in the barracks, talking to another GI—he’s back polishing his boots, or his brass, and we’re talking war stories. I was really astonished!”

Storytelling (as well as reciting poetry and sharing jokes) is another important piece of the Brenners’ work, as they outline in the book. “Moments when patients are sharing their stories are moments when they are present with us. These moments, no matter how brief or how fleeting, can be times of great meaning and wonderful, deeply felt connection,” the Brenners write. “It is these moments of soul-to-soul connection that are captured in the stories that people tell us. It is through these stories that the spirit of the people we meet in our work comes shining through the fog of dementia.”

You Say Goodbye and We Say Hello is an inspiring, eye-opening look into how using The Montessori Method and creating a positive environment can deepen the connection between caregivers and the people they love.

You Say Goodbye and We Say Hello is available through Amazon.com and as an iBook through the Apple Store. You can learn more about Brenner Pathways at their website, www.brennerpathways.org.
A program aimed at engaging older Americans with the arts in public libraries that began in New York has now rolled out to 18 public libraries in Boston, Dallas and Miami, thanks to continued support from MetLife Foundation.

The MetLife Foundation Creative Aging Libraries Project is designed and administered by New Rochelle, New York-based Lifetime Arts, Inc. This second phase of the project began in December 2012 and continues through this spring. The project connects professional teaching artists with older adults in free instructional arts workshops (in all disciplines) held at public libraries. The project is designed to foster mastery and promote meaningful social engagement, considered two key ingredients for positive aging.

“With this new set of creative aging programs, MetLife Foundation is helping us share Lifetime Arts’ successful program model with major library systems beyond New York and helping shift ‘senior’ programming from passive entertainment to engaged learning,” says Ed Friedman, Executive Director of Lifetime Arts.

We spoke with Lifetime Arts President and CEO Maura O’Malley about this new phase of the project and the broader implications of positive aging nationwide.

**Preserving Your Memory: When we last spoke, you mentioned that the MetLife Foundation Creative Aging Libraries Project would roll out to libraries beyond New York State. That has now happened. How did it happen?**

**Maura O’Malley:** It happened initially because MetLife Foundation supported pilots in three cities—Miami, Dallas, and Boston. MetLife Foundation had been paying attention to our work in New York City, which had received national attention because it demonstrates that active, engaged learning in the arts has significant benefits for older adult participants—and because it provides new programming for public libraries — helping them to respond to the growing demand for meaningful programs for today’s older adults (55+). MetLife Foundation wanted to bring the work out beyond New York City, and now we’ve rolled out to 18 libraries in three cities. In each of those cities we trained artists and library personnel. The libraries were chosen because of their interest in serving older adults, demographics, and other factors, such as the strength of their arts communities. These programs are getting under way shortly and throughout the spring. They run the gamut, all disciplines. The projects have been enthusiastically received and endorsed. It’s fun working with the different cities. The Institute for Museum and Library Services (the federal agency that oversees libraries from a federal level) is encouraging us to roll this out more broadly, so we’re currently writing a proposal to expand our work out to 18 more library systems across the country. Right now we’re in the midst of a two-year pilot. We’ve been encouraged by all of our partners to roll this out in a sort of national expansion to create an affiliate group of libraries, and we’ll work with them over the next 3 years to help them build their capacity to do this work, including professional training, access to resources, etc. With the American Library Association we’re currently developing an online toolkit that we’ll have ready by June 2013, which will provide information, templates,
etc., to librarians across the country. So this is becoming very rapidly a national initiative. Our role in helping build this is becoming more prominent, too. AARP Foundation has taken notice of the work and they’re supporting the libraries project, and they’re taking a look at this work because it is effective in combating isolation among older adults. In a series of 8-10 weeks, people come together around the learning facilitated by a professional teaching artist, and these artists are able to create an environment where adults can learn new skills and build community. These projects have all been unique, every library program is unique because the adults who come to them are unique, as well as the teaching artists who conduct the programs. Public libraries are free and open to the public, welcoming to older adults. People can take risks around learning, they’re encouraged, and their achievements are honored and shared. They have an enormous impact on people’s lives.

One example: In one of the culminating events of a choral ensemble program, two people announced their engagement.

Preserving Your Memory: The project promotes mastery of an art form as well as meaningful social engagement for its participants. Why are these facets so important to project participants?

Maura O’Malley: By this we mean learning new things, and making new friends. Part of the idea is that as people age, this sort of natural aging process, people experience a series of losses—they stop working, people move away, kids leave home, sometimes they lose a spouse. So making connections is critical, and these projects where people come together around learning are extremely potent vehicles for helping people connect in new ways to other people and to their own lives. In every case, people have had amazing things happen. People are learning new things and sharing them. Every project culminates with a public sharing of some kind—a performance, or an art show, etc. So it begins to shift the way people think about aging, away from the negative view of aging to a positive view, one where life is ripe with opportunity and challenge and engagement. So all this kind of resonates with lots of different people, everyone in this age range, 55 and up, up to 95 and 98 years old. All kinds of people are all the sudden unleashed and able to express themselves. We’re all in this same club, we’re all headed in this direction, and even now we have elderly parents, or we’re boomers and getting there ourselves. The teaching artists find a new way of thinking about what it means to age, and what it means to learn and be a community.

Preserving Your Memory: What sort of feedback are you getting from the librarians, artists and participants?

Maura O’Malley: Overwhelmingly positive. It’s our mission to continue bringing together all the partners to make this kind of work happen. Arts education,
library services, cultural institutions—all these come together in this work to make the projects happen. So it’s continuing to expand and grow. We’re also partnering with American Library Association and Temple University’s Intergenerational Institute.

**Preserving Your Memory: What is required for libraries across the nation to develop their own programs? What resources are available to them?**

**Maura O’Malley:** We’re developing a training curriculum that will roll out over the next three years that includes everything from how to pay the artists, to how you engage the community, etc. It’s a shift in thinking about older adults, who we are, and what we’re capable of. In terms of public libraries, services for older adults have been assigned to the outreach department. This work is shifting that view from the needy, negative deficit view to the positive, engaged, active view. So it’s been extremely fulfilling and we’ve learned so much from our partners. We learn every day about new ways to do this work, how to share the information.

