Hard Candies for Granddad: A Teen’s Sweet Tribute

Do Anesthesia, Hospitalization Trigger Cognitive Decline?

Understanding Dementia = Positive Interactions

SUMMER 2014 A free publication of the Alzheimer’s Foundation of America
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Teen scholarship winner offers sweet tribute to her granddad.

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Understanding dementia can spark positive interactions.

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Hospitalization places some people at risk for cognitive decline.

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Cover Image: © Tatjana Baihakova | Dreamstime.com
I invite you to join me behind the scenes at the Alzheimer’s Foundation of America (AFA).

In upcoming issues of care ADvantage magazine, I will introduce you to the inner workings of AFA and, moreover, who makes things happen. First up: AFA’s social services team.

Charged with responding to queries from the public—who individuals with memory concerns, family caregivers, healthcare professionals, or others—our team is composed of licensed social workers with backgrounds in long-term care, hospital and organizational settings.

They field queries from the simple (e.g., a referral to a local support group) to the more complex (e.g., concerns about abuse or neglect). No issue is too big or too small. In addition to offering information and resources, sometimes, it’s all about listening, whether for a few minutes or an hour.

According to client feedback, our social workers earn kudos for their expertise and knowledge. But their insights, compassion and dedication stand out most.

For example, “Thanks for your help and kindness to me … (I’m totally out in left field!),” wrote one caregiver to Heather.

Keren, another team member, received this email from a daughter, who, for the first time, asked for help: “It brought tears to my eyes to know there are people like you out there who know how to point me in the right direction in such a supportive manner.”

Their work doesn’t end there. Our social workers influence other AFA services, including dementia care training, national care standards, and memory screening initiative. Join them as they facilitate online or phone support groups and Care Connection, AFA’s monthly teleconference for caregivers. And read their responses to questions from caregivers in the very pages of this magazine.

You can contact our social services team via our toll-free hotline (866.232.8484), email (info@alzfdn.org), and, most recently, live chat and Skype (www.alzfdn.org). Choose the method that best fits your timeline and comfort level.

I understand that it’s often difficult to reach out for assistance, that it takes a lot of courage to make that first call or send that first email. But I encourage you to do so. Our social services team is here to help.

Sincerely,

CHARLES J. FUSCHILLO, JR.
CHIEF EXECUTIVE OFFICER
ALZHEIMER’S FOUNDATION OF AMERICA

We all know how understanding can have a powerful impact on micro and macro levels. Understanding dementia can do the same.

Teenager Laura McCarter, who earned the top spot in AFA’s college scholarship competition this year, “gets” it (Page 10). It is one of those life-altering lessons that the 17-year-old had to learn the hard way after her grandfather was diagnosed with Alzheimer’s disease. Today, she understands that despite the disease, “My granddad is and will always be the kind, giving gentleman who is always asking, “Would you like to have a hard candy?”

Likewise, our article “Got to Get You Into My Life” emphasizes that “people living with dementia are still the same people they always were” (Page 12). The key is to take the time to understand what is happening to our loved ones. Building on that knowledge can reduce frustration for the individual with dementia and family members—and, most importantly, spark positive interactions.

Beyond the connection aspect of dementia, understanding complicated health-related issues can help foster informed decision-making. Anyone facing surgery, anesthesia or hospitalization now or in the future would be well-served to read, “Unexpected Complications: Hospitalization Places Some People at Risk for Cognitive Decline” (Page 14). The main question here: Do these losses last?

With article after article in each issue of care ADvantage, our goal is to take you farther and farther along the path toward understanding dementia.

Take care,

CAROL STEINBERG
PRESIDENT, ALZHEIMER’S FOUNDATION OF AMERICA
EDITOR-IN-CHIEF, CARE ADvANTAGE
READERS’ NOTES

My neighbor handed me a back copy of your wonderful magazine, care ADvantage, and I’d like very much to receive a free subscription if that is possible.

I have three loved ones in different stages of Alzheimer’s disease … So, my interest in Alzheimer’s disease is much more than casual.

I think information can be a powerful tool. And your magazine is excellent. I was also deeply moved by the Glen Campbell story (Fall 2013).

CYNTHIA H. LEGORRETA
NEW YORK, N.Y.

I thoroughly like the care ADvantage publication and keep two or three issues in my briefcase to hand out when facilitating my men’s Alzheimer’s support group each month.

RALPH SMITH
BELLEVUE, NEB.

WRITE TO US…

Please send your letters, questions and “Heart and Soul” submissions to: careadvantage@alzfdn.org or care ADvantage, Alzheimer’s Foundation of America, 322 Eighth Ave., 7th floor, New York, NY 10001.

Published contributions may be edited for length and clarity.

“If you find it in your heart to care for somebody else, you will have succeeded.”

— Maya Angelou
A Q&A WITH HEATHER SAPOSNICK, LMSW, QDCS, A SOCIAL WORKER AND PROJECT COORDINATOR AT THE ALZHEIMER’S FOUNDATION OF AMERICA

Question: I am a certified financial planner and have a client whose wife was diagnosed with young-onset Alzheimer's disease. Can you assist me in calculating a realistic life expectancy to help the couple plan financially for what is to come?

Answer: Your client is right to be concerned about the financial future. Currently, dementia is the most costly chronic disease in the U.S.—beating out heart disease and cancer. The average annual cost for a person aged 70 and older with dementia was between $41,000 and $56,000 in 2010, according to a 2013 study by the RAND Corporation.

But figuring out just what a financial safety net should look like is not as cut-and-dried as it might appear. Many factors—both the known and the unknown—should be considered.

First, we know that Alzheimer's disease typically progresses from two to 20 years, and individuals live on average for eight to 10 years from diagnosis. The brain disorder tends to advance more quickly when it strikes people younger than 65 (young-onset), compared to late-onset Alzheimer's disease. However, each case, regardless of when symptoms appear, progresses differently.

Many people with Alzheimer's disease also have co-existing conditions and are three times as prone to hospitalization versus people without the disorder. Both factors can affect nursing home placement and mortality. So obtain from your client his wife's complete medical history, and conduct due diligence regarding the long-term impact of other existing conditions.

