preserving your Memory
The Magazine of Health and Hope
Spring 2015

Still Alice
We chat with Lisa Genova, author of the novel

Fisher Center Adds New Dimension to Alzheimer’s Research
Handling Extreme Emotions

Julianne Moore, Oscar-winning star of the film Still Alice

Plus the latest news on Alzheimer's research and treatment
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   Give your brain a workout with these brainteasers.
Many people welcome the beginning of Daylight Saving Time and the extended hours of sunlight that come with the onset of spring. But, initially, losing that hour of sleep can be a challenge. Studies have shown that a loss of even one-half hour of sleep can impact things like body weight and metabolism. Alzheimer’s can make sleeping especially daunting—both for the person with Alzheimer’s and the caregiver. If you are In Search of a Good Night’s Sleep, we have some tips for you (page 25).

Does the thought of eating the recommended daily amount of vegetables leave you less than enthused about mealtime? In Go Green (page 22) we offer ideas on getting that proper nutrition via a “liquid salad,” also known as a smoothie. Variations on vegetable smoothies are endless and offer a surprisingly tasty way to eat your veggies.

And we are thrilled to feature Lisa Genova, author of the book, Still Alice, in our lead story this spring issue. Still Alice is also now a film starring Academy Award® winner Julianne Moore in the role of Alice; a highly successful woman who is diagnosed with early onset Alzheimer’s. Preserving Your Memory spoke with this Harvard-trained neuroscientist (page 18) about why she’s made it a mission to raise Alzheimer’s awareness.

The issue is filled with additional features and tips to support caregivers and their loved ones with Alzheimer’s and other neurological conditions. Thank you for your interest. I hope that you will find the articles in this issue both useful and informative.

Sincerely,

Kent L. Karosen
President & CEO

Please send your tips, stories or questions to:
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About the Fisher Center for Alzheimer’s Research Foundation
Since 1995, the Fisher Center Foundation, a 501(c)(3) nonprofit organization, has been providing hope and help to the public by funding research into the cause, care, and cure of Alzheimer’s disease and creating much needed educational programs. We are one of the world’s largest research teams leading the battle against Alzheimer’s disease. Our team of internationally renowned scientists, under the direction of Nobel Laureate Dr. Paul Greengard, has been at the forefront of research that has provided a conceptual framework for modern-day investigations into Alzheimer’s disease. Oprah’s O Magazine listed us as the top charity to give to for Alzheimer’s. The Fisher Center Foundation has earned Charity Navigator’s highest 4-Star rating for fiscal management and commitment to accountability and transparency. For more information or to make a donation, go to www.ALZinfo.org.
The Latest News on Alzheimer’s Disease and Brain Health

Immune Cells Help Clear Brain of Beta Amyloid, Study Finds
In a promising new development, researchers at the Keck School of Medicine at the University of Southern California (USC) discovered that blocking a substance called interleukin-10 activates an immune response to clear the brain of the beta-amyloid plaques, thus restoring memory loss and reversing brain cell damage.

The immune system, when functioning normally, rids the body of toxic substances. But when Alzheimer’s disease is present, the immune system becomes imbalanced and inefficient at clearing those plaques.

In the study, researchers used mice afflicted with a mouse version of Alzheimer’s disease that causes the mice to have learning and memory problems and fills their brains with beta-amyloid plaques. But when these mice had their immune cells activated, their learning and memory problems disappeared and so did a lot of their plaques, and their behavior more closely resembled that of mice that didn’t have the disease.

“Alzheimer’s disease is the public health crisis of our time, and effective treatment does not yet exist,” said Terrence Town, Ph.D., professor of physiology and biophysics at the Keck School of Medicine at USC and the study’s senior author. “Our study shows that ‘rebalancing’ the immune response to wipe away toxic plaques from the brain may bring new hope for a safe and effective treatment for this devastating illness of the mind.”

FDA Approves New Combination Drug
The Food and Drug Administration (FDA) approved a new drug that combines two commonly used medications to combat the symptoms of Alzheimer’s disease in December.

The new drug is called Namzaric™. It combines two Alzheimer’s medications that are often prescribed together: memantine hydrochloride extended-release (Namenda®) and donepezil hydrochloride (Aricept®). Namzaric is used to treat the symptoms of moderate to severe Alzheimer’s. There is currently no cure for Alzheimer’s disease or approved method of stopping or slowing its progression.

Namzaric is available as a capsule and is taken once a day. It is available in two strengths. Patients who have trouble swallowing can have the capsules opened and the medication sprinkled on food.

New Noninvasive Test for Alzheimer’s Developed
A team of scientists and engineers at Northwestern University has created a test for detecting Alzheimer’s disease at its earliest stages, even before symptoms begin to appear.

The test works by pairing a magnetic nanostructure (MNS) with an antibody that locates the beta-amyloid brain toxins associated with Alzheimer’s. The MNSs cause the accumulated beta-amyloid toxins to show up as dark areas in an MRI scan of the brain.
Neuroscientist Dr. William Klein, who first identified a toxic form of beta-amyloid in 1998, and materials scientist Vinayak P. Dravid led the team of researchers. “We have a new brain imaging method that can detect the toxin that leads to Alzheimer’s disease,” said Dr. Klein, who is a professor of neurobiology in the Weinberg College of Arts and Sciences. “Using MRI, we can see the toxins attached to neurons in the brain. We expect to use this tool to detect this disease early and to help identify drugs that can effectively eliminate the toxin and improve health.” This new technique differs from other methods currently used to form images of beta-amyloid plaques.

Details of the new technique were published online in the Dec. 22 edition of the journal Nature Nanotechnology.

Meditation May Help Protect Against Alzheimer’s

Emerging research has shown a possible connection between meditation and improved attention and focus, reduced symptoms of anxiety and depression, and better cognitive control and executive functioning. Now a new study from the UCLA Brain Mapping Center demonstrates evidence that meditation may also help protect the aging brain.

The study, conducted by a team from UCLA and the Australian National University, showed that those who meditate tend to experience less of the brain’s natural atrophying (reduction in size) than do those who do not meditate. Researchers looked at the brains of 100 participants, 50 who meditated and 50 who did not, using functional MRI (fMRI) scanning. While both groups showed a decline in the brain’s gray matter, the meditators experienced smaller reductions in gray matter volume than did their non-meditating counterparts.

“This study builds on a 2011 study conducted by the same team that showed that meditators show less age-related atrophy in the brain’s white matter than do non-meditators. White matter makes up nearly half the brain and contains many of the nerve fibers the brain uses to communicate.

“Older adults should be aware that many medications—including some available without a prescription, such as over-the-counter sleep aids—have strong anticholinergic effects,” Gray said in a statement. “Of course, no one should stop taking any therapy without consulting their health-care provider. Health-care providers should regularly review their older patients’ drug regimens—including over-the-counter medications—to look for chances to use fewer anticholinergic medications at lower doses.”

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

Seeking answers about chronic traumatic encephalopathy (CTE)

As doctors and researchers dig deeper into the complexities of memory loss, they learn more about the distinctions among the different types of progressive degenerative brain disease that can lead to cognitive impairment. One condition in particular is garnering increased attention, not just in medical circles but also among former athletes and others who have sustained repeated blows to the head: chronic traumatic encephalopathy (CTE). Characterized by a build-up of tau protein in the brain, CTE is a suspected outcome of repetitive brain trauma and causes symptoms similar to those of Alzheimer’s disease (AD).

To learn more about CTE and the latest efforts to identify, treat and prevent it, we spoke with two people at the forefront of CTE research and awareness: Robert A. Stern, Ph.D., from the Boston University (BU) CTE Center, and Lisa McHale, who is affiliated with both the Sports Legacy Institute and the BU CTE Center.

Robert A. Stern, Ph.D.
Professor of Neurology, Neurosurgery, and Anatomy & Neurobiology
Director, Alzheimer’s Disease Center Clinical Core
Director of Clinical Research, Boston University CTE Center

Preserving Your Memory: How are CTE symptoms different from AD symptoms?

Robert A. Stern, Ph.D.: One of the challenges of CTE is that it has a variety of symptoms that can present at different ages and can either look very similar or very dissimilar to Alzheimer’s disease or fronto-temporal dementia. Thanks in large part to the work of [the BU CTE Center’s] Dr. Ann McKee, the neuropathological description of CTE is becoming much clearer and appears to be unique from all other neurodegenerative diseases.

PYM: How do CTE symptoms present themselves?