We actually measure the impact of the work on older adults in terms of quality of life, particularly in terms of combating isolation. We’ll also be partnering with Self Help Inc. They have created a computer system for isolated older adults. They set up computers in homes of homebound older adults, one that has a touch-screen system, so they can actually virtually join live programs in senior centers and participate in the program. In partnership with Queens Public Library and Self Help, Inc., we’ll be piloting this technology in two libraries with creative aging programs. As many as five or six people can be virtually there in the room, and there is live interaction between the teaching artists and the participants there with them, as well as the homebound people via the Internet. Organizations and agencies are excited about the opportunities to partner, and we’re finding that people have the same goals: improving the quality of life for older adults, increasing the importance of public libraries as community institutions.

**Preserving Your Memory: Ultimately, what would you like to see in terms of spreading the Creative Aging Libraries Project to more libraries?**

**Maura O’Malley:** What we’re trying to build is an affiliated network of practitioners. There’s an enormous need for training, on both the library side and the artist side, on the community side and the individual side. Our efforts are to deliver programming that’s meaningful to the local population. One of the ways we’ve been doing this is working from the top down and the bottom up. So we’re bringing people together to meet these goals. What we hope to see is, over time, that libraries across the nation are able to deliver this kind of programming. No one can do this work on their own. The more we combine resources and work together, the greater the likelihood that more adults will be engaged—it’s a strategic rollout of the program itself, along with the dissemination and sharing of information. We need to make a big effort to share the information and show what happens. People need to see how it works and to see that it’s beyond passive entertainment, and that we adults need to identify as part of the group ourselves. There’s a better way to grow older in this country, and that’s what we’d like to see—meaningful arts programs all over the country in which libraries and older individuals are creatively engaged in a vital community. ■
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.
Penny Marshall with her mom, Marjorie, on the set of *Laverne & Shirley*.

A Penny for Her Thoughts:
An Interview with Penny Marshall

By Tamekia Reece
Photos from Penny Marshall’s personal collection
Many know her as the spunky Laverne DeFazio of Laverne & Shirley fame. Others know her as the award-winning director who worked magic on films such as A League of Their Own, The Preacher’s Wife, Awakenings, and Big, which was the first female-directed movie to gross over $100 million at the U.S. box office.

What many people don’t know about Penny Marshall is she, like many others, is the child of a parent who developed Alzheimer’s. Her mother, Marjorie Marshall, died of the disease in 1983. Penny’s memoir, My Mother Was Nuts, gives a humorous and brutally honest look at the relationship the two shared and how Penny went from dancing in the basement to calling the shots on the big screen. We talked with Penny about her mom’s experience, her own health issues, and how her mother’s memory will live on—even after Alzheimer’s.

Preserving Your Memory: Obviously, people will wonder about the title of your memoir. Why did you choose that title?

Penny Marshall: Because my mother was nuts. Not because of Alzheimer’s, but before that. She said some of the weirdest and harshest things. She had a love for teaching dance. She wanted to be a dancer, but in the period when she grew up that wasn’t something you did. So she taught dance to everyone. She thought it was very important that everyone got the chance to see what it’s like to entertain. I did tap dance mostly, but she taught ballet, acrobatics, and jazz. She always compared me to the 360 kids she taught in the basement of our building. However, she wasn’t a stage mother. She was just pushy.

Preserving Your Memory: You describe her as being obsessed with her work as a dance teacher.

Penny Marshall: She wasn’t only obsessive about teaching dance; she was obsessive with dancing itself. That’s all she liked to do. She tapped all around the house. She’d tap dance around the kitchen when she was eating or cooking, tapping on the linoleum. It’s what she lived for. We’d hear that tapping noise all day long.

Preserving Your Memory: She hoped you would follow her dancing footsteps. Were you a good dancer?

Penny Marshall: I was good at it, but I didn’t like it. Especially as I got older, I was a little boy crazy. I wanted to hang out with the boys, and I didn’t care about dancing school. But we did every benefit where they would feed us, we went. We were three-time winners on the Ted Mack’s Original Amateur Hour; we were on The Jackie Gleason Show. We did everything.

Preserving Your Memory: How did you go from dancing to acting and directing?

Penny Marshall: I didn’t want to be in show business, but I had sort of been in it already. I didn’t call it show business; to me, it was just my mother’s weirdness. After I got divorced, I moved to California. My brother [producer Garry Marshall] lived there, and he helped me land a few small acting roles. Then he asked if Cindy [Williams] and I wanted to play the role of two “fast girls” on Happy Days. Those roles led to the spinoff Laverne & Shirley. Later on, I had directed a few Laverne & Shirley episodes and was then asked to take over directing the movie Jumpin’ Jack Flash [starring Whoopi Goldberg]. Then came Big …

Preserving Your Memory: Can you tell me a bit about your mom’s first signs of Alzheimer’s?

Penny Marshall: It happened some time in the early ’70s. I think it was when she performed on The Odd Couple. She wasn’t quite there, but we didn’t know what it was, you know? And the doctors didn’t know what it was. Later, when she did Happy Days and a couple of Laverne & Shirley episodes, she could still tap, but she couldn’t say a line because she couldn’t remember.

Preserving Your Memory: In your memoir, you say, “her feistiness was turning into forgetfulness.”
**Penny Marshall:** Yes, because when we were kids, she would call us different names, and that was before the Alzheimer’s. She would make up names for all of us. That was just her. She would say, “Well, don’t you get tired of being called the same name?” So with the onset of whatever it was, because they didn’t know what it was back then, we weren’t sure whether she got forgetful or it was just part of her “thing.”

**Preserving Your Memory:** Tell me about the official diagnosis. What was your reaction?

**Penny Marshall:** The doctors said, “It’s dementia,” because that’s all they knew back then. It was like, “well everyone gets that as they get older.” But it was shocking because she wasn’t even old. She was in her 60s or 70s. She was still running around.

**Preserving Your Memory:** What were some of the challenges your family faced with the Alzheimer’s?

**Penny Marshall:** They had to take her car keys away because she couldn’t remember where she lived. She’d take the bus and not know where to get off. One time the police picked her up and took her to the jail. She was telling them stories of when she was younger and of her dancing school. It’s weird. She could remember everything about music, the dancing school, and all that, but she couldn’t remember present day. When her memory got worse, we eventually had to have someone come in for 24-hour care. She would watch TV and laugh. We felt as long as she was still laughing, it was worthwhile. For the last two years, it was terrible because she was in more like a vegetative state. She had been such an active and lively woman, so that was the hardest part.

