preserving your Memory
The Magazine of Health and Hope

Taking Care with Joan Lunden

Just Diagnosed—Now What?

The National Alzheimer’s Action Plan: What You Need to Know

The latest news on Alzheimer’s research and treatment
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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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Turning Inward

As the weather chills, we all head inside to stay warm. We hope this issue of *Preserving Your Memory* helps keep you comforted during these cooler months.

We spoke with Joan Lunden about the challenges and rewards of caregiving (page 18). We also talked with Kathleen Kelly of the Family Caregiver Alliance about the new National Plan to Address Alzheimer’s Disease and what it means to caregivers (page 27).

You’ve just found out a loved one has been diagnosed with Alzheimer’s disease. What’s your next step? We are here to guide you (page 8). We take the guesswork out of handling pet care (page 12) and personal care (page 30) for loved ones who have Alzheimer’s.

On the research front, we talk to Fisher Center scientist Dr. Marc Flajolet about an exciting new direction in Alzheimer’s research (page 11). And we meet three researchers who were honored with awards by MetLife Foundation (page 14).

We hope you enjoy this special issue of *Preserving Your Memory*.

Betsey Odell
Editor in Chief

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About the Fisher Center for Alzheimer’s Research Foundation

Since 1995, the Fisher Center Foundation, a 501(c)(3) nonprofit organization, has been providing hope and help to the public by funding research into the cause, care, and cure of Alzheimer’s disease and creating much needed educational programs. We are one of the world’s largest research teams leading the battle against Alzheimer’s disease. Our team of internationally renowned scientists, under the direction of Nobel laureate Dr. Paul Greengard, has been at the forefront of research that has provided a conceptual framework for modern-day investigations into Alzheimer’s disease. Oprah’s *O* Magazine listed us as the top charity to give to for Alzheimer’s. The Fisher Center Foundation has earned Charity Navigator’s highest 4-Star rating for fiscal management and commitment to accountability and transparency. For more information or to make a donation, go to www.ALZinfo.org.
Ginkgo Biloba Not Helpful in Warding Off Alzheimer’s

A new French study found no significant effect of using the supplement ginkgo biloba in preventing Alzheimer’s disease, adding to the growing body of research refuting the herb’s purported effectiveness.

The study, published in the journal *Lancet Neurology*, followed 2,800 people over the age of 70 who have memory problems. About half of the study population received a 240 mg dose of ginkgo biloba, while the other half received a placebo. Scientists followed the patients for up to five years and gave them annual cognitive tests.

In the ginkgo biloba group, 61 people were diagnosed with likely Alzheimer’s, as opposed to 73 people in the placebo group. The difference is not statistically significant, which means it could have been due to chance alone.

Commenting on the study, Dr. Lon Schneider, director of the California Alzheimer’s Disease Center, said, “The idea of popping a pill or food supplement to prevent Alzheimer’s is just an exercise in hope at this point. If something doesn’t do what you want it to do, why continue taking it?” Instead, Schneider recommended focusing on healthy lifestyle habits, such as a healthy diet, regular exercise, and controlling risk factors for cardiovascular disease. This informative study does not, however, address the question as to whether ginkgo biloba would be useful at preventing dementia if given to younger people who have not yet developed memory problems.

New Compound Shows Potential as Alzheimer’s Treatment

Researchers at the Cleveland Clinic’s Lerner Research Institute and Anesthesiology Institute have discovered that a compound developed to treat neuropathic pain may also hold promise as a new Alzheimer’s disease treatment.

The compound, called MDA7, acts on a key receptor in the brain that plays a role in the neurodegenerative process that characterizes Alzheimer’s. In the study, MDA7 reduced inflammation, which limited the disease’s development in an animal model. Treatment with MDA7 also restored cognition, memory and synaptic plasticity.

“Our findings show it could represent a novel therapeutic target in the treatment of Alzheimer’s disease,” said Mohamed Naguib, M.D., professor of anesthesiology. “Development of this compound as a potential drug for Alzheimer’s would take many more years, but this is a promising finding worthy of further investigation.”

Higher Dose of Exelon Patch Approved for Use

The U.S. Food and Drug Administration (FDA) announced in September that a higher dose of the Exelon patch, made by Swiss pharmaceutical company Novartis AG, has been approved for the treatment of people with mild to moderate Alzheimer’s disease.

In the double-blind phase of the 48-week OPTIMA study, patients showed
significant overall improvement using the 13.3 mg/24 h patch, as compared to the 9.5 mg/24 h dose. Also, the percentage of patients with adverse events leading to discontinuation of the medication was lower with the 13.3 mg patch as opposed to the 9.5 mg patch even though there were slightly more adverse events noted for the higher dose.

“Alzheimer’s disease is marked by progressive symptomatic decline, resulting in an increasingly large physical and emotional challenge for the patient and caregiver,” said Jeffrey Cummings, director of the Cleveland Clinic’s Lou Ruvo Center for Brain Health. “Having multiple options for the treatment of mild to moderate Alzheimer’s disease will help physicians better care for patients with the hope of improving function and cognition.”

Alzheimer’s Blood Test May Be on the Horizon

The promise of a blood test to detect Alzheimer’s disease has shown promise in the past, but research success has been difficult to replicate in follow-up studies. But research published in the journal *Neurology* in August has uncovered a consistent set of markers that may herald the development of an inexpensive blood test.

Researchers at the University of Pennsylvania and Washington University in St. Louis measured the blood levels of 190 proteins in 600 study participants. Among them were healthy patients and those diagnosed with Alzheimer’s disease or mild cognitive impairment (MCI), thought to be an early stage on the path to Alzheimer’s.

Comparing the subset of proteins that were different in the study participants with data from the 566-participant, multicenter Alzheimer’s Disease Neuroimaging Initiative, scientists identified four distinct proteins. Changes in the levels of these four proteins in the blood correlated with the measurement of beta-amyloid proteins in the cerebrospinal fluid of the same patients. These results point the way to a possible reliable blood-testing standard.

“We were looking for a sensitive signal,” said lead author William Hu, MD, PhD, assistant professor of neurology at Emory University School of Medicine. “MCI has been hypothesized to be an early phase of AD, and sensitive markers that capture the physiological changes in both MCI and AD would be most helpful clinically. The specificity of this panel still needs to be determined, since only a small number of patients with non-AD dementias were included.”

New Recommendations to Guide Research into Why Women Get Alzheimer’s More Often

Nearly two-thirds of people who get Alzheimer’s disease are women, but no one is sure why that is. A recent roundtable panel of experts has issued research recommendations that will seek to guide future studies into that issue.

The panel, convened by the *Journal of Women’s Health*, sought to identify guidelines for future research, including the link between sex and Alzheimer’s incidence, and the importance of sex differences in experimental design and data analysis of studies on disease risk, early diagnosis and drug discovery.

“There are still major gaps in our knowledge of the role of sex and gender in the onset and progression of Alzheimer’s disease, and these recommendations will provide a useful guide for future research in this area,” said Dr. Susan Kornstein, editor in chief of *Journal of Women’s Health* and executive director of the Virginia Commonwealth University Institute for Women’s Health in Richmond, Va.

Check the Fisher Center website (www.ALZinfo.org) often for up-to-date and expert-reviewed scientific news.
The Alzheimer’s Diagnosis: Now What?

Learning of an Alzheimer’s diagnosis is a profound event in the lives of a person and the family. Where do you go from there? Here’s what you need to know.
A diagnosis of Alzheimer’s disease can be devastating, not only for the person receiving the news, but also for their family. Before long, they all face a difficult, urgent question: What do we do now? The many decisions to be made can be overwhelming. It’s best to focus on becoming educated about the disease and connecting with others who have been in the same situation. Look into possible drug therapies, enlist the right specialists and make simple but beneficial lifestyle changes.

But first things first. Before you do these things, make sure the diagnosis is accurate. “People may lose their memory and other cognitive abilities for reasons other than Alzheimer’s,” says Gary Small, M.D., co-author of The Alzheimer’s Prevention Program and director of the UCLA Longevity Center. “It could be a situation that is correctable such as a thyroid disorder, an infection, a tumor in the brain or a side effect from medication.”

**Gain Understanding**

If the diagnosis is confirmed, the entire family should learn about Alzheimer’s to understand the issues their loved one is facing. In basic terms, Alzheimer’s occurs because of a build-up of plaque and tangled proteins inside the brain in the areas that control thinking, memory, mood and other functions. Having Alzheimer’s means these changes in the brain impair a person’s mental abilities to the point where they need help with daily living.