Also when doing financial planning, it is important to explore expressed wishes and practical considerations related to long-term care. Costs vary widely based on the setting (e.g., home, assisted living, nursing home) and payment method (e.g., long-term care insurance, Medicare/Medicaid, out-of-pocket). What are the person's wishes regarding end-of-life care? Will the family caregiver be able to care for the person at home—with or without assistance? When might a move to a long-term care setting occur?
When Alzheimer's disease strikes at a younger age, other financial factors enter the picture. People with young-onset may be in their prime earning years, saving for a child's college education and for retirement. Will all of this come to a screeching halt? As well, will a spouse need to adjust work hours or stop working entirely?

Having a financial roadmap is a vital part of overall planning in the face of Alzheimer's disease. Next step: Encourage your client to consult a lawyer so that legal affairs are in order as well.

**Question:** My mother-in-law was recently diagnosed with Alzheimer's disease and has difficulty telling time and comprehending what time it is. Are there any techniques to help with this loss?

**Answer:** With Alzheimer's disease, actions that were often done without thought, like telling time, can become challenging. Due to memory issues, confusion, an inability to complete complex tasks, and disorientation, individuals with the disease may not know what time or day it is, or their exact location. Sometimes individuals will lose their sense of time first, followed by place.

For starters, visual aids can help. Use digital watches and clocks. Post a calendar; mark off past days so the current day is clearer, and affix stickers as reminders of birthdays or other special events. Obtain the daily newspaper, which will display the date.

In addition, communicate the day and time. Always speak slowly, clearly and concisely when providing these verbal reminders. For example, you could say, “Good morning, it's 8 a.m. We are going to eat a delicious breakfast.”

And stick to routines for bathing, going to sleep, meals, etc., since routines can make a person feel safe.

By adopting appropriate techniques, caregivers can help reduce their loved one's fear, anxiety and frustration that result from disorientation or other changing abilities.

**Question:** My mom had a scare with choking on food last week so I took her to a speech pathologist for an evaluation. Thankfully, she does not have a swallowing problem and does not need any changes to her diet. Just in case this happens again, what should I know to ensure her safety?

**Answer:** As a caregiver, you did the right thing by taking her to a speech pathologist. And you are doing the right thing now by taking steps to educate yourself on life-saving techniques that can help your loved one in an emergency.

First aid training is essential. Two of the most important life-saving procedures to learn are the Heimlich maneuver and cardiopulmonary resuscitation (CPR). The Heimlich maneuver is a method for freeing a person's windpipe when the airway becomes blocked by food or other object that could result in suffocation. CPR is an emergency technique, useful in situations such as heart attacks or near drowning, to restore breathing and blood flow when someone is unresponsive with limited or no breathing.

Knowing the exact way to perform both of these can enable caregivers to act quickly and confidently in emergencies. Even though, as a caregiver, you might start the steps for both, it is important to contact 911 for emergency medical services so that paramedics can evaluate and treat your loved one.

Many hospitals, wellness centers, schools, fire departments, and national and community organizations offer this training to the general public. For example, both the American Heart Association (www.heart.org) and the American Red Cross (www.redcross.org) offer accredited CPR training classes.

Since we are talking about life-sustaining procedures, it is important in discussing CPR to be aware of your loved one’s advance directives. If there is a Do Not Resuscitate (DNR), a legal order written by a physician or hospital staff member based upon a person's previously-expressed wishes in an advance directive or living will, this notifies healthcare professionals that an individual does not want to have CPR. Family members need to follow this, and it should be provided to paramedics or other professionals in order to honor the person's wishes.

For immediate assistance, call 866.232.8484 or email info@alzfdn.org. Also, SKYPE and chat live with AFA social workers at www.carecrossroads.org.

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If someone you care for has dementia

Uncontrollable crying?

Uncontrollable laughing?

It could be PseudoBulbarAffect: PBA

PBA is a neurologic condition that triggers sudden outbursts of crying or laughing in people with brain injuries or neurologic conditions such as Alzheimer’s disease or dementia.

29% of Alzheimer’s patients had symptoms of PBA in a recent national study of more than 5,000 patients with a variety of underlying neurologic conditions.*

‘PBA FACTS’ is a FREE kit that explains the science of this treatable condition, how it’s different from depression and includes a simple test that can help you and your doctor determine if you have PBA.

For your FREE ‘PBA FACTS’ kit, call 1-800-810-3188 or go to pbafacts.com

*A PRISM was a nationwide study of patients 18+ with brain injuries or certain neurologic conditions, including 1799 who had Alzheimer’s disease. Assessed PBA symptoms were measured by the Center for Neurologic Study-Lability Scale (CNS-LS) scores. A CNS-LS score ≥13 may suggest PBA symptoms and merits further diagnostic assessment. Patients or caregivers completed the assessment.
A study of more than 4,000 older adults free of dementia found that a person's history of high blood pressure in middle age may impact brain structure, memory and thinking in older age. Those who currently have high blood pressure but no history of the condition in middle age and those with low blood pressure and a history of high blood pressure are at increased risk for brain shrinking and cognition problems later on.

The relationship between modifiable lifestyle and health factors and risk of subjective memory impairment (SMI) occurs in a broad range of ages, according to a new study. After interviewing 18,000 people aged 18 to 99, researchers found that depression, lack of exercise, high blood pressure, and lower levels of education were significantly linked to SMI across all age groups.

A new study of healthy men aged 40 to 60 supports a previous hypothesis that there is a link between poor sleep and increased risk of Alzheimer's disease. Based on monitoring of cerebrospinal fluid to compare beta amyloid 42 protein levels (a hallmark of Alzheimer's disease), researchers found that those study participants who had one night of unrestricted sleep had a 6 percent decrease in the beta amyloid peptides, whereas the men with one night of sleep deprivation had levels that remained constant.

New research reveals that emergency room visits for people with traumatic brain injuries, including concussions, rose nearly 30 percent between 2006 and 2010. The study also notes that the increase may be due to greater awareness and better diagnosis of brain injuries.

People aged 65 and older with memory and thinking issues—but who do not have dementia—may have a lower risk of dying from cancer than people who have no memory and thinking problems, according to a study. The study found that participants who experienced the fastest decline in mental skills over an average of 13 years were about one-third less likely to die of cancer.