RAS: There are three primary types of changes that can occur with CTE: cognitive, mood and behavior. Cognitive problems include memory impairment as well as difficulties with executive functioning—in other words, planning, organization, multitasking and judgment. Mood problems include depression, anxiety, hopelessness and suicidality. Behavior changes include impulse control problems, aggression and rage. So with all of those different types of symptoms, you can see how a diagnosis based purely on symptoms could be very difficult.

PYM: Is there only one form of CTE?

RAS: What we’ve found so far in our research is that there may be two different sub-types of CTE clinical presentation: one having more of the mood and behavioral changes that begin to show at an earlier age, and the other having more of the cognitive changes that show up later. It’s not uncommon for us to hear a history of someone who had no other changes earlier in life but started having significant memory and other cognitive changes in their 50s or 60s that then progressed.

PYM: What causes CTE?

RAS: Unlike Alzheimer’s, which has no known specific trigger, CTE is believed to be caused, at least in part, by a history of repetitive brain trauma, including concussions and sub-concussive trauma. That trauma appears to start a cascade of events in the brain that eventually leads to progressive neurodegeneration.
CTE Defined

Chronic traumatic encephalopathy (CTE) is a progressive degenerative disease of the brain found in athletes (and others) with a history of repetitive brain trauma, including symptomatic concussions as well as asymptomatic subconcussive hits to the head. CTE has been known to affect boxers since the 1920s. However, recent reports have been published of neuropathologically confirmed CTE in retired professional football players and other athletes who have a history of repetitive brain trauma. This trauma triggers progressive degeneration of the brain tissue, including the build-up of an abnormal protein called tau. These changes in the brain can begin months, years or even decades after the last brain trauma or end of active athletic involvement. The brain degeneration is associated with memory loss, confusion, impaired judgment, impulse control problems, aggression, depression and, eventually, progressive dementia.

In both sets of photographs, above, the brain tissue has been immunostained for tau protein, which appears as a dark brown color. Tau immunostained sections of medial temporal lobe from 3 individuals:
- Top left: Whole brain section from a 65 year old control subject showing no tau protein deposition
- Bottom left: Microscopic section from 65 year old control subject also shows no tau protein deposition
- Top middle: Whole brain section from John Grimsley showing abundant tau protein deposition in the amygdala and adjacent temporal cortex
- Bottom middle: Microscopic section showing numerous tau positive neurofibrillary tangles and neurites in the amygdala
- Top right: Whole brain section from a 73 year old world champion boxer with severe dementia showing very severe tau protein deposition in the amygdala and thalamus
- Bottom right: Microscopic section from a 73 year old world champion boxer with severe dementia showing extremely dense tau positive neurofibrillary tangles and neurites in the amygdala

Photo by Ann C McKee, MD, VA Boston/Boston University School of Medicine.
PYM: Will everyone who has had concussions develop CTE?

RAS: Not everyone who has a history of repetitive hits to the head develops this brain disease. What we currently know is that every case of neuropathologically confirmed CTE was in a person with a history of repetitive head impacts. It’s never been seen in anyone without that kind of history. One of my areas of research is to try to understand what other variables may contribute—such as genetic predisposition as well as what specific types of brain trauma—to put someone at risk for developing this disease.

PYM: How is CTE diagnosed?

RAS: At this point, a definitive diagnosis for CTE can only be made postmortem, which is also true of Alzheimer’s disease. Fortunately though, we’ve gotten much better at diagnosing Alzheimer’s more accurately before death, and we can exploit that knowledge to develop methods of diagnosing CTE during life.

PYM: Are there any effective treatment options?

RAS: Just like with Alzheimer’s, there is no real treatment available that can alter the course of CTE itself, although many of the symptoms can be treated to improve one’s functioning, at least temporarily. For example, the symptoms of depression may still be amenable to medications used for other types of depressive conditions. It may be that medications currently available for Alzheimer’s, such as Aricept, could be useful in early stages of memory problems associated with CTE.

PYM: Does CTE only affect athletes?

RAS: No. Even though CTE is the same thing as what is sometimes referred to as being “punch drunk,” we now know that it’s not just boxers who get their heads hit over and over again. CTE has been diagnosed in people with a variety of types of exposure to repetitive head impacts, including former football players and other contact sport athletes, as well as military service members. It’s also been seen in individuals with a history of domestic abuse, developmental disabilities with head banging behaviors, and people with seizure disorders.

PYM: Does the BU CTE Center accept brain bank donations?

RAS: Yes. Anyone who suspects that they or their loved one may be suffering from CTE may contact us at any stage of the illness to discuss the possibility of a donation to our brain bank (which is run through a partnership between the Sports Legacy Institute, Boston University and the VA). We work directly with families from all over the country, and there is no cost to participate. Donors are never identified in our research data; although, families receive detailed reports summarizing our findings regarding their loved ones.

PYM: How does organ donation benefit CTE research?

RAS: The value of brain donations is tremendously important. The brain is the only organ in our body that cannot be accurately diagnosed for disorders during life. The only way we can move forward in our research, and understand the underlying causes of the disease to develop potential treatments, is to study the brains of individuals who have passed to improve our ability to diagnose the disease during life. Because CTE is only recently receiving adequate scientific attention, we need to study the brains of as many individuals with a history of repetitive brain trauma as possible in order to further our knowledge. We can only move forward with the help of people who are willing to participate in the research process.

Lisa McHale
Director of Family Relations,
Sports Legacy Institute

PYM: What is your personal connection to CTE?

Lisa McHale: In May 2008, my amazing husband, [former NFL player] Tom McHale, passed away at 45 years of age. I was contacted by [Sports Legacy Institute Co-Founder and Executive Director] Chris Nowinski, who requested Tom’s brain for scientific study. I had never known my husband to have suffered a concussion, so I saw no connection between concussions and his later
difficulties. Still, I gave my permission for the donation, thinking that it might somehow help future generations of athletes. When the results came back, they showed that Tom had indeed had this disease they were looking for. That was the first time I heard the term CTE.

**PYM: Did your husband exhibit symptoms of CTE prior to his passing?**

**LM:** Knowing now what the signs of CTE are, I recognize that he was extremely characteristic. He didn’t exhibit a great deal of rage, but he showed dramatically increased irritability and discontent; a shorter fuse. He began to get very upset over little things that would not have normally been on his radar screen. The other thing that became increasingly obvious was a debilitating depression in a man who never experienced anything of the sort. He had a very dynamic, vibrant and positive personality. So feeling depressed and lethargic, with a lack of motivation and drive, was very taxing on him.

**PYM: Did he show any signs of forgetfulness or confusion?**

**LM:** Because he passed away so young, I didn’t recognize much in the way of forgetfulness. I did notice that he was constantly making lists to orient his day and plan what he needed to get done, which was not something he’d done in years past. There were lists everywhere. He also gradually became less dependable when I asked him to do things. So there was diminished capacity in terms of executive function but no significant changes in memory. When I think back about Tom, I realize I could see changes in his late 30s and early 40s, and then, he was gone by the age of 45. It never would have occurred to me that dementia or any kind of neurodegenerative disease was at play. When you think of dementia you think of a much older person, not a person in his 30s or 40s suffering from symptoms and having difficulty maintaining daily tasks.

**PYM: What compelled you to become a CTE advocate?**

**LM:** After donating Tom’s brain, I got to know the research team from the BU CTE Center and I read Chris Nowinski’s book, Head Games. That opened my eyes to the issue of concussions and the risks of failing to recognize and treat them appropriately. I learned about second-impact syndrome, post-concussion syndrome and CTE. Meanwhile, I was reaching out to folks locally—Pop Warner coaches and administrators, the superintendent of our school district, and even former NFL players who knew my husband—to get some discussion started and was amazed at the lack of interest. They just didn’t want to hear it. But it’s not something you can just set aside. I wanted to make people aware so others wouldn’t have to suffer the same fate my family did. So I reached out to Chris Nowinski at the Sports Legacy Institute and told him I’d like to help in some way.

**PYM: Describe your role as Director of Family Relations with the Sports Legacy Institute and the BU CTE Center.**

**LM:** If a family reaches out with questions about whether their loved one would be a good candidate for a donation, I connect them with the right people at BU who can help them make all the arrangements. My primary role begins once a donation has been made, when I serve as the liaison between family members and the doctors with whom they’ll be interacting during the research process. For many family members, that connection continues even after the process is completed through their participation on the SLI Family Advisory Board, which was created to keep interested family members informed on the progress of CTE research and updated on efforts to translate that new knowledge into safer sports for future generations.