One way to make this situation easier is to spend time with others who have faced the same challenges. “In the early stages of the disease, this type of connection is extremely beneficial,” says Jan Dougherty, M.S., R.N., director of family and community services at Banner Alzheimer’s Institute in Phoenix, Ariz. “Becoming involved in a group and hearing other people discuss their experiences can help someone learn how to live with Alzheimer’s. Family members can join the group to learn how to care for their loved one. People who aren’t comfortable in groups should find someone they can trust who will listen and give support.”

At this early stage, the family should meet to discuss medical, legal and financial issues and learn their loved one’s preferences for care. Completing healthcare power-of-attorney forms is important. Also, a person with Alzheimer’s will need more and different care as the disease progresses—learning about options for future care and how to pay for it must be discussed.

**Give Medications a Chance**

Another topic to discuss is FDA-approved drug therapies that can help in the early stages of Alzheimer’s and possibly even in later stages. These medications—cholinesterase inhibitors called Aricept, Exelon and Razadyne, and another type of medication, Namenda—won’t stop the disease, but they can improve learning, memory and attention span and slow the progression of symptoms for six months to a year in some patients. There is also evidence that they may slow disease progression over the long term, if taken chronically.

Small cautions families to avoid a common mistake with these drugs: “Some patients take them and don’t experience much improvement right away, or they improve slightly and after a while they start worsening, so their family takes them off the medications. Studies show, however, that if the drugs are producing benefits and you stop these medications too soon the patient might decline more rapidly, so even if symptoms don’t improve substantially, staying on these medications can help slow symptom progression.” It is also important to realize that cholinesterase inhibitors, like most drugs, can have unwanted side effects. So it is important to keep the patient’s physician informed about any changes in well being that occur while using these drugs.

While dealing with all of these issues, it’s essential to team up with the right healthcare providers. Many primary-care physicians can competently treat people with Alzheimer’s. Ideally, a neurologist, geriatric psychiatrist or geriatric internist should also provide care. Social workers and psychologists can help family members learn new coping skills. Many university medical centers with a focus on Alzheimer’s have teams of professionals who care for families.

**Lifestyle Changes Can Help**

Along with specialized professional care, simple changes can be very beneficial. “It’s important that people combine proper medical management with a healthy lifestyle,” says Dr. Small. “When my patients who are in the early stages of Alzheimer’s start a regular exercise program, eat healthy foods, minimize stress and learn to stimulate their minds at the proper level, they do much better.”

Also, consider these steps:

**Get help now:** A serious mistake families make is not asking for help soon enough. “The independent nature of most people leads them to shoulder all of the burden of care instead of asking family and friends to help with even the smallest tasks,” says Dougherty. “No one can do it all without becoming stressed and exhausted. It really does take a community to provide care.”
Stay at home: Someone in the early stages of Alzheimer’s is coping with frightening changes in the way their mind works. Don’t make their situation worse by changing their living environment as well. “Some families make the mistake of moving their loved one to a different house to provide a change of scenery or taking them on a trip,” says Small. “We know that once dementia begins, any kind of change is difficult for a person to handle, so their symptoms might get worse if they’re faced with these types of changes.”

Get a move on: In *The Alzheimer’s Prevention Program*, Small details the ways that exercise can improve the symptoms of Alzheimer’s: “Most studies that show significant brain-health benefits from exercise have involved walking, but any form of cardiovascular conditioning has similar effects on increasing blood flow to the brain, which can improve mental performance. Studies also show that strength training can improve cognitive function and brain health as well.”

Sharpen your memory: Research shows that practicing basic memory-improvement techniques sharpens memory and slows the mental decline associated with aging. “Using these techniques can activate and strengthen specific neural circuits in the brain’s frontal lobe, a critically important memory-processing center,” says Small. “With practice, the brain develops more efficient strategies for both learning and recall.”

Food for thought: “What we eat affects our brain function,” says Small. “Scientific evidence points to foods that promote brain health and others that are best to avoid.” Emphasize complex carbohydrates such as whole grains and avoid processed foods; eat omega-3 fats from fish at least twice a week to protect the brain and stabilize mood; fruits with a high level of antioxidants such as berries, prunes, plums, apples and apricots may help boost brain function.

Reduce stress: In addition to causing a variety of ailments from ulcers to heart disease to depression, stress can also affect brain health because it releases hormones that damage the brain’s neurons and weaken memory. Getting plenty of sleep, adding aerobic exercise to the daily routine and giving meditation or yoga a try can protect someone with Alzheimer’s from stress. Just as important, cultivating fulfilling friendships and asking friends for help when necessary can lighten the load.

Stay positive: In dealing with Alzheimer’s, keeping an optimistic attitude can lift spirits and help a family make the most of its time together. “It’s common for someone with Alzheimer’s and their family to experience depression and feelings of loss because it’s a progressive disease,” says Dougherty. “Too often they focus on what the person can’t do anymore rather than taking inventory of what they still can do! Despite the problems that Alzheimer’s causes, there is always help and hope for both patients and families.”

**For More Information …**
Learn more by visiting these websites:

- Fisher Center for Alzheimer’s Research Foundation
  www.ALZinfo.org

- National Institute on Aging—Alzheimer’s Disease Education and Referral Center
  www.nia.nih.gov/alzheimers/

- National Library of Medicine—Health Information on Alzheimer’s

- Current Clinical Trials and Research on Alzheimer’s
  http://clinicaltrials.gov

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Preserving Your Memory talked to Dr. Marc Flajolet, Research Assistant Professor at the Fisher Center for Alzheimer’s Disease Research Laboratory, about the work his team is 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. Marc Flajolet:** I am a molecular biologist by training, working on brain signaling in the context of aging and especially Alzheimer’s disease (AD), for over 12 years now. In Dr. Greengard’s lab, we use an elaborate set of state-of-the-art techniques (ranging from molecular biology to behavioral studies) to discover novel biological functions relevant for AD. Our interest is to identify novel cellular targets or pathways important for AD and study how those can be used to design new drugs that would be beneficial for AD. I also work on identifying novel small molecule compounds that affect AD models and cultured cells in ways that show a potential to treat the disease.

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

Dr. Greengard’s laboratory identified Gleevec, an FDA approved anti-cancer drug, as a novel potential drug to treat some aspects of AD. A few years later, we identified GSAP (gamma secretase activating protein) as the cellular target of Gleevec. Currently we are characterizing the role and the biological function of GSAP in order to better design interfering molecules that could be used therapeutically to treat AD. We have also identified that Casein Kinase 1 (CK1) might represent an interesting target. Inhibition of CK1 could lead to improvement in two major hallmarks of AD: reduction in beta amyloid production and reduction in Tau phosphorylation. We are currently working to establish the CK1 mechanism and we hope to bring to light the cellular target of CK1 that leads to these effects.

Along those lines we have recently shown that a small compound (SMER28) could be beneficial for AD via its role in autophagy activation. We hope to further develop this family of compounds and optimize their brain permeability in order to test their efficacy in vivo.

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

Our role most likely will impact the treatment much more that the diagnosis, but there are also chances that the genes we identified (such as the ones encoding proteins that interact with GSAP) could become important markers for the diagnosis of AD.

Any of the small molecule compounds that we identify has the capacity to become a drug to treat AD and therefore we put a lot of effort in this direction. We are working in a quite unique scientific environment that allows us to have access to a unique combination of techniques. This should help us tremendously to stay competitive and work at the highest possible pace.

**What directions can you see your work taking in the future?**

We hope and believe that we will be able to move away from simple systems such as cellular tests and go forward toward more complex systems, and ideally bring some of our discoveries into pre-clinical studies and clinical trials.
When Your Loved One Can’t Care for a Pet

What to do about pets when a loved one has Alzheimer’s is a delicate issue. Here’s some guidance to help you make the right decisions.

For Rose Holland, Sparky was a constant companion who kept her company after Rose’s husband died 11 years ago. But when Rose developed Alzheimer’s and her memory got worse, taking care of the miniature chihuahua became increasingly difficult. Family members noticed that Sparky was gaining weight, while Rose was becoming thinner. Rose often fell when she picked up Sparky and tripped over his leash when she took him outside.

When her memory deteriorated, Rose’s family placed her in Autumn Leaves, an assisted-living facility in McKinney, Texas, where she was allowed to keep Sparky. But the problems didn’t go away. “She would stay in her room with the dog because she worried about him running away or somebody taking him,” says her granddaughter, Jamie Lopez, vice president of healthcare at Constant Care, the company that runs Autumn Leaves. “And at meal time, she couldn’t take the dog with her, so she’d ask to have the meals sent to her room.”