A new study revealed that managing risk factors such as cardiovascular disease, hypertension and diabetes could lessen a person’s chances of developing Alzheimer’s disease, delay onset, and shorten the duration. These changes could also impact healthcare costs. For example, a 10 percent drop in the prevalence rate of cardiovascular disease could save an estimated $20 billion for Medicare and $17 billion for Medicaid in Alzheimer’s-related expenses, suggests the study, which was funded in part by the Alzheimer's Foundation of America.
THE SITUATION
As we age, it takes our bodies longer to bounce back from even the most minor scrapes, bumps and bruises. Aging causes our skin to thin and lose elasticity and moisture, making it more prone to skin tears, infections and bedsores. And chronic conditions, including dementia, diabetes and vascular disease, can complicate this even more. For example, falls, incontinence, limited mobility, inadequate nutrition and hydration, and other issues that result from dementia can do all sorts of skin damage. Because of these factors, what often starts as a minor wound can progress to something much more serious.

THE SOLUTION
- **Strengthen the skin’s ability to heal.** Apply moisturizer twice a day, but do not go overboard; too much moisture can harm surrounding skin. Use mild soaps, detergents and other products suitable for sensitive skin. Think warm, not hot, when it comes to bathing. Use a humidifier during colder weather, when the heat is turned on and the air is drier.
- **Protect skin from incontinence.** Urinary and/or fecal incontinence increase wound risk by creating excess moisture—which can lead to chafing—and by exposing skin to the chemical properties of urine and feces. It may help to use skin protectant creams, which can form a barrier between any moisture and the skin’s surface. The person should visit the toilet about every two hours during waking hours; if applicable, change adult incontinence products frequently; and wipe properly to be clean and dry.
- **Reduce risk factors for falls.** Clear clutter from walkways and stairways, wear shoes with slip-resistant soles, and ensure adequate lighting and smooth walking surfaces.
- **Heed healthy lifestyles.** Follow a diet in line with nutritional needs. In certain cases, a doctor or dietitian may recommend increasing the amount of calories, protein or fluids being consumed, as well as supplements like vitamin C and zinc. Stay hydrated. And do not smoke; since smoking reduces the amount of oxygen in the blood, smokers’ wounds can be more severe and heal more slowly.
- **Prevent pressure ulcers.** Pressure ulcers or pressure sores, also known as bedsores, are among the most common types of chronic wounds in older adults—and can lead to severe pain, infection and even mortality. They most frequently occur on skin that covers bony areas of the body—elbows, heels, talbone, ankles, hips, spine, and shoulder blades—that are exposed to long periods of pressure that restrict blood flow to the skin or tissue. This can happen from limited mobility, such as being bedridden or in a wheelchair. Frequently reposition the person, at least every two hours if bed-bound and every hour if seated, to help maintain circulation to at-risk areas. Also relieve pressure with cushions and pillows, padding on wheelchair arm and leg rests, and special mattresses, such as air-fluidized mattresses.
- **Keep wounds clean.** To prevent infection, gently wash the skin—only if unbroken—with mild soap and pat—to dry. Apply bandages and dressings to help protect a wound against dirt and infection, as well as to keep it moist. Cleanse open sores with saline when dressings are changed.
- **Stop “picking.”** Individuals in the later stages of Alzheimer’s disease may begin to pick at their skin, which can ultimately lead to serious wounds. Check with a dermatologist to be sure there are no infections. Since this behavior may be caused by feelings of anxiety, boredom or frustration, try engaging the person in enjoyable, safe recreational activities for tactile stimulation and self-soothing. If the behavior persists, filing nails or wearing soft gloves may reduce the development of a wound. Consult with a healthcare professional. Look for indications of severe pain or signs of infection, such as fever, drainage, or a foul odor from the wound, or increased heat and redness in the surrounding skin. A clinician may need to take action; depending on the severity of the wound, interventions might include prescribing antibiotics, removing dead or infected tissue, or performing more invasive surgery.

PREPARE IN ADVANCE
Since someone in the more advanced stages of dementia may not experience pain or be aware of changes to the body, inspect the person’s skin for signs of potential issues. A good time is during bathing or dressing.
EXCELLENCE IN DESIGN: CREATING DEMENTIA-SUPPORTIVE LIVING SPACES

As the number of Americans living with Alzheimer’s disease and related illnesses continues to rise, so too does the need for innovative approaches to residential care facilities that cater to the unique needs of these individuals and their caregivers.

With that in mind, the Alzheimer’s Foundation of America (AFA) and Perkins Eastman, a leading planning design and consulting firm, have produced a comprehensive report, entitled, “Excellence in Design: Optimal Living Space for People With Alzheimer’s Disease and Related Dementias.”

As explained in the report: “Just as advocates are increasingly raising awareness of Alzheimer’s disease, from the symptoms to the importance of better and earlier diagnosis and treatment, there has also been an evolution in the philosophy and environments of care” over the past two decades.

“Everyone wants—and deserves—a supportive place he or she can call home,” said Emily Chmielewski, EDAC, an associate with Perkins Eastman and the report’s author. “Our goal in developing this report was to present a philosophy of both care and design that will help change the long-term care landscape to meet the needs of residents, their families and professional caregivers.”

The report presents best practices in the physical environment for people with dementia, addressing person-centered care, comfort, engagement, and safety issues in living spaces that mimic the look and feel of a residential home. These spaces boast design elements such as:

- creating clusters or “households” of 10 to 14 residents, with shared kitchen, dining room and living room;
- sensory cues and visual cues, like glass-doored kitchen cabinets stocked with healthy snacks, to encourage residents to eat;
- personalization of bedroom entrances, like a memory box with personal photos;
- unrestricted access to secure, inviting outdoor spaces, with continuous walking paths and nontoxic plantings; and
- integrating the staff workstation into the household, like a residential-style desk or adequate space and equipment at the kitchen counter.

Several case studies of residential settings bring the guidelines to life.

The design guidelines complement AFA’s “Excellence in Care” program, which evaluates and consults with long-term care settings to ensure that they meet the organization’s national standards of optimal care for people with dementia.

