Advance Medical Directives: Planning Now for Later

Special Teens Section: Lessons in Caregiving from AFA’s 2015 Scholarship Winners
The National Memory Screening Program ensures that screenings are available during National Memory Screening Week (November 1 - 7, 2015) as well as year-round.

National Memory Screening Program is one of the highlights of AFA's ongoing national effort to promote early detection of memory problems, including Alzheimer's disease, and to encourage appropriate intervention, including medical treatments, social services and other resources.

What You Need To Do:

✓ Along with this expanded program, we are rolling out a brand new system and turnkey website. Please register your site at www.afascreenings.org/register.
✓ Host screenings during National Memory Screening Week, at one-day events, or throughout the year!

FOR MORE INFORMATION: CALL 866-232-8484 OR VISIT WWW.NATIONALMEMORYSCREENING.ORG

“Cell phones have gotten so small, I can barely dial mine.” Not Jitterbug®, it features a larger keypad for easier dialing. It even has an oversized display so you can actually see it.

“I had to get my son to program it.” Your Jitterbug set-up process is simple. We’ll even pre-program it with your favorite numbers.

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“My friends all hate their cell phones… I love mine!” Here’s why.

Say good-bye to everything you hate about cell phones. Say hello to Jitterbug.

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WE’D LOVE TO HEAR FROM YOU
Please send your comments, questions or feedback on AFA Care Quarterly to Amanda Secor asecor@alzfdn.org. We may include your note in a future issue.

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For many of us, summer means a chance to spend more time with family. And the season’s graduations and family gatherings remind us that, as parents, there is nothing more gratifying than seeing one’s children succeed and begin to forge their own path in life. I share those feelings as I watch my own children embark on internships, new courses of study and volunteer activities.

But as the incidence of Alzheimer’s disease continues to rise, this generation is fast finding themselves in another role—the role of caregiver. This was evident in the more than 1,300 entries we received in the 2015 Alzheimer’s Foundation of America (AFA) Teens for Alzheimer’s Awareness college scholarship competition. We received essays from teens whose great-grandparents, grandparents, family friends and even parents have or had Alzheimer’s disease and learned how that experience has impacted their lives and the lives of their families.

Their words, courage and candor truly touched each of us at AFA. In total, we awarded $15,000 in scholarships and I’m proud to share three of those incredible teens’ stories with you in the pages of this publication.

I’d also like to introduce you to Meagan Ryerson, AFA’s young leadership coordinator. Meagan oversees our teen and college divisions, which provide high school and college students educational materials, supportive resources and the opportunity to raise awareness for the cause among their peers and in their communities.

In addition to the college scholarship competition, AFA Teens offers an annual video competition and provides an opportunity for high school students to form clubs at their schools. For college students, AFA on Campus provides many of the same benefits and then some. Last fall, we kicked off the Raise Your Voice for Care college tour at Frostburg State University in Maryland and this spring, the tour rolled into New York’s Hofstra University. The events provide a full day of Alzheimer’s awareness activities on campus, including an overview of the disease, panel discussions on careers in aging and healthcare, music therapy, and more. The Raise Your Voice for Care tour will make three additional stops in the fall of 2015—at Adelphi University in Garden City, N.Y., Loyola University in Baltimore, Md., and Washington University in St. Louis, Mo.—and will visit several more campuses in 2016.

As always, I welcome your comments and feedback and encourage you to reach out for support. Our national toll-free helpline is now staffed by English- and Spanish-speaking licensed social workers from 9 a.m. to 9 p.m. EDT Monday–Friday. Simply call 866-232-8484.

Take good care,

Charles J. Fuschillo, Jr.
President & CEO
Alzheimer’s Foundation of America
QUESTION: My husband seems to have a serious gag reflex especially in the morning. Is this common to dementia or is it a separate problem?

ANSWER: The gag reflex, also referred to as pharyngeal reflex, is very important to human survival as it helps prevent choking and ingesting harmful substances. Once the gag reflex is triggered, the muscles in the back of the throat start to contract in order to reject something harmful and stop us from swallowing something that could make us stop breathing. Gagging can also be caused by psychological factors such as panic related to a feeling that something is about to threaten our breathing or swallowing.

Since there could be various reasons why he is having this problem, it is imperative that he be evaluated by his primary care physician who can determine the cause. For example, could it be a swallowing problem? Swallowing issues can occur as Alzheimer’s disease or related dementias progress due to the degeneration of the brain. Such problems include, coughing while eating or drinking (also known as dysphasia) and aspiration (not being able to cough up food or liquid that “went down the wrong pipe”) and both of these can trigger a gag reflex.