On top of losing weight, Rose had stopped socializing. Her family grew worried. Finally, in the fall of 2011, after consulting with other caregivers, Lopez and her mother and siblings decided to let another caregiver at Autumn Leaves take Sparky. These days, Sparky visits Rose once or twice a week and lives with the caregiver. Rose, now 88, has gained back 12 pounds and is socializing again.

A Delicate Balance

It isn’t easy when a loved one with Alzheimer’s can no longer care for a pet. The companionship and love that comes with having a pet must be weighed against any health and safety issues that arise from the responsibilities of owning a pet.

Mike Kiger, of Lake Oswego, Ore., for instance, couldn’t imagine separating his mom, Katie Kiger, 81, from her dog Keemac. So when she was diagnosed with Alzheimer’s in November 2011, his brother agreed to let her live with him and his wife. “We were told that if we were to take her dog away from her that she would go down quicker,” Kiger says. “She needed the dog for therapy, and the dog needed her. She would be completely lost if we had taken her dog away from her.”

But as any pet owner knows, having a pet is a responsibility that involves feeding, walking and bathing, tasks that can be a challenge when memory and balance are compromised.

Lopez says her family struggled with the decision to separate her grandmother from Sparky. “Looking back, we knew what had to be done, but it was hard to recognize that when we knew how beneficial the dog was,” Lopez says. “In fact, I think it was harder on us than it was on her. We had so much guilt about taking Sparky away. Sparky has been her lifeline since my grandfather died.”

Having a pet is a responsibility that involves feeding, walking and bathing, tasks that can be a challenge when memory and balance are compromised.

What to Do

Whether to remove a pet from a person with Alzheimer’s requires careful thought and consideration. The key is to be honest about the situation and what needs to be done, Lopez says. Here’s what you should do:

- Pay attention to signs that the pet’s care is compromised. One of the biggest tip-offs is a change in weight. People with Alzheimer’s may struggle with remembering whether
they fed their pets or forget that they did. Other signs include frequent accidents in the house, which indicates the pet isn’t being taken out regularly.

• **Take your cues from your loved one.** Does your loved one resist the idea of separating from her pet? Or is she becoming agitated by the animal’s unpredictable behavior? Although health and safety are important considerations, it’s also important to look at her behavior around the pet and to consider what she wants.

• **Choose your words wisely.** Lopez said her grandmother wouldn’t listen when family members first suggested removing Sparky. “She didn’t see that feeding the dog was a problem or that if she fell it was the dog’s fault,” Lopez says. “But she was much more receptive to the idea when we told her, ‘We know you want Sparky to get a bath every three days and to go the park every day.’”

• **Find ways to get hired help if you choose to keep the pet.** Ask the home health care aide to add pet chores to her responsibilities for a small fee. If there are friends or other family members nearby, ask if they could drop in and take the dog on a walk or change the cat’s litter box. If you must remove the animal, find ways to arrange visits, so the pet remains a presence in your loved one’s life.

Pets can be wonderful therapy, but they require care and maintenance.
In May, MetLife Foundation announced the honorees of its 2012 Awards for Medical Research in Alzheimer’s Disease. Clifford R. Jack Jr., M.D., professor of Radiology and The Alexander Family Professor of Alzheimer’s Disease Research at Mayo Clinic in Rochester, Minn., and Christine Van Broeckhoven, Ph.D. D.Sc., professor and department director of the VIB Department of Molecular Genetics at the University of Antwerp, Belgium, received Awards. In addition, Randall J. Bateman, M.D., associate professor of Neurology at the Washington University School of Medicine in St. Louis, received MetLife Foundation’s Promising Investigator Award.

All three winners were recognized at a scientific briefing and awards ceremony in New York. Dr. Jack and Dr. Van Broeckhoven each received a $200,000 research grant to their institutions to further their work, as well as a personal prize of $50,000. Dr. Bateman received a $100,000 grant to his institution to further his work in Alzheimer’s disease.

After a scientific briefing from the award recipients, journalist and author Gail Sheehy gave the keynote address.

To date, the MetLife Awards for Medical Research in Alzheimer’s Disease have recognized 67 recipients, two of whom have gone on to win Nobel Prizes.

An innovator in clinical studies of brain structure in disease, Dr. Jack developed and applied imaging methodologies to determine and track the stages of Alzheimer’s disease. Dr. Van Broeckhoven is a basic scientist and expert in molecular genetics. She made groundbreaking discoveries establishing the genetic basis of inherited Alzheimer’s disease and other disorders. Dr. Bateman is a neurologist and biochemist who pioneered the use of measurements of beta-amyloid protein in the brain to better understand the biochemical basis of Alzheimer’s disease.

“MetLife Foundation is proud to present these awards that recognize outstanding achievements in medical research,” said Dennis White, president and chief executive officer, MetLife Foundation. “Doctors Jack,
Van Broeckhoven and Bateman have made significant contributions to our understanding of Alzheimer’s disease and their dedication helps bring us closer to finding a cure for Alzheimer’s disease.”

The American Federation for Aging Research (AFAR) manages the awards for MetLife Foundation. AFAR champions the cause and supports the funding of science in healthier-aging and age-related medicine. The organization was founded in 1981. For more information about AFAR, please visit www.afar.org.

“We have selected these individuals because of their novel and significant approaches to Alzheimer’s disease, which are paving the way for additional discoveries that are important for diagnosis and treatments for this disease,” said Donald L. Price, M.D., chair of the MetLife Awards for Research in Alzheimer’s Disease Advisory Committee, which selected the award recipients. Dr. Price is professor of Pathology, Neurology and Neuroscience at Johns Hopkins School of Medicine and is a previous recipient of the MetLife Award.

**Dr. Clifford R. Jack, Jr.**

Dr. Jack pioneered medical imaging methods that identify biomarkers for Alzheimer’s disease. A major objective in understanding and developing treatments for the disease, identification and validation of biomarkers are characteristics that measure a biological state, such as a stage of disease. Dr. Jack introduced imaging methods beginning in the 1990s that help distinguish manifestations of the disease in the brain, assess severity, measure progression and make predictions about its future course. The concepts Dr. Jack introduced have been widely adopted.

Dr. Jack’s initial studies focused on anatomic MRI, a type of brain imaging. But he also contributed pioneering work in MR spectroscopy, diffusion imaging, functional MRI, high-field microimaging and amyloid PET analyses of amyloid burden. He has also integrated information from measures of biomarkers for the disease, taken from studies of central nervous system imaging and levels of markers in cerebrospinal fluid, into a comprehensive model of brain abnormalities in parallel with clinical features. His model served as the basis for the staging of presymptomatic (preclinical) Alzheimer’s disease in recently published National Institute of Aging criteria.

**Dr. Christine Van Broeckhoven**

A recognized leader in the molecular genetics of Alzheimer’s disease and other complex neurological and psychiatric disorders, Dr. Van Broeckhoven established critical features of the genetic basis of different types of dementia through her research. She identified the gene encoding APP (amyloid precursor protein), the first gene linked to familial Alzheimer’s disease, nearly 30 years ago.

Dr. Van Broeckhoven and her colleagues also demonstrated the involvement of the brain’s blood vessels in the neurodegenerative process. She contributed to the identification of the presenilin-1 gene on chromosome 14 as an additional gene involved in inherited cases of Alzheimer’s disease, and she aided in the identification of apolipoprotein E4, a lipid-binding protein, as a risk factor for both late-onset and early-onset Alzheimer’s.

To date, the MetLife Awards for Medical Research in Alzheimer’s Disease have recognized 67 recipients, two of whom have gone on to win Nobel Prizes.
Her most recent work has delved into the genetics of other neurodegenerative diseases. Along with her colleagues, she identified the gene that encodes the protein progranulin, an achievement that provided the first evidence that growth factors play an important role in neurodegeneration in certain types of dementia.

**Dr. Randall J. Bateman**

Dr. Bateman pioneered the use of Stable Isotope Labeling Kinetics (SILK) measurements of Alzheimer’s disease markers in cerebrospinal fluid. Using this technique, Dr. Bateman has shown that people with Alzheimer’s do not eliminate beta-amyloid from the brain as well as those who don’t have Alzheimer’s. (Beta-amyloid is the protein that builds into plaques inside the Alzheimer’s-affected brain.)

In order to come up with better diagnostic and treatment strategies, Dr. Bateman’s lab keeps a primary focus on ways in which the disease changes the brain’s functional properties. The lab is currently beginning to study additional Alzheimer’s-related proteins and their potential roles in the disease’s process.