DETAILS

ow about a hard candy for each of you?” My granddad’s brown eyes are staring at the wall as he mutters this phrase while guiltily shoving every butterscotch candy into his already stuffed shirt pocket. Every now and then he takes a break to look around and make sure nobody is watching. If he catches me watching his petty act he’ll slyly set down the candy dish and put a mask of innocence on. That is, until he forgets why he stopped grabbing candies five minutes later and continues again on his never-ending task. I lean back into my grandparents’ large, overworn couch and remember the times he used to say this phrase and mean it. My hands were covered in sticky apple juice and a huge grin was spread across my face. Granddad was standing next to me holding a small, round crab apple that I had just picked off the ground next to their apple tree. My sisters were next to us at the top of the long driveway cheering my granddad on. With extreme expertise, he leaned forward and pelted the apple down the hill towards the end of the driveway. My sisters and I squealed and chased after the rolling apple, waiting to see where it would come to stop on the side of the smooth pavement. It was a sort of contest to see who could roll their apple the farthest. As the sun was setting my granddad gathered all of us around and exclaimed, “How about we head inside and each of you girls can get a hard candy?” “Would you like a hard candy?” I flash back into reality to see my granddad coming towards my grandmom with a half-eaten unwrapped caramel candy in his hand. “No thank you,” my grandmom turns and answers. She turns and looks at me, and we share a smile. For the past few years as Alzheimer’s disease has grown into a part of her daily life my reverence of her never-failing strength has grown. Just by witnessing her calm and dignified attitude towards this unfortunate event has taught me so much.

Instead of making every day seem like a struggle, she finds the strength to care for my granddad the same as she has since the day they met. Not only am I in awe at the power of her love, I am also proud to know that her Southern strength runs in my blood. She is not one to give up without a fight or dismiss a problem to someone else, and through this experience I have learned that this trait is a gift I was given. I have an immense amount of respect towards how my grandmom has dealt with this situation, and I know that she will continue to make the rest of my family and me proud during these hard times.

The sun was shining through the grove of trees. Granddad and I were walking along one of the many paths through the forest in their backyard. “This one’s a poplar. See the leaves? It’s nice and straight. Good for wood.” I tried to soak up every bit of knowledge I could about the woods in their backyard. As we reached their house after a long looping trail, I ran inside, excited to share my new
information about different trees with my family. My grandfather followed after me and grabbed up the candy dish. “Some hard candies for my three favorite granddaughters?” he asked us with a glow in his eyes. “A hard candy for John?” my granddad asks himself. He’s not even standing at the candy dish anymore; he’s busy inspecting the wood grains of the front door. “I think you have some candies in your pocket Granddad,” I tell him with a grin. He reaches back into his overstuffed pocket and his eyes light up as he pulls out a handful of his favorite butterscotch candies. He thanks me with a smile sweeter than all of the butterscotch candies in the world. While experiencing my granddad being overcome with Alzheimer’s disease, I have learned a lot about myself. It has taken a lot of patience and perseverance to keep up with this change, but I have surprised myself by taking it in stride and finding the strength to get through it. I have learned that staying calm and keeping a positive outlook on any situation is the best way to go. Getting angry about something you can’t change won’t do anything except make you more frustrated. In coping with my granddad’s illness, I have learned to stay patient and strong.

It was winter and every tree in my grandparents’ backyard had a blanket of frosty snow clinging to each branch. My granddad was walking down the sloped hill behind their house; my sisters and I were following, stepping in each of the footprints that he made in the snow and giggling. We made it to the bottom of the hill and turned to face the ice-covered pond awaiting us. With slightly numb fingers we awaited our chance to go—we knew the drill! We watched as granddad walked out into the center of the pond, jumped up and down a few times, and then shouted, “All clear! The ice is safe.” My sisters and I slid and wobbled our way around the pond, having the time of our lives, until suddenly my bundled-up self took a fall. At the young age of six, falling on the ice was one of the biggest disasters ever. Tears ran down my face, and through my blurred eyesight I could see my granddad coming over. After helping me up, he declared, “How about we go inside. Do you know what might make you feel better? One of those hard candies.”

The setting sun appears through the window. I look over and see my sleeping granddad with a pile of hard candy wrappers sitting next to him on his couch. In the past couple of years, I have picked up on so much information about my granddad’s disease. My granddad is still the same person; he only needs a little more guidance to remember everyday things. In my mind I compare it to people walking through a forest as the sky gets dark: They are still in the same situation and have the same ethics, they just need a flashlight to help find their path. In my mind that is what my family members and I are doing; we’re flashlights guiding my granddad through everyday tasks. I have made it a point to help guide my granddad in any way that I can. Whether secretly baking vegetables into his cookies so that he gets enough vitamins in his diet, helping him find a place to settle down in new environments, or just letting him know everything is okay, I am there for him always. The fact that a phrase such as, “Would you like a hard candy?” would be one to get stuck in my granddad’s vocabulary as the rest of it disappears means a lot to me. This means that my granddad is such a genuinely giving person because he must have said that candy-offering phrase enough for it to get ingrained in his mind. I am honored to have been raised in the presence of such a kind, giving granddad, and he still means as much to me as he did when I was a child.

Coping with Alzheimer’s disease has impacted my life in that I have become a “flashlight” guiding my granddad in his life. Through coping with his disease, I have learned many things. I have learned that my grandmom has a heart of strength. I have learned that I, too, can handle situations with the strength and grace that she does, and I have learned that my granddad is and will always be the kind, giving gentleman who is always asking, “Would you like to have a hard candy?”

LAURA McCARTER, of Newark, Del., is a recent graduate of the Charter School of Wilmington, Del., and will attend Georgia Southern University, in Statesboro, Ga., beginning this fall. McCarter, 17, is the grand-prize winner of the 2014 Alzheimer’s Foundation of America’s AFA Teens for Alzheimer’s Awareness College Scholarship; this guest column is the essay she wrote for the competition, inspired by her 81-year-old grandfather, John McCarter, who has been living with Alzheimer’s disease for five years.

Editor’s Note: All of the essays written by the runners-up and honorable mention recipients in the 2014 AFA Teens for Alzheimer’s Awareness College Scholarship competition are posted on www.youngleadersofafa.org.
It is often made even worse by well-meaning caregivers who insist that the person:

“Just ate 10 minutes ago, don’t you remember?”
“Just saw your daughter this morning, don’t you remember?”
“Just went outside for a walk, don’t you remember?”

The problem is, of course, that people with dementia don’t remember these episodes that just happened. That magic wand wipes the slate clean again and again and again.

To make our lives and the lives of people living with dementia a bit easier, we recommend losing the word “remember.” This is not an easy thing to do. In the course of a conversation, it is very natural to ask each other if we remember a person or event.

But, asking people living with Alzheimer’s disease to remember is like asking them to jump up and fly around the room. It is an impossible request, and we must avoid direct requests for information recall. When people with dementia are asked to remember something, this request can make them anxious or frustrated and may cause them to become very angry, depressed or withdrawn.

