preserving your Memory
The Magazine of Health and Hope

Sandra Day O’Connor, Former Associate Justice of the U.S. Supreme Court, Gives Alzheimer’s Testimony

Your Alzheimer’s Resource Connection

New Alzheimer’s Drugs Work in Novel Ways

2008 National Family Caregiving Awards
You’d be surprised how early the effects of Alzheimer’s can set in.

It not only steals grandparents, it steals normal life from caregivers, spouses, children and grandchildren alike. That’s why for over 20 years, MetLife Foundation has supported programs for family members and caregivers and has been a leader in funding research to find a cure for Alzheimer’s – contributing over $10 million.
Features

New Drugs for Alzheimer’s Work in Novel Ways
Doctors have hope that a new class of drugs will offer effective new treatments for Alzheimer’s disease.

Caring for Caregivers
MetLife Foundation and the National Alliance for Caregiving acknowledge caregivers with the 2008 National Family Caregiving Awards.

Former Associate Supreme Court Justice Sandra Day O’Connor Gives Alzheimer’s Testimony
Members of the Alzheimer’s Study Group spoke to Congress about the impact of Alzheimer’s on the American public.

Build Your Library with Alzheimer’s Resources
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A leader in finding an Alzheimer’s cure
Remember the autumns of your childhood and adolescence? You probably spent a week or two buying school supplies, making book covers, learning your class schedule, and a dozen other seemingly inane activities. But as tedious as it all seemed, these tasks were necessary. They prepared you, letting you know exactly where you needed to be and what you needed to have with you. Now, with each autumn, we get further away from those school days of the past—but not from the need to be prepared for what we’re facing next. If you or a loved one has been diagnosed with Alzheimer’s disease, you’re probably feeling that need more keenly than ever.

While you can never be fully prepared to deal with a life-altering disease, you can cope better with the right resources. One of the main reasons we publish Preserving Your Memory is to bring those resources to you. Each issue strives to provide you with information on research, legislation, coping, and much more. In the spirit of back-to-school time, we’ve filled this issue with more resources than ever.

In addition to our regular features, we’re connecting you to resources outside the pages of this magazine. For example, this issue’s fitness article, “Fitness Programs Close to Home” is a guide to finding fitness programs and facilities—suited especially for your needs—in your own community. “Build Your Library with Alzheimer’s Resources” highlights books dealing with Alzheimer’s and caregiving, while “From Donation to Inspiration: Get Involved” shows you were to go for ideas on raising awareness about Alzheimer’s disease and contributing to research.

If you find yourself looking for more resources, check out our website, ALZinfo.org, where you can search the latest research or read messages from other Alzheimer’s caregivers.

Whether it’s online, at your doctor’s office, or in the pages of this magazine, prepare yourself with resources that will aid you in the challenges ahead. It could be the most important education of your life.

Please send your tips, stories, or questions to the Fisher Center for Alzheimer’s Research Foundation, West 46th St. & 12th Ave., New York, NY 10036, or by e-mail to betsey@alzinfo.org
The Latest News on Alzheimer’s Disease and Brain Health

Older Drug Shows Promise as Alzheimer’s Treatment

A recently reported 12-month study found that Dimebon, a 25-year-old Russian antihistamine, appeared to stabilize Alzheimer’s disease. The Dimebon study showed the largest effect size over placebo in an Alzheimer’s treatment. Patients taking Dimebon for 12 months improved a bit. Those continuing to take Dimebon for 18 months did not decline from when they started in the study, while those taking placebo declined significantly. Researchers aren’t certain why the drug worked so well in the trial, but its effects endured throughout the 18-month trial—a significant finding.

Dimebon researchers are currently recruiting patients for a phase III clinical trial, the last hurdle before FDA approval becomes possible. The trial will be conducted in about 30 clinical centers across the United States and will last for six months. If all goes well, Dimebon could be in pharmacies in two to three years.

New Drug Improves Brain Function in Alzheimer’s Patients

Research recently published in the British journal *Lancet Neurology* showed improved brain function in early-stage Alzheimer’s patients who received PBT2, a new drug. The drug appears to check the accumulation of a key protein, beta-amyloid, that occurs in Alzheimer’s disease by regulating copper metabolism in the brain. It confirms the positive results from a previous study of PBT2 in laboratory mice.

Compared to the control group, those receiving 250 mg of PBT2 demonstrated better performance on a battery of cognitive tests designed to measure executive brain function. While memory loss is the characteristic symptom of Alzheimer’s, executive cognitive functions also tend to deteriorate in the disease’s early stages.

The next step for PBT2 is a larger clinical trial with a longer duration. Researchers hope that if all goes well, this or similar drugs could be on the market in five years or so.

Researchers Find New Alzheimer’s Gene

A gene that increases the risk of late-onset Alzheimer’s has been identified, giving researchers a new potential target for developing treatments. The new research was published in the journal *Cell*.

The gene, Calcium homeostasis modulator 1 (CALHM1), is a significant factor in the occurrence of late-onset Alzheimer’s. One copy of the gene drives the risk up 44 percent compared to the risk of people without the gene, while two copies increase risk 77 percent. Researchers indicate that about one-quarter of the population has the gene.

The gene tends to affect the hippocampus, the part of the brain where memories are processed, by spurring production of beta amyloid within cells. This part of the brain is most susceptible to the symptoms of early-stage Alzheimer’s.
Rate of Change in Brain Ventricle Size Linked to Alzheimer’s in Study

Ventricles—the fluid-filled cavities in the brain—tend to increase in size in Alzheimer’s disease as a result of loss of brain cells. Researchers at Robarts Research Institute at The University of Western Ontario have discovered that the rate at which ventricles increase in size may be a good predictive measure of how fast the disease is progressing —better in fact than relying solely on cognitive tests.

These results could prove useful in gauging the effectiveness of prescribed treatments, researchers say.

Exercise Shows More Benefits for Early-Stage Patients

The health benefits of exercise are well known, but new research findings indicate that Alzheimer’s patients who are physically fit experienced less brain shrinkage than did their less-active counterparts.

In research published in Neurology, people age 60 and older were tested for physical fitness and underwent MRI brain scans. Scientists used the VO2 peak measure, which gauges how much oxygen the body is using during exercise. While fitness and cognitive performance weren’t clearly linked, the new research points to a positive new direction for researchers.

Dr. Jeffrey Burns, lead researcher and director of the Alzheimer’s and Memory Program at the University of Kansas School of Medicine in Kansas City, says the team is already designing a follow-up study to examine what role exercise and fitness may play in the progression of Alzheimer’s disease.

Experimental Alzheimer’s Drug Advances to Late-Stage Trials

Bapineuzumab, an experimental Alzheimer’s drug now undergoing testing, showed promise in mid-stage trials in people with early to moderate Alzheimer’s disease. The drug, made by the drug companies Wyeth and Elan, is aimed at beta-amyloid, a protein that can build up in the brains of those with the disease. The drug is a monoclonal antibody (an immune-system molecule) that clears toxic beta-amyloid from the brain.

In phase II clinical trials, bapineuzumab slowed the progression of memory loss and other symptoms. Brain scans also showed that some of those taking the drug had less loss of brain volume than those taking a look-alike placebo pill.

But the drug provided benefits only in those who did not carry the APO-E4 gene. An estimated 40 percent to 70 percent of people with Alzheimer’s disease carry that gene, which can be inherited from one or both parents.

The results were promising, the drug companies announced. As with all drugs, some people suffered side effects. However, the pharmaceutical sponsors felt the drug was safe enough to continue testing.

More advanced phase III trials were started late in 2007. However, it will likely be several years before the results of those trials are known.

Living Alone Drives up Alzheimer’s Risk, Study Finds

People in their 40s and 50s who live alone had a 50 percent greater risk of developing Alzheimer’s disease than their counterparts, new research from Sweden reveals.

That trend was particularly true for people who were widowed and had never remarried (six times the risk), as well as those who were divorced and remained single (three times the risk). Social interaction might delay the cognitive decline associated with Alzheimer’s disease, the researchers suggest.

Lead researcher Krister Håkansson of Sweden’s Karolinska Institute speculated that social and intellectual stimulation, as well as previous emotional trauma, affect how people age. If further research confirms this, interventions could be developed to reduce the risks for single people at risk or widowed or divorced people.

Check the Fisher Center website (www.ALZinfo.org) often for up-to-date and expert-reviewed scientific news.
A new class of drugs called gamma-secretase modulators works to reduce the buildup of toxic proteins in the brains of people with Alzheimer’s disease, giving doctors hope that these medications may offer effective new treatments for the devastating brain ailment. Results of advanced-stage testing of one of these drugs, called Flurizan, failed to show any benefit. This unfortunate failure does not signal that other drugs, based on the same principle—called gamma-secretase modulation—will fail.