Upon evaluation, a primary care physician might refer your husband to a specialist, such as a speech pathologist or dentist. A speech pathologist may conduct tests, such as a video x-ray or videofluoroscopy, which can evaluate the pathways of food and liquid during swallowing. A speech pathologist can also offer recommendations on how to change one’s diet to improve swallowing, and promote safe eating.

A dentist can help determine if any oral issues are to blame. Conditions such as dry mouth, ill-fitting dentures and pain in the gums and teeth may cause a gag reflex. The dentist may be able to treat the dry mouth or pain and can check to ensure that dentures fit securely.

If your husband has been checked by his physician and specialists and they have not found a medical or physical reason for his gagging, there is a possibility that it can be related to anxiety. For example, you noticed his gagging is prevalent in the morning. It may be helpful, to journal and write down any visible triggers that may be associated with the gagging. It may be possible to alter his care routine once the trigger is identified, and thereby increase his comfort and quality of life.

QUESTION: I am so confused. What is the difference between Alzheimer’s and dementia, is it the same?

ANSWER: Alzheimer’s disease is a type of dementia. Dementia is a general term that describes a group of symptoms, such as loss of memory, judgment, language, complex motor skills, and other intellectual functions. Some cases of dementia are caused by medical conditions, such as a thyroid problem, vitamin B12 deficiency, which can be treated; however, the majority of cases cannot be reversed.

The clinical symptoms and progression of dementia vary, depending on the type of disease causing it, as well as the location and number of damaged brain cells. Some types progress slowly over years, while others may result in sudden loss of intellectual function.

The two most common causes of dementia are Alzheimer’s disease and vascular dementia. Other causes include dementia due to sustained alcohol abuse, dementia caused by trauma (head injury), and dementia with Lewy bodies.

Your loved one’s physician will be able to provide you an overview of the various types of dementia and how each affects the individual. You can also reach out to AFA’s social services team through our national toll-free helpline (866-232-8484) or visit the National Institute on Aging’s Alzheimer’s Disease Education and Referral Center at https://www.nia.nih.gov/alzheimers.
People with brain injuries or certain neurologic conditions like Alzheimer’s disease or dementia, may experience frequent outbursts of uncontrollable crying or laughing called **PseudoBulbar Affect (PBA)**.

In a recent national registry of more than 5,000 patients with a variety of neurologic conditions, 29% of the 1,799 patients with Alzheimer’s disease had PBA symptoms.*

‘**PBA FACTS**’ is a FREE KIT that explains the facts and science behind this treatable neurologic condition. For yours, call 1-800-810-3188 or go to pbafacts.com.

**Choosing to cry or laugh should be up to you, not PBA.**

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*PRISM was a nationwide registry of adult patients with brain injuries or certain neurologic conditions, including 1,799 who have Alzheimer’s disease. PBA symptoms were defined as a Center for Neurologic Study Lability Scale (CNS-LS) score ≥13. This CNS-LS score may suggest PBA symptoms and merits further diagnostic assessment. Patients or caregivers completed the assessment. The CNS-LS has been validated in ALS and MS patient populations.*
RESEARCH CLIPS

**Translational Psychiatry • June 16, 2015**
A study from Kings College London indicates that a blood protein may signal whether an individual may develop mild cognitive impairment (MCI). Researchers examined data collected from more than 100 sets of twins and found that one protein, MAPKAPK5, was on average, lower in people whose cognitive abilities declined during a 10-year period. The study’s authors suggest that these findings could lead to the design of better prevention trials.

**Neurology • June 10, 2015**
New research suggests that certain brain proteins, known as lysosomal proteins, can be detected in the blood long before symptoms of Alzheimer’s are present. These proteins are thought to aid in the removal of damaged nerve cell material. Blood levels of these proteins were higher in people with normal memory and thinking skills as early as 10 years before they developed Alzheimer’s disease.

**Science Daily June 1, 2015**
Researchers from the University of Virginia School of Medicine recently determined that the brain is directly connected to the immune system by lymphatic vessels previously thought not to exist. The findings change the way scientists perceive the neuro-immune reaction. This discovery could have major implications for diseases from autism to Alzheimer’s to multiple sclerosis.

**Neurology (online) • May 20, 2015**
A large study revealed that people with depression may be more likely to develop Parkinson’s disease. Researchers began by looking at all Swedish citizens age 50 and older at the end of 2005. From those, they examined the 140,688 people who were diagnosed with depression between 1987 and 2012. These people were then matched with three control participants of the same sex and year of birth who had not been diagnosed with depression, for a total of 421,718 control participants. The participants were followed for up to 26 years. During this time, 1,485 people with depression developed Parkinson’s disease, or just over one percent, while 1,775 people (0.4 percent) of those who did not have depression, developed Parkinson’s disease.