Declarative memory also affects language, and that is why people living with dementia often struggle to remember names of common objects, or the names or faces of people they have known most of their lives. The constant struggle for words can be exhausting and enraging.

As is often the case on the dementia journey, just when we think we have a handle on understanding, something wild and unexpected happens. We may have worked hard to forget the word “remember,” when suddenly the person we love remembers us or some event from their lives. This may last only a few seconds or a few minutes, but it is like the sunlight breaking through the clouds when it happens. For a fleeting moment, we have the person we knew and loved with us again. Then, heartbreakingly, it is gone; the light goes out, the cloud descends.

We must learn to appreciate these brief encounters, these moments of connection. They are like little jewels that are strung on the necklace of time. To keep the ones we love in our life, it is important to understand that
These fleeting moments of recognition or remembrance are causes for celebration, not despair.

The declarative memory system also affects recent episodes or events. This is why people living with dementia may ask the same question over and over again. They may not remember that they just ate lunch or that their grandchildren just came to visit.

Demanding that people with dementia remember that they just ate lunch or getting irritated with them because they can't remember things that have just happened are counter-productive for all involved.

Dementia also tends to affect the part of the declarative memory system where we store facts and common knowledge. So, a person who was very involved in politics now cannot tell you the name of the president of the U.S. Someone who worked as a carpenter now cannot remember how many inches are in a foot.

As caregivers, we know the person we love better than anyone, and we know what will grab the person's attention and interest and what won't work at all. Create games and exercises to keep the individual engaged, active and successful for as long as possible.

The last part of the declarative memory system that is affected by dementia is executive function. Executive function includes the ability to plan, to begin an activity, or stop an activity, and helps us understand that our actions have consequences. At its more basic level, executive function helps us recognize the order of steps needed to perform simple tasks, such as making a peanut butter and jelly sandwich or getting dressed in the morning.

This is when we often see people leaving little notes for themselves—reminders of how to perform simple tasks, where they parked the car, how to use the telephone, etc. These are often the first clues to family members that the person they love is struggling with memory function.

Even the most simple, mundane, daily task can seem difficult and overwhelming if you can't remember how to start, if you no longer know where to begin. This failure to initiate, this inability to begin a task is the point where many people with dementia begin to give up. They don't know where to start, so they don't start. It is our job as caregivers to help them find a way to begin again.

The declarative memory system can be greatly affected by dementia, but it does not mean that the person we love is no longer the person we love. We have to find new paths to reach our loved ones with dementia, new ways to engage them, new techniques to help them maintain their strengths and abilities for as long as possible. We all like to feel that we can be successful, that we have something positive to contribute, even when we are living with dementia.

TOM BRENNER, an educator and researcher for the Illinois Department on Aging, and KAREN BRENNER, a writer and consultant, are the founders of Brenner Pathways, a Chicago-based consulting firm offering Montessori-inspired brain fitness strategies that utilize the five senses to maintain connections for people with memory loss. This article is based on an excerpt from the couple's book, “You Say Goodbye and We Say Hello: The Montessori Method for Positive Dementia Care” (Brenner Pathways, 2012).
Three years ago, William Fleming was 64 and enjoying retirement until a sudden gallbladder infection landed him in the intensive care unit (ICU) at a hospital in his hometown of Jacksonville, Fla. By the time he got to the emergency room, he was in septic shock; a bacterial infection was flowing through his pancreas. After surgery to remove his gallbladder and antibiotics to control the runaway infection in his body, Fleming was sedated and put on a breathing machine. He remained in the ICU for a month.

His surgeon told him that his body would need time—about a year—to fully recover. Fleming’s physical health did improve. But his mental functioning did not. Post-surgery, he was not able to think straight. He was unable to concentrate for more than a few minutes, was slow to react to things, was extremely forgetful, and could not stay alert long enough to drive to a nearby store. These problems still exist today.

Fleming and his wife did not link the hospital and surgical experiences to these new and disturbing cognitive problems. To their untrained eyes, the problems looked like Alzheimer’s disease. They sought the help of a neurologist, who said the symptoms were due to sleep problems and depression.

Then, a few years later, the couple read an article about research underway at Vanderbilt University in Nashville, Tenn., on lasting cognitive problems among people who had spent time in an ICU—symptoms very similar to Fleming’s.

“I felt that this was finally explaining everything I have been through in the last three years,” said Fleming, who is now undergoing cognitive rehabilitation to help try to reclaim some of the mental skills that he lost.

Fleming is not alone. More and more people are sharing stories about people of all ages, especially the elderly, whose thinking and memory declined after surgery, general anesthesia, extended time in the ICU, and/or prolonged hospitalization. Scientists are studying the relationship between each of these experiences, the persistence of cognitive disabilities, and the onset and progression of various neurodegenerative diseases, including Alzheimer’s disease. Experts agree that it is impossible to isolate one factor, such as anesthesia, and say that is driving cognitive changes.

There is growing evidence that many factors that lead to a hospitalization can take their toll on a person’s cognitive reserve in the short term and over time. These may include: an infection or illness and the body’s inflammatory response to the physical challenges; elements of the hospitalization itself, such as surgery, anesthesia, sedatives, pain medications, lack of sleep, or remaining bedbound too long; and other factors such as age, medical history and frailty.

Delirium—defined as a temporary, acute confusion—is one of the most troublesome post-operative and ICU issues. Besides temporary confusion, people may be disoriented, agitated, and see or hear things that aren’t there. Individuals with certain conditions, including preexisting dementia, are at a higher risk for developing delirium. This delirium can last for hours or days, but most people will bounce back. However, older people with delirium, especially those with neurodegenerative diseases, have a harder time returning to their pre-hospital state.

Guidelines on delirium management adopted by the American College of Critical Care Medicine indicate that “delirium is associated with increased mortality, prolonged ICU and hospital length of stay, and development of post-ICU cognitive impairment in adult ICU patients.” These guidelines recommend routine monitoring of delirium in these patients. Current evidence suggests that the longer delirium goes untreated, the greater the impact on cognitive impairment.

Every year, 5 million people wind up in ICUs. Roughly 80 percent survive to discharge. The scientific literature is limited, but several researchers have raised concerns that sustained cognitive decline following major surgery, general anesthesia, extended time in the ICU, and/or prolonged hospitalization may be relatively common—posing a serious public health issue.