**Preserving Your Memory:** Your mom’s battle with Alzheimer’s had a lot to do with your decision to direct *Awakenings*, correct?

**Penny Marshall:** Well, I read the script, and it read like a medical mystery to me. It was about four people who were in a comatose state, and because of my mom’s Alzheimer’s, you wonder if they hear you. And I think it’s important to treat them like human beings, instead of just letting them waste away in a corner. So it did affect my feelings toward the movie. I thought it was a great script, but part of my reason for doing it was because of my mother.

**Preserving Your Memory:** You and your siblings built a dance theater in her honor?

**Penny Marshall:** At Northwestern University where my brother and sister went to college. We built the Marjorie Ward Marshall Dance Center. She was still alive for the groundbreaking and my brother tried to explain we were doing it because they didn’t have a dance facility at the school.

**Preserving Your Memory:** The relationship between you two was sometimes rocky. Now that you’re older and have a daughter of your own, what were some of your mom’s strengths that you didn’t recognize when you were younger?

**Penny Marshall:** She did what she was supposed to do in a very odd way. She chose to work as far as having a dancing school. I was a working mother, so I know it’s hard. And she made dinner like a restaurant. This one would only eat this, that one would only eat that, my blind grandmother didn’t know what she was eating.

**Preserving Your Memory:** It sounds like she was a short order cook.

**Penny Marshall:** Yeah. And she dropped the turkey on the floor all the time. But she could make a good turkey. She made stuff that we still talk about today because we liked it.

**Preserving Your Memory:** Many people whose parents developed Alzheimer’s worry about their own memory. It seems yours is very good. For this book, you turned on a tape recorder, talked about your memories and then had it transcribed?
Penny Marshall: Transcribed, and then fixed some of what was transcribed. But I am getting like my ma in that I don’t know what I did yesterday. I know I was eating potato chips. Other than that, I can’t really remember. But I do remember everything from back in the days.

Preserving Your Memory: You were treated for lung and brain cancer a few years ago. How is your health now?

Penny Marshall: I’m fine. I’m clean. I go when I’m supposed to go for the PET, CAT, and MRI scans. I eat better.

Preserving Your Memory: Any advice you would give to others who have had a loved one diagnosed with the disease?

Penny Marshall: It’s a terrible disease, and I wouldn’t wish it on anyone. It’s a bummer, but you have to try to do the best you can. Just try to keep going even though they’re not the same at times. Keep trying to do what they like, whatever it is. Try your best to help them keep smiling and laughing.
For most caregivers, a typical day can include plenty of physical activities—lifting, stretching, carrying, walking, climbing steps, driving … you name it. To handle all that without injury or exhaustion, health experts recommend that caregivers pay special attention to their “core strength.” The muscles associated with your abdominals, chest, and upper and lower back make up the core that helps you carry out the many physical activities associated with caregiving.

There are many abdominal and back exercises that can help you strengthen your core. Plus, yoga and Pilates classes are great ways to work on these core muscles. But core exercises don’t require expensive equipment or a gym. Many of them can be done right in your own home.

In fact, a new national exercise campaign from the National Institute on Aging (NIA), called Go4Life, offers a variety of simple and safe exercises that can improve the four basic categories of all exercise and physical activity—endurance, strength, balance, and flexibility. Aimed at men and women 50 years and older, Go4Life can be used by caregivers of any age to improve their core health.

The campaign grew out of concern that many older adults are not physically active. About 30 percent of Americans 45 to 64 say they engage in regular physical activity, while only a quarter of those 65 to 74 do. And although people 85 and older can benefit from exercise, only 11 percent report being active. For caregivers working with loved ones with Alzheimer’s disease, being physically active is vital for maintaining health and independence as they age.

“You’re never too old to increase your level of physical activity and exercise,” says NIA Director Richard J. Hodes, M.D. “Go4Life is based on research demonstrating real health benefits of exercise and physical activity. It shows how to exercise safely.”

Most people tend to focus on one activity or type of exercise—endurance, strength, balance, or flexibility—and think they’re doing enough. Each type is different, though. Doing them all will give you more benefits. Mixing it up also helps to reduce boredom and cut any risk of injury. Some activities fit into more than one category. For example, many endurance activities also build strength. Strength exercises also help improve balance. The goal is to use all four types to help build your core strengths for everything you do.

Here are four easy-to-do exercises, one for each type of activity. For more examples, visit Go4Life at www.nia.nih.gov/Go4Life. It is always a good idea to discuss any exercise program with your healthcare provider first.

### Strength Exercise

Strength exercises build muscle, and even very small changes in muscle strength can make a real difference in your ability to perform everyday activities like carrying groceries, lifting a grandchild, or getting up from a chair.

**Exercise Instructions:**

**Targeted Muscles:** Shoulders

**What You Need:** Hand-held weights

1. Stand with your feet shoulder-width apart.
2. Hold weights straight down at your sides, with palms facing backward.
3. Keeping them straight, breathe out as you raise both arms in front of you to shoulder height.
4. Hold the position for 1 second.
5. Breathe in as you slowly lower arms.
6. Repeat 10-15 times.
7. Rest; then repeat 10-15 more times.
Balance exercises can help prevent falls. Many lower-body strength exercises also will improve your balance. You can't balance without good core strength, endurance, and control. Balance becomes especially important as you get older.

**Exercise Instructions:**

**What You Need:** Sturdy chair

You can do this exercise while waiting for the bus or standing in line at the grocery. For an added challenge, you can modify the exercise to improve your balance.

1. Stand on one foot behind a sturdy chair, holding on for balance.
2. Hold position for up to 10 seconds.
3. Repeat 10-15 times.
4. Repeat 10-15 times with other leg.
5. Repeat 10-15 more times with each leg.

Flexibility exercises can help your body stay limber.

**Flexibility Exercise**

Flexibility exercises stretch your muscles and can help your body stay limber. Being flexible gives you more freedom of movement for other exercises, as well as for your everyday activities.

**Exercise Instructions:**

**Targeted Muscles:** Shoulders and upper arms

**What You Need:** Towel

1. Stand with feet shoulder-width apart.
2. Hold one end of a towel in your right hand.
3. Raise and bend your right arm to drape the towel down your back. Keep your right arm in this position and continue holding on to the towel.
4. Reach behind your lower back and grasp the towel with your left hand.
5. To stretch your right shoulder, pull the towel down with your left hand. Stop when you feel a stretch or slight discomfort in your right shoulder.
6. Repeat at least 3-5 times.
7. Reverse positions, and repeat at least 3-5 times.