Researchers at the Mayo Clinic report that gamma-secretase modulators work to reduce the production of long pieces of a protein called beta-amyloid that builds up in the brains of those with the disease. These drugs also appear to promote the production of shorter forms of beta-amyloid that may inhibit the longer forms from sticking together and forming brain-damaging clumps, at least in experimental models.

Doctors have long known that beta-amyloid builds up in the brains of people with Alzheimer’s disease. But scientists still don’t know exactly why or how this occurs—or how it may lead to the onset of memory loss and dementia.

Beating Back Beta-Amyloid

The Fisher Center Foundation funds scientists who continue to be at the forefront of research into the understanding of beta-amyloid, a protein that is at the root of Alzheimer’s disease. Beta-amyloid forms dense protein deposits called plaques found in the brains of people with Alzheimer’s. These and other forms of beta-amyloid are believed to cause most of the devastating, degenerative changes in the Alzheimer’s brain. Fisher Center scientists were among the first to define the specific steps by which beta-amyloid is produced, and their discovery that pharmacological substances can interrupt this process set off a worldwide race to develop drugs to inhibit beta-amyloid buildup. Fisher scientists’ beta-amyloid research is now focused on a protein called amyloid precursor protein (APP). Fisher scientists are unraveling the process by which APP is broken down to form beta-amyloid. Their immediate goal is to develop ways to slow the accumulation of plaque and other forms of beta-amyloid in the brain and reduce their toxic effects on nerve cells, moving much closer to a cure for Alzheimer’s disease. In fact, Fisher Center scientists are
making significant progress in developing therapies aimed at reducing the production of toxic beta-amyloid, an achievement that might ultimately prevent, slow, or even cure the disease.

Fisher scientists have also recently discovered how beta-amyloid damages communication between brain cells and how fibers connecting brain cells can be grown or made to shrink. With this understanding, it may be possible to devise therapies that protect the brain even when beta-amyloid production goes awry.

Beta-amyloid by itself is not necessarily bad. It is formed from a larger protein called amyloid precursor protein, or APP, that can be snipped into shorter segments by proteins called secretases. One of these secretases is called gamma secretase.

It acts on a fragment of APP, shearing it like a pair of molecular scissors into smaller fragments of beta-amyloid of varying length.

One resulting form of beta-amyloid, consisting of 42 protein building blocks called amino acids, appears to be particularly toxic to the brain. This 42-amino acid form of beta-amyloid is the main form that builds up in the brains of those with Alzheimer’s disease to form plaques. A hallmark of Alzheimer’s is the formation of these plaques, which are believed to damage neurons in complex ways that are not yet fully understood.

But beta-amyloid also exists in shorter forms, like the 38- and 40-amino acid segments that appear to be less harmful. These shorter segments may even be beneficial, helping to prevent the longer, and toxic, 42-amino acid form from sticking together.

How the New Drugs Work
The new drugs, the gamma secretase modulators, are believed to act on APP, rather than the gamma secretase enzyme directly. As a result, when gamma secretase shears the larger APP protein, it tends to form shorter snippets of nontoxic beta-amyloid. At the same time, less of the toxic form of beta-amyloid is produced. These findings appeared in the June 12 issue of the scientific journal Nature.

“So, as these compounds lower the amount of the bad, longer beta-amyloid peptides in the brain, they increase the quantity of shorter beta-amyloid peptides that may protect against development of Alzheimer’s disease,” says the study’s senior author, Todd Golde, MD, PhD, chair of the department of neuroscience at the Mayo Clinic in Jacksonville, Fla.

“In a very general sense, the action of these gamma secretase modulators on beta-amyloid might be analogous to some cholesterol-lowering drugs that can lower LDL, the bad cholesterol that sticks to your arteries, but not lower HDL, the good cholesterol,” Dr. Golde says.

There is also some evidence that the gamma secretase modulators actually stick to the toxic beta-amyloid already in the brain, keeping it from clumping together.

“Surprisingly, this means that these compounds may do three things that may be beneficial with respect to Alzheimer’s disease: They inhibit production of long beta-amyloid, may block aggregation of beta-amyloid, and increase production of shorter beta-amyloid peptides that may in turn inhibit beta-amyloid aggregation,” says the study’s lead investigator, Thomas Kukar, PhD.

Because these experimental drugs lower levels of toxic beta-amyloid, they are sometimes also referred to as selective amyloid lowering agents, or SALAs.

Despite Flurizan Failure, Hope Remains
The first new gamma secretase modulator to complete clinical trial testing was Flurizan, known by the generic name tarenflurbil. An advanced phase III clinical trial of the drug in 1,684 patients from 131 medical centers was recently completed. Unfortunately, the drug failed, and further testing has been discontinued by the company that owns it, Myriad Genetics.

These results contrast with results of recently released data from an earlier, mid-stage (phase II) trial in patients with mild Alzheimer’s disease who took Flurizan and showed marginally less decline in their ability to carry out everyday tasks than those taking a dummy pill. The larger, more recent phase III trial, showing no benefit, is considered more reliable, however, because of its size, and is considered the “final word” on the subject.

Currently available drugs for Alzheimer’s, like Aricept, Razadyne, Exelon, and Namenda, may ease symptoms for a time in some patients. But these drugs do not modify the long-term worsening of the disease.

“Millions of people suffer from Alzheimer’s disease, and treatment options are limited,” says Paul Greengard, PhD, the Fisher Center for Alzheimer’s Disease Research director at The Rockefeller University. “Existing drugs may mask symptoms for a time but do nothing to stop the relentless downward progression of Alzheimer’s. What is needed are safe and effective medications that will halt, or even reverse, the relentless progression of the underlying disease.”

Researchers hope that disease-modifying drugs that inhibit beta-amyloid may alter the progressive memory loss and other cognitive problems that devastate those with Alzheimer’s disease. It may take years, however, before any drugs that alter production of beta-amyloid are proven safe and effective against Alzheimer’s disease.

There is still hope for these kinds of drugs, though. According to Dr. Golde, “anytime we gain an increased understanding of the precise molecular action of a drug, that enhances our ability to make better drugs.” Still, the process of drug testing is complex. A drug may seem to work well in an experimental model but fail when given to a human being, the ultimate testing ground.

Mom was rarely sick, so when it became evident there was a problem—other than old age—it was oddly surprising. My wife and I had moved back to Dallas in 1999 to be closer to our parents as all four approached or were past age 90. We knew we were lucky to still have all of them but we knew something eventually would happen, and felt more comfortable being close enough to help.

For someone with back troubles and remissive prostate cancer, Dad was doing pretty well. Mom had two rotator cuff surgeries and an occasional bout with the flu, but otherwise seemed OK until 2001. My siblings and I recognized something was amiss with Mom. Her memory was failing, and she began developing unusual compulsions. We talked to Dad about it but he kept saying, “She’s OK. She’s just getting older.”

Normally, we accepted Dad’s opinion on things, especially medical, but Mom’s condition seemed to be getting worse so we began researching symptomatic mood swings and memory loss. Alzheimer’s kept coming up as a potential cause, but Dad said: “I talked to her doctor, and he felt it was simply old age.”

This is when I began considering documenting her “quirks.”

One day Mom called and said there was “a strange man in the house.” We rushed over and the “Strange Man” was, as we suspected, Dad. It was pretty obvious at this point that Dad was covering for her. Dad confessed that she had been diagnosed with probable Alzheimer’s in 2001 and he was taking care of her. That’s when I began writing and taking pictures of Mom’s journey.

She was still the beautiful woman we had known our entire lives, but her eyes were different and rarely had that sparkle and emotion we’d grown to know and love. Quite often her eyes looked almost vacant.

Several times I simply set the camera on a tripod in the corner and would snap a few pictures when the light was right or Mom relaxed into a pose. Mostly, she paid no attention to what I was doing, and I purposely avoided posing her.

It has now been seven years since she was diagnosed with Alzheimer’s; she has lived in a special care unit almost a year. She still looks like Mom, but the disease is taking its toll.

Allen Crenshaw
Dallas, Texas
WHO ARE YOU? – Jackie watches as I photograph her. On this day, she was not sure who I was or what I was doing.

RELAXING AFTER LUNCH (l)– In her new room in the special care unit, Jackie relaxed after lunch and fell asleep several times while sitting in the chair. This photograph was taken just after she awoke and was watching the birds outside her window.