**PYM: What is the value of spreading awareness among CTE sufferers and their families?**

**LM:** So many families affected by this share a feeling of, “I wish I had known better when my loved one was alive what was really going on. I would have been less angry, less resentful, more understanding, more patient.” Of the people who have donated to our brain bank who were diagnosed in life with dementia, most were presumed to have Alzheimer’s. But we hear all the time from families whose loved ones spent time in residential care that experienced staff would tell them, “This just didn’t seem like Alzheimer’s. It was different.” So the more we learn about the particulars of CTE, the better we can take care of the people who have it.
Handling the Tough Emotions of Alzheimer’s Disease

Patricia Maron was always a gentle, kind and soft-spoken woman. So when the 81-year-old retired office manager developed dementia and started having uncharacteristic fits of rage, her son Mark was stunned.

“My mother was never the type to get angry,” says Mark, 51, of Clifton Park, N.Y., who is his mother’s primary caregiver. “Never. I wonder now if she was just holding it all in.”

In the four years since his mother was diagnosed with dementia, Mark has grown accustomed to Patricia’s anger and now knows how to handle it. He responds by looking her in the eye, nodding his head and saying “I know, Mom.” He has also learned to never take it personally, even when her fury is directed at him. “Sometimes, she tells me I amounted to nothing,” says Mark, who runs a property inspection company. “I just nod and tell her ‘Yes, I know. I’m sorry’.”

Extreme emotions like anger, fear, anxiety and depression are hallmarks of Alzheimer’s disease, and are often more difficult for caregivers to handle than physical challenges, says Barry Jacobs, PsyD, a clinical psychologist and author of The Emotional Survival Guide for Caregivers—Looking After Your Loved Ones and Yourself While Helping an Aging Parent (Guilford, 2006). Alzheimer’s disease damages different parts of the brain, including those parts that regulate emotional expression.

“This is what produces what appears to be the personality changes in Alzheimer’s patients,” Jacobs says. “A loved one who was previously quiet and reserved may, after developing dementia, easily explode with anger when frightened or frustrated. A loved one who was previously talkative and animated may be stone-faced, barely noticing or reacting to others around him. These changes are all due to the disease and do not reflect any intention on the part of the Alzheimer’s patient to defy the caregiver.”

While caregivers may come to understand that difficult emotions are the result of the illness, it can still be a challenge to manage a loved one during a bout of deep depression, a fit of rage or an attack of paranoia. The key is knowing what to expect, learning to spot and avoid the triggers, and having an assortment of responses that help soothe or calm your loved one.

The Emotional Rollercoaster

According to Jennifer L. FitzPatrick, MSW, a spokesperson for the National Association of Social Workers and an expert in caring for people living with Alzheimer’s, individuals with Alzheimer’s experience a range of emotions depending, in part, on the stage of the disease. In the early stages, they may be fearful about the future, anxious about their waning memory and depressed if they have a history of that condition. Some get angry when they learn they have Alzheimer’s.

Over time, the emotional responses may become less rational as the disease progresses, and their cognitive capabilities diminish. “A patient might feel anxious because she’s certain that she needs to pick up her daughter from school,” FitzPatrick says. “This is completely irrational because the daughter is now in her 50s and certainly doesn’t need to be picked up from school. But reasoning with the patient and telling her that often frustrates her further.”

The onset of delusions and hallucinations is a common symptomatic progression of Alzheimer’s disease, and to the patient, the delusions and accompanying emotions will seem very real.

Emotional Rescue

Often, even as people with Alzheimer’s gradually lose their cognitive abilities, their emotional sensibilities still remain intact, says Robert Ryan, LPLC, a psychotherapist in Chicago who works with caregivers as well as patients with dementia.

“Alzheimer’s initially attacks the cognitive functions of the brain, so sufferers are said to be existing in an emotional world rather than the rational,” Ryan says.
“A loved one who was previously quiet and reserved may, after developing dementia, easily explode with anger when frightened or frustrated. A loved one who was previously talkative and animated may be stone-faced, barely noticing or reacting to others around him.”

—Barry Jacobs, PsyD

Focusing on soothing the person’s emotions instead of trying to reason with him often makes it easier for a caregiver to manage someone who has become difficult and irrational. “Being confronted by reasoning that the Alzheimer’s sufferer may not understand will cause confusion and anxiety, leading to emotional outbursts,” Ryan adds.

Here are other tactics that experts recommend:

**Validate Their Feelings**

No one likes it when their emotions are dismissed, and people with Alzheimer’s disease are no different. That’s why it’s important to let your loved one know that you empathize with their feelings. “Dismissing the emotion makes the patient feel alone,” FitzPatrick says.

Maron says he never tells his mom he doesn’t understand something she says or questions what she means—even when he has no idea. “If I do, it just makes her struggle to explain, and that causes more frustration,” he says. “I just pretend that I understand and stay in rapport with her, and I watch other signals for clues to what she is feeling or trying to say.”

He also makes a point to make eye contact. “I stare at her when she speaks and acknowledge that I’m listening, even if I don’t completely understand what she is saying,” he says. “Eye contact is important to validate her position.”

**Keep Calm—Especially When They’re Not**

Many people with Alzheimer’s become angry, paranoid and fearful for reasons that the caregiver can’t understand. Rather than react with your own anger, respond to difficult emotions in a calm voice, using soft and comforting tones, Jacobs says.
“Agitated loved ones need this reassurance to help them feel less afraid and to de-escalate,” he says. “It would be a mistake for caregivers to meet a loved one’s anger with their own anger; this is likely to only cause more agitation.”

Your tone of voice is critical to calming someone who is agitated. Ryan says that how you say something is actually more important than what you say. Strive to be calming and reassuring, not irritated and annoyed.

Devote Time and Attention
Giving your loved one some extra TLC can go a long way toward defusing feelings of depression. Unlike anger, fear and paranoia, people with Alzheimer’s who become depressed will often withdraw from life and shut down. “Both are coping mechanisms for a world out of the individual’s control,” Ryan says.

Soothe the sadness by spending time with your loved one and demonstrating genuine interest and concern. Try just listening and coaxing your loved one to share stories from his past.

A good activity, Ryan says, is looking at old family photos. “Don’t worry about correcting misinformation in their stories,” he says. “The caregiver’s role is to build new emotional bridges. There is no better way to build bridges than to share stories, true or not.”

Maintain a Calm Environment
Too much excitement and chaos in a person’s surroundings can set off upsetting emotions and trigger meltdowns, so Jacobs recommends keeping noise and other stimulants to a minimum. “That means lowering the volume on the television and limiting the number of people who are in the room,” he says. “That usually has the effect of decreasing agitation.”

Avoid Triggers
Everyone has “buttons” that, when pushed, can elicit raw emotional responses—even people who don’t have Alzheimer’s. But when someone has dementia, the inability to reason can make it hard to for someone to get past a distressing event.

The best thing to do is to avoid what upsets your loved one in the first place.

Pay attention to the particular situations that set them off. Maron says his mother often reacts negatively when someone challenges a delusion that she is convinced is real.

“For instance, my mom will say she wants to go home now,” her son Mark says. “A trigger would be to say that ‘you’re already home.’ Instead, it’s better to agree with her and tell her that we’re about to go home really soon.”
Try Distraction

Next time your loved one is having emotional difficulty, divert their attention to something unrelated. Jacobs says he once calmed his angry stepfather, who was shouting at his mother, by turning on the Golf Channel. “My stepfather was quickly taken in by the beautiful fairways and putting greens, and he soon relaxed,” Jacobs says.

It can also help to distract your loved one by engaging him in an activity with you, Ryan says. “This can be a very effective means of alleviating the troubling emotion,” he says. “The individual is often seeking connections, and sharing an activity is a key way to build connections.”

Sometimes, something as simple as taking your loved one into a different room can do the trick, Ryan adds.

Consider Medications

It’s not uncommon for people with Alzheimer’s to have depression, anxiety or both. If you suspect that your loved one has one of these mental health conditions, talk to a doctor about medications. Both conditions can be effectively treated.

Give Yourself a Timeout

Looking after a loved one with a chronic and demanding illness like Alzheimer’s takes its toll, so it’s important to practice good self care. Being in good health yourself will prepare you for the challenges of managing these tough emotions. Get your rest, and look for ways to reduce your stress. If possible, consider going away for the weekend, taking a yoga class, reading a good book, or listening to music. Lessening stress will make it easier for you to manage and tolerate the mood swings in your loved one.
Scientists at the Fisher Center for Alzheimer's Research Foundation strive to understand Alzheimer's disease (AD) by studying brain cells and the molecules within brain cells that function in health and disease. Their goal is to translate this knowledge—the knowledge they gain at the laboratory bench—into treatments that prevent, slow or cure AD. To accomplish this and to accomplish it sooner rather than later, the Fisher Center has expanded its efforts beyond basic research to include the creation and discovery of drugs that will target AD.