Endurance exercises are activities that increase your breathing and heart rate for an extended period of time. Examples are walking, jogging, swimming, raking, sweeping, dancing, and playing tennis. Build up your endurance gradually, starting with as little as 5 minutes of endurance activities at a time, if you need to. Then try to build up to at least 30 minutes of moderate-intensity endurance activity on most or all days of the week.

**Exercise Instructions:**

**Targeted Muscles:** Shoulders and upper arms

**What You Need:** Towel

1. Stand with feet shoulder-width apart.
2. Hold one end of a towel in your right hand.
3. Raise and bend your right arm to drape the towel down your back. Keep your right arm in this position and continue holding on to the towel.
4. Reach behind your lower back and grasp the towel with your left hand.
5. To stretch your right shoulder, pull the towel down with your left hand. Stop when you feel a stretch or slight discomfort in your right shoulder.
6. Repeat at least 3-5 times.
7. Reverse positions, and repeat at least 3-5 times.
Food

Preserving Your Memory

Vitamin D and Your Brain

Forgot where you placed your keys? Can’t remember your new neighbor’s name? Wondering where you parked your car? If memory lapses have you fretting about your brain health, you may need more vitamin D.

A growing body of research suggests that the sunshine vitamin is involved in cognitive function. Among the findings:

• A study published in 2012 in the *Journals of Gerontology* looked at vitamin D levels in 6,257 elderly women and found that those with levels below 10 nanograms per milliliter (ng/mL) had more cognitive dysfunction than women with vitamin D levels of 30 ng/mL and above.

• Researchers at the University of Manchester measured vitamin D levels in 3,133 middle-aged and older men in Europe and found that those with higher levels did better on tests for attention and speed of information processing.

• A 2009 analysis using data from the Third National Health and Nutrition Survey (NHANES) showed that vitamin D deficiency is associated with an increased risk for cognitive impairment.

“Overall, we are learning more and more about the benefits of vitamin D,” says Sharon Brangman, MD, a geriatrician and professor of medicine at Upstate Medical University in Syracuse, N.Y. “It is the only vitamin that can reduce the risk of falls when it’s replaced in people who are deficient, and there is emerging research that it is also important for brain health.”

D for Discerning

Exactly how vitamin D functions to preserve cognitive function is unclear, Brangman says. “It may increase acetylcholine, a brain chemical and neurotransmitter important for memory and other brain functions, that is found in low levels in many patients with dementia,” she says. “Current drugs for treating Alzheimer’s disease, the acetylcholinesterase inhibitors, work to increase the amount of acetylcholine in the brain. Vitamin D may also help nerve cells grow by increasing levels of nerve growth factor. The information transmitted by the nerve cells in the brain is the foundation of everything our brains do, including memory, decision-making, judgment and complex thinking.”

Vitamin D is a fat-soluble vitamin best known for its role in bone health because it aids in the absorption of calcium. Vitamin D also plays a critical role in cell growth, immune function, and the formation and development of the brain.

“The presence of vitamin D receptors in the brain implies it may have some effect on the function of the brain. Some scientists have tentatively classified vitamin D as a neurosteroid. Research has also shown that vitamin D affects proteins in the brain that are involved in learning, memory and motor control.”

Still, experts agree that more research is needed before declaring a direct link between vitamin D and cognitive function.

The Rx for Now

In the meantime, it’s important to get enough vitamin D in your diet. The amount you need varies by age and depends on whom you ask. “Scientists and other public health organizations are debating the amount that should be recommended based on recent studies indicating the benefits of vitamin D,” Dubost says. The National Osteoporosis Foundation, for instance, recommends 400 International Units (IU, equivalent to 0.01 mg) to 800 IU (0.02 mg) of vitamin D daily for adults under age 50, and 800 IU to 1000 IU (0.25 mg) for older adults.

An important source of vitamin D is sunshine. The body makes vitamin D when the skin is exposed to the sun. Dubost recommends sensible sun exposure, which she describes as five to ten minutes two or three days a week. This will vary depending on the season and where you live (latitude).

Getting vitamin D from food isn’t easy since few foods contain it naturally. Some exceptions include oily fish—salmon, tuna and mackerel—cod liver oil and egg yolks. (See recipe on the next page.) Fortified foods like low fat milk, non-dairy milk alternatives, and 100 percent orange juice are healthy options, too. You can also get vitamin D from supplements (also called vitamin D3).

“Vitamin D supplements may be necessary for older people, those who do not consume adequate amounts through their diet, people living in northern latitudes, and for dark-
In addition to sunshine, you can get vitamin D from salmon, tuna, mackerel, cod liver oil, egg yolks, low fat milk, non-dairy milk alternatives, 100 percent orange juice and supplements.

skinned people who need increased exposure to the sun,” Dubost says. “You may want to have your doctor test your vitamin D level in your blood to ensure you have adequate amounts, which could then determine how much vitamin D you may need to receive through diet and supplements.”

(For recipe, see page 26)
Healthy Recipe

Grilled Tuna With Warm Cherry Tomato Salsa

Here’s an easy tuna recipe that blends the freshness of Napa, the seafood of California, and the Tuscan way of spicing food. If you can’t find fresh tuna, use any firm fish, such as halibut or salmon.

Ingredients

- 4 small tuna steaks (about 4 to 6 ounces each, with bone)
- 1 tablespoon plus 2 teaspoons extra-virgin olive oil, divided
- 1 tablespoon lemon juice
- Vegetable oil cooking spray
- ½ teaspoon salt
- ¼ cup finely diced red onion (½ onion)
- 2 cloves garlic, minced
- 2 cups cherry or pear tomatoes, cut in halves
- 2 tablespoons chopped fresh flat-leaf parsley
- 1 tablespoon capers, optional
- Freshly ground black pepper, to taste

Directions

1. Rinse the fish and pat it dry with paper towels. Place it in a glass pie plate and drizzle with olive oil and lemon juice. Let the fish marinate in the refrigerator for at least 15 minutes and up to 4 hours.