We’d Love to Hear From You
Join Allen, and share your caregiving story with other readers. Contact The Fisher Center for Alzheimer’s Research Foundation, West 46th Street & 12th Avenue, New York, NY 10036, or e-mail them to betsey@alzinfo.org
From Donation to Inspiration: Get Involved

Want to help promote Alzheimer’s awareness and research? Fisher Center’s online resource offers ideas and tips that will help you take action.

Donate
Donating money is one of the most powerful things you can do to aid Alzheimer’s research. If you’d simply like to make a donation, you can click the “Give the Hope of a Cure” button anywhere on the Fisher Center website, or you can fill out the response card in this issue of Preserving Your Memory. Find these other donation ideas on our “Get Involved” page:

• Contact your company’s HR department about corporate gift matching.
• Add Fisher Center’s donation button to your own website so that you can encourage others to donate.
• Donate advertising space on your website to Fisher Center.

Shop
Raising money for Alzheimer’s research can be as simple as going shopping:

• 10 percent of every purchase you make at GiftBack.com will be donated to the Fisher Center.

Get the Word out
We want our Get Involved resource to provide you with many ideas for raising awareness about Alzheimer’s disease and research. For example:

• Raise money for Fisher Center through online shopping at Giveness.com.
• Visit Fisher Center’s Café Press store at www.cafepress.com/alzinfo to buy merchandise with our logo on it.
• Purchase Dicksons gifts at www.dicksonsgifts.com, and a portion of the proceeds will go to the Fisher Center.

Volunteer
If you’re in the New York City area, we have several volunteer opportunities available:

• Sign up for a Fisher Center internship and gain valuable job experience while helping make a difference at the organization with the world’s largest Alzheimer’s research team.
• Help out in a variety of our departments, from administrative work to event planning.

Share with Others
Make others aware of Alzheimer’s impact and the need for a cure. If Alzheimer’s has affected your family, share your story with others:

• Blog about Alzheimer’s news and research.
• Write a letter to the editor of your local newspaper encouraging others to contribute to research.
• Call in to a radio station with your story.

Find Inspiration
There are many more ways you can get involved. For further ideas, visit www.alzinfo.org/getinvolved.
Anyone who has provided care for someone with a debilitating disease such as Alzheimer’s can recognize the challenges of correctly interpreting and applying a doctor’s instructions. The American Medical Association (AMA) Foundation understands these challenges. That’s why it provides physicians with the resources to help caregivers, patients and physicians communicate effectively with one another to ensure that patients receive the best care possible.

To help you get the most from doctor visits, follow these tips:

- **Write down questions.** Prepare a list of questions to ask the doctor before your visit.
- **Bring your care recipient’s medicines.** Bring all prescription and over-the-counter medicines your care recipient is taking.
- **Report changes.** Tell the doctor about any new or different symptoms your care recipient is having.
- **Ask questions.** Before you leave the doctor’s office, make sure you understand what the doctor has told you. Remember, the doctor is there to help.

The AMA Foundation serves as the philanthropic arm of the AMA, developing programs to support medical education, public health and research.

Visit [www.amafoundation.org](http://www.amafoundation.org) to learn more.
When you have a child, there is the expectation that you will be taking on the role of feeding, bathing, clothing, and protecting the baby until he or she is an adult. That is what a parent does. Far fewer of us expect to be performing the same caregiving tasks for the older adults in our lives, be they parents, spouses, friends, or other relatives.
Odds are that for many Americans these expectations may need some revising. According to a 2003 study conducted by the National Alliance for Caregiving (NAC) in collaboration with AARP and funded by MetLife Foundation, there are approximately 44.4 million caregivers in the United States over the age of 18. That means over a fifth of our population is providing unpaid care to an older adult.

The Caregivers Among Us

While it is impossible to profile who is or will be a caregiver, the NAC study found that a “typical” caregiver is a 46-year-old female, who has some college education, works, and spends more than 20 hours a week providing care to her mother.

“People do caregiving because they love their family members and feel this person took care of me and now I need to take care of them,” explains Gail Gibson Hunt, president & CEO, National Alliance for Caregiving. She explains that half of the people providing care are offering personal care, such as feeding, bathing, and dressing. “For most adult children, this type of care is above and beyond what they ever expected they were going to do.”

Hunt adds, “People have always done it and will continue to do it. We need to, as a society, recognize the tremendous value of what caregivers do and honor them for it.”

Providing Acknowledgement

In that vein, the NAC created the National Family Caregiving Awards three years ago to honor non-profit, community-based programs that support caregivers who are providing assistance for older adults. The MetLife Foundation has supported the awards since their inception.

It is estimated that family caregiving provides $306 billion of unpaid care every year, more than the value of home care and nursing care together. “Family members provide much of the day-to-day care needed by older adults who are frail, impaired, or in poor health,” says Sibyl Jacobson, president, MetLife Foundation. “We recognize these programs for the enormous contribution they make to family caregiving.”

Awards are given to two categories of programs—caregiver support programs and caregiver education programs. These categories are further broken down to programs for small communities (with a population of 100,000 or fewer) and large communities (100,001 or more). Six programs, three support and three education, receive $25,000 each to be used to further their efforts. In addition, a $5,000 seed grant is given to an organization that wants to start a caregiver program.

“I see the goals of the awards program as recognizing exemplary caregiving programs across the country, those programs that are making a difference in the lives of caregivers of older adults, and also to spread the word about these programs,” says Kathleen Cameron, a consultant for the awards. “A lot of the ideas from these programs can be replicated.”

Cameron explains that the awards advisory committee, which is made up of experts on caregiving, as well as a previous award winners, judge applicants in the following categories: innovation, effectiveness or impact, basis in research, diversity, and potential for replication or adaptability.

Shining Examples

For Cameron, one of this year’s most interesting award winner’s story is that of Memory Mobile. The Gulf Coast chapter of the Alzheimer’s Association purchased an RV and created a mobile office—Memory Mobile—to go around their 17-county area in Florida.

(continued on page 16)
They were having difficulty reaching people in the more rural areas,” explains Cameron. “So they created an office that went to the people.” Not only does the Memory Mobile reach people who might not have otherwise had access to an assessment or the Alzheimer’s Association’s educational programs, the RV itself has spread the word. “They painted the Alzheimer’s Association’s 800 number on the RV,” Cameron says. “Now they get calls from people that see it on the highway who didn’t know it existed before. They have tripled the number of assessments they do since the RV was up and running.”

The Memory Mobile truly exemplifies the innovative aspect that the awards program is looking to support. Cameron believes that the RV has been a really smart way of reaching people. “It was expensive at first, but worth it—there is a lot of cost spent on an office too, and the impact the RV is having is tremendous.”

Equally impressive to Hunt was the Old Order Amish Caregiver Program provided by Mid-Illinois Senior Services. “It is difficult to get their (the Amish’s) acceptance,” Hunt says. “This group worked at it, and finally were able to say that there would be a program for the Amish to go in and offer some respite care and some support.”

Not only was the program considered enough of a success by the NAC’s standards to win the award, but also the Amish involved were equally pleased. When they were told about the award, the elders gathered $25,000 of the community’s own money to match the award and make the program even bigger. According to Hunt, this story left many at the awards ceremony noticeably moved. “It speaks to how valued the program was in the Amish community,” she says.

The 2008 Awards
The winners of the National Alliance for Caregiving and MetLife Foundation 2008 Family Caregiving Awards are a diverse group of programs from across the country, which serve the needs of many different communities.

Caregiver Support Awards
• The Asian Community Center of Sacramento, California, for the Drop-In Respite and Caregiver Cooperative, in which caregiver-volunteers “earn and buy” respite time with other co-op members, sharing their caregiving methods and engaging in self-learning, while building a community resource.

• The Center for Intergenerational Learning at Temple University in Philadelphia, Pennsylvania, for its Time Out Respite Program, which mobilizes college students to provide in-home respite services to caregiving families throughout the Philadelphia area.

• The Alzheimer’s Association–Gulf Coast Chapter in Pinellas Park, Florida, for Memory Mobile, the only mobile Alzheimer’s outreach, support, and caregiver education service delivery vehicle in the country targeting isolated, rural families dealing with or at risk for Alzheimer’s disease.

Caregiver Education Awards
• The National Bone Marrow Transplant Link in Southfield, Michigan, for Caregivers’ Guide for Bone Marrow/Stem Cell Transplant, which was developed to educate loved ones about their vital role through the experiences and perspectives of fellow caregivers.

• CancerCare in New York, New York, for Online Caregiver Support Groups, which provides virtual 24/7 access to support and information for people across the country caring for a loved one with cancer.