New research studies suggest that 30 to 50 percent of discharged patients may have cognitive deficits that they did not have upon entering the hospital; and that people who develop acute delirium are twice as likely to have a...
functional decline over the first month following their illness and medical interventions.

A paper, published in October 2013 in “The New England Journal of Medicine,” revealed that cognitive impairment after critical illness is very common and in some patients persists for at least one year. It affects young and old adults, the previously healthy and the sick.

The study followed 821 critically-ill patients, with only 6 percent having evidence of cognitive impairment prior to hospitalization. Three-quarters of them developed delirium while in the hospital. One year after discharge, about 26 percent had cognitive impairment similar to people with mild Alzheimer’s disease, and 34 percent had losses typically associated with moderate traumatic brain injury.

“This is not a debate about whether it is a problem,” declared E. Wesley Ely, M.D., M.P.H., the study’s author and a professor of medicine at Vanderbilt University School of Medicine. “The question is what is the source of the problem. It may not be a single factor but a combination of things.”
The idea that cognitive decline could be sparked by surgery goes back to a medical report in 1882, four years after the discovery of the first anesthetic.

In this century, the issue of cognitive dysfunction following major surgery first gained ground in a paper published in “The New England Journal of Medicine” in 2001 by Mark Newman, M.D., and his colleagues at Duke University Medical Center, in Durham, N.C.

They followed 261 patients who underwent coronary artery bypass surgery, and found that the incidence of cognitive decline was 53 percent at discharge, 36 percent at six weeks, and 24 percent at six months. Five years later, cognitive decline still persisted for 42 percent of them. Significant factors for the long-term decline included older age, lower level of education, and evidence of cognitive decline at discharge.

“This is the new kid on the block, and we need to pay attention to this.”

Alex Bekker, M.D., Ph.D., chair of the Department of Anesthesiology at Rutgers New Jersey Medical School, in Newark, N.J., likens these post-surgical and ICU effects to an inflammatory response to a viral infection. An otherwise healthy older person will be sick for a few days and get better. But a person with pre-clinical dementia or mild cognitive impairment (MCI) already has an abnormal inflammatory response, and the extra hit can make it harder to recover.

Bekker collaborated with colleagues at New York University Medical Center in New York who conducted repeated neurological assessments on 670 patients who had undergone surgery between the first and second evaluations. In 2010, the team reported in the “American Journal of Surgery” that individuals with a diagnosis of MCI had a greater decline in performance on a test of attention and concentration post-surgery than those who had no evidence of cognitive impairment on the first assessment.

Two years later, several of these same researchers published another study looking at brain scans from people enrolled in a longitudinal study, “The Alzheimer’s Disease Neuroimaging Initiative.” They examined scans from people with MCI pre-and-post surgical experience and those who had no surgery between those two time-points. Surgical patients (between five and nine months post-operation) had increased atrophy (shrinking) in several brain regions, versus no shrinkage in the nonsurgical control group.

Mixed research findings highlight the complexity of the issue. David Knopman, M.D., a professor of neurology at the Mayo Clinic, in Rochester, Minn., noted that many researchers point to anesthesia as the culprit for dementia, “but it is too simplistic. You can’t disassociate the disease from the surgery itself. There are too many confounding factors.”

Knopman and his colleagues conducted a retrospective study of the medical records of residents in Olmstead County, Minn., who were diagnosed with dementia of any cause, including Alzheimer’s disease, between 1985 and 1994, as well as a control group of dementia-free residents living in the same area. From the records, they obtained information about exposure to general anesthesia, including the type of sedative used, medical procedure, and duration of the anesthesia.

In an article published in 2013 in the “Mayo Clinic Proceedings,” the researchers concluded after analyzing 877 cases of dementia that receiving general anesthesia for procedures after age 45 is not a risk factor for incident dementia.

James Jackson, Psy.D., an assistant professor of medicine at Vanderbilt University School of Medicine and a neuropsychologist in the university’s ICU Delirium and Cognitive Impairment Study Group, noted: “Teasing out the contributions to the cognitive deficits is challenging. It is complicated because when you are talking about anesthesia, you are talking about surgery, and the underlying disease that led to the surgery. Then, there may be mechanical ventilation, other medications, and the hospital environment itself.

“Some people may head into surgery without knowing that they have mild cognitive impairments that could one day lead to Alzheimer’s.” The events in the hospital, he said, “may accelerate a problem that has not yet surfaced. What could have happened over a span of years can now happen over months.”

Many of Jackson’s post-ICU patients report new problems related to thinking, remembering, organizing, solving problems, and paying attention. Accountants can no longer balance checkbooks. Doctors can no longer practice medicine.

It is still not clear whether these deficits progress over time, remain stable, or improve. Jackson said that he has seen some post-ICU older adults progress into what clinically resembles full-blown Alzheimer’s disease, but it is not certain what actual damage has occurred in the brain.

Some studies are using brain scans to help diagnose Alzheimer’s disease or mild cognitive impairment in post-ICU or post-surgical patients.

“And what is troubling is that we can’t tell them immediately on the heels of their critical illness whether they will get better or worse,” Jackson said. “This is a terrifying revelation for people.”

In looking at potential triggers for these changes, old
age is not always a factor. Ely's study found that even healthy people in their 30s and 40s developed cognitive problems post-ICU.

Four years ago, Joan Healy of Centerport, N.Y., had a blood infection that landed her in the ICU for one week. Since then, the 45-year-old mother says that she is doing many of the same things that her father did when he was first diagnosed with Alzheimer's disease.

She makes lists for everything. Still, she puts signed checks in her filing cabinet instead of putting them in an envelope for mailing. She forgets about events even though they were on the list. She can no longer run her husband's medical practice.

Today, Healy works hard at strengthening her brain every day, reading for a few hours and attempting to complete a Sudoku puzzle.

“I knew life was not going to be the same,” she said. “I am finding ways to embrace this new me.”

So where does this leave people who face surgery, anesthesia or prolonged hospitalization now or in the future?

James Rudolph, M.D., an associate professor of medicine at Harvard Medical School in Boston, and chief of geriatrics and palliative care at the VA Boston Healthcare System, suggests that the problem is that doctors do a physical workup to see whether a person can make it through surgery but do not assess “whether their brain would make it through surgery.”