Dr. Bateman conducts clinical trials and is director of the Therapeutic Trials Unit of the Dominantly Inherited Alzheimer’s Network, which is the largest international study of autosomal-dominant Alzheimer’s disease. He has spearheaded efforts to make effective experimental treatments available to people who have the hereditary form of the disease. The goal is to prevent clinical dementia before cognitive impairments become manifest.

“Doctors Jack, Van Broeckhoven and Bateman have made significant contributions to our understanding of Alzheimer’s disease and their dedication helps bring us closer to finding a cure for Alzheimer’s disease.” —Dennis White, president and chief executive officer, MetLife Foundation

“We have selected these individuals because of their novel and significant approaches to Alzheimer’s disease, which are paving the way for additional discoveries that are important for diagnosis and treatments for this disease.” —Donald L. Price, M.D., chair of the MetLife Awards for Research in Alzheimer’s Disease Advisory Committee
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.

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Taking Care with Joan Lunden

For 17 years, Joan Lunden woke the country up as the co-host of Good Morning America. Now, the award-winning journalist and mom of seven is giving America a new wake-up call. As a spokesperson, host of a TV series, and co-author of the recently released Chicken Soup for the Soul: Family Caregivers, Joan is spreading awareness about dementia, which affects her 93-year-old mother, Gladysce.

Preserving Your Memory magazine spoke with Joan about her role in educating families affected by dementia and caring for her mother from afar.

Preserving Your Memory: Can you describe your initial reaction to your mother’s diagnosis?

Joan Lunden: It’s interesting because dementia is not like you go in and they find cancer somewhere in your body. It happens little by little. Forgetful becomes frightful. Somebody would walk up and say, “Hi Gladys.” And my mom would look at them and not have a clue as to who they were. Sometimes you can say, “She hasn’t seen that person in 10 years.” But then she didn’t remember the people who were taking care of her on a daily basis. We all tend to want to stick our heads in the sand because we want them to stay as they used to be. But it’s really more the realization. At some point you have to finally acknowledge it.

PYM: Your mother and your brother, who had type 2 diabetes, lived in a condo together. After your brother passed, you went to pack your mother’s things because she couldn’t live alone. You had trouble finding her driver’s license, social security card, even accessing her bank account.

JL: I don’t know what the explanation is, but almost everybody’s home you go into that’s older, they tend to keep everything. I went in and there must have been ten thousand pieces of paper, just not the important ones. When I asked about her driver’s license, she said, “I don’t know. You know I stopped driving a long time ago.” “Okay, where’s your Social Security card?” Her response was, “I don’t know. I don’t take care of that anymore.” I couldn’t find anything.

PYM: What steps do you think caregivers and future caregivers need to take so they don’t face a similar situation?

JL: You should have a copy of your parents’ (and even your spouse’s) driver’s license and passport. You should know where their health and life insurance papers are, the
There comes a time when you have to say, “What’s the safe thing to do for my parent?” You have to really come to terms and acknowledge when you can’t leave them in that situation for their own good.

mortgage or rental agreement to where they live, and the car title. You also need to have a legal and medical power of attorney so you can act on their behalf, a HIPAA release so medical institutions can release information to you, an advanced healthcare directive, otherwise known as a living will, and you need to know whether they have advanced long-term healthcare insurance.

PYM: Deciding when (or whether) to place a loved one in assisted living is difficult. What advice would you give to families struggling with this decision?

JL: There comes a time when you have to say, “What’s the safe thing to do for my parent?” A lot of people say, “My folks are going to stay right where they are until the end.” It’s wonderful when you can do it, but you have to really come to terms and acknowledge when you can’t leave them in that situation for their own good.

PYM: Your mother moved to a few different facilities. Tell us about the moves.

JL: The first place had a beautiful dining room and she had her own one-bedroom apartment. The only problem was it was probably the perfect place for my mom about 10, 15 years ago. She hadn’t lived alone in a long time and didn’t want to, was fearful of it. She also had what’s called “sundown syndrome,” so when the sun started to set and the shadows started changing, she would come unglued. I found another place that gave more care but it still wasn’t enough because she would get out of bed and fall. After three or four falls, the doctors said, “You can’t put her back in this kind of setting. She needs around-the-clock care.” That’s where she is now.

PYM: Any tips to make moves easier for loved ones?

JL: Moving completely disconnects them from their reality one more time and they’re in a new place, everything is situated in a new way. The last time we moved my mom, my daughter Lindsay went out with me and she had this fantastic idea to photograph everything in mom’s old room. When we moved her into the new place, we looked at those pictures and put everything back as best as we could. It seemed to be less disconcerting to mom.

PYM: You’ve mentioned experts helped you get a better handle on things. What kind of experts did you find to be helpful?

JL: I got an elder lawyer in Sacramento where my mom lives. It didn’t cost much. You’re not talking about thousands of dollars. It was hundreds of dollars. She was able to help me put together the important documents I needed.

PYM: Taking Care with Joan Lunden is running on RLTV. How did the idea for this series come about?

JL: We do this as a joint project between AARP and RLTV, but they came to me because they’d read a story somewhere and knew of my mom’s situation. Doing a program like this, interviewing different experts and real families going through the journey, it helps when you’ve done it yourself and know the frustrations, roadblocks, and questions to ask. Now I speak all over the country about this.

PYM: Taking Care focuses on many aspects of caregiving. One thing it addresses is different types of senior housing. Did you struggle when finding a place for your mom?

JL: Each time I’d gone out to Sacramento, I’d get in a car, look around, and ask people for word-of-mouth recommendations. I think back on it now. If I wanted to buy a house, would I have gotten in my car, driven around the neighborhood and looked? Never in a million years. I would’ve called a realtor. I would have gotten a professional to help me. Yet, when you’re presented with these issues as a caregiver, it’s a frustrating and frightening feeling.
PYM: You’re a spokesperson for A Place for Mom, a senior living referral service. Can you tell me about the service? Any tips for caregivers navigating the world of senior housing?

JL: A Place for Mom helped me get my last place, the place that was finally right for my mom. They told me about the places available in the area, the pros and cons of each one, and they took me to see them. They also walk into a place and ask questions you’re not inclined to ask. I never would have walked into the kitchen and opened the refrigerator to see if they cook fresh food or give them frozen TV dinners. I never would’ve walked into someone else’s bedroom or bathroom to see how clean it was. But those are the things you need to do. And they do it. And it doesn’t cost you anything.

PYM: How do you keep in touch with her?

JL: I visit every five or six weeks. And I keep a good relationship with the people who are in charge of her care. If you sit and talk with the people who take daily care of your loved one, they have more information to make your loved one more comfortable on a daily basis. I talk about what mom was like growing up, what my dad was like, what we were all like as a family, where she lived in the area, and it allows them to come up with all kinds of information to connect her with life as she knew it. I also send little things. When I go out of town, I’ll pick a postcard, quickly address it to her, and say, “Hi from Philadelphia!” Or I’ll send a magazine with a little paper clip and piece of paper in there that says, “Hi, Mom. Thought you’d enjoy this article.” It means she gets mail, opens it, and there’s a connection to me.

PYM: You’re part of the ‘sandwich generation’ — caring for children while also caring for a parent. How difficult is it to maintain balance, especially with your career?

JL: It’s very difficult. It’s said the average caregiver is a woman who is 49 years old and still caring for kids, whether they’re in the home or you’re financing them through college, and you have a job outside the home, and now you’re caring for a loved one. It all adds up. It’s enough to take anyone down.

PYM: What advice would you give to others in this situation?

JL: Get support, whether it’s online support, through your local church, or a program in your area. If there are other siblings around, ask them for help as well. You have to seek help and advice so that you don’t totally burn out.

PYM: How is your mom doing now?

JL: She’s actually doing okay. My mom doesn’t have any kind of actual health problem, like high blood pressure or anything. The dementia is really the one overriding factor. But she’s happy where she is. They take fantastic care of her. It’s great to put my head on my pillow and go to sleep with peace of mind that the people who are with my mom are compassionate, kind, and smile at her from morning to night. Therefore, I take my hat off to all caregivers who do that on a daily basis, whether it’s at home with a loved one or at a facility taking care of the older people in our country. That, to me, is priceless.
When you’re a busy caregiver, taking a shower and eating a proper meal might sometimes feel like a challenge. Making the time to take a walk, go for a swim or hit the gym might seem like a downright luxury.