• Mid-Illinois Senior Services, Inc. in Sullivan, Illinois, for Old Order Amish Caregiver Program, which provides support, counseling, and training—with intense emphasis on cultural sensitivity to the Amish beliefs and ways—while overcoming obstacles that have kept the Amish from seeking help outside their faith.

Honorable Mention Awards
• Healing Hearts Center for Grieving Children and Families
  Regional Hospice of Western Connecticut
  Danbury, Connecticut

• Future Care Planning Services
  Lifespan
  Rochester, New York

Seed Grant Award Recipient
• Future is Now!
  The Rehabilitation Research and Training Center on Aging with Developmental Disabilities
  University of Illinois at Chicago
  Chicago, Illinois
Beta-amyloid is believed to cause most of the degenerative brain changes underlying Alzheimer’s disease. Scientists at the Fisher Center for Alzheimer’s Disease Research at The Rockefeller University have been pursuing which types of beta-amyloid protein may be responsible for these degenerative brain changes, as well as how each disrupts the transmission of nerve impulses in the brain. In recent years it has become clear that beta-amyloid exists in a variety of forms in the brain and that not all of its forms are equally toxic. For one thing, a longer form of beta-amyloid, designated amyloid beta 42, is known to be more toxic than the more common, shorter form, known as amyloid beta 40. The reason for this has to do with the tendency of beta-amyloid molecules to stick to each other, forming groups composed of two, three, four, and even hundreds of individual beta-amyloid molecules (amyloid beta 42 is stickier). The largest of these groupings form the plaques found in the Alzheimer’s patient’s brain. Most importantly, it has been shown that the forms of beta-amyloid that are toxic, consist of groups rather than individual molecules.

Dr. Dennis Selkoe and his colleagues at Harvard University recently removed beta-amyloid from the brains of deceased Alzheimer’s patients. He and his colleagues then exposed animal models to preparations containing different size groupings of beta-amyloid derived from the human brains. The researchers observed that the “dimers” of beta-amyloid (those groupings consisting of just two molecules of beta-amyloid) prevented the models from learning simple tasks. The researchers also exposed the animal models’ brain tissue to the beta-amyloid groupings and found that it disrupted the normal transmission of signals between brain cells. These fascinating results will have to be repeated by other laboratories if “dimers” are to be accepted as the primary cause of the symptoms of Alzheimer’s. Many scientists believe larger forms of beta-amyloid groupings will also be toxic and it is not yet certain which forms actually exist in the human brain. Nevertheless, the Harvard study is an important step forward.

These observations, and those of the Fisher Center for Alzheimer’s Disease Research, are important because they suggest that scientists may be able to create drugs or treatments that inhibit formation of the specific, toxic beta-amyloid group(s). In addition to finding which groupings are toxic, the Fisher researchers are determining how the groupings work to disrupt brain cell communication. By answering this question, they can seek or develop treatments that prevent beta-amyloid from causing the damage to the brain that leads to Alzheimer’s.

By ALZinfo.org, The Alzheimer’s Information Site. Reviewed by William J. Netzer, PhD, Fisher Center for Alzheimer’s Research Foundation at The Rockefeller University.
When a loved one becomes ill, there are many issues that must be dealt with. First and foremost are decisions regarding the person’s health and the type of care needed. This may not only cause the ill person a great loss of personal autonomy, but also a tremendous financial expense. The potential loss of significant personal assets due to the catastrophic cost of taking care of someone with a chronic illness can be devastating.

For many of us, our primary asset is our home. There are a number of ways to protect one’s home when discussing long-term care planning; however, there are many issues that must be considered when choosing the appropriate option. How the property is titled, the potential tax ramifications if sold, and possible liens are all issues that must be addressed before deciding which option is best.

The home may be owned in one person’s name alone or it may be held jointly with another person(s), affecting his or her ability to engage in planning options. There are a number of ways to own property along with another person. The property may be held as tenants in common, meaning each person has an undivided interest in the whole property. The respective interests of each owner may be different. Thus, one person may have a 60-percent interest in the property and the other co-tenant might have a 40-percent interest. During the lifetime of the owners, a co-tenant of the property can sell his interest in the property without the consent of the other co-tenant. Upon the death of one of the property owners, his or her share would be conveyed to persons designated in the will, or, according to state law if the property owner dies without a will. Therefore, it is entirely possible that the original co-tenant would not end up owning the entire property but, instead, would own the property with someone else, perhaps someone who they do not even know.

Conversely, a home may also be held jointly with rights of survivorship, giving each owner an equal share in the property. In this case, when one of the owners dies, the remaining owner(s) will inherit the other’s interest. The joint tenancy with rights of survivorship will take precedence over any contrary intentions expressed in a last will and testament or otherwise. During the lifetimes of the joint tenants, the consent of all joint tenants must be obtained prior to selling the property. If consent cannot be obtained, then it may be necessary to bring a partition proceeding in order to be able to dispose of one joint tenant’s interest in the property.

Another form of home ownership is tenancy by the entirety. In most states, this is the presumptive form of home ownership between married persons. Tenancy by the entirety is basically a form of joint tenants with right of survivorship where the two joint tenants are married. This form of home ownership provides added protection against creditors in the event one of the spouses is sued and has a judgment entered against him or her.
Regardless of your form of home ownership, it may be important to you to protect your home in case you need long-term care. For many people, setting up a life estate is the most simple and appropriate alternative for protecting the home. A life estate is a form of ownership of property between two or more people, whereby one (or more) person owns the right to live in the property during his lifetime (the life tenant) and others (remaindermen) receive the property upon the life tenant’s death. Each person has an ownership interest in the property but for different periods of time. The person holding the life estate possesses the property currently and for the duration of his life. The other owners have a current ownership interest but cannot take possession of the property until the end of the life estate, which occurs at the death of the life estate holder.

In a typical life estate transaction, an individual owns a home and conveys a remainder interest to others while retaining a life estate in the home. This ensures that the property goes to the people you want at the time of your death. Retaining a life estate in the property avoids the need for probate with respect to the home as the ownership will automatically pass to the remaindermen. By reserving a life estate, you are ensuring that you have the legal right to live in your home for the rest of your life. You cannot be evicted and the home cannot be sold without your consent.

Another benefit of reserving a life estate, compared to simply gifting your home to your children, is that upon your death the children can sell the property without incurring any capital gains taxes. This is due to a provision in the tax law which provides that the basis of property inherited as a remainderman of a life estate is equal to its fair market value on the date of death of the life tenant. If you were to transfer your home to your children while you are alive without retaining a life estate, then the children would be responsible for capital gains taxes when the property is sold. Although the current maximum federal capital gains tax rate is only 15 percent, there is talk that this tax rate might increase after the Presidential election. Capital gains tax is always a relevant consideration when discussing the transfer of your property, given that many of us purchased our homes at a much lower price than what it is worth today. Although your home may not be worth what it once was, it is probably still worth significantly more than what you paid for it if you purchased the home decades ago.

Life estates are also a valuable tool when considering eligibility for Medicaid benefits. Under the laws of most states, a life interest in property is not considered an available resource with respect to someone’s eligibility for Medicaid. Although the conveyance of the remainder interest to your children will be subject to the five-year Medicaid look-back period, the retention of the life estate should not disqualify you for Medicaid benefits. Additionally, on your death Medicaid has no lien or right of recovery against property subject to a life estate in most states.

Your home is your castle; however, without proper planning the home is at great risk if you become incapacitated or require long-term care. By considering all available planning options, you can ensure that your home stays in your family and is passed on to your loved ones.

Bernard A. Krooks, J.D., CPA, LL.M (in taxation), CELA is immediate past President and founding member of the NY Chapter of the National Academy of Elder Law Attorneys and a nationally known and widely quoted expert on elder law. For more information, visit the firm’s website at www.littmankrooks.com.
“I became an Alzheimer’s caregiver when my husband John was diagnosed with Alzheimer’s in 1990, and I have a first-hand understanding and a profound empathy for the millions of other caregiving families around the nation,” said former Justice Sandra Day O’Connor in her written testimony to a special hearing of the U.S. Senate Special Committee on Aging in Washington, DC. “Alzheimer’s is a tragic disease for families, but it is also fast becoming a national disease—a national health crisis. That is why I am here today as a member of the Alzheimer’s Study Group, which represents an important step in helping the United States meet a bold national goal—one that seeks nothing less than to eradicate Alzheimer’s disease.”