This new dimension of the Fisher Center is being pursued in collaboration with Dr. Subhash Sinha, a synthetic organic chemist at The Rockefeller University, who along with his colleagues, Drs. Anjana Sinha and Weilin Sun, synthesize new drug-like molecules that are then tested by Fisher neuroscientists to discover drugs that treat the symptoms and causes of AD. All of this is under the direction of Fisher Center Director, Dr. Paul Greengard, 2000 Nobel Laureate in Medicine/Physiology.

Several years ago, Fisher scientists discovered that the anti-cancer drug, Gleevec® (generic is imatinib), lowers the production of beta-amyloid, a protein fragment whose toxic forms are believed responsible for causing the symptoms and brain ravaging effects of AD. Finding a drug that prevents the buildup of beta-amyloid and, at the same time is non-toxic, remains a sought-after goal of drug companies and Alzheimer's researchers worldwide. At first, imatinib seemed to possess the right mix of properties. It inhibited beta-amyloid but not other cellular functions that are vital to health—a property other amyloid-lowering drugs didn't possess. It quickly became apparent, however, that imatinib could not be used to treat AD because it was prevented from accumulating in the brain in amounts sufficient to block beta-amyloid, and it lacked other necessary properties.

Then Fisher scientists joined forces with Dr. Subhash Sinha, who has the ability to make molecules related to imatinib but that differ in small ways. This has allowed Dr. Sinha to determine which parts of the imatinib molecule are needed for lowering beta-amyloid and which parts affect other properties necessary for producing a successful drug.
drug to combat AD. He has also developed compounds based on other drug-like chemicals that, like imatinib, also lower beta-amyloid. Currently, this research is ongoing and has expanded to other projects at the Fisher Center where scientists have identified targets within brain cells that could be addressed by other drugs to change the course of AD.

Recently, Fisher scientists discovered that an extract of a Chinese herb, which has been used for centuries to treat dementia, lowers beta-amyloid production by blocking an enzyme necessary for amyloid formation. The herb contains hundreds of chemicals, but through careful analysis, Fisher scientists were able to identify the major active chemical in the extract having an effect on beta-amyloid production. Dr. Sinha and his colleagues are currently producing related forms of this chemical and have so far discovered forms that are more potent than the original herb. It also appears that some of the new compounds are highly specific and, therefore, not likely to inhibit vital life processes that would cause them to fail as drugs.

In addition to these programs, Fisher scientists are investigating several promising AD projects that are providing information about specific proteins in the brain that might affect the course of AD. Some of these proteins appear to be responsible for accelerating AD and causing mental deterioration to become progressively worse. Other proteins are proving to be beneficial in experimental models and appear to protect brain cells from the ravages of beta-amyloid. Some of the proteins are likely to be promising drug targets. The Fisher Center’s collaborative effort with Dr. Sinha, who with his colleagues will synthesize drug molecules that address these targets, is likely to result in new drugs for combating AD and give scientists new tools for investigating its causes.

Dr. Sinha notes, “Alzheimer’s disease is becoming more prevalent in aging populations around the world because people are living longer. Efforts to combat this devastating and complex disease will need to be waged on many fronts. Scientists are working hard to develop new treatments, but we also need to maintain healthy life styles that include regular exercise, consumption of healthy foods and taking measures to reduce stress and anxiety.”
Lisa Genova: An Inside Look at Alzheimer’s

Author and neuroscientist Lisa Genova’s novel about early-onset Alzheimer’s disease, *Still Alice*, is now an Academy Award-winning major motion picture. We talked with the writer about the novel, the movie and her growing body of work.

It’s not often that a first-time author makes the *New York Times* bestseller list. It’s even rarer for that first book to be adapted for the big screen, with Julianne Moore in the lead role. (Moore’s performance was honored with the Academy Award® for Best Actress.) But that’s how things worked out for Lisa Genova, author of *Still Alice*, a novel about a 50-year-old Harvard professor’s experience with early-onset Alzheimer’s. Written from the perspective of Alice Howland, the book’s main character, *Still Alice* gives readers a firsthand look at what Alzheimer’s is like—from first signs to diagnosis to forgetting one’s children’s names and beyond.
Surprisingly, becoming a novelist wasn’t one of Lisa’s lifelong dreams. In fact, she’s a Harvard-trained neuroscientist and spent many years studying the workings of the brain. When a family member was diagnosed with Alzheimer’s, Lisa wanted to know more about the disease. Her research led to a better understanding of the illness, a career as a bestselling author and the award-winning movie, Still Alice. Preserving Your Memory talked to Lisa about Still Alice and why she’s made it a mission to raise education and awareness about Alzheimer’s and other neurological conditions.

Preserving Your Memory: Why did you write Still Alice? What was your experience with Alzheimer’s?

Lisa Genova: My grandmother had Alzheimer’s. She was 85 when she was diagnosed. I read everything I could find about Alzheimer’s to better understand what was going on with her and to help my family be better caregivers. We learned a lot of information, but the one thing that we didn’t learn that I really wanted to know was what it feels like to have this. Everything I read was very scientific, clinical, or written from the point of view of a caregiver, a clinician or a social worker. They were all views from the outside looking in. And so, that question, “What does it feel like to have this?” was really the seed for Still Alice.

PYM: How did you come up with the title? Why Still Alice?

LG: While researching the topic, I came to know 27 people living with early-onset or early-stage dementia. I was emailing with them every day for the year and a half that I was writing Still Alice. Before I finished writing the book, I was trying to come up with ideas for a title. So I went through the hundreds of email conversations that I had with these people. I noticed that the word “still” was in every single email from people talking to me about what it felt like to live with Alzheimer’s. Things like, “I’m still here.” “I still matter.” “I still love my family.” “I can still contribute.” “I can still drive a car.” “I can still….” So, it was obvious to me that “still” should be part of the title. “Alice” came because I picked a name that began with “A” in honor of my grandmother whose name was Angie.

PYM: How long did your grandmother have Alzheimer’s?

LG: Well, she probably had Alzheimer’s for a good ten years before she was diagnosed. Our family assumed that her forgetting was a normal part of aging for way too long. She died when she was 89.

PYM: Do you think Alzheimer’s is often misdiagnosed or written off as other things? In the book, Alice initially thinks her memory lapses are just one of those things that go along with menopause.

LG: Absolutely. It’s certainly misdiagnosed a lot, or the diagnosis is delayed in someone younger because Alzheimer’s just isn’t on people’s radar as they’re in their 40s, 50s and 60s. You tend to think, “Well, I’m just not getting enough sleep” or “I’m just so busy that I’m not paying attention” or “Maybe it’s depression.” And then
there are a lot of causes of dementia other than Alzheimer’s that need to be ruled out. So it’s usually a long, convoluted journey to diagnosis, especially in someone who’s younger like Alice. I’d say that’s probably the only place in the book where I sort of veered from what would actually happen in real life as I gave Alice a straight and narrow shot to diagnosis.

**PYM:** Why did you focus on early-onset Alzheimer’s?

**LG:** There are a couple of reasons. One is that the people I came to know while trying to understand what it feels like to have AD were all young-onset. These are people in their 40s, 50s and 60s, who could still articulate what it feels like, and who are still struggling to live with all that they are every moment while they still can. Coming to know these people, I developed a very strong sense of urgency and responsibility to tell their story because they typically don’t get included when people talk about Alzheimer’s. I think the public perception of Alzheimer’s has historically and generally been someone who’s in their late 80s, lying in the nursing home bed and doesn’t remember anyone anymore. And that’s an easy population to ignore, unfortunately. So I wanted to give this younger group a face and a voice because I think if we’re going to get to the point where we have Alzheimer’s survivors, we need to talk about it and include everyone who’s got it. The younger crowd is far more difficult to ignore than the older crowd. The second reason I chose early-onset is because in terms of writing, you always want to raise the stakes as high as possible whenever possible. People with early-onset are in their 40s, 50s and 60s, and they’re in the prime of life—in the middle of jobs, raising families and leading very busy, active lives. To show someone in that phase of life having to deal with Alzheimer’s is just a more dramatic, higher-stakes story.

“I sat in on neuropsych testing. I interviewed genetic counselors, general practice physicians, social workers who lead caregiver support groups, and then, I came to know the people who have Alzheimer’s through The Dementia Advocacy and Support Network International, an online support group formed by and for people living with dementia. We interacted through email, chat, phone, and sometimes, we’d meet in person. It became a very interactive kind of research.