But in reality, regular exercise should be considered a necessity for caregivers, experts say. “Exercise like other health-promoting behaviors is good for caregivers,” says Richard Schulz, PhD, associate director of the Institute on Aging at the University of Pittsburgh. “However, due to the demands and stresses of caregiving, exercise, like other self-care behaviors, is often neglected.”

Adds Barbara Bushman, PhD, editor of ACSM’s Complete Guide to Fitness & Health (2011, Human Kinetics) and a professor of kinesiology at Missouri State University, “I can’t think of a more important group that needs to take care of themselves. They need to take care of themselves first in order to take care of the person they love.”

The Perks of Exercise

Exercise does wonders for your physical health by improving strength and balance, making it easier to perform daily activities. It also helps rev up your metabolism. “As you get older, your metabolism gets slower,” Bushman says. “We have less muscle mass and higher body fat. Some of that is due to decreases in activity, and some is due to the aging process. Less muscle mass means we need fewer calories for overall body weight.”

Exercise helps caregivers boost their metabolism.

The right combination of exercises can also help maintain your flexibility, and maintain healthy heart and lung functioning.

Regular exercise has psychological benefits too, and is a good antidote for depression that often comes with caregiving. Research has found that caregiv-
ers who exercised 30 minutes three times a week had less stress and depression. “Regular activity enhances your mood state, and has social benefits if you do it with others,” Bushman says. “It’s a huge stress reliever. It also reduces anxiety and in the long-term, promotes improved feelings of well-being.”

Exercising regularly can also slow age-related cognitive declines, improve the way your brain processes information and preserve motor control for more precise movement. “With exercise, we’re helping to not lose those capabilities as quickly,” Bushman says.

**Get Down to It**

Knowing that exercise matters is one thing, but actually doing it is another. The key is placing value on exercise and recognizing that it’s important not only for you, but your loved one. “You have to go back to what you value and really grab onto what the benefits are and then really enjoy what you are doing,” Bushman says. “Hopefully you’re doing things that not only make you feel better tomorrow, next week or next year, but it should feel really good to you right now.”

It also helps to change your perspective on exercise. Instead of saying “I can’t fit this into my schedule,” say, “I will fit this into my day,” Bushman suggests. “You change your perspective to set the habit,” she says. “Once you’ve set the habit, it will seem strange when you don’t do it.”

Even with all the new ways of thinking, making room in your life for exercise isn’t easy. “Finding the time for exercise is a major challenge,” Schulz says. “An ideal scenario would be to combine exercise with respite, and have someone else care for the patient while the caregiver takes an exercise break.”

The other challenge to overcome, he says, is exhaustion. Caregivers are often too tired physically and emotionally to do any exercise. Schulz says that finding respite could also help with that.

For those who haven’t exercised in a while, figuring out what to do can be difficult. Here are some tips to get you started:

- **Set some goals.** Create distinct and measurable goals on what you plan to do. It might be taking a 10 minute walk after breakfast every day, or doing hand weights during commercials for your favorite hour-long TV show twice a week. “Goal setting is vital for everybody,” Bushman says. “Without them, it’s like starting out on a road and not knowing where you’re going.”

- **Write it down.** Bolster your commitment by putting your plans on paper. Schedule it on your calendar as you would any other appointment. Then keep a log of what you do each day, so you can map your progress.

- **Work toward total body conditioning.** To get the most from exercise, work up to doing a cardiovascular workout three to four times a week, strength training twice a week, balance training two or three times a week and flexibility at least twice a week. Visit www.easyforyou.info for more ideas on specific exercises.

- **Check out your options.** Be open to different ways of exercising. Consider checking out classes at the local gym, senior center or YMCA for a more social workout. If you prefer exercising at home, looking into purchasing or borrowing exercise DVDs or investing in a treadmill or stationary bike.

Whatever you decide to do, the key is to be active—and to enjoy it.

“If you’re walking around the neighborhood, enjoy the scenery,” Bushman says. “If you’re walking at the mall, enjoy the social interaction. You have to really enjoy what you are doing.”
When you think of the holidays, you cannot help but think first of the food. Those moist, buttery mashed potatoes, the creamy green bean casserole with those crunchy fried onions, the prime rib, the crisp skin of the turkey fresh out of the oven, and all of those desserts, each an attempt to outdo the other! The eating starts early in the day and rambles on through parades, football games, and a 24-hour cycle of *A Christmas Story*. At some point, you will pat your belly, thank your elastic waistband, and need a nap. It is heaven for your taste buds. But not necessarily so for your brain health.

“Fat trumps everything in brain health,” says Katherine Tallmadge, MA, RD, and author of *Diet Simple: 195 Mental Tricks, Substitutions, Habits & Inspirations*. Fats, whether saturated or unsaturated, end up in all of your body’s cells, including your brain. Saturated fats, those that turn solid at room temperature, like butter, reduce blood flow and cellular flexibility and functioning. “When you look across a table full of holiday foods, anything that has butter or shortening are your worst offenders,” says Tallmadge. That includes those aforementioned dishes that got your mouth watering. However, unsaturated fats have the opposite effect. Healthy oils, such as olive or canola oils, act as a cell lubricant and improve brain functioning. But will a meal low in saturated buttery goodness taste as great? Absolutely.

**Start with your centerpiece meat.** Prime rib is a very fatty red meat. “If you restrict your intake of meats like this to just one or two meals over Christmas, you’re probably OK, but you have to be careful,” says Tallmadge. However, you can find more healthful and delicious options.

The leanest red meat is the round, which makes a nice pot roast or stew. A tasty marinated pork tenderloin cooks in just 10 minutes (leave it a little pink in the middle) and is as lean as chicken if you take the fat off. Salmon provides an abundant serving of omega-3 fats, which is associated with a decreased risk of numerous cardiovascular problems.

**Skip the butter.** No one will notice. “Whip mashed potatoes with lowfat...”
buttermilk and add some olive oil and garlic, and people won’t miss the butter,” says Tallmadge. Cream spinach, green beans, or kale with a rich béchamel sauce that calls for olive oil and 1% milk (see recipe). You can even find mouth-watering recipes for cookies, pound cake, and dense chocolate cake that only use olive oil.

The right variety is the spice. “Humans have a natural urge for variety,” says Tallmadge, but you shouldn’t feed that urge with an army of starchy foods and desserts. Instead, offer a range of interesting vegetable and fruit dishes. Put out just one appetizer and one rich dessert along with some fruit. Otherwise, you and your guests will load your plates with every cake, pie, and brownie offered, and you’ll wind up feeling uncomfortable.

Distance yourself. To keep eating and drinking in check, keep the food and alcoholic drinks in the kitchen and not on the table or in the living room where people can just keep serving themselves. Keep water at the ready in a nice pitcher and always offer diet soda, herbal teas, or sparkling water with a splash of juice as an option.

Start a new tradition. Exercise tends to fall by the wayside during the holidays, but it’s critical to stay active. Walk with your family in the mornings, after meals, or, if you can, to religious services. Develop a new tradition where you shoot some hoops or go sight-seeing.

The holidays don’t have to sabotage your efforts for a healthy lifestyle. A few tweaks along the way can shift your yuletide memories from overstuffed sedentary gluttony to sweet and savory energetic fun. One day your children will pull out those delicious recipes from childhood, they’ll keep up those new traditions, and your family will enjoy a happy and healthy future.■

(For recipe, see page 26)
From *Diet Simple*:

**Kale and Spinach Gratin with Garlic, Rosemary and Thyme**

Any greens will do in this versatile recipe. Deep-green leafy vegetables have the highest antioxidant content of all vegetables. High in fiber, they are rich in minerals, B-vitamins, beta-carotene, and lutein, a compound that may help reduce the risk of age-related macular degeneration (the leading cause of preventable blindness). Absorption of carotenoids, such as lutein, in your body is increased by cooking and by the presence of fat (so cook in a little healthy olive or canola oil!). Serves 6.

**Ingredients**

- 1 pound kale, cleaned and stems removed
- 2 pounds spinach, cleaned and stems removed
- 1 tablespoon olive or canola oil
- 1 large garlic clove, minced
- 2 teaspoons fresh rosemary, chopped (or 1 tsp dry)
- 1 teaspoon fresh thyme leaves, chopped (or ½ tsp dry)
- 1 recipe *Olive Oil Béchamel Sauce* (see recipe)
- salt and freshly ground pepper to taste
- ¼ cup parmesan or gruyere cheese, freshly grated

**Directions**

Preheat oven to 400 degrees F.

Wash the kale and spinach and remove the tough stems. Chop roughly.

Heat the oil in a large iron skillet over medium-low heat. Add the garlic and cook until it just begins to color. Add the greens, the rosemary, and thyme to the pan, and let cook a couple of more minutes while stirring until the greens are wilted.