2. Preheat grill. Place the tuna on a double-thick sheet of aluminum foil that has been sprayed with the cooking spray; place it on the grill. Grill the fish, turning it once, until it flakes and is not quite opaque in the center. This takes between 4 and 8 minutes per side, depending on the thickness of the fish.

3. Preheat oven to 400°F. Combine the remaining 2 teaspoons of olive oil, the chopped onion, and the garlic in a glass, oven-safe pie plate. Bake for 7 to 8 minutes, stirring halfway through. Mix the salt into the tomatoes; stir the tomatoes into the onion mixture and continue to roast for 4 to 5 minutes, until the tomatoes are warmed and the onion is starting to brown. Remove from the oven, stir in the chopped parsley and capers, if using. Spoon the mixture evenly over the grilled tuna steaks. Add the desired amount of black pepper.

Source: Academy of Nutrition and Dietetics
The challenges that come with memory loss are difficult enough. When a definitive diagnosis is hard to pin down, it complicates things even further. Unfortunately, there are several realities among the so-called “dementing disorders”: there are many of them, their symptoms often mimic one another, and doctors sometimes disagree when it comes to diagnosing them. However, treatment options and coping
strategies do vary by condition, so there is enormous value in an accurate diagnosis.

For those reasons and more, patients and caregivers dealing with dementia—in any form and identified by any label—should always consider pursuing a second opinion.

The Right of Every Patient and Caregiver

It’s a good idea to seek a second opinion following any serious medical assessment, whether it’s a diagnosis or a recommended course of treatment. Patients and family members are becoming increasingly engaged in their own healthcare, and seeking the input of more than one physician is more common than ever. Following such a serious diagnosis as Alzheimer’s disease, it might even be considered irresponsible not to pursue the expertise of at least one other doctor.

“People sometimes worry they’re going to offend their doctors by bringing up the subject of second opinions,” says Aimee Chagnon, MD, a neurologist who runs a private practice in Sonoma, Calif. “I tell people that it’s not going to hurt my feelings or insult me. I don’t want anyone to have any kind of lingering doubt or question whether they could have done something different—especially with a devastating diagnosis.”

If you are interested in seeking a confirming diagnosis and your original physician objects to the idea, patient advocacy experts consider such resistance a red flag and an indication that the doctor is more concerned with personal ego than patient outcomes. “It doesn’t matter if the doctor likes you or is annoyed with you just because you want a second opinion. Keep your eye on the ball,” urges Andrew Schorr, founder of the advocacy portal Patient Power and author of The Web-Savvy Patient. “This is about you or your loved one having the best possible health and quality of life. That’s what matters.”

Many Dementias Look the Same

In her practice, Dr. Chagnon has seen plenty of patients whose symptoms have been difficult to place into tidy diagnostic categories. Having issued initial, confirming and alternative diagnoses for numerous brain disorders, she knows that the nuances of each case can affect how it is labeled, managed, and treated.

“It’s not uncommon for people to be diagnosed with Alzheimer’s and end up having Lewy body dementia, which is a combination of symptoms that look like Parkinson’s disease but involve quite a bit of hallucination and significant behavioral changes,” she says. “The other thing we often see is people being diagnosed with Alzheimer’s who actually have frontotemporal dementia, which can lead to behavioral changes and language problems. When those things happen before memory issues are obvious, it can actually be misdiagnosed as a psychiatric issue.”

Normal pressure hydrocephalus, or excessive fluid on the brain, is another condition that causes memory and balance problems that mimic those of Alzheimer’s disease, notes Dr. Chagnon. The important difference between hydrocephalus and Alzheimer’s, she points out, is that the former is treatable when caught early enough. “By the time hydrocephalus gets obvious, it’s sometimes too late to do anything,” she says. “So we always encourage people with worrisome symptoms to get evaluated and get brain imaging if at all possible.”

Properly identifying these subtle distinctions among conditions, she explains, can benefit patients and caregivers alike. Memory, balance and behavioral issues could also be symptoms of a thyroid problem, a vitamin deficiency or a slow-growing tumor. “Those are things we can do something about before they cause irreversible damage,” says Dr. Chagnon. In these cases, second opinions that confirm initial diagnoses help clarify the proper way forward.

Grappling with the Decision

Given the emotionally wrenching nature of memory loss, families can feel overwhelmed just by the realities they face every day. Adding potential stress by seeking a second diagnostic opinion might seem like too much to bear.

“If a family is really struggling with an Alzheimer’s diagnosis or if they have reason to question it, I’ll remind them that they always have the option of getting a second opinion,” explains Patricia Brooks, LCSW, PhD, a psychotherapist who counsels individuals and families experiencing anxiety or depression related to illness, chronic pain, and cognitive disorders. “But sometimes, people question a diagnosis because they’re in denial, in which case we need to spend time educating them as a way of helping them understand and accept the diagnosis.” In those cases, she works with caregivers to facilitate realistic expectations and help them prepare for and adapt to the changing abilities of the patient.

As necessary, Dr. Brooks helps identify resources for her clients, assists them in pursuing additional medical opinions and contributes her own expertise to help determine the most effective next steps. “If I have a question about a client’s diagnosis, I ask whether a neurologist or other specialist was consulted, I look at what kinds of tests were done, whether an MRI or CAT scan was done, etc. Then I may recommend that they seek a second opinion to take a more thorough look at what’s going on,” she says.
Coping with the Findings

When a second opinion confirms an initial diagnosis, it can clear the way for patients and caregivers to begin focusing on managing the condition rather than questioning it.

However, when a second opinion contradicts an initial diagnosis, it’s important to figure out why. “If conflicting diagnoses come from two different neurologists, then I would ask the two physicians to discuss the case,” Dr. Chagnon says. “Many times, especially early on, symptoms of these conditions can fluctuate from day to day. Patients will have very good days and look great, and the very next day they’ll turn around and behave totally differently. When doctors actually communicate and report to one another what they saw and what family members describe as normal, then you can often get consensus on a diagnosis.”

Dr. Chagnon recommends that families also include the patient’s primary care doctor in any group discussions whenever possible. “Even though the primary isn’t spending a lot of time with the patient, it can be helpful,” she says. “If we talk to each other, we can usually come to the right conclusions.”

Weighing the Value of Neuro-Psych Testing

When a definitive diagnosis is particularly difficult to come by, memory loss patients and caregivers have the option of requesting neuropsychological evaluations.