This was Justice O’Connor’s first public statement about her commitment to fighting this disease that has struck her husband John and over 5 million other Americans. O’Connor testified on May 14, 2008, with Former Speaker of the House Newt Gingrich before the committee that was convened by Chairman Senator Herbert Kohl (D-WI) specifically to hear updates on the fight against Alzheimer’s disease.

O’Connor Makes Personal Plea for Alzheimer’s Support

“Our nation certainly is ready to get deadly serious about this deadly disease,” she told the Senate Special Committee on Aging. She has a personal stake. “My beloved husband John suffers Alzheimer’s,” she said. “He is not in very good shape at present.”

O’Connor stepped down as the first female Supreme Court justice in 2005 to move her husband to an assisted care center in Phoenix, near two of their children. Intensely private, she has said little until now of the family’s experience except that she regretted having to leave the high court so soon.

“I suspect that you will not hear from many of my fellow caregivers directly … simply because they do not have the resources to take time away from their loved ones in order to come before you,” O’Connor said in her prepared testimony. Against that somber backdrop, a group of scientists, former politicians, and well-known names have teamed up to create what they call a “national strategy” to jumpstart efforts to speed research into new Alzheimer’s treatments and improve help for caregivers.

Statistics on Alzheimer’s

As many as 5.5 million Americans are living with Alzheimer’s disease. The number is poised to skyrocket, with 16 million people forecast to have the mind-destroying illness by 2050. Today’s treatments only temporarily alleviate symptoms. Already, there are estimates that 10 million people share the overwhelming task of caring for a relative or friend with it.

Alzheimer’s disease is now the fifth leading cause of death for persons age 65 or older, and was recently declared
the sixth leading cause of death for persons of all ages, surpassing diabetes. While heart disease, breast cancer, prostate cancer, and stroke deaths are declining, death from Alzheimer’s is on the rise, and is reported to have risen 44.7 percent from 2000 to 2005 by the Centers for Disease Control and Prevention.

O’Connor testified before the U.S. Senate Special Committee on Aging.

The Alzheimer’s Study Group Outlines a National Plan

Justice O’Connor is a member of the Alzheimer’s Study Group, an independent and bipartisan alliance of national leaders. The Study Group was launched in 2007 with the bipartisan support of the Congressional Task Force on Alzheimer’s Disease to develop a coordinated national plan to fight the disease. Speaker Gingrich, who co-chairs the Alzheimer’s Study Group with former U.S. Senator Bob Kerrey, outlined the Group’s work in his testimony.

“You will never meet an Alzheimer’s survivor—there are none,” former House Speaker Newt Gingrich said in his testimony.

Alzheimer’s by the Numbers

5.5 million people in the United States are living with Alzheimer’s.

Every 71 seconds, someone develops Alzheimer’s disease.

Alzheimer’s costs $148 billion each year to Medicare, Medicaid, and businesses.

10 million baby boomers will develop Alzheimer’s in the United States.

Alzheimer’s disease is 100 percent fatal.

(From 2008 Alzheimer’s Disease Facts and Figures)

The Alzheimer’s Study Group has identified five specific issues that will form the core of its strategic recommendations. Because the Group’s approach is to integrate various perspectives, it will announce recommendations in the form of a coordinated national plan in early 2009. The Group has created a task force to develop recommendations for each of these issues:

• Encouraging Collaboration among Researchers. Scientific researchers from academia, government, and industry need the tools and incentives to scan the growing body of Alzheimer’s research for relevant breakthroughs and more efficient collaboration on solutions, regardless of organizational boundaries.

• Improving Alzheimer’s Clinical Trials.

Sandra Day O’Connor, former Associate Supreme Court Justice, and Newt Gingrich, former Speaker of the House, testified before the U.S. Senate Special Committee on Aging in Washington, D.C., on May 14, 2008.

(continued on page 22)
Alzheimer’s clinical trials must be better supported and coordinated to reduce delays, improve efficiency, and ultimately allow the faster identification of promising new treatments.

- ‘Rapid Learning’ from Large Electronic Health Datasets. Cutting-edge tools and methods of “data mining” have the potential to revolutionize how we prevent, treat, and care for Alzheimer’s through a 21st-century version of the Framingham Heart Study.

“Alzheimer’s is a tragic disease for families, but it is also fast becoming a national disease—a national health crisis. ... Our nation certainly is ready to get deadly serious about this deadly disease.”

—Sandra Day O’Connor

- Integrating a Community-Based Care Model. Innovative approaches to care that better support patients and families and help manage costs must be developed from best case practices and made available to all Americans.

### About the Alzheimer’s Study Group

The Alzheimer’s Study Group is an independent, non-partisan, non-profit organization created for the sole purpose of creating the National Alzheimer’s Strategic Plan to overcome America’s mounting Alzheimer’s crisis. Established on July 11, 2007, the ASG began its work with an assessment of the country’s current efforts and is now developing strategic recommendations to accelerate progress toward overcoming this disease. The work of the ASG has been funded by the Alzheimer’s Association, the Dwyer family, Pfizer-Eisai, the McCance Foundation, the Vraedenburg Foundation, and Wyeth. The ASG has also received an in-kind contribution of substantial project management and research support from Booz Allen Hamilton. The effort is being administered and managed through the Center for Health Transformation. For more information, visit the Alzheimer’s Study Group website at www.alzstudygroup.org.

- Providing Better Information to Policymakers. Government leaders must be given meaningful and timely information on the mounting impact and potential responses to Alzheimer’s if they hope to assess progress, set funding priorities, and exercise strategic oversight.

“We need to move now to reinvent and reinforce our fight against Alzheimer’s. For the baby boom generation, this is certainly one of our last chances,” explained Gingrich at the hearing. “We have many of the pieces already but we have to break down organizational barriers that prevent us from putting them together. Expect updates from the Alzheimer’s Study Group in coming months as we move toward a bold action-oriented plan next year. We have the nation’s future to protect.”

### Take Action

Retired Justice Sandra Day O’Connor took her family’s private battle with Alzheimer’s disease public as she urged Congress to speed research and aid to fight the coming epidemic of the mind-destroying illness. Learn more about what you can do to help fight Alzheimer’s, see page 12.
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.*
Pass the Sweet Potatoes, Please

One of this season’s favorite foods might help preserve memory.

Sweet potatoes are like the redheaded stepchildren of starchy vegetables. They’re often overlooked.

Although they share a spotlight at the Thanksgiving table, sweet potatoes are usually smothered under butter, brown sugar, and marshmallows in casseroles or mashed with eggs and sugar to make sweet potato pie. But buried beneath those rich ingredients lies a low-calorie treasure that’s so healthy, you should add it to your table year-round.

“A powerhouse of nutrition, the sweet potato is a perfect example of good food that’s good for you,” says The U.S. Sweet Potato Council. The orange flesh and skin of the sweet potato is fat-free, full of vitamins, and loaded with fiber.

Another important reason to indulge in sweet potatoes this fall—and all year long: It might aid in preserving memory.

Beta-Carotene and the Brain

Like carrots and cantaloupe, sweet potatoes have healthy doses of beta-carotene, a pro-vitamin known to enhance vision—and now, possibly, the mind.

Research published in the Nov. 12, 2007, issue of Archives of Internal Medicine showed that men who took high doses of beta-carotene for an average of 18 years scored higher on several cognitive function and verbal memory tests than participants who only took a placebo.

Francine Grodstein, ScD, of Brigham and Women’s Hospital and Harvard Medical School, along with colleagues, utilized two groups: 4,052 men who in 1982 began taking either beta-carotene or placebo every other day and 1,904 short-termers who joined the study in 1998. Both groups were monitored through 2003, and while the newer group exhibited no cognitive benefit, members of the older group who took beta-carotene scored modestly higher on several tests.

While some studies on beta-carotene and cognition have been inconclusive, several population studies have suggested that a diet rich in antioxidants, including beta-carotene, may help lower the risk of Alzheimer’s and preserve memory. Beta carotene is also found in dark green vegetables such as spinach, broccoli, and dark-leaf varieties of lettuce.

Low-Calorie, High-Fiber Food

Beta-carotene isn’t the only selling point for sweet potatoes. They’re a superstar of nutrition. Sweet potatoes are both fat-free and low in calories. “One medium sweet potato contains 120 calories,” says Tara Gidus, MS, RD, CSSD, LD/N, national spokesperson for the American Dietetic Association. “I consider that a low-calorie food.”

When eaten with the skin, sweet potatoes contain more fiber than oatmeal. One 4-ounce sweet potato baked with the skin also has about four times the recommended daily allowance of vitamin A and almost half the recommendation for vitamin C, says The U.S. Sweet Potato Council. Additional nu-
trients include potassium, copper, vitamin E, vitamin B6, and folic acid.