Stir the Béchamel sauce into the greens. Add salt and pepper. Pour into an oiled 2-quart soufflé or heat resistant glass dish and sprinkle the cheese on top. Bake at 400 degrees F for 20 to 30 minutes, or until the top is just beginning to brown.

**Olive Oil Béchamel Sauce**

This is a classic French white sauce, but using healthy olive oil instead of butter. Makes 2.5 cups

**Ingredients**

- 3 cups 1% milk
- 2 tablespoons olive oil
- 2 tablespoons flour
- salt and ground pepper to taste
- pinch of grated nutmeg (optional)

**Directions**

Simmer the milk in a saucepan on medium-low heat. Meanwhile, heat the olive oil in a heavy skillet. Add a bit of flour, and when it sizzles, add the rest. Stir constantly with a wooden spoon or whisk over medium heat. Do not brown.

Whisk in the hot milk. Return the mixture to the heat, stirring until the sauce thickens. Reduce to low making sure it does not burn. Add salt, pepper and nutmeg to taste.
In May of this year, the U.S. Department of Health and Human Services released a comprehensive action plan to combat Alzheimer’s disease and other dementias. Designed as a follow-up to President Obama’s 2011 National Alzheimer’s Project Act (NAPA), the National Plan to Address Alzheimer’s Disease includes specific strategies for prevention and treatment, along with an ambitious target to manage the disease by 2025.

The plan, which is supported by a proposed $100 million in additional funding from the President’s fiscal year 2013 budget, is built on five central goals:

1. Prevent and effectively treat Alzheimer’s disease by 2025
2. Optimize care quality and efficiency
3. Expand supports for people with Alzheimer’s disease and their families
4. Enhance public awareness and engagement
5. Track progress and drive improvement

“These actions are the cornerstones of an historic effort to fight Alzheimer’s disease. This is a national plan—not a federal one, because reducing the burden of Alzheimer’s will require the active engagement of both the public and private sectors.” —Kathleen Sebelius, Health and Human Services Secretary

A Conversation with Kathleen Kelly of the Family Caregiver Alliance

By Mary Adam Thomas

Kathleen Kelly, MPA, executive director of the Family Caregiver Alliance
To hone in on some of the ways in which the plan will affect the people who care for loved ones with Alzheimer’s disease or other forms of dementia, Preserving Your Memory spoke with Kathleen Kelly, MPA, the executive director of the Family Caregiver Alliance (www.caregiver.org), a national non-profit advocacy organization.

Preserving Your Memory: How does this legislation reflect the increasing attention being paid to Alzheimer’s disease and other dementias and the need to support the growing community of family caregivers?

Kathleen Kelly: There is a large amount of research happening in the private sector, at pharmaceutical companies, at research institutes and from the government’s investment in this crisis. I think that we’ll be able to make great research strides by 2025. It’s important that we do, because that’s when the Baby Boomers will be aging into the higher-risk groups for developing dementia.

PYM: Let’s talk about the five goals of the plan. What stands out among them from a caregiver’s perspective?

KK: From my vantage point, prevention is one of the keys to managing this disease, so it’s appropriate that it is the first strategy defined in the national plan. We should be out beating the prevention drum much more loudly, particularly as it relates to dementia that can have its causation in metabolic issues. For example, there’s a correlation between diabetes and dementia, so it’s very important that we educate people about preventing diabetes as a way to lower the risk for dementia. We have an accelerated research mode right now that is going into action, which is great, especially with early detection and diagnosis. However, we really need to link the prevention issues to other kinds of causations of dementia. It’s all about good health—weight control, healthy eating and exercise—that can promote wellness in general too.

PYM: What is significant about the plan’s second goal related to care quality and efficiency?

“We need to step up now and figure out how to solve this challenge through research, prevention, treatment, training and support for families.”
KK: We don’t have uniform quality standards across care settings, particularly when it comes to treating persons with dementia. There are skill sets in different parts of the country and across different settings, but now we need to take those best practices and integrate them in all health care settings. We also need to require standardized clinical training and continuing education on Alzheimer’s disease for health care professionals—from diagnosis and treatment to working with the whole family on care and support issues. I’m hopeful this national plan will further the effort to fund additional training.

PYM: Tell us your thoughts on the plan’s goal of expanding supports for Alzheimer’s patients and family members.

KK: When it comes to this goal, I do think the strategies are really well addressed. The plan calls for an investment of $10 million in fiscal year 2013 to support the needs of caregivers. That’s nice, but on a national level it’s really a drop in the bucket. The kinds of supports we fund through public dollars for families are minimal. If you add up the funding that’s exclusively for non-veteran family caregivers—and a large number of family caregivers who reach out for services are dealing with somebody who has dementia—it comes to roughly $200 million. This includes the National Family Caregiver Support Program (at around $158 million) and various state-funded caregiver support programs across the country. If you weigh that against the 42 million caregivers in the country who provide the bulk of long-term assistance at a value of $450 billion, you can see that we’ve made a fairly small investment in the workforce that provides the majority of care to individuals. The long-term support and assistance provided by families and their economic value dwarfs the public expenditures. The plan’s $10 million is a starting point, but when you think about the overwhelming need across the country, it’s really a down payment. We need more resources in the area of support for family caregivers.

PYM: How does this legislation shine a new light on the challenges faced by caregivers?

KK: I think anything that raises awareness about caregiving is really a good thing, because in the policy world if you’re faced with cutting budgets or programs, the unspoken assumption is that family will step in to care for their own. In other words, family caregivers are often assumed to be the providers of last resort. So when you have a national plan that acknowledges that we have this critical problem and that it will get even more pressing as Baby Boomers age, it’s saying, “We need to step up now and figure out how to solve this challenge through research, prevention, treatment, training and support for families.” Stepping up the pace and funding for research is critical, but so is increasing caregiving support. Family caregivers should be considered part of the workforce so they’re not impoverished for the rest of their lives for quitting their jobs and providing care if they have to. The real issue is: Families need practical support in the home and they need it at an affordable rate.

PYM: Does this legislation have any precedent?

KK: The plan is hugely important, as we have no national policy plan for the rising challenge of those with Alzheimer’s disease or their families. We have had national research and program initiatives regarding Alzheimer’s disease and we do have the National Family Caregiver Support program, but there is a definite need for more resources and better coordination at the national level.

PYM: Do you think the National Plan to Address Alzheimer’s Disease will go far enough in making a real difference in the fight against dementias?

KK: It’s an important first step. The plan raises the visibility of the policy issues, which is a good thing. It helps shape the public conversation about Alzheimer’s disease and about caregiving. We need to be talking about these issues more, not less. Having this national plan can jumpstart a national discussion about these challenges. But we can’t lose sight of the fact that family caregiving puts people under great emotional and financial stress as they deal with very complex medical conditions in the home, whether it’s a child with an illness or it’s someone with Alzheimer’s. As a country, we’ve taken on big challenges in public health and have lowered the rates of major diseases like heart disease and cancer. We can do this again with the National Plan to Address Alzheimer’s Disease if we all work together.


Read the Older Americans Act, including Title III-E (the National Family Caregiver Support Program) at www.aoa.gov/AoARoot/AoA_Programs/OAA/index.aspx.
At various points in history, it was considered a hallmark of wealth and status for a lady or a gentleman to have assistance in getting dressed and groomed each morning. Of course, times have changed dramatically since those periods, and independence is the goal of most modern people. Because of this, adults who have been accustomed to self-reliance may find a transition to dependence difficult. This can be especially true when it comes to private matters like bathing and dressing. Unfortunately, dementia can make a person incapable of properly taking care of him or herself, and a caregiver must then adopt the role. If you and a loved one with Alzheimer’s disease are facing such a life change, these tips can help you adjust to it.

Evaluating Stages of Dementia

The degree of personal care assistance a person with Alzheimer’s disease will require depends on what level of dementia he or she is experiencing.

• Early to middle stages: During early stages of the illness, a person may require little to no additional help. However, he or she may start needing to rely on others beginning with the late mild stage. Cognitive changes during this period can make a person less likely to remember personal care behaviors or how to use the required tools, like toothbrushes or razors. At first during this period you will want to assist as little as possible. Your goal should be

If your loved one with Alzheimer’s is still living at home, a personal care assistant can help ease your role as a caregiver.
to encourage your loved one’s independence for as long as you can. One of the keys to doing this is to give him or her longer to complete personal care tasks. Of course, with all of this being said, you should still supervise your loved one’s personal care and intervene if he or she is getting frustrated or doing something unsafe.