**PYM:** Initially, you self-published the book.

**LG:** I did. I had a hard time finding a literary agent who would represent it. I sent out 100 query letters and heard back “no” from almost all of them. I did get a “yes” to reading the manuscript from four agents. I never heard back from one and the other three ultimately said no. “Alzheimer’s is kind of too scary a topic for general readers.” “General readers aren’t going to want to read about this. It’s only going to be people who are affected by Alzheimer’s and no one else.” “I see you’ve got this Ph.D. in Neuroscience from Harvard. You should write nonfiction.” “I see you’ve got this Ph.D. in Neuroscience from Harvard. You should write nonfiction.”

At this point, I had run out of options, and the choices were to stick the book in a drawer and go back to brain research or strategy consulting, or I could self-publish it. So I sold the book out of the trunk of my car and at local independent bookstores for ten months before word of mouth led to a literary agent who agreed to represent the book and then immediately sold it. It was published by Simon & Schuster in January 2009.
**PYM**: The book touches on the topic of suicide. From your research, is contemplating suicide common for people with early-onset Alzheimer’s?

**LG**: Yes. This topic came up often in the support group. Some people plan to, and some people don’t. And everyone has their very good reasons why they would choose either side of this sort of argument. I don’t pass judgment on either side, but what I found extraordinary is it was people in their 40s, 50s and early 60s all considering whether or not they would take their own lives. This is not something the average 40-, 50- or 60-year-old has to wrestle with. So I knew this was something I needed to include in the book in the interest of telling the truth.

**PYM**: What are your thoughts on the movie?

**LG**: They did a magnificent job! I’m so proud of the writers and the directors. I’m so proud of the actors, especially Julianne Moore, who just really did her homework. She, like me, came to know people with Alzheimer’s. She went through the neuropsych testing. She really did an amazing job letting all of that education inform the decisions she made as an actress. She’s just so ridiculously talented that I can’t imagine anyone else being able to do what she did. I’m so grateful and proud of her. It’s a beautiful movie. I’m so happy with it.

**PYM**: Tell me about the other books you’ve written since *Still Alice*. It seems you’ve found a niche writing about medical conditions.

**LG**: I write about people living with neurological diseases and conditions that are ignored, feared or misunderstood. Putting it in story form makes it more accessible. So I can write about brain injury, Alzheimer’s, autism and Huntington’s disease and a lot more people will read about it if it’s a novel. My next book is *Inside the O’Brien’s* [scheduled for publication in April, 2015]. It’s about an Irish Catholic family in Charlestown, Massachusetts, dealing with living with Huntington’s disease. It’s a really brutal, terrifying, awful disease. Yet, living with it provides the opportunity for hope in a situation that feels hopeless, for finding light in the darkness, for sort of how to live every moment to its fullest. My books, while they’re about really difficult and scary topics, are also meant to show the resilience of the human spirit while giving people an opportunity to learn about people living with neurological diseases they maybe wouldn’t know of otherwise.
Go Green

Vegetable smoothies are a fast and fresh way to “eat” your veggies.

Getting the right nutrition is important at any age, but especially so as we grow older. Drinking a “liquid salad”—also known as a vegetable smoothie—is a quick and easy way to get the nutrients you or your loved one needs … and it tastes good, too!

Getting Your Daily Serving
The United States Department of Agriculture (USDA) recommends that adults 51 years and older, who get less than 30 minutes per day of moderate physical activity, eat 2 cups of vegetables daily; 2½ cups per day for men. (Visit choosemyplate.gov for more information.)

A vegetable smoothie can provide several servings of your daily recommendation in a convenient, easy-to-prepare way.

“There are numerous health benefits associated with an adequate intake of fruits and vegetables, including for heart health, digestive health, eye health, weight management, and others,” says Linda Easter, MS, RD, LDN, Nutrition Research Coordinator, Sticht Center on Aging, Wake Forest Baptist Medical Center. “While there is no known specific benefit of consuming vegetables in a liquid form as opposed to having them as part of a dinner plate or as a fresh salad, making them into a smoothie may be a new, different, and interesting way to serve them.

“In addition to the variety of flavor combinations that can be achieved, once vegetables are finely chopped and mixed into a beverage, the amount seems less and may be more easily consumed. In the end, anything which adds another way to encourage the regular intake of a variety of fruits and vegetables is a success.”

Variety Is Key
You’re probably most familiar with fruit smoothies. So how are vegetable smoothies different, other than containing vegetables?

“Most recipes that are being promoted as ‘liquid salads’ or ‘veggie smoothies’ differ from fruit smoothies in that they contain one or more vegetables usually in addition to fruits, and they less often include a dairy base, such as milk or yogurt, than fruit smoothies do,” says Easter. “The nutritional content of such smoothies varies widely depending on the individual recipe and its ingredients.”

Although, says Easter, there is no current research to support the concept that vegetable smoothies have any greater benefit to people with Alzheimer’s than they do to other people, there is research showing that higher intake of fruits and vegetables...
may be associated with a reduced risk of Alzheimer’s disease in people who do not have the disease.

“All fruits and vegetables provide important nutrients for human health, so eating a variety of them in any form—fresh, frozen, canned, cooked, raw, liquid or solid—is recommended,” she adds.

Easter suggests that recipes be carefully evaluated for ingredients such as sugars and other sweeteners that add calories, but no other important nutrients.

“It is also particularly important that safe food storage and handling techniques, especially washing of all fresh produce, be followed when preparing fruit and vegetable recipes,” she adds.

For more tips on healthy smoothie ingredients, see the “Healthy Additions” sidebar.

Choosing a Blender

What should you look for when choosing a blender to prepare your smoothies? Here are a few tips:

- **Power:** You want a machine powerful enough to blend nuts, seeds, tough greens and frozen fruits or vegetables. A motor with 500 watts is good; 750 or more is ideal.

- **Container:** In order to yield a 700 ml serving, the pitcher of your blender should hold at least 40 ounces.

- **Clean-up:** If cleaning becomes a chore, you’ll probably lose interest in making smoothies. A blender with parts that are easy to disassemble and clean is a plus.

- **Price:** Ultimately, your budget will be the deciding factor. Choose the best blender you can afford. Read reviews online and check the manufacturer’s warranty before making a purchase. Expect to pay between $39 and $60 for a low-end 500-watt blender, all the way up to $800 for a top-of-the-line 1,000-watt Vitamix blender.

Healthy Additions

Try adding these ingredients to your smoothie for even more health benefits:

- **Chia, flax, or hemp seeds:** Provide healthy omega 3s, as well as a variety of vitamins and minerals.

- **Coconut water:** Hydrates and contains important electrolytes, such as potassium.

- **Brazil nuts, cashews, and sunflower seeds:** Good sources of selenium

- **Pineapple:** Provides sulfur

- **Green pumpkin seeds:** Provides magnesium and zinc

- **Leafy greens, such as spinach, kale, Swiss chard:** Provides vitamin E

- **Raw or cooked oatmeal or wheat germ:** Provides vitamin B6

- **Collards, yeast or green leafy vegetables:** Adds folate

- **Spices and herbs such as cinnamon, turmeric or ginger:** Contain beneficial compounds called phytochemicals, which have a positive effect on various body systems

- **Try “eating the rainbow”:** Adding a variety of colorful fruits and vegetables to your smoothies will automatically provide vitamins, minerals, antioxidants and phytochemicals.

Amber Lagerwey of Bastyr University's MSN Nutrition/DPD program contributed to this sidebar.
Breakfast Energy Drink

Makes 2 (approx. 1½ cup) servings

Ingredients
2 medium kale leaves, stems removed
1 cup spinach leaves loosely packed
½ cup fresh or frozen fruit
½ cup plain canned pumpkin
3 tbsp. sesame or hemp seeds, or nuts (peanuts, cashews, almonds, etc.)
1 tbsp. chia seeds
½ tsp. cinnamon
¼ tsp. nutmeg
1¼ cups soy or dairy milk
½ cup water
6-8 ice cubes (1 cup)

Directions
Combine all ingredients in blender or food processor and blend on high until smooth. Let sit for 1 minute to thicken before serving.

Per serving: 231 calories, 12 g total fat (1 g saturated fat), 24 g carbohydrate, 13 g protein, 8 g dietary fiber, 111 mg sodium.