“They are also high in antioxidants that have been shown to be beneficial in preventing cancer,” says Gidus.

Purchasing and Storing

Often sweet potatoes are described as yams, but that’s a common misnomer. A true yam is an entirely different vegetable grown in Africa that can reach up to 100 pounds in size. All yams grown in the United States are really sweet potatoes, but the term “yam” is also accepted.

Although sweet potatoes—or yams—are harvested from August through October, they are available for purchase all year. If not available fresh in the produce section, you can find sweet potatoes in the freezer section or canned food section of your supermarket.

When shopping for fresh sweet potatoes, choose firm, small- to medium-sized potatoes without wrinkles. Avoid spots, bruises, or rotten areas, says Gidus. “Look for smooth skin without major growths of string,” she recommends.

To keep sweet potatoes fresh, store them in a dry, cool spot like a cellar, pantry, or garage and use within a couple of weeks. Do not store sweet potatoes in the refrigerator, or they will develop a bitter taste, says Gidus.

Avoid washing sweet potatoes until just before cooking, as moisture will speed up spoilage. When ready to cook, brush off loose dirt and wash sweet potatoes well. Cook them whole whenever possible since most of the nutrients are next to the skin.

Cooking Suggestions

Eat your sweet potatoes naked—skip the butter or sugar that only covers up their natural taste while adding unnecessary fat and extra calories. “You can simply poke a few holes in them and bake or microwave them,” suggests Gidus. Sprinkle your baked sweet potato with spices like nutmeg or cinnamon to complement their naturally sweet flavor.

Pass up the frozen French fries when shopping, and make your own sweet potato fries at home. “I like to peel, slice thin, toss with a bit of olive oil, a dash of salt, nutmeg, cinnamon, and a pinch of brown sugar and lay them out on a baking sheet for 30 minutes at 375 degrees,” says Gidus. “If you slice them and don’t bake them right away, keep the slices in water until you are ready for them.”

Start serving up nutritious sweet potatoes more often. These versatile vegetables deserve a spot on your table for more than one day of the year. Like all redheaded stepchildren, sweet potatoes just need a little love.

Sweet Potato Salad

Number of Servings: 10

Ingredients
2½ lbs. sweet potatoes
2 medium-sized tart green apples, unpeeled, and cut in ½-inch dice
1 small fresh pineapple, cut into ½-inch chunks or 1 20-oz. can pineapple tidbits
½ cup golden raisins
½ cup mayonnaise
½ cup plain yogurt
1½ Tbsp curry powder
½ tsp salt

Directions
In a saucepan, cover potatoes with salted cold water. Bring to a boil, reduce heat and simmer, covered, until just tender, about 15 to 20 minutes. Drain potatoes well. Peel potatoes while warm and then allow to cool completely before cutting into ¼-inch chunks and place in large bowl. Add the apples, pineapple, and raisins; set aside. In a small bowl, whisk together remaining ingredients. Add to potato mixture and toss gently until well combined. Chill for a minimum of 1 hour before serving.

Nutrition per Serving: calories: 200; total fat: 6g; cholesterol: 5mg; sodium: 300mg; total carbohydrate: 36g; dietary fiber: 4g; sugars: 20g; protein: 3g; vitamin A: 280%; vitamin C: 35%; calcium: 6%; iron: 8%

Source: Centers for Disease Control and Prevention

See page 32 for another sweet potato recipe.
Still Alice
By Lisa Genova PhD;
Publisher: iUniverse, Inc

Alice Howland is a 50-year-old cognitive psychology professor at Harvard University and a world-renowned expert in linguistics. She attributes fleeting episodes of forgetting and disorientation to signs of normal aging. As her memory lapses worsen, she learns that she has early-onset Alzheimer’s Disease. The fictional Alice loses her cerebral life at Harvard, where she’d placed her worth and identity. Without it, she embarks on a desperate search for answers. Through an ever-thickening haze of dementia, she fights to hold on to essential pieces of herself and to find meaning and intimacy with her disconnected family.

The Majesty of Your Loving: A Couple’s Journey through Alzheimer’s
By Olivia Hoblitzelle;
Publisher: Green Mountain Books

When Hob and Olivia Hoblitzelle received his diagnosis of Alzheimer’s, the enormity of the prospect propelled them to make a pact with one another: They would negotiate the illness “consciously and lovingly” to the end. The Majesty of Your Loving is Olivia Hoblitzelle’s account of their courageous story. Olivia and Hob shared a rich background in psychology and Buddhist practice. Hob, ordained a Dharmacarya (wisdom teacher) by Thich Nhat Hahn, embraced his illness with a rare combination of wisdom and humor. Olivia shares the inspirations that sustained them throughout the journey, and how their experience was one of growing wisdom and deepening love.

Mothering Mother: A Daughter’s Humorous and Heartbreaking Memoir
By Carol O’Dell; Publisher: Kunati Inc.

Touching and entertainingly humorous, Carol tells her story of caring for her Alzheimer’s- and Parkinson’s-stricken mother along with her husband and three daughters. Witness her struggles, rewards, how she copes with tending to her needy family, and watch how strong she becomes. This is a human story, where the author is faced...
with the weight of her individual world on her shoulders, seeking to care for the mother who adopted her when she was age 4.

**Learning to Speak Alzheimer’s:**
*A Groundbreaking Approach for Everyone Dealing with the Disease*
By Joanne Koenig Coste;
Publisher: Houghton Mifflin

With a forward from Robert Butler, MD, this guide on reaching an Alzheimer’s patient is full of information on dealing with all stages of the disease. *Learning to Speak Alzheimer’s* also offers practical solutions for coping with the diagnosis, making the patient comfortable with everyday life, tackling the issue of driving, and dealing with mental hurdles such as wandering and paranoia. Her method of communication, called habitation, helps the caregiver understand the disease as if the caregiver was speaking that particular language.

**Drawn from Memory:**
*A Personal Story of Healing Through Art*
By E.J. Cockey;
Publisher: Strategic Book Publishing

While dealing with a multitude of problems in her own life, art therapist E. J. Cockey found her way from hopelessness to happiness when she met a 90-year-old Alzheimer’s patient. Setting out on a new course in life, she began to use art therapy as a way to reach Alzheimer’s patients—enriching their lives and her own in the process. *Drawn from Memory* shares these stories, showing that hope can come in many forms. Cockey continues to work with Alzheimer’s and dementia patients in the Baltimore area.

**An Uncertain Inheritance:**
*Writers on Caring for Family*
Edited by Nell Casey;
Publisher: William Morrow Publishing

Viva variety! This collection of caregiver essays show what it’s like to care for and be cared for when suffer-
The Fisher Center for Alzheimer’s Research Foundation receives questions from readers like you about Alzheimer’s disease. In our effort to provide easy-to-access information to help those who need it most, we have compiled our most frequently asked questions from our website: www.ALZinfo.org and our toll-free number: 1-800-ALZ-INFO (or 1-800-259-4636). As always, if you have any questions—no matter how big or small—you can call, or write us: info@alzinfo.org. We look forward to hearing from you and hope you gain some insight into the treatment and care of Alzheimer’s disease.

**Activities for People with Alzheimer’s**

There are many different stages that a person with Alzheimer’s and dementia will go through; therefore, activities for individuals in the early or middle stages of the disease will differ from the end stage of Alzheimer’s.

- When planning activities for the person with Alzheimer’s disease, creating routine and structure is extremely important.
- In order to improve quality of life at each stage of the disease it is important to focus on the patient’s strengths and abilities, as well as their growing weaknesses. It is important to look at what the patient can do, not just what they cannot do. Planning activities is a process of trial and error involving...
continual exploration, experimentation, and adjustment.

• Activities can be passive or active. Some patients may participate in an activity, while others may only observe or watch.

Communicating with an Alzheimer’s Patient
• As Alzheimer’s disease affects each area of the brain, certain functions or abilities can be lost. It is important for caregivers to remember that changes in a person’s behavior and ability to communicate may be related to the disease process.
• Alzheimer’s disease has a profound effect on language. The disease affects speech and the use of words, as well as the understanding of words. As the disease progresses, language as a means of communicating becomes less effective. Caregivers need to use different ways of communicating their message and staying in touch.
• When speaking to an Alzheimer’s patient, make sure there are few distractions. It is easier to communicate if other things are not happening at the same time. Television or radio should be turned off.
• The tone of your voice is very important in speech. Speak slowly and articulate to help the person hear and process the words. Sit facing or stand in front of the person and make eye contact. When doing something, like dressing, for an Alzheimer’s patient, ask the patient if it’s OK first. Simply moving a patient in the early or mid-stage of the disease around without respecting their physical integrity can have very negative effects.