• **Middle to late stages:**

  It’s during this period of time that a person with dementia starts requiring constant assistance with personal care. (It should also be noted that someone with an early stage of Alzheimer’s might fit into this category if he or she has additional health problems.) By the middle to late stages, basic functions of the body—such as walking and eliminating—become compromised. This means basic care can no longer be handled by the person with the disease. During the late stages of Alzheimer’s, even a caregiver will be unable to meet his or her loved one’s personal care needs alone. Once around-the-clock care is required, additional help will be a necessity.

**Hiring a Personal Care Assistant**

If your loved one with Alzheimer’s is still living at home, a personal care assistant can help ease your role as a caregiver. Personal care assistants aren’t nurses; they can’t provide any type of medical care to someone with dementia. However, they can help out a lot with some of the day-to-day tasks associated with caring for someone with Alzheimer’s disease, such as:

• Bathing
• Dressing
• Grooming
• Changing bedding
• Light housekeeping
• Grocery shopping
• Administering prescription medications
• Providing companionship and supervision

Personal care assistants are available to help out several hours a day, as needed. Fees vary per agency and geographic area but usually range from $10 to $40 an hour. If you choose to have one of these helpers live in your home, the cost will likely be around $120 to $200 a day.

When you’re interviewing personal care assistants, feel free to ask for references. It’s also a good idea to chat with the man or woman who will be providing care to your loved one to get a sense of his or her attitudes about caring for someone with dementia, as well as his or her comfort levels with certain personal care tasks. Write up a list of questions ahead of time so that you’ll be prepared for the conversation.

**Additional Personal Care Tips**

Until your loved one gets to the late stages of Alzheimer’s disease when he or she needs full-time care, you can follow these tips in assisting him or her:

• When possible, allow your loved one to do things on his or her own—but be available to coach him or her along.
• Use the “watch me” technique when walking your loved one through something like brushing teeth or combing hair.
• Assist with respect and humor.
• Be discreet and provide as much privacy as possible. For example, hold up a large towel as he or she gets in and out of the tub.
• Add safety rails or chairs to the bathtub and shower.
• Use colored toilet lids so that the toilets are easily located.
• Look for indicators, such as pacing, that can mean your loved one needs to use the bathroom.
• Buy bedding and clothing designed for adults with incontinence.
• Seek assistance from another family member or professional assistant if you’re physically unable to assist with some tasks, like lifting someone out of the tub, or if you want your loved one’s personal care assistance to be provided by someone of the same sex.

While personal care assistance can be a challenging experience for both the caregiver and the person with Alzheimer’s disease, the right strategies can make the process easier. If you’re looking for additional information or support on this matter, you can find tips and information—by Alzheimer’s disease stage—on personal care and other caregiving issues at www.caring.com/steps-stages/alzheimers.
Understanding the New Health Care Law

For people planning for lifelong health care and other long-term needs, coming to grips with the Patient Protection and Affordable Care Act is essential.

By now, you’ve probably heard plenty about the new health care law, sometimes referred to as “Obamacare” but officially known as the Patient Protection and Affordable Care Act. The law brings about significant changes both to Medicare and Medicaid.

The place to start is what hasn’t changed, and won’t change: Your Medicare benefits won’t be reduced or taken away in any way. Nor will your choice of primary care doctors be changed.

Medicare Preventive Services

The law introduces new benefits for Medicare plan participants. If you are on a Medicare Part B (medical insurance) plan, your “Welcome to Medicare” initial checkup is now completely covered provided that you get it done within the first 12 months of your Medicare membership. Other preventive procedures that are covered, without deductible or copayment, include:

- Abdominal aortic aneurysm screening
- Alcohol abuse screenings and counseling
- Bone mass measurements (bone density)
- Cardiovascular disease screenings (including cholesterol screenings)
- Cardiovascular disease (preventive behavioral therapy)
- Colorectal cancer screenings
- Depression screenings
- Diabetes screenings
- Diabetes self-management training
- Glaucoma tests
- HIV screenings
- Mammograms (screening)
- Nutrition therapy services
- Obesity screenings and counseling
- Pap tests and pelvic exams (screening)
- Prostate cancer screenings
- Sexually transmitted infections screening and counseling
- Shots:
  - Flu shots
  - Hepatitis B shots
  - Pneumococcal shots
  - Tobacco quitting counseling
  - Yearly “Wellness” visit

There are a few things to realize here. For one, while you’ll pay nothing for the services listed above, you may have to pay co-insurance (part of the cost) of the office visit when you get these services done. Also, the first yearly wellness checkup must come at least 12 months after your “Welcome to Medicare” checkup. And if you’re on a Medicare Advantage Plan, be sure to check with your plan to see if these benefits are also free to you.
Medicare Advantage Plans
The law changes how the government subsidizes Medicare Advantage plans, rewarding those that provide high-quality care but cutting subsidies to the plans to bring them more in line with Traditional Medicare.

Medicare Advantage plans that are rated three out of five stars or better will receive bonus payments. The plans must use at least some of this bonus money to provide extra benefits and rebates to plan participants.

In order to save money, Medicare began reducing subsidies to Medicare Advantage plans in 2012. Some of this money saved is being used to close the donut hole in Medicare prescription drug coverage.

Medicare Drug Benefits
As you may know, there is a coverage gap in the Medicare Part D drug benefits sometimes called the “donut hole.” This refers to the gap between where Medicare Part D benefits end and where Medicare’s “catastrophic” coverage begins. While in this gap, Medicare participants are responsible for the entire cost of their prescription drugs. The new health care law will close the donut hole significantly by 2020, and in the meantime, it offers a 50 percent discount on covered brand-name drugs. And in the intervening years, the benefits will gradually improve:

- 2012: You pay 50% for brand-name drugs and 86% for generic drugs
- 2013: 47.5% for brand-names and 79% for generics
- 2014: 47.5% for brand-names and 72% for generics
- 2015: 45% for brand-names and 65% for generics
- 2016: 45% for brand-names and 58% for generics
- 2017: 40% for brand-names and 51% for generics
- 2018: 35% for brand-names and 44% for generics
- 2019: 30% for brand-names and 37% for generics
- 2020: 25% for brand-names and 25% for generics

There are rules affecting who can get the extra savings, however. To qualify, you must be enrolled in a Medicare Prescription Drug Plan or a Medicare Advantage Plan that covers prescription drugs. You cannot receive assistance from Medicare’s Extra Help program, which helps people of limited means afford prescription drugs. And, of course, you must have reached the donut hole in your drug coverage. Keep in mind that while you pay only 50 percent of the cost of a brand-name drug, the entire cost counts toward the level at which your catastrophic coverage kicks in.

Health Insurance
For people who don’t qualify for Medicare, the law introduces a new requirement that protects those with pre-existing conditions from being denied insurance. This provision, called the Pre-existing Condition Insurance Plan, is currently available in every state. To qualify, you must be uninsured for six months and denied coverage because of your health.

Likewise, insurance companies can no longer drop you if you get sick, so long as the premiums are paid and up-to-date. And lifetime limits on benefits are now banned, with a ban on annual limits going into effect in 2014.

One of the law’s innovations is the creation of health insurance exchanges, which will be state-run marketplaces where you can compare health insurance plans side-by-side. Enrollment in every state begins in 2013, and the exchanges become active in 2014. All plans sold in health insurance exchanges must cover certain essential health benefits, such as hospitalization, medical care, mental health services, prescription drugs and rehabilitative services.

Long-Term Care
As you may know, neither Medicare nor most private health insurance plans pay for long-term care. Medicaid provides for most long-term care, but you must qualify, and qualifications vary by state. The new health care law will make Medicaid more broadly available beginning in 2014 in every state that chooses to participate. The Supreme Court held unconstitutional the provision of Obamacare that required all states to participate.

For families with loved ones in elder-care facilities, such as nursing homes, the new law provides that more thorough information about such facilities be made available to the public. This information includes ownership of the facility, how much the home spends on resident care versus administrative expenses, how many hours of nursing care residents receive, how much turnover there is in staffing, and the number of complaints and violations. The states will be required to post this information on a website.

Getting Help
Careful planning is essential for preparing for long-term care needs, and the services of an elder-law attorney are ideal for getting the help you need to prepare. You can find an elder-law attorney in your area through the searchable directory at the National Elder Law Foundation’s website (www.nelf.org).