**Neurology • April 8, 2015**
A new study indicates that adults who participate in arts and crafts activities, use computers and who socialize during middle and old age may retain cognitive abilities longer. The study involved 256 people with an average age of 87 who were free of memory and thinking problems at the start of the study. After an average of four years, 121 people developed mild cognitive impairment (MCI). Participants who engaged in arts in both middle and old age were 73 percent less likely to develop MCI than those who did not report engaging in artistic activities. Those who crafted in middle and old age were 45 percent less likely to develop MCI and people who socialized in middle and old age were 55 percent less likely to develop MCI compared to those who did not engage in similar activities. Computer use in later life was associated with a 53 percent reduced risk of MCI.

Get your FREE PBA FACTS kit

Learn about this treatable neurologic condition.

- Read how PBA differs from depression.
- Learn what doctors have to say.
- Hear stories from patients and their caregivers.
- Take 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.
When I speak to groups about planning in advance for the possibility of mental incapacity—most often due to some form of dementia in old age—I acknowledge right off the bat that it seems like a depressing topic. I’d like to propose, however, that maintaining control of one’s quality of life, should you ever fall victim to a severe cognitive disease, is one of the most powerful, positive things you can do for yourself and your future caregivers.

Caregivers are often in the throes of covering basic care needs, busily weaving safety nets around loved ones and putting out the fires that crop up with medical and care coordination crises. Sometimes confusion or arguments abound, giving rise to the question: who should be in charge of caring for a loved one with dementia? Having an advance medical directive, in the event you are unable to communicate your wishes in the future, is like granting your future caregivers psychic abilities.

An Advance Medical Directive (AMD) has two components:

Healthcare Power of Attorney - who will be in charge of decisions regarding your health and well-being when you can no longer manage?
Living Will - the type of treatment you do or don’t want in the event you become terminally ill, and treatment would serve only to prolong the dying process.

So, how does one go about setting up an AMD?

• Choose someone you truly trust to be in charge. Don’t forget to select a back-up as well.
• Think deeply about the things in your life that are meaningful to you and determine your personal cut-off for medical interventions.
• Once you’ve decided, arrange to sign the AMD and have it notarized in front of witnesses.

I once had a client who insisted that if she were ever to have dementia to the degree that she could no longer make sense, her caregivers were to continue to take her to lunch each Sunday, and permit her to eat ice cream even if her doctors thought it was bad for her. Exactly what is the definition of bad? That client would have said not being allowed to eat ice cream when she already has late stage dementia is much worse for her than avoiding it. She would rather fly in the face of heart disease and diabetes than give up her sweets. I really couldn’t blame her.
There are limits of course. Public policy and inherent humanity won’t allow us to sit back and allow a frail, confused elder to live in a way that is dangerous and likely to cause pain and suffering. But ice cream? Check. Making sure you maintain your comforting lifetime routines such as being bathed in the evenings instead of mornings? Check. Wanting to have a pet, or at least be signed up for a visiting pet service that enhances the quality of life through the healing touch of soft fur and wagging tails? Yes, these are the kinds of things you can include in an AMD.

Many caregivers are infinitely more tired and frustrated because they didn’t know their loved one’s wishes in advance. Often, an adult child will enter the picture after a crisis with his or her parent, only to realize that not only has dementia set in, but it is worse than they thought and there is no instruction book. Did mom want to live at home with an aide if she could no longer drive and be out and about? Would dad want the activities and companionship of a community living setting? As a healthcare power of attorney, it would be your job to make such a decision after weighing a doctor’s advice for your loved-one.

So, how detailed should an advance directive be? I always say, “more is more,” with a caveat or two. It is important to keep financial feasibility and practicality in mind. Start with identifying the really big things such as, “if I have late-stage Alzheimer’s and am stricken with breast cancer, I DO/DO NOT (choose one) want such curative treatments as surgery or chemotherapy.”

Next, include the things you feel will garner you a higher quality of life. Then sit down with the person or people you’ve appointed to be in charge if that day ever comes. Talk with them about your feelings and your wishes. Ask if they have questions, and explain that your hope is that taking these steps now will lighten the load of them having to make decisions for you down the road.

There is hope for caregivers that one major burden won’t come to fruition—the guessing and wondering what a loved one would want. All it takes is the decision to take the reins now and not put this vital task aside for another day.

Buckley Anne Kuhn Fricker is the nation’s only licensed attorney and certified geriatric care manager. Her background in estate planning and elder law allows her to answer almost any question on the spectrum of elder care issues from retirement to legal to medical, financial, care and housing options. She is the author of “Elder Care: The Road to Growing Old is Not Paved,” a reference manual on legal, financial, and healthcare considerations from retirement through end-of-life care. She is the founder of Buckley’s For Seniors, LLC, which helps organize home care for senior citizens.