Some patients and caregivers pursue neuropsychological evaluations when their doctors have difficulty reaching a definitive diagnosis. “Many patients fall into the cortical dysfunction categories, which have red flags that neurologists should be able to identify. But if that’s not enough to clearly identify what’s going on, then thorough neuro-psych testing might be worthwhile,” says Dr. Chagnon. “It’s a long process and some patients find it tedious, but it can really be worth it because it allows us to see what parts of the brain are really affected.”

Neuropsychological testing, according to Dr. Chagnon, reveals where in the brain the problems reside, which helps classify the pathology. For example, if early testing reveals frontal brain dysfunction, that’s unusual for Alzheimer’s disease, which doesn’t affect the front portions of the brain until later in the disease’s progression. If, on the other hand, testing reveals a mixed pattern of dysfunction, it might be sign of vascular disease and should be treated accordingly.

Neuro-psych testing can also help shed light on near-and long-term realities. “Sometimes, I’ll recommend a neuropsychological evaluation so that we can make a determination about a treatment or care plan,” says Dr. Brooks. “Identifying the client’s strengths along with their liabilities can help families understand what level of care will be required and what coping strategies we can begin to put into place for caregivers.”

The Power of Information

Memory loss is all about unanswered questions. Second opinions can help patients and caregivers feel more in control by arming them with information. Bringing a fresh medical perspective to a case doesn’t always change its outcome, but it often helps home in on a patient’s condition in ways that can have a positive impact on care. ■
Hitting the Target:
Researchers Take Aim to Find a Drug Therapy for Alzheimer’s Disease

The latest clinical studies investigate different paths to a cure.

There is no drug that can cure Alzheimer’s disease, but there are reasons for hope. A group of medications can ease the symptoms of Alzheimer’s and researchers are tirelessly exploring many paths in their quest for a cure.

It’s important to understand how existing drugs work as well as their limitations. “These drugs work for some people in slowing the progression of symptoms,” says Laurie Ryan, Ph.D., Program Director for Alzheimer’s Disease Clinical Trials at the National Institute on Aging. “They can help for a period of time, but as the disease progresses, it overpowers the drugs and they lose their effectiveness.”

During mild to moderate stages of Alzheimer’s, FDA-approved medications called cholinesterase inhibitors (sold as Aricept, Exelon and Razadyne) slow progression of the disease and sharpen learning and attention span. Scientists don’t have a complete understanding of how they work, but research shows that these drugs prevent the loss of a chemical in the brain that is essential for memory and reasoning.

Namenda, a drug classified as an NMDA antagonist, helps in the moderate to severe phases of Alzheimer’s. This medication keeps the amount of the brain chemical glutamate at a steady level, which helps maintain normal brain function longer.

Temporary improvement from these drugs is beneficial for people with Alzheimer’s, but researchers are constantly searching for a treatment that will permanently restore normal brain function and quality of life.

A Long, Complex Process

Research for a drug that cures Alzheimer’s is a complex, challenging process that relies on scientific discoveries of new ways to attack the disease. The process is expensive. According to the National Institutes of Health (NIH), it takes 10 to 15 years from the discovery of a way to create a new drug until it reaches the marketplace, with an average total cost of $1.8 billion for research and development.

Scientists are making large-scale efforts to find a drug that cures Alzheimer’s. One example is the Alzheimer’s Disease Translational Research Program. Orchestrated by the NIH, this program has conducted more than 60 research projects and produced several compounds that pharmaceutical companies have chosen for further development.

A Variety of Approaches

Researchers at the University of Minnesota Center for Drug Design have created a promising synthetic compound that, in laboratory trials with mice, prevents the mental decline from Alzheimer’s.

“The goal of our research was to find a way to stop the body from producing beta-amyloid protein, which can accumulate in the brain and form hard plaque that causes changes in the brain associated with Alzheimer’s,” says Swati More, Ph.D., Research Associate at the Center for Drug Design. “We developed a drug candidate called psi-GSH that prevents the accumulation of this protein. Psi-GSH acts in a way that has never been tried before for the treatment of Alzheimer’s disease.”

Another new path that researchers are taking is using brain imaging to assess the effects of early treatment for Alzheimer’s. Many current drug trials include brain imaging and testing of blood or spinal fluid.

One reason for this is that scans of the brain—such as magnetic resonance imaging (MRI) and positron emission tomography (PET)—can now detect plaque in the brain thanks to a substance called Amyvid. This liquid, which is injected into the bloodstream, attaches to beta-amyloid plaque in the brain, making the plaque visible in the scan.
“Until now, we haven’t been able to detect beta-amyloid plaque in the brain,” says Richard Mohs, Ph.D., Executive Director, Neuroscience Clinical Development, Eli Lilly and Company, “but with the diagnostic agent Amyvid, we can use a PET scan to estimate the amount of plaque in adult patients who are being evaluated for Alzheimer’s disease and other causes of cognitive decline.”

**Targeted Research**

Many researchers believe that a drug therapy that cures or manages Alzheimer’s will involve a “cocktail” of medications aimed at several targets, an approach that is similar to current treatments for many cancers, hypertension and diabetes.

One of these possible targets is a protein called tau. With Alzheimer’s, this protein in the brain becomes tangled and reduces the ability of brain cells to function properly. Finding drugs that prevent tau from twisting into tangles is a goal of current research.

Inflammation is another research target. Studies have revealed a lot about the body’s overall inflammatory response and these insights might lead to anti-inflammatory treatments that manage Alzheimer’s.

Recent studies have shown that the way brain cells process insulin may be linked to Alzheimer’s disease. Scientists are assessing the role of insulin in the brain and these studies may produce medications that support cell function and prevent Alzheimer’s.

“Drug therapies hold great promise for the future, but it’s important to keep in mind that lifestyle factors can also have an impact,” says Dr. Ryan. “Exercise, good nutrition and staying mentally active lead to healthier brain aging, which won’t prevent someone from getting Alzheimer’s but will keep their quality of life at a higher level longer. We can’t change our genetic makeup, which is a factor in developing Alzheimer’s, but we can take control of our lifestyle.”