Facts about Alzheimer’s Disease
• Alzheimer’s disease is the most common form of dementia affecting 5 million to 5.5 million Americans.
• 1 in 10 Americans over the age of 65 and nearly 1 in 2 Americans over age 85 currently have Alzheimer’s disease.
• Alzheimer’s disease is a progressive disease which advances in stages from mild forgetfulness and cognitive impairment to wide spread loss of mental abilities and total dependence on a caregiver. The time from the onset of symptoms until death ranges from three to 20 years with the average duration lasting about eight years.
• The progressive loss of cognitive function is accompanied by pathologic (disease-associated) changes in the brain.

The Importance of Pre-Planning: Alzheimer’s Disease and Health Care Proxies
• Alzheimer’s disease is one of the most emotionally draining and traumatic diseases for patients and families alike. The progressive, degenerative nature of Alzheimer’s disease presents unique challenges for health care proxies.
• During the end stages of Alzheimer’s disease, the patient typically loses the ability to communicate effectively with their loved ones, adding an additional burden to the health care proxy.
• It is essential for families to openly discuss end-of-life care early while the person with Alzheimer’s still has the ability to communicate their wishes.
• Families can often benefit from a mediator (an independent third party, usually a social worker) to facilitate the discussion of end-of-life care.

Steps to Healthy Aging
• Normal aging does not have to mean forgetfulness and memory loss.
• Studies have shown that staying physically active reduces the risk of Alzheimer’s disease, stroke, and bone loss caused by osteoporosis.
• Daily exercise of only 30 minutes can improve blood flow to the brain, and aerobic exercise, like brisk walking, swimming, or bicycling increases stamina and endurance as well as mood.
• At any age, the brain can continue to absorb new information, make new connections, and acquire new skills, which all help to enhance memory. Learning new things creates excitement, which helps to keep your mind active and sharp.

Warning Signs and Symptoms of Alzheimer’s Disease
• Difficulty performing otherwise familiar tasks, such as preparing a meal, opening a car window, or using a household appliance can be signs of Alzheimer’s disease.
• Memory loss that affects job skills. It is normal to occasionally forget an assignment or a colleague’s phone number, but it is not normal to frequently forget such things or to become so confused that you are unable to concentrate and can not perform your job functions.
• Problems using language may be a sign of Alzheimer’s disease. Although it is normal to forget words, people with Alzheimer’s disease may become hard to understand and may substitute unusual words or phrases for forgotten ones. A person with Alzheimer’s disease may appear to have become less fluent and may also have difficult writing coherently.
• Disorientation to time and place can be a sign. It is normal to sometimes lose track of time or to become lost, but a person with Alzheimer’s can forget what year it is and can become lost on familiar streets and not be able to find their way home.

Do you have a question you would like to ask the experts at the Fisher Center for Alzheimer’s Research Foundation? If so, please call 1-800-ALZINFO, visit ALZinfo.org, send surface mail to Fisher Center for Alzheimer’s Research Foundation, West 46th Street & 12th Avenue, New York, NY 10036, or e-mail info@alzinfo.org.
Senior-Friendly Fitness Programs Close to Home

Exercise is not only good for your body; it’s good for your brain. Physical activity encourages regular brain functions and helps keep the brain active. A study by the University of Washington found regular exercise reduces the risk of dementia and Alzheimer’s disease by as much as 40 percent. For people with dementia, exercise can improve sleep, reduce boredom, and quiet restlessness.

Older adults who exercise are more equipped to carry out everyday activities such as getting dressed, preparing meals, shopping, and housekeeping. The Rush Alzheimer’s Disease Center in Chicago found that for healthy seniors with intact memory, the risk of becoming disabled fell 7 percent for every hour spent each week being physically active.

As a caregiver, you and your loved one have a lot to gain from exercise, but how do you find the right fitness program to meet your needs? Before starting any exercise program, check with a physician to make sure the older adult does not have health limitations that would make exercise harmful.

First Stop: the Phonebook

“Typically, the first place to start is a medical center or hospital,” says Robyn Stuhr, exercise physiologist and executive vice president of the American Council on Exercise. “Contact the mental health or community health departments first; they’re likely to have a list of resources.”

Many hospitals and medical centers offer exercise and wellness programs specifically for seniors. A sampling of exercises include light weights, gentle yoga, low-impact water aerobics, walking around a track or on a treadmill, and seated workouts in chairs. Exercise physiologists are usually available to answer questions and to guide participants during exercise to avoid injury.

Another option is calling the local Y. “The YMCA and similar community organizations tend to cater to a broad range of age groups, including seniors,” says Stuhr. Older adults are among some of the most loyal members of Ys, where they take part in low-impact water workouts and exercise classes like tai chi. The Y is also a great place for older adult caregivers to meet and talk to peers through social clubs and senior centers, which enriches the exercise experience.

Regardless of the program you choose, as a caregiver you may need to participate in the exercise program with your loved one. A person with dementia may not be able to remember instructions from class to class, Stuhr points out. “They may need you to repeat and demonstrate things.”

Stuhr also recommends scheduling classes during early morning hours. “Some clinicians have found that programs earlier in the day are better tolerated, because people with Alzheimer’s have more restlessness and agitation later in the day.”

Free Fitness Ideas

If your budget is tight, inexpensive or free exercise programs are usually offered by churches and other religious institutions, community centers, and community colleges.

Take time to call ahead or visit the location first before signing up for classes. Make sure it’s the right environment for your loved one by asking how many people typically attend a class and if the room can get loud. Scientists have found that people with Alzheimer’s disease often become agitated in certain social situations, so it’s best to choose a fitness program that isn’t crowded or too noisy.

Although noisy environments are detrimental to people with Alzheimer’s disease, soft background music actually can keep people with dementia more calm. Stuhr says music that seniors may recognize from their teenage or young adult years, such as tunes from the swing era, can be soothing and motivating while exercising.

As a caregiver, you can also accompany your loved one on regular walks. Local greenways and city parks are nearly empty during weekdays, but avoid these public walking trails in the evenings or on weekends when they can become crowded. During cold weather, move your walking routine into an indoor shopping mall. Malls often sponsor free walking programs just for seniors. Mall walkers meet early, about 30 minutes before stores open, so shoppers are just beginning to arrive by the time the walk is over.

An ideal place to exercise is a fitness center that caters exclusively to seniors. One such program is SilverSneakers®, which has locations nationwide. If you belong to a participating Medicare health plan or Medicare Supplement carrier, it’s free to join.

Exercise classes are available for older adults who are fit and active as well as those who are sedentary or unfamiliar with exercise. Classes last from 45 to 60 minutes and are offered several times per week. Participants move to music while exercising with hand-held weights, a ball, or elastic tubing with
handles. A chair can be used for seated or standing support.

The SilverSneakers program also features a senior-friendly, certified staff, says Stuhr. “Their instructors are trained to work with older adults on such things as balance and strength.”

Exercise Training 101

Once you’ve made the decision on where to exercise, you should know what to expect. According to Stuhr, there are four basic types of exercise training:

**Strengthening exercise.** Regardless of your age, you can still build muscle, and you don’t need a bench press or weight lifting machine to get stronger. Older adults can use stretch bands, light weights, or wrist weights to achieve a stronger body. Muscle-building exercises also help caregivers provide better care. “Strengthening exercises help older adults do for themselves and get around more easily,” says Stuhr.

**Flexibility exercise.** Exercises performed gently through a range of motion help keep joints flexible. “As the body ages, tissues start to change, and tendons and joints are not as flexible as they used to be,” says Stuhr. Tai chi is an excellent exercise to gain flexibility, especially for people who are getting older. Some simple versions of tai chi repeat movements, which is helpful for people with memory problems.

**Basic balance.** Tai chi also improves balance, which can prevent falls in older adults. Stuhr says another way to improve balance is to hold a bar, rail, or chair and try to balance on one foot or with feet front to back. A personal trainer can introduce more challenging balance exercises.

**Cardiovascular or aerobic fitness.** Exercising in a pool is a great way to get a heart-pumping workout while going easy on the joints. The natural resistance of the water turns the pool into a “liquid weight room,” says Stuhr. Warm water pools promote fluid movement and provide resistance and buoyancy, which can be helpful for older adults with osteoarthritis. Exercise bikes are another option for aerobic fitness, especially when a person is overweight or suffering from knee problems.