Jeffrey H. Silverstein, M.D., a professor of anesthesiology, surgery, and geriatrics and palliative medicine, and senior associate dean of research at Mount Sinai School of Medicine in New York, noted: “When I see robust older people I tell them that they have very little reason to suspect they will have a long-term cognitive problem. When I see frailty and some cognitive problems I say it is worth thinking about what kind of surgery they are having and weigh the benefit and risks.”

According to P. Murali Doraiswamy, M.D., professor and director of the Neurocognitive Disorders Program, Department of Psychiatry and Behavioral Sciences at Duke University Medical Center in Durham, N.C., the “bottom line” for people with dementia is to avoid general anesthesia if local or regional anesthesia will suffice.

In addition, he said, since muscle relaxants used during general anesthesia can have toxic interactions with some existing drug therapies for Alzheimer's disease, the anesthesiologist needs to decide whether to suggest stopping these medications prior to surgery.

Soo Borson, M.D., professor emerita, University of Washington School of Medicine in Seattle, and Dementia Care Research and Consulting, noted, “Anesthesia as such may be less important than the underlying illness or injury that altered body responses before surgery.”

But, she added, “These results illustrate the importance of thoughtful planning when surgery is a treatment option rather than a necessity. Because people with underlying brain dysfunction—mild cognitive impairment or dementia—are at special risk for worsening after surgery, physicians need to incorporate baseline cognitive status in counseling patients and families about risks and benefits.”

Some clinicians have been pushing for new types of interventions to reduce the risk of cognitive deficits—such as careful monitoring of the acute state of delirium, earlier attempts at reducing sedative doses, and getting patients up and moving as early as possible. Ely plans to study whether delivering cognitive rehabilitation, such as memory exercises, while patients are in the ICU can prevent or reduce the severity of symptoms.

“We need to do a much better job identifying these problems early and offering interventions so that these people don’t suffer,” Ely said. “This is the new kid on the block, and we need to pay attention to this.”

JAMIE TALAN, of Boise, Idaho, is editor-in-chief of “Narrateur: Reflections on Caring,” a literary journal of the Hofstra North Shore-LIJ School of Medicine in Hempstead, N.Y., and an assistant professor of science education at the school. She is a writer specializing in brain diseases.
My Dad loved to read and write and talk. How he loved to talk! He always had stories to tell and retell and retell again. He had so many kids he couldn’t remember which ones had heard his tales and which ones had not. So we listened patiently, and sometimes not so patiently, as he told the same stories to us over and over again.

It was easy to buy gifts for birthdays and Father’s Day and Christmas. Barnes and Noble gift cards were always welcome. He loved books, especially history books and baseball books and anything by Tom Clancy. He devoured pages and pages of words amidst all the noise of his seven kids, their stereos and their television shows. He absorbed every detail and fashioned these into new stories to tell at the dinner table. He delighted in presenting these oral book reports and, on occasion, encouraged one or two of us to ask to borrow the latest novel or biography when he was finished with it.

Early in his Air Force career, Dad was stationed in Thule, Greenland—750 miles north of the Arctic Circle—for a year. My mother watched over the first four children in the yet unfinished clan at home stateside where the climate was considerably more agreeable. We were all under the age of five at that time. I am sure that my mother rejoiced every night when we had all fallen asleep, leaving her with a few hours of silence and relaxation.

When Dad returned to the States, he shared black and white 8 x 10 photos of astounding icebergs and told tales of the frigid, yet peaceful, environment he had called home. He talked of the articles he wrote for the base newsletter as well. I was mesmerized. He sparked an interest in me that has yet to be extinguished. I wanted to be a writer just like him.

About a year ago, my father was diagnosed with semantic dementia, a villainous eraser of words. He
slowly forgot our names, our relationships, our lives. One day a few months ago, he said to me, his now 54-year-old son, “Well, sir, I really didn’t get to know you very well ...”

Dad has rapidly melted before our eyes. He sits in the house he moved his family to 44 years ago when the Air Force gave him his last set of orders, and tells my siblings and me, “It’s nice here, but I wish I could go home.”

The killer of words has played nasty tricks on his mind. It has left him with a gigantic jumbled vocabulary that is connected and disconnected and unconnected all at the same time. Perhaps he knows what he wants to say but is trapped somewhere inside, thinking, “If only I could make them understand. Help! I can’t get out!”

How utterly frustrated this master of words must now be, unable to read or write or even talk.

Today, as a writer myself, I understand first-hand what my father must have known all along: There is magic in the telling of stories, a powerful force that lights a fire within the souls of the writer and his readers alike.

Writing is an incredible outlet for me personally as well—an avenue for me to channel my thoughts and feelings. It is often an arduous task, but when I finally complete a piece, I am overwhelmed by a wonderful feeling of accomplishment. Some writers liken this feeling to the euphoric rush of a parent who has just brought a new child into the world. Indeed, my written pieces are my “babies.” Not all have been perfect, and many have surprised me by the reactions they stir. But all are important to me. Each one is a part of me.

In school, I listened to my peers whine, “Why are we writing again?” I definitely could not relate to them for my own voice was begging, “When are we writing again?” I was fortunate to have teachers who understood my need and who celebrated my efforts. And I was equally fortunate to have a mother and father who lovingly encouraged me to keep putting my pen to paper.

There are still so many stories yet to be told ... and so little time. Now, as an official AARP member nearing my mid-50s, I am beginning to realize that I won’t live forever!

My father used to be full of stories. The dementia that has taken his mind hostage has stripped him of any possibility of further sharing his tales from the past with any of his children. This saddens me and frightens me at the same time.

Will I face the same fate as I near my golden years?

Will I lose all of the words that float within my mind hoping they will be chosen for the next masterpiece? I shudder to think of not leaving my own child a plethora of stories, essays and poems that can remind her of her father’s life experiences, of his imagination, of his soul’s interpretation of the world.

I must write.

Dad turned 80 this August. God bless my mom who cares for him as she has done for the past 56 years. And God bless him for telling us how much he cared for us ... when he had the words to do so.

TIM RAMSEY, of Avondale, Ariz., is a veteran educator who has taught fifth through 12th grades and served as a school administrator. His experiences are shared in his e-book, “The Hugs on My Shirt.” Ramsey’s work has also been published in several “Chicken Soup for the Soul” editions.

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Taking a trip down memory lane with individuals with Alzheimer’s disease can be a powerful activity—both intellectually and socially—when it involves the past, since long-term memories remain intact more than short-term ones.