**Three Drugs to be Tested**

Researchers are preparing to test three drugs to determine their effectiveness in treating early-onset Alzheimer’s disease, which is genetically determined and can affect people who are as young as in their 40s. The goal is to find a treatment that can help prevent memory loss and thinking problems associated with Alzheimer’s from occurring in the first place. The drugs to be studied all combat the toxic effects of beta-amyloid. They are:

- **Gantenerumab**, an antibody that attaches to beta-amyloid and helps to remove it from the brain.
- **Solanezumab**, an antibody which binds to beta-amyloid before it clumps together, inhibits the plaque formation process.
- **LY2886721**, a drug that blocks an enzyme, beta-secretase, which is critical for beta-amyloid formation, thereby reducing the amount of beta-amyloid produced in the first place.

The study will involve 160 volunteers who have one of several genes that cause early-onset Alzheimer’s. “In most trials in Alzheimer’s disease, people are treating the disease after the damage is being done to the brain,” says study leader Dr. Randall Bateman of Washington University. “And in this trial we’re trying to treat the disease before that damage gets done.”
The Will and Beyond

Now is the best time to plan for the distribution of your wealth, and a will is one important tool for doing just that.

After we pass, we leave behind our worldly effects—all of our assets and belongings, as well as our debts. If you’re an older person, you should have a plan for how your finances will be handled up until and after your death, and crafting that plan requires far more than just writing a will.

“You’re talking about the disposition of a lifetime of accumulated wealth,” says Dana B. Perry, Shareholder and Certified Elder Law Attorney with Chambliss, Bahner & Stophel, P.C., in Chattanooga, Tenn. “And the will is the last layer of designating how that wealth will be managed after your death,” says Perry, “while many people think it’s the first.”

Where to Begin

A will establishes in advance how you want your assets and belongings handled when you’re gone. It also designates an executor who will oversee the disbursement of your estate. However, the will only applies to property that does not already have a beneficiary. Insurance policies, retirement accounts, and joint accounts designate a beneficiary or joint owner, which overrules anything in the will. Before you walk into a law office, take an inventory of your assets, both the types and their beneficiaries or joint owners.

Harold L. Grodberg, a Certified Elder Law Attorney, also encourages you to consider the second level of heirs, in case your children predecease you. “If you die without heirs, the law says who’s going to get the assets,” says Grodberg.

Trusts You Can Trust

Grodberg also takes stock of potential complications. Are any of your heirs incapacitated? Are they spendthrifts? Are they minors or impulsive young adults? In these cases, a lump sum inheritance could cause problems for heirs who are ill equipped to handle the responsibility.

Likewise, second marriages can create conflict after you’re gone. For instance, a surviving spouse may decide to rewrite her will to exclude children and grandchildren from a previous marriage. In all of these cases, Perry says, “A trust is an underutilized tool for preventing your heirs from using your hard-earned money against your wishes.”

A trust puts someone else in charge of your money and allows controls to be put when funds become available, on how they can be used. In the case of a second marriage, you can place the money in a trust where your surviving spouse can access it but cannot change who inherits it when she dies. Be open to your attorney’s suggestions about how to structure your plan.

Of Sound Mind

When someone is diagnosed with dementia, amending an existing legal arrangement or setting up a new one can further complicate matters. And here, reasonable attorneys can disagree on a course of action. In such cases, Perry seeks a letter from a gerontologist or neurological specialist that states that her client is of sound mind.
mind. If someone with cognitive issues—or even just a person in their 80s—wants to write out members of their family, that presents a heightened level of scrutiny. The letter, in Perry’s view, helps to make the will immune to challenge. However, “if there was a case where a doctor was not willing to give a letter, it likely would prompt me to consider whether the client should be executing another will,” she says.

Grodberg disagrees. He believes such a letter opens the will to challenge. He believes that incapacity is a legal issue, rather than a medical one, and “until a person is adjudicated as an incapacitated person, they have capacity,” he says. Instead, Grodberg prefers to write a memo to the file of his own evaluation of his client’s competence, that he met with his client, they had a conversation that was coherent, and the next day the client remembered what was said. Either way, both attorneys caution that major changes to your estate at this point in your life can rankle your heirs, and you should consider whether your choices will leave a legacy of conflict.

After a Diagnosis
If you are married and you have been diagnosed with Alzheimer’s or dementia, Grodberg focuses his efforts on rewriting the healthy spouse’s will. The spouse who is suffering will most likely divest their assets and put them in the healthy person’s name. For the healthy spouse, the ailing spouse will no longer be the entire heir. Instead, Grodberg advises establishing a trust that leaves one-third to the incapacitated spouse and two-thirds to the next person. In some states, this arrangement could help the incapacitated spouse become eligible for Medicaid assistance, and/or it can ensure that the incapacitated spouse has the funds for medical needs. Keep in mind, having Alzheimer’s, especially early stages, does not mean you cannot do a will. A will requires the lowest form of capacity of any legal document.

Communicate Your Wishes
Work toward simplifying and streamlining your financial situation. Organize your forms and files in one place, and aggregate your investments into one or just a few accounts if possible. Leave a letter of instruction with your heirs that details your wishes for a funeral and points them to the will and other important documents. Keep your will in a fireproof box or cabinet—and make sure someone knows the combination. Or, better yet, have your attorney hold your will. Most attorneys do not charge for this service. In many states if you lose your will and die, you are deemed to have revoked it, but not so if your attorney was in possession of it.

Where possible, communicate your wishes to your heirs with the aim of minimizing disagreements. If you are a child managing a parent’s estate, try to coordinate the discussion of your parent’s finances with the whole family present, and as you enter the process, Perry says, “You need to be open to your parents’ wishes and be prepared to let the process go where it will.”

The Right Lawyer
Managing your estate in your twilight years is vastly different from writing a will in your 40s or 50s. An elder law attorney has the specialized experience to anticipate your needs and to minimize your estate’s and your heirs’ tax liabilities. Additionally, laws differ state by state and year to year. You’ll need to reassess your affairs at least every three to five years, if not yearly. A trusted lawyer—and executor—can help you manage the process so that all of your hard work continues to benefit the right people, even after you’re gone.

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 identify these stars by matching them to their birth names?

1. ___ Charlie Sheen a. Eric Marlon Bishop
2. ___ John Wayne b. Maurice Micklewhite
3. ___ Alan Alda c. Allen Koningsberg
4. ___ Michael Caine d. Marion Morrison
5. ___ Lauren Bacall e. Reginald Dwight
6. ___ Woody Allen f. Carlos Estevez
7. ___ Portia de Rossi g. Laszlo Lowenstein
8. ___ Marilyn Monroe h. Betty Joan Perske
9. ___ Jamie Foxx i. Alphonso D’Abruzzo
10. ___ Whoopi Goldberg j. Amanda Lee Rogers
11. ___ Elton John k. Caryn Johnson
12. ___ Peter Lorre l. Norma Jean Mortenson

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.