Inspiration to Get Moving

Water exercise may be right for you but not for your loved one with Alzheimer’s disease. While maintaining a reasonable level of exercise is important to the overall health of Alzheimer’s patients, the type of exercise any patient engages in should be individualized to his or her abilities. You should talk with your doctor about whether exercise is right for both you and your loved one. Even if your loved one is a lifelong swimmer, you should not allow them in the water without supervision, and it might be recommended that they remain in shallow sections of the pool.

The consequences of not exercising cannot be denied. Just like an unused bicycle left out in the rain, your body can get rusty when you don’t take time to exercise.

Exercise can relieve stress, prevent disease, and improve mood for caregivers and their loved ones alike. Caregivers need physical fitness to accomplish everyday tasks and to continue to provide the care and attention their loved one needs. A person with dementia needs exercise to improve not only health but also quality of life.

“That person still inhabits the body,” says Stuhr. “Choose an exercise program he or she enjoys.”
Sweet Potato Soup

Preparation Time: 10 hours  
Number of Servings: 10

Ingredients
6 sweet potatoes, peeled and cubed  
2 leeks, chopped  
2 onions, chopped  
4 rib celery, chopped  
2 cups chicken broth, low sodium  
1 Tbsp parsley flakes  
1 tsp tarragon  
5 cups water  
1 tsp black pepper  
1 13-oz can fat-free evaporated milk  
2 Tbsp chopped chives

Directions
Combine all ingredients except milk and chives in slow cooker. Cover and cook on low 10-12 hours, or HIGH 3-4 hours. Stir in milk during last hour; if desired, mash potatoes before serving and garnish with chives.

Nutrition per Serving: calories: 130; total fat: 0g; cholesterol: 0mg; sodium: 115mg; total carbohydrate: 26g; dietary fiber: 3g; sugars: 11g; protein: 6g; vitamin A: 300%; vitamin C: 25%; calcium: 15%; iron: 8%

Source: Centers for Disease Control and Prevention
Living with Alzheimer’s Disease

Products That Make Life Easier, Simpler, and Safer

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

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

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

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

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

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

For more information and many more helpful products, go to www.alzstore.com or call (800) 752-3238.
Brain-Boosting Puzzles

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

(Answers on page 37)

MATCH THESE

Can you match each animal to its appropriate designation?

1. _____ Male elephant  a. Cow
2. _____ Male antelope  b. Tom
3. _____ Female bear   c. Doe
4. _____ Female whale  d. Hen
5. _____ Female rabbit  e. Vixen
6. _____ Male sheep    f. Buck
7. _____ Male turkey   g. Stallion
8. _____ Female chicken h. Ram
9. _____ Female fox    i. Bull
10. _____ Male zebra   j. Boar
11. _____ Male caribou k. Sow
12. _____ Male pig     l. Stag

LEAPFROG

Here’s a list of ships — two for each number. Their letters are in the correct order, but they overlap. All you have to do to find the terms is separate the letters.

Example: DTESEN TRODEYERR — DESTROYER, TENDER

1. S F C E R O W Y
2. S U C R U B I M S A R E I N E R
5. C R U U N A T B O T E U R T
6. C A T R A N R K E I R E R
7. T R L A N A U S P O R N R C H T

DROPLINE

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

THEE FAKEA EDEBBAAK
W I H L F I O K H R H S E E C R
TLR LORTLTR YFU
YOU LORW Y O

T
We have provided two crosswords here to sharpen your puzzle skills. Start with the one on the left, which is the easier puzzle. In this one we have provided solving aids, such as the number of words in multi-word clues. The puzzle on the right is a medium-level puzzle and the number of words in the answers have been eliminated. The second puzzle is also a thematic puzzle: the title “Ordinary Ordinals” is a hint. Have fun testing your knowledge while doing something that’s good for you!

Across
1. List-ending abbr.
2. 20th-century art movement
3. Ranch unit
4. Anger
5. Leading
6. Smart talk
7. President Grant
8. “Tell ___ story” (2 wds.)
9. Actress Grier
10. Damask, e.g.
11. Meadow moms
12. Actress Thompson
13. Sun planter’s choices
14. Cultivate
15. Govt. watchdog agcy.
16. Lou Gehrig’s position
17. Equine duo
18. “___ Were the Days”
19. Jailed one
20. Shorts topper
21. Word of assent
22. Pianist Peter
23. Neighbor
24. Label
25. “Aw, shucks’” quality
26. “___ in a Lifetime”
27. Eggs
28. Prying tools
29. Sweater pests
30. Close friend
31. That fella’s opposite
32. Ecstasy
33. Network of locales (abbr.)
34. Boat paddle
35. Four-year degs.
36. Home to Kenyon, Antioch, and Oberlin
37. Walks in water
38. Greatest in size
39. Best man
40. “___ Alone”
41. Rainbow shape
42. Ingested
43. Narcissist’s obsession
44. “___ of a Preacher Man”
45. “Oops!”
46. Like Miss Congeniality
47. Hang back
48. Donate
49. She starred opposite Gable in “GWTW”
50. 2001 role for Will Smith
51. Jekyll’s counterpart
52. “___ is the charm”
53. “Man on the Moon” group
54. J. Lo’s
55. Travel like Superman
56. “___ in a Lifetime”
57. Actress ___ Rachel Wood
58. Williams or Weems
59. Pope’s output
60. Teller’s cry
61. Bray beginning

Down
1. Bequest
2. Kind of enemy
3. Endorsed
4. Puts off
5. 2001 role for Will Smith
6. Gossip, slangily
7. Desirable quality
8. Police dept. alert
9. Material for Gumby and Pokey
10. Damask, e.g.
11. Meadow moms
12. Kind of enemy
13. Beach, Florida
14. Cage
15. Ex of Artie and Mickey
16. IRS worker
17. Made pulp
18. IP address
19. Smart talk
20. Ex of Artie and Mickey
21. Pothole filler
22. City dweller’s bldg.
24. City dweller’s bldg.
25. Blackbeard, for one
26. “___ of a Preacher Man”
27. Jailed one
28. Prying tools
29. Sweater pests
30. Close friend
31. That fella’s opposite
32. Ecstasy
33. Network of locales (abbr.)
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56. “___ in a Lifetime”
57. Actress ___ Rachel Wood
58. Williams or Weems
59. Pope’s output
60. Teller’s cry
61. Bray beginning

(Answers on page 37)
All the words in the list, which are all electric gadgets, can be found in the letter grid reading across, up and down, and diagonally. When you have found them all, read the leftover letters to discover an apt quote by comedian George Carlin.

You are looking for a 41-letter phrase.

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

```
 1 7 6
 3 2 6
 8 9

 8 7 1 2
 2 1 5
 9 1 6 7

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

Droplines
The farther back you look, the farther forward you will likely see.

Leapfrog

Hidden Message
Electricity is really just organized lightning.

PUZZLE ANSWERS

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Agnes

(continued from page 27)

ing from diseases such as cancer and Alzheimer’s. Each author has his or her own take on caregiving, whether it is through dark humor, emotional heartstrings, or detailed illustrations. All sorts of relationships are examined in this compilation of stories. Ann Harleyman faces the decision of placing her husband in the care of an institution, while Sam Lipsyte talks about caring for his mother with breast cancer after he just left rehab. Coping with hard choices and living with those resolutions is at the heart of each story.

Frank McCourt, Pulitzer Prize-winning author of *Angela’s Ashes*, provides the foreword.

This game gives Memory a new name. Used by caregivers, doctors, nurses, activity planners, and partygoers alike, this book produces triggers that help people remember smells, sounds, sights, and tastes. Fill in the blank and describe the scene to the best that you or your loved one can remember. This process helps keep your mind sharp and your memories vivid. The book is good exercise for people of any age.

The books mentioned in this article are suggestions only. The Fisher Center for Alzheimer’s Research Foundation has not endorsed these materials.

Mothballs in my Attic
By Cindy O’Neill and Barbara Iderosa; Available only at www.mothballsinmyattic.com

“To get away from my parents I would hide _________.”

“The store where my friends and I would buy candy and gum was ______.”

(38) Preserving Your Memory fall 2008
The Fisher Center for Alzheimer’s Research Foundation is dedicated to attacking the scourge of Alzheimer’s with a 3-pronged assault focused on the cause, care, and cure for Alzheimer’s disease as well as supporting the public with educational programs. Our goals are to: Understand the Cause of Alzheimer’s, to find a cure for this devastating disease, and improve the care of people living with the disease to enhance their quality of life and that of their caregivers and families.

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

For more information, visit our website at www.ALZinfo.org or call 1-800-ALZ-INFO.

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