In choosing activities, focus on a person’s remaining strengths and the level of engagement and enjoyment that it brings. Word games, brainteasers and puzzles tied in some way to the past can prompt a person to think, remember and then voice a response.

If the player becomes frustrated or shows disinterest, as evidenced by confused facial expressions or verbal agitation, this can indicate that the game is too difficult. In this case, it may help to provide continuous cueing or to move on to another pursuit.

One way to blast into the past is with an activity tied to television. Ever since the first black and white TVs, the tube was a central gathering point, and actors, TV personalities and newsmakers become part of the “family.” With that in mind, the “Who, What Show” game will jog recall of some of these regulars. The goal is not necessarily to obtain the right answers, but more to enjoy the trip!

Here are some questions to answer:

1. Who said, “Here’s Johnny?”
2. Who sings, “Singing in the Rain?”
3. Who is known as “Old Blue Eyes?”
4. Who is “Uncle Milty?”
5. Who said, “Goodnight Gracie?”
6. Who was known as the “Greatest?”
7. Who is the “Rhinestone Cowboy?”
8. Who is the “Coal Miner’s Daughter?”
9. Who said, “Kids Say the Darndest Things?”
10. Who is “I Love Lucy?”
11. Who said, “We Shall Return?”
12. Who is “Wilt the Stilt?”


Contributed by GLENN SEYMOUR, the author of “Glenn’s Games” (AuthorHouse, 2013). When he moved to Country Terrace Senior Apartments in Hoopeston, Ill., at the age of 90, he created hundreds of puzzles, brainteasers and word games, which are included in his book, to “keep his own mind active and to share with other residents.” Seymour was still making up games until he passed away just shy of his 99th birthday. This article is adapted with permission from his book.
What is NAMENDA XR?
NAMENDA XR is a prescription medication used for the treatment of patients with moderate to severe Alzheimer’s disease.

Who should NOT take NAMENDA XR?
NAMENDA XR should not be taken by anyone who is allergic (hypersensitive) to memantine, the active substance in NAMENDA XR, or who has had a bad reaction to NAMENDA XR or any of its ingredients.

What should I discuss with the healthcare provider before taking NAMENDA XR?
Before starting NAMENDA XR, talk to the healthcare provider about all of your past and present medical conditions, including:

- Seizure disorders
- Difficulty passing urine
- Liver or kidney problems

If you are taking other medications (including those without a prescription), ask the healthcare provider if NAMENDA XR is right for you.

- Use caution when taking Namenda XR with other medications. Certain medications, changes in diet, or medical conditions may affect the amount of NAMENDA XR in the body and possibly increase side effects.

What are the possible side effects of NAMENDA XR?
The most common side effects in patients taking NAMENDA XR were headache, diarrhea and dizziness. This is not a complete list of side effects.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

How should I take NAMENDA XR?
- Take NAMENDA XR exactly as your doctor tells you to take it.
- Take NAMENDA XR one time each day with or without food.
- NAMENDA XR capsules must be swallowed whole and never crushed, divided or chewed.
- NAMENDA XR capsules may be opened and sprinkled on applesauce before swallowing, but the entire contents of the capsule should be taken and the dose should not be divided.
- If you forget to take one dose of NAMENDA XR, do not double-up on your next dose. Take only your next dose as scheduled.
- If you have forgotten to take NAMENDA XR for several days, do not take the next dose until you have talked to your healthcare professional.

What if I take more NAMENDA XR capsules than I should?
If you accidentally take more NAMENDA XR capsules than you should, inform your healthcare professional that you have accidentally taken more NAMENDA XR than you should have. You may require medical attention. Some people who have accidentally taken too much memantine have experienced dizziness, unsteadiness, weakness, tiredness, confusion, as well as other symptoms.

What other information should I be aware of?
- The use of NAMENDA XR in children is not recommended.
- You should not breast-feed during treatment with NAMENDA XR.
- Tell your healthcare provider if you are pregnant or planning to become pregnant.

This section summarizes the most important information about NAMENDA XR. Talk to your healthcare provider for more information.

To learn more, go to www.NAMENDAXR.com or call 1 800-678-1605.
Please also see full Prescribing Information at www.namendaxr.com.

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Based on PI 62-12000315-BS-A-RMC8791-04/13
Forest Laboratories, Inc., the maker of NAMENDA® (memantine HCl) tablets, plans to discontinue the sale of NAMENDA 5 mg and 10 mg tablets in Fall 2014.

This is not due to any safety or efficacy issue related to NAMENDA tablets. The oral solution of NAMENDA will continue to be available.

NAMENDA XR® (memantine HCl) extended-release capsules will also continue to be available.

- NAMENDA XR is an extended-release formulation of NAMENDA that offers convenient, once-daily dosing
- Like NAMENDA, NAMENDA XR is indicated for the treatment of moderate to severe Alzheimer’s disease. NAMENDA XR capsules can be opened and the contents sprinkled on applesauce
- NAMENDA XR is available by prescription only
- Importantly, physicians can switch patients from NAMENDA to NAMENDA XR the very next day without titration, according to the FDA-approved package insert

There is no evidence that NAMENDA XR prevents or slows the underlying disease process in patients with Alzheimer’s disease.

Please work with the healthcare provider as soon as possible to discuss transitioning to NAMENDA XR to facilitate continuity of treatment.

Forest remains committed to making a difference in the lives of people with Alzheimer’s disease.

If you have any questions, please call our hotline at 1-844-TREAT-AD (1-844-873-2823) or visit www.NamendaXR.com.

Important Risk Information

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What should be discussed with the healthcare provider before taking NAMENDA XR?

Before starting NAMENDA XR, talk to the healthcare provider about all of the patient’s past and present medical conditions, including:

- Seizure disorders
- Difficulty passing urine
- Liver or kidney problems

If the patient is taking other medications (including those without a prescription), ask the healthcare provider if NAMENDA XR is right for the patient.

- Certain medications, changes in diet, or medical conditions may affect the amount of NAMENDA XR in the body and possibly increase side effects.

What are the possible side effects of NAMENDA XR?

The most common side effects associated with NAMENDA XR treatment are headache, diarrhea, and dizziness. This is not a complete list of side effects.

Please see brief summary of Important Risk Information for NAMENDA XR on adjacent page.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.FDA.gov/medwatch or call 1-800-FDA-1088.

Forest Laboratories, Inc.