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 Konigsberg
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. GEMOARSOGEN
3. BYRIOGUHANGM
4. HOJOPHKINSS
5. HMOOLUYONKET
6. DOOMLINDION
7. TVIERGICHIA
8. SLAWARRAENCHE
9. BMARYWRN
BRAIN-BOOSTING CROSSWORDS

(Answers on page 37)

We have provided two crosswords here to sharpen your puzzle skills. Start with the one on the left, which is the easier puzzle. In this one we have provided solving aids, such as the number of words in multi-word entries. The puzzle on the right is a medium-level puzzle and 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!

Across

1. Campers’ vehicles (abbr.)
2. Crawl
3. Card with two spots
4. Dracula’s garb
5. Howl
6. Allege
7. Layers
8. Singer Shore
10. Good work
11. Sluggish
12. “___ Ordinary Man” (2 wds.)
13. Officeholders
14. Attainment of wealth
15. Olympus and Olympia: abbr.
16. Smear
17. Warsaw’s country (abbr.)
18. Dunderhead
19. Husk
20. Young fellow
21. Full of energy
22. Blender button
24. Grating
25. Mother: Fr.
26. First stock sale: abbr.
27. Allege
28. Wallop
29. Sty sound
30. FBI employee: abbr.
31. Ginger’s partner
32. Tighten a spring
33. The Eternal
34. Zodiac sign
35. Some terriers
36. Oasis!
37. Portion (out)
38. “GOOD___”
39. Dieter’s focus
40. Where Tel Aviv is: abbr.
41. Scope
42. Dialogue-
sculptor
43. Allege
44. Shakespearean
45. Civil War side:
46. “All About ___”
47. GOOD ___
48. “GOOD___”
49. Asphalt
50. “Alley ___”
51. ___-Wan Kenobi (“Star Wars”)
52. Times Square site: abbr.
53. Sick-bed
54. Hand out hands
55. Pass
56. Slip up
57. Pitch
58. Huge work
59. Open champ
60. “All About ___”
61. Top banana
62. Olden car
63. Oil org.
64. Parks of the civil rights movement

Down

1. Brit. VIP’s
2. Grassy meadow
3. Upper limb
4. Long
5. Dieter’s focus
6. FBI employee: abbr.
7. Retiree’s acct.
8. Tablecloths
9. Donations
10. 1995 U.S.
11. Top banana
12. Olden car
13. Oil org.
14. Parks of the civil rights movement
15. Stay sound
16. Biblical
17. Flaxen-haired
18. Outcomes (abbr.)
19. People
20. Young fellow
21. Blender button
22. Strong desire
23. ____ pass
24. Strong desire
25. Like lather
26. Ripening factor
27. Bend the truth
28. Wallop
29. Sty sound
30. Biblical
31. Ginger’s partner
32. Sparklers on a freezing day
33. ____ Magic”
34. Fire, in France
35. Immune system
36. Saudi capital
37. Army soldier
38. Dialysis
39. Blacktop
40. Where Tel Aviv is: abbr.
41. Scope
42. Head, to Mimi
43. Alleve
44. Shakespearean
45. King
46. Civil rights
47. Earth Forms”
48. Fire, in France
49. Asphalt
50. “Alley ___”
51. ___-Wan Kenobi (“Star Wars”)
52. Times Square site: abbr.

It’s All Good

Across

1. Stage drama
2. They came
3. Arrange (2 wds.)
4. Sparklers on a freezing day
5. Howl
6. Accountants’ initials
7. Layers
8. Singer Shore
9. Follow
10. Proofs of age (abbr.)
11. Outcomes (abbr.)
12. ____ Ordinary Man” (2 wds.)
13. Officeholders
14. Wish undone
15. ____ a plea
16. Olden car
17. It’s All Good
18. Warsaw’s country (abbr.)
19. Husk
20. Young fellow
21. Full of energy
22. Blender button
24. Grating
25. AOL, e.g.
26. First stock sale: abbr.
27. Allege
28. Wallop
29. Sty sound
30. FBI employee: abbr.
31. Ginger’s partner
32. Tighten a spring
33. The Eternal
34. Zodiac sign
35. Some terriers
36. Oasis!
37. Portion (out)
38. “GOOD___”
39. Dieter’s focus
40. Where Tel Aviv is: abbr.
41. Scope
42. Head, to Mimi
43. Alleve
44. Shakespearean
45. King
46. Civil rights
47. GOOD ___
48. “GOOD___”
49. Asphalt
50. “Alley ___”
51. ___-Wan Kenobi (“Star Wars”)
52. Times Square site: abbr.
BRAIN-BOOSTING PUZZLES
HIDDEN-MESSAGE WORD-FIND™

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.

<table>
<thead>
<tr>
<th>BUTLER</th>
<th>NANNY</th>
<th>SR L</th>
<th>ORIENTAL RUGS</th>
</tr>
</thead>
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<td>ORIENTAL RUGS</td>
<td>SE K Y T R E P O R P T I E E</td>
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<tr>
<td>CHAUFFEUR</td>
<td>PERSONAL TRAINER</td>
<td>D N O O V I N G U I E N M S H</td>
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<td>PREP SCHOOLS</td>
<td>N I L H O N A E H J O O W E T</td>
<td></td>
</tr>
<tr>
<td>DIAMONDS</td>
<td>PRIVATE JET</td>
<td>O A U I S C D S E E H I C S O</td>
<td></td>
</tr>
<tr>
<td>FULL-TIME COOK</td>
<td>PROPERTY</td>
<td>M R N W V N E T I N M S H R L</td>
<td></td>
</tr>
<tr>
<td>GRANDEUR</td>
<td>RACEHORSES</td>
<td>A T T N A E A M O M H N A O C</td>
<td></td>
</tr>
<tr>
<td>ITALIAN SHOES</td>
<td>SWIMMING POOL</td>
<td>I I S R Y V I I I O M A U H R</td>
<td></td>
</tr>
<tr>
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<td>VACATION HOMES</td>
<td>D A G A I N T N L T Y M F E E</td>
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<tr>
<td>MANSION</td>
<td></td>
<td>C N L R O A G B M A L S F C N</td>
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<td>S E L E E M C H A M P A G N E</td>
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<tr>
<td></td>
<td></td>
<td>P P R E P S C H O O L S T Y D</td>
<td></td>
</tr>
</tbody>
</table>

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.

![Sudoku puzzle image]

•VISIT US AT KAPPAPUZZLES.COM•
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.
On June 12, Lewis Colam, a 24-year-old Englishman, finished his 1,800-mile solo row from Miami to New York City. By taking on this monumental challenge, Colam managed to raise more than $33,000 for the Fisher Center for Alzheimer’s Research Foundation, all of which will go directly to research.

Colam encountered some difficult weather and other threats, including sharks and water snakes, in his open-deck 15-foot rowboat. But he persevered to the end; the journey took him 101 days to complete. He had no prior seafaring experience, but enjoyed plenty of vocal support along the way. Colam ended his journey beside the USS Intrepid in New York City, and after a reception there, he flew back home to London.

After losing his grandmother to Alzheimer’s disease, Colam was motivated to take on an adventure to raise money to fight the global threat.

Upon completing his adventure, Colam wrote on his Facebook page, “Thank you all for supporting me along the way and if you were hoping to help the Fisher Center for Alzheimer’s Research Foundation it’s not too late to donate ... they are making amazing developments.”

“We are very gratified that Lewis chose the Fisher Center for his fundraising effort, and what an effort it was,” said Kent Karosen, President of the Fisher Center for Alzheimer’s Research Foundation. “His journey will make a difference in the ongoing search to find better treatments and even a cure in the fight against Alzheimer’s disease.”

Above: Lewis Colam rows his way through the Atlantic. Below: Colam (center) is honored for his efforts by a supporter (left) and Kent Karosen, President of the Fisher Center for Alzheimer’s Research Foundation (right).
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

*Content has been altered to protect user identity and data.*
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Give to Alzheimer’s research
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www.ALZinfo.org
1.800.ALZ.INFO
(1.800.259.4636)

Our Tax ID # is: 13-3859563
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The Fisher Center for Alzheimer’s Research Foundation is one of the world’s largest research teams leading the battle against Alzheimer’s disease—and you can help us! The tax-deductible donation you make today will help us continue to fund important research to find a cure for Alzheimer’s.

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By Phone: Call toll-free 1-800-ALZINFO (259-4636)

By Internet: Go to www.ALZinfo.org and click on “Donate Now!”

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The Fisher Center for Alzheimer's Research Foundation is one of the world's largest research teams leading the battle against Alzheimer's disease—and you can help us! The tax-deductible donation you make today will help us continue to fund important research to find a cure for Alzheimer's.

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