Reprinted courtesy of the American Institute for Cancer Research
Sleeping soundly through the night can be a real challenge for people with Alzheimer’s disease and their caregivers. Alzheimer’s can cause problems with fearfulness, agitation, confusion and even wandering, and caregiver’s regularly report that disruptions can occur throughout the night. “People with AD tend to have more awakenings at night, and have trouble consolidating their sleep in the evening, and thus, sleep more during the daytime,” says Robert Turner, LPC, RPSGT, Clinical Supervisor at Rose Medical Center Sleep Disorder Center and a counselor in private practice. “They are also more susceptible to related disorders, such as sleep apnea and restless leg syndrome.”

Beyond the obvious problems with spotty sleep, other health concerns can arise. Without sufficient nighttime rest, the body doesn’t get an opportunity to rejuvenate, depriving it of needed energy through the day. “There are a lot of sleep disruptions connected with Alzheimer’s disease. What we don’t know is whether the sleep disruptions contribute to AD, or does AD contribute to sleep disruptions?” says Turner, who is a member of the American Counseling Association and Behavioral Sleep Medicine of Colorado.

Research indicates that the brain uses periods of deep sleep to help clear out neurotoxins. A lack of sleep can interfere with mental performance and mood stability, which can in turn exacerbate the problems of restlessness for people with Alzheimer’s. It can turn into a vicious cycle for the loved one and caregiver alike. “The caregiver’s sleep can be significantly disrupted due to multiple interruptions. This can lead to chronic sleep deprivation and increase the caregiver’s risk of developing various medical issues,” says Dr. Aparajitha Verma, Sleep Neurologist at Houston Methodist Hospital and Assistant Professor of Neurology, Weill Cornell Medical College. “It can contribute to the development of sleep maintenance insomnia, can affect their memory, [lead to an] inability to perform optimally with their activities of daily living, inability to multitask and to even drive safely.”

Sleep disruption can be a problem for any older adult. Alzheimer’s disease further interferes with the body’s natural circadian rhythm, which is the natural cycle of body temperature, sleep, wakefulness and metabolism.

Tips for a Better Night’s Sleep

There’s no quick fix for the problem, but according to the National Sleep Foundation, there are things you and your loved one can do to help get a good night’s sleep:

- **Create a routine, and stick to it.** It’s easier to get to sleep—and stay asleep—if you go to bed at the same time every night and wake up at the same time every morning. Eating meals at the same times every day also helps in this regard. Make a habit out of good sleep habits.

- **Keep rooms dark at night, light in the daytime.** It may help a person with Alzheimer’s to have a clear idea of what time of day it is, with regard to sleep. Plenty of sunshine during the day encourages activity and discourages sleeping during the day. At night, keep rooms as dark as possible to encourage sleep.
• **Keep napping to a minimum.** Sleeping during the day can make it harder to sleep at night. It may be best to avoid napping altogether, but if that isn’t possible, try to limit your loved one to one 30-minute nap a day, preferably in the early afternoon. In general, the less one sleeps during the day, the more likely they will be able to sleep better at night.

• **Consider the sleep environment.** How is the bedroom arranged? What distractions may be present? What’s the temperature like? You want a room to be between 60°F and 67°F at night for ideal sleep. Consider using a fan or humidifier to help create a good sleep environment. Keep clutter to a minimum, especially in the floor spaces.

• **Think about your bed’s age.** A good mattress and box springs set has an average life expectancy of 9 to 10 years. How old is yours? It may be time to invest in a new one. Remember, a significant amount of time is spent in bed—it’s worth the investment.

• **Avoid caffeine.** It may be part of the morning routine, but rethink that routine. Caffeine disrupts sleep, and it isn’t just in coffee; it hides in sodas and chocolate, among other foods and beverages.

• **Get physical activity to the extent possible.** This can be a challenge for Alzheimer’s sufferers, but even if it’s just a walk around the block or some time spent on the lawn or garden, try to work in some physical activity every day.

• **If medication is prescribed, help your loved one take it as prescribed.** Medication can affect sleep habits, as well. For some people, medication can help, but for others it can actually have the opposite effect. Notice how your loved one is doing with the medication he or she is taking, and report any negative effects on sleep or other behaviors to the doctor. A change in medication type or dosage may help the unwanted side effects go away.
• Be aware of the possibility of obstructive sleep apnea (OSA). OSA is a condition in which the breathing during sleep is repeatedly interrupted because the muscles in the back of the throat can’t keep the airway open. OSA can cause difficult, fitful sleep. Research indicates that OSA may be more common among people with Alzheimer’s than among others. If OSA is diagnosed, talk with the doctor about what treatments might be appropriate.

Dealing with Wandering

One particular symptom of Alzheimer’s disease is the propensity to wander. People who wander are typically experiencing profound confusion about where they’re supposed to be, who they’re supposed to be with, and other factors. “They experience confusion about who they are and what they need to be doing,” says Turner. “They can sometimes even have hallucinations about someone being after them or feel the need to do something they don’t really need to do.” When it’s dark out, wandering is even more of a concern because of the many potential safety issues.

Wandering can be curtailed and even treated to a certain extent. Turner suggests making changes where appropriate to the physical environment. “Make sure you have adequate systems in place, such as a door alarm so you know as soon as they try to open the door to go outside. Adequate locks that are challenging to work can also help provide some security,” he advises. “On top of that, making sure that you have some activity that will engage them enough, to where they won’t feel the need to go away.” There’s no guarantee that any of these steps will be sufficient, though. “None of these methods is foolproof, however,” he cautions.

Another important step to take to deal with wandering: bringing a physician in to help solve the problem. “Nocturnal agitation and wandering can be limited by exploring, appropriately diagnosing and treating the potential cause,” says Dr. Verma. “It is important to screen for any underlying sleep disorders that might be causing or contributing to this issue. There are various pharmacological treatments that are available but the exact type of medication and the dosage need to be closely monitored and checked by the treating physician.”

Report any side effects of medications to your loved one’s doctor.
MAKING A DAY’S PLANS

Making plans for a day’s activities can be a challenge in the best of circumstances. How much time for commuting, meals and other necessities? It’s often educated guesswork to schedule activities in advance.

Even if we plan carefully, a day can get away from us. We often bump into time constraints when activities run longer than expected, traffic slows us down, or we get a later start on the day than we planned.

When planning activities for you and a loved one with Alzheimer’s disease, those challenges multiply.

Distractions and Other Factors

Debbie Hardy knows this all too well. Hardy is the Administrative Coordinator in University Communications at the University of Richmond in Richmond, VA, and has served as co-chair of Elder Care for the University of Richmond since that program started four years ago. Hardy’s mother and grandmother both lived with Alzheimer’s disease. Her mom was diagnosed with the early-onset form of the condition at 63 or 64 years of age, and her grandmother in her late 80s or early 90s.

What were some of the challenges Hardy faced when planning activities for her mother or grandmother? “Their attention span, for one thing,” she says. “Depending on their stage of the disease, it affects each one differently.”
So, distractions will be a given, not something that may happen. 
Another consideration: The beauty of simplicity. “Sometimes they’re easily frustrated, so you have to keep it simple. It can be tricky,” Hardy says.

**Tips for Making Plans**

Brian Carpenter, Ph.D., is an associate professor of psychology at Washington University in St. Louis and an expert on handling Alzheimer’s-related behaviors. Dr. Carpenter has a few recommendations to keep in mind:

- **Capabilities**
  Understand the person’s preserved capabilities and be realistic about their current limits. What can the person still do? What might they have more difficulty with?

- **Time of day**
  Be aware of whether the person with Alzheimer’s has better times of day or worse times of day. Some individuals may be energetic in the morning, while others may be more energetic in the afternoon. It’s important to understand the person’s typical daily rhythm.

- **How the day is going**
  Recognize that the person with Alzheimer’s will have good days and bad days, so even the best thought-out plans may not work if the person is having a bad day.

- **Safety concerns**
  Be aware of safety issues—who the person has issues that may provoke
safety concerns, such as wandering or physical limitations. 
(For more on wandering, see article on page 25.)

• **Enthusiasm for the activity**
  There are lots of things out there to do, but if it’s not going to be valued by the person with Alzheimer’s, it might not be worth doing. Try new things, but whatever the activity, it’s wise to choose activities that are important and meaningful to the person, not just something to keep them busy.

**What to Avoid**
Dr. Carpenter notes that there are some situations best avoided altogether in planning activities.

• **Complexity**
  Keep things simple in making plans. Activities that are too complicated for the person with Alzheimer’s can make them feel overwhelmed and confused.

• **Stimulation**
  Activities that are too stimulating for the person (too noisy, crowded, etc.) also can be distressing.

• **Duration**
  Activities that are too long may lead to fatigue.

**What to Consider**
Dr. Carpenter reminds us not to neglect activities within the home. “At-home activities are beneficial because the home environment is familiar, comfortable and safe,” he says. “That could include reviewing photos, listening to music, reading aloud and exercising together.”