LEAPFROG

Here’s a list of U.S. colleges and universities — one two-word school for each number. Their letters are in the correct order, but they overlap. All you have to do to find the schools is separate the letters.

Example: NODATMREE — NOTRE DAME

1. FOWRAEKSTE
2. GEMOARSGEN
3. BYRIOGUHANGM
4. HOJOPHKINSS
5. HMOOLUYONKET
6. DOOMLINDION
7. TVIERGICNHIA
8. SLAWARRAENCHE
9. BMARYWRN
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 “It’s All Good” is a hint. Have fun testing your knowledge while doing something that’s good for you!

**BRAIN-BOOSTING CROSSWORDS**

(Answers on page 37)

**It’s All Good**

**Across**
1. Stage drama
2. Howl
3. Police abbr.
4. Mother: Fr.
5. Farming prefix
6. G. Carroll (“Topper” actor)
7. GOOD_
8. Ordinary (actor)
9. Hand out hands
10. Slip up
11. Huge work
12. Name of the country (abbr.)
13. Farming prefix
14. Authority (abbr.)
15. Diameter (in abbr.)
16. Long (in abbr.)
17. Olympus and Olympia: abbr.
18. Dweller: abbr.
19. Slackens
20. Wolves’ den
21. GOOD_
22. First stock sale: abbr.
23. Allege
24. She was pursued by (sport)
25. Expectation
26. Age (abbr.)
27. Allegation
28. Boxer’s home town
29. Flight
30. She was
31. Bend the truth
32. “All About ___”
33. Tighten a spring
34. Swelter
35. Some terriers
36. A rich legacy
37. Lawn moisture
38. Boxing
39. Sculptor
40. Where Tel Aviv is: abbr.
41. Scope
42. Head, to Mimi
43. Accumulation
44. Shakespearean king
45. Civil War side: abbr.
46. “All About ___”
47. GOOD_
48. Fire, in France
49. Asphalt
50. “Alley ___”
51. ___-Wan Kenobi (“Star Wars”)
52. Times Square site: abbr.

**Down**
1. Stage drama
2. Scroll
3. Police abbr.
4. Mother: Fr.
5. Farming prefix
6. G. Carroll (“Topper” actor)
7. Ordinary (actor)
8. Hand out hands
9. Slip up
10. Huge work
11. Ordinary (actor)
12. Diameter (in abbr.)
13. Long (in abbr.)
14. Name of the country (abbr.)
15. Farming prefix
16. Authority (abbr.)
17. Diameter (in abbr.)
18. Long (in abbr.)
21. Slackens
22. Wolves’ den
23. First stock sale: abbr.
24. Allege
25. She was pursued by (sport)
26. Expectation
27. Allegation
28. Boxer’s home town
29. Flight
30. She was
31. Bend the truth
32. “All About ___”
33. Tighten a spring
34. Swelter
35. Some terriers
36. A rich legacy
37. Lawn moisture
38. Boxing
39. Sculptor
40. Where Tel Aviv is: abbr.
41. Scope
42. Head, to Mimi
43. Accumulation
44. Shakespearean king
45. Civil War side: abbr.
46. “All About ___”
47. GOOD_
48. Fire, in France
49. Asphalt
50. “Alley ___”
51. ___-Wan Kenobi (“Star Wars”)
52. Times Square site: abbr.
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 the end of a quip that begins “Real luxury is...”. The words are found in the diagram reading forward, backward, up, down, and diagonally, and always in a straight line.

You are looking for a 51-letter phrase.

**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.

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

Dropline
Regardless of which line you get into, the other ones move faster.

Leapfrog

Hidden Message
(Real luxury is) living in a house with so many closets that one of them is empty.

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Barnet suggests you also consider easy-to-remove layers. Items like a shawl or a cape can provide warmth, when needed, but can also be removed easily if your loved one gets overheated. “These kinds of garments are ideal because there are no arm holes to deal with,” she points out.

A type of clothing you may not have considered is a bath cape. “When you’re caring for an adult, it’s important to always respect that individual’s modesty and dignity,” says Barnet. “A bath cape can provide these benefits to a person who has to be bathed by a caregiver.”

When purchasing specialty items, such as a bath cape, it can be helpful to shop with a company that specializes in clothing for people with Alzheimer’s disease.

Organizing and categorizing items—shirts with shirts, pants with pants, etc.—is a helpful way to assist your loved one.

“When you’re caring for an adult, it’s important to always respect that individual’s modesty and dignity.”
—Brittany Barnet

Dressing Dos and Don’ts

For a caregiver, dressing a loved one with dementia can be a dreaded event. It’s often physically demanding. And, as with any interaction with a person with dementia, it can be mentally exhausting.

In the early stage of Alzheimer’s disease, your loved one may be able to dress him or herself—with supervision. You can provide assistance, but allow as much independence as you can during the dressing process. As the disease progresses, however, you’ll need to get more involved.

Regardless of stage, Barnet offers these tips for making dressing easier on both you and your loved one:

**Dos**

- Do establish a routine by having dressing occur at the same time each day.
- Do give clear instructions about what’s expected to happen. For example, “put on your sweater” is more helpful than “get dressed.”
- Do lay your loved one’s clothing out in the order the clothes will be put on.
- Do always respect your loved one’s modesty and dignity when you’re assisting with dressing.
- Do compliment your loved one on how good he or she looks. Everyone wants to look and feel good.

**Don’ts**

- Don’t take over if your loved one is able to dress him or herself, no matter how long it takes.
- Don’t rush the process. Doing so will only create stress for both of you.
- Don’t fuss over details like mismatched clothing.

With Alzheimer’s disease, dressing is usually the first daily challenge of many. Approaching this activity with the right attitude and techniques can help set the tone for the entire day.
Charitable Cause Warmer: **Forget-Me-Not**

Alzheimer’s is an especially cruel disease. It robs us of the very essence of who we are: our memories. Currently, one in eight older Americans have Alzheimer's, affecting 54 percent of families. It is estimated that by midcentury, 16 million Americans will suffer from this disease if a cure is not found.

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