That said, you don’t want to become shut-ins. “You also want to get people out of the house and into the community. Activities that are socially stimulating, that involve contact with other people; activities that are cognitively stimulating, that really challenge the person to think; activities that engage all of a person’s senses and any activity that is beneficial for a person’s health in general is a good activity,” Dr. Carpenter notes. “For example, we know exercise is good for anyone. For a person with Alzheimer’s any activity that involves movement can be helpful. There are many museums in different communities that are organizing museum visits for people with dementia. Docents at the museum provide a short tour, describing art works to participants, and this kind of activity stimulates the mind, gets people out and walking, and has a social component as people with Alzheimer’s and caregivers get to interact with each other.”

**“Size 6 Shoes”**
As the Scottish poet Robert Burns once wrote, “The best laid plans of mice and men gang oft agley”—or in modern English, be prepared for plans to unravel on the spur of a moment when Alzheimer’s is a factor, particularly when the loved one suddenly reacts negatively to a situation. Keep your senses on alert.

In Hardy’s experience, she found it best to keep a loose grip on the day’s plans—and a firm grip on her sense of humor. “I kept my sense of humor with my mom, who had AD for 10 years,” she says. And when things went awry, she employed tactics to help address the situation at hand. “It’s good to distract them, change the subject, or even make light of the situation, and agree with them regardless of whether they’re right or not,” Hardy adds.

Hardy has distinct memories of her mother’s and grandmother’s struggles suddenly arising during outings. Once, while out with her grandmother at a shoe store, she encountered just such a situation. “My grandma was trying on shoes and insisted that she wore size 6, when she’d always worn a size 9,” Hardy recalls. “She got so upset that she threw the shoe across the store and nearly hit someone! So, we just told her that they didn’t have that particular shoe in a size 6, but they had others—and we’d find a good ‘size 6’ shoe for her.”

“Caregivers are usually really good detectives, and they typically know the person with Alzheimer’s very well. So they are good at figuring out what’s causing the reaction,” Dr. Carpenter says. “So if a person with Alzheimer’s seems distressed in a situation where they normally aren’t, the caregiver needs to figure out what’s going on right now for them that might help solve the problem.”

The next step is to address the situation. “Is the person with Alzheimer’s overwhelmed, hungry, tired, in pain, and is there something immediate that can be done to help them?” Dr. Carpenter asks. Effectively assessing the situation and taking appropriate action will help to defuse a potentially tricky situation.

It’s good to know what calms the loved one. “Knowing how to soothe the person with Alzheimer’s is also helpful,” says Dr. Carpenter. “Would listening to some music or taking a brief walk help in this situation?”

Ultimately, the caregiver has to be prepared to change plans on the fly. “You have to be willing to stop the activity if it’s not working out. Even though you may have planned this in advance, if the person is not enjoying it and having a negative reaction, sometimes it’s better just to leave and go home,” says Dr. Carpenter. “So don’t get too invested in the plans and be flexible.” ■
Coping with Alzheimer’s disease is stressful for everyone involved, but when legal disputes arise about healthcare, money or living arrangements, the situation can become even more difficult. There are ways to handle these issues, however, to make them manageable and, in many cases, productive.

First, let’s take a look at the kinds of conflicts that can occur. Patricia E. Kefalas Dudek, a Board Member of the National Academy of Elder Law Attorneys (NAELA; www.naela.org), who practices elder law in Farmington Hills, Mich., describes how these disputes have changed: “In the past, family law was an area of legal practice where families were fighting over custody, support, education and medical care for their children. I’ve seen a major change occur. Now, since people are living longer, many of these conflicts involve the children in a family arguing about health and financial issues for their parents and grandparents.”

Planning Is Essential

In most conflicts, the problem can be traced to a lack of planning. It’s critically important to plan far in advance rather than after the loved one’s condition worsens.

“Many people don’t like dealing with the issue of mortality, but sometimes, when a person develops Alzheimer’s, the loved one and their family never actually begin the process of planning,” says Michael Amoruso, an Officer of NAELA and elder law attorney in Rye Brook, N.Y.

“Many people who come to me for help don’t have powers of attorney or healthcare powers of attorney established. Without those documents in place—and if the loved one with Alzheimer’s doesn’t have the capacity to sign them—the family will have to go through a difficult court proceeding in which those powers are given by the court, usually to someone in the family.”

Dudek adds another reason for families to start planning way ahead of time—the planning process itself can present problems: “Our system of long-term care in this country is extremely limited if you don’t have long-term care insurance, so we advise people about obtaining that type of coverage. Some states make it very difficult for middle-income seniors to do any type of long-term care planning through Medicaid. It’s a federal program, but each state...
has its own rules, and unfortunately, they tend to change the rules often.”

**Family Squabbles**

Squabbles over assigning power of attorney—naming the person who can act on the loved one’s behalf—can affect a family dynamic for years to come. Even when loved ones with Alzheimer’s plan ahead and create the necessary legal documents before they’re impaired by the illness, there can be ongoing strife among siblings and other family members.

Hyman Darling, CELA, CAP, a Board Member of NAELA who practices elder law in Springfield, MA, describes the specific types of conflicts that can happen within the family of someone with Alzheimer’s: “The disputes can be about money, care or who is in charge. When no planning has been done, there can be disputes among family members over who is going to be in charge of the person who is incapacitated. Sometimes this can turn into a battle between the children in the family that, in essence, is about control. Issues among the children in a family can stem from grudges and resentment over things that happened many years ago. When this battling within a family is going on, the person with Alzheimer’s can suffer the most because there might not be someone taking steps to address their needs.”

**Financial Abuse**

Families must stay on the lookout for financial abuse, not only from people outside of the family, but from those inside it as well. In some cases, a power of attorney was signed so a family member can manage the loved one’s affairs, but instead of thinking of the loved one’s best interests, that person thinks of their own.

“This type of abuse becomes apparent when you see a decline in the loved one’s money or property is transferred to the family member with power of attorney,” says Amoruso. “The responsibilities of caregiving can be a full-time job, and when family members who are caregivers also have to handle their own family responsibilities, they can start to feel that they’re sacrificing, and that can lead to a feeling of entitlement. This can make other siblings angry or unhappy and conflicts start.”

In other situations, predators from outside the family see the loved one as vulnerable. In fraudulent scams, people will call the loved one and pretend they’re the IRS or a charitable foundation. Once they make contact with the person with dementia or Alzheimer’s, a barrage of phone calls begins. “These people utilize fear as an intimidation factor,” says Amoruso. “The phone calls can sound legitimate, but they’re not. Sometimes, intervention by the court is truly needed, as well as the involvement of other authorities, to help protect the individual.”

Here are some tips on handling disputes when they arise or preventing them from happening in the first place.

**Do Your Planning**

Establishing power of attorney and a healthcare power of attorney will give an individual—usually a family member—the authority to make decisions about a loved one’s finances, healthcare and living arrangements. It’s also important to plan for payment of funeral and burial costs, or better yet, to pay these costs ahead of time.

**Get a Durable Power of Attorney**

“In drafting estate plans for their clients, most estate planning attorneys prefer to draft a document that is called a durable power of attorney,” says Dudek. “With some power of attorney documents, the power of attorney ends when the loved one becomes disabled or dies. A durable power of attorney continues past disability—it is drafted to be used when the person can no longer make their decisions themselves.”
Review Documents Annually

After documents for power of attorney are created, it’s best to review them every year and revise them if things have changed within a family. “Most times, the documents won’t need to be changed,” says Darling, “but in the event that something changes for the person who is the main caregiver—such as an illness or a different living situation—the documents must be changed and someone else named the main caregiver.”

Bring in an Arbitrator

“When there is a contested matter in a family, we sometimes bring in a negotiator, geriatric care manager or social worker who has the skill to resolve these issues before they’re taken to court,” adds Darling. “Once a dispute gets to court, people dig in their heels and say terrible things that they can’t take back. Families can become dissolved when that happens. Using a third-party arbitrator at an early stage can prevent that from occurring.”

Be Sensitive to Changes

When interacting with someone who has Alzheimer’s, keep in mind that the way that person communicates will change over time. “Many of the frustrations that loved ones and the people caring for them experience in these difficult situations are due to a lack of effective communication,” says Amoruso. “Try to stay aware of how the person’s ways of communicating change as their disease progresses. Make extra effort to figure out exactly what they’re trying to say. They might not have the vocabulary to express exactly what they mean, so being diligent in asking questions will help everyone communicate better and resolve disputes.”

What is Best for Your Loved One?

Many conflicts arise not because of money but because of healthcare choices. Should a loved one with Alzheimer’s stay at home or live in an assisted-care facility? “This is a very emotional issue for most families, so it’s important to stay focused on what is best for the loved one with Alzheimer’s,” says Darling. “Most people want to stay in their home, but in many cases, around-the-clock care is the best way—sometimes, the only way—to keep the person safe and healthy.”

Determine Who Gets the Stuff

“When a loved one dies, family members tend to fight about their ‘stuff,’ their personal effects,” says Dudek. “In some cases, that can be a hopeful sign about a family because they’re talking about things that they remember fondly, things with which they have an emotional attachment. But to keep peace within the family, do your planning for this, too. Have a family meeting to discuss who will get what and make a list so your lawyer can use it as a guide. This can eliminate disputes about the loved one’s possessions.”

Try to Be Objective

Amid the stress and high emotion involved in making difficult, critically important decisions for your loved one, it can be hard to think rationally. But before a situation becomes a conflict or dispute, take a step back and try to be objective. “Many people, when they’re making end-of-life planning decisions, sometimes make decisions based on emotion rather than logic,” says Dudek. “If there’s a conflict within a family, it’s usually best to consider the overall situation—and the fact that your loved one is relying on you for help—and ask yourself, ‘Is this battle really worth it?’”

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

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

(Answers on page 37)

MATCH THESE

Can you match each of these Americans who achieved their greatest fame in the first half of the 20th century to his or her field?

1. _____ Jane Addams a. Architecture
2. _____ Luther Burbank b. Aviation
3. _____ W.E.B. DuBois c. Evangelism
4. _____ Frank Lloyd Wright d. Civil rights
5. _____ Louis Brandeis e. Horticulture
6. _____ Aimee Semple McPherson f. Industry
7. _____ Clare Boothe Luce g. Jurisprudence
8. _____ Irving Berlin h. Warfare
9. _____ Henry Ford i. Politics
10. _____ Paul Robeson j. Singing
11. _____ Amelia Earhart k. Social work
12. _____ John J. Pershing l. Songwriting

ROADLINE

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 witticism. 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 world capitals — the city and its country. The letters of the two words are in the correct order, but they overlap. All you have to do to find the terms is separate the letters.

Example: LPIORST8UOGANL — LISBON, PORTUGAL

1. COATNATADWAA
2. DIRUEBLALNIND
3. BRBUELSGSIEULSM
4. SMAPADIRIND
5. TLRIBPOYLIA
6. ACUASNBTREARLIRAA
7. POWALARSANWD
8. JINADOKANERSIATA
9. SACNTHIAILGOE
BRAIN-BOOSTING CROSSWORDS

We have provided two crosswords here to sharpen your puzzle skills. Start with the one on the left, which is the easier puzzle. In this one we have provided solving aids, such as the number of words in multi-word entries. The puzzle on the right is a medium-level puzzle and the number of words in the answers have been eliminated. The second puzzle is also a thematic puzzle: the title “Just a Quick Note” is a hint. Have fun testing your knowledge while doing something that’s good for you!

(Answers on page 37)

Just a Quick Note

Across
1. PDQ, to your boss
2. Provide weapons
3. Like
4. Picture, for short
5. Wise men
6. Mirror
7. Change back
8. Pilot’s stunt
9. “Wanna Lazy River”
10. Aviators
11. Wants
12. “___Wanna Do” (2 wds.)
13. Cut open
14. Shoreline scavenger (2 wds.)
15. Shoshonean
16. Mild exclamation
17. R followers
18. Group of buffalo
19. Kindergartner’s glue
20. Ascended
21. The ___ of Liberty
22. Vegas intro
23. Woeful cry
24. Incinerate
25. First
26. Most engaged
27. Senior
28. Bony fish
29. Ballet garb
30. Biblical queen
31. Top
32. Intl. pact
33. Like sleepers’ eyes
34. Actor Kinnear
35. Broadway racehorse
36. Records (abbr.)
37. Clear a drain blockage
38. Office document
don’t
39.Tree parts
40. Departure’s opposite (abbr.)
41. Chewed items machine (abbr.)
42. Indian emblem
43. Garfield’s buddy
44. Nicholas or Garfield’s (2 wds.)
45. “Are you a man ___ mouse?”
46. Football

Down
1. “Rumaround ___”
2. “Runaround machine”
3. Cash
4. Picture, for short
5. Eel type
6. Actress MacGraw
7. Enlisted men, for short
8. Propose
9. Neighbor
10. Bread
11. Prayer finale
12. Neighbor
13. Like some as-is units (abbr.)
14. Newsman
15. Shosenne
16. Mild exclamation
17. Kindergartner’s glue
18. Door part
19. Certain
20. Taking
21. Pathway to nostalgia
22. Vegas intro
23. Woeful cry
24. Incinerate
25. First
26. Most engaged
27. Senior
28. Bony fish
29. Ballet garb
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44. Nicholas or Garfield’s (2 wds.)
45. “Are you a man ___ mouse?”
46. Football

Across
1. Circle part
2. Start to awaken
3. Deli sandwich
4. Door part
5. Biblical queen
6. Mirror
7. Change back
8. Pilot’s stunt
9. Wanna Lazy River
10. Aviators
11. Wants
12. “___Wanna Do” (2 wds.)
13. Cut open
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Answers on page 37
The names of these charitable organizations 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 from English author and physician Sir Thomas Browne. You are looking for a 41-letter phrase.

**Hidden-Message Word-Find**

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.

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

**Sudoku**

To visit us at Kappapuzzles.com.

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

Dropline
No two people are exactly alike, and both of them are glad of it.

Leapfrog

Hidden Message
Be charitable before wealth makes thee covetous.

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www.ALZinfo.org
As your loved one ages, the need for sensitive—and sometimes difficult—conversations can arise more frequently. No one likes to spend time contemplating a future where they cannot take care of themselves independently, but as a caregiver, it’s imperative that you’re aware of your loved one’s health history and views on future care.

The fact is that you may one day become your parents’ number one advocate, and it’s important to arm yourself with the knowledge that can give them their best life. Here are five tips on talking to your loved ones about their future care.

1. **Talk Early and Often.**
Your parents may be in good health, but waiting until a health emergency to start your conversation is not recommended; starting the conversation early can avoid a situation where an unexpected event requires answers and your loved one is unable to give them.

Look for conversation-starters in everyday life, such as a newspaper article or a friend’s illness. Once you begin the dialogue, set aside some dedicated time for a longer conversation, when you both can be mentally prepared. Avoid busy times like holidays, where stress levels can be high, and revisit the conversation as needed, especially if you notice changes in your loved one’s condition.

2. **Do Your Homework and Start with the Basics.**
A good way to remove stress from your conversation is to come prepared with a checklist that includes questions about health history, views on future health care, finances, and legal documents. You can add your own questions, covering even the smallest details like care for family pets.

If you need a crash course in senior care, helpful online tools like SeniorAdvisor.com are an excellent place to start. You can call (866) 333-0742 toll-free to be connected with a specialist who can walk you through the details of the senior care industry and even help you find appropriate options in your area.

3. **Speak with Respect.**
Despite aging, your loved ones still need to feel control over their lives. While it is necessary to balance independence with safety, try putting yourself in their shoes, and treat them with the respect they’ve earned during such a long life.

4. **Listen.**
Assuming that your views are naturally in-line with your parents’ is a common mistake, so instead do your best to listen with an open mind and avoid criticism. It’s often best to offer options rather than opinions, and you may at times have to agree to disagree. Remember, your ultimate goal is to help preserve their wishes and advocate for them when they cannot; their requests should prevail until you see a health or safety concern.

5. **Create Your Plan.**
Once you’ve gathered a framework for a future care plan, research your local resources. SeniorAdvisor.com allows you to view details on local options for free, including directories of care providers and thousands of reviews from families in a similar situation. With a little research, you’ll be able to form a plan of action that preserves your loved one’s wishes with the care they may need.

If you ever need additional advice or help on ways to navigate a difficult conversation with a senior loved one, speak with one of the experts at SeniorAdvisor by calling (866) 333-0742. A free service, they will also help guide you in your search for senior care and housing.
Set Up Your Profile in 1 Easy Step

Get Answers to Your Questions

ALZTalk.org, is a free and easy way to make new friends and stay connected with those in the Alzheimer’s community. Join today to post messages and share pictures and favorite links. ALZTalk.org gives users a voice and allows them to share tips and stories about coping with loved ones with Alzheimer's. It also offers the ability to ask our experts questions no matter how large or small.

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