To discuss care options with a professional in your area visit www.caremanager.org
To locate an elder law attorney who can draft advance medical directives visit www.NAELA.org
“Well hello...Tyla,” Pop would say in his slow, thick Texan accent. “Hooow was...yerrr day?” This was a classic American family man, a tall, lanky fellow that people look up to with utter respect and inspiration. He had owned a family clothing retail store, taken part in long-distance walking, biking and hiking, and even been the mayor of a small town. He was a kind and gentle man, one who, with the biggest grin I’ve ever seen, instantaneously made everyone near him feel loved. However, this man had faded near the end of his life, a figurative shell of the person we all knew and loved. I tell this story not out of remorse or pity, but out of gratitude, a way of manifesting the retro-spect of a man who made a significant impact on my life. Pop may not have had the same competency or awareness in his final days, but one thing is for sure: he never lost his love for family, friends and life.

Pop loved his oatmeal. He knew the measurements by heart, a staple of his ever–so–healthy diet. He cooked it himself every single day up until the last year of his life, often more than once. “This oatmeal...sure holds me good;” he would always say. Then he would say it again a few minutes later. He would spend hours lingering over the kitchen counter preparing his bowl of heaven while the rest of us carried on with our day around him. Pop was always content with his lengthy process, and the anticipatory grin he maintained throughout was simple assurance that we shouldn’t interfere or offer assistance. Even after completing his work of art, he would insist that the first person to walk through the kitchen eat it, assuring them with utmost sincerity it was absolutely no bother for him to prepare another for himself.

About three years before the end, Pop began to acknowledge his mental decline, plummeting him into a constant state of anxiety. The Alzheimer’s and Parkinson’s together became a nasty combination, stripping his sanctity day by day. It was heart-breaking for my family to watch him fight himself, a metaphysical war raging just behind his eyes every minute of the day. The simple, “Did you sleep OK?” inquiry that he repeated three or four times to every person in the morning was routine, and after a while it became so characteristic that we began to just love it. We appreciated the sincere thoughtfulness that we knew it stemmed from, regardless of its eventual monotony. He was sadder and quieter at this time, so conversation of any kind was a blessing for us to hear. Group settings were impossible for him, looking like a deer in the headlights any time the conversation became multifaceted. Consequently, living in the present was difficult for him, as well, and any relatively normal conversations he could have consisted mostly of his days back in his department store. “Haggard slacks are the best...I always went to their New York market week...They have features no others do.” As a 15–year old boy, I had no clue as to what Haggard slacks were, or if they even still existed, but at least I could witness the genuine delight it brought him to give advice on something as simple as the ideal trousers.
Within two years of the end, even the simple things started to fade. He was no longer aware of his environment, but rather was engulfed with the bohemian state of mind of a child. After returning from a week away at summer camp, I was greeted with the question, “What did...y’all get at the supermarket?” Nothing was the same. My family had to care of him as if he was a toddler, as leaving him alone at any point in the day would compromise his safety. We would all take turns “sitting” with him, or at least that's what we called it. He would read from the book he had read 10 times over, and then struggle to explain the surprise ending to us like it was the first time. We would try to give my grandmother a break from the caretaking, as Gran was otherwise burdened with constant surveillance of his every move. We even set up a separate room for her with a bed, couch and computer, which we affectionately called “The Gran Cave.” His innocence made it impossible to get frustrated with him, but it was a constant drain on my grandmother to be back in a position like that of a young mother at the age of 70.

The last year of his life was the hardest on our family. Pop's innocence and iconic grin had faded into agitation with his status, a man clouded by dangerous hallucinations and utterly frustrated with his misunderstood abilities. The first indication of seriousness was putting himself in danger, like when we would catch him shaving with his toothbrush and brushing his teeth with his razor. Eventually, he began acting out in ways contrary to his lifelong peaceful personality. At times, he was mean and even physically rough, pushing my grandmother away and fighting off any help she tried to give with walking, bathing, eating or changing. Our family was extremely conflicted and saddened, especially Gran. She and Pop had made a promise to take care of each other until the end, and she had diligently done so for years without a break or a complaint. However, Pop's state of mind and abrupt shifts in demeanor were putting Gran at risk. We, as a family, decide we had no choice but to put him in a skilled nursing facility in February of 2014.

Within two weeks of this transition, Pop passed away.

This was a time of mixed emotions, bittersweet, yet these circumstances confirmed for us that moving Pop was indeed the right decision and that his agitation was his desperate way of conveying the need for a resting place. It seems to us now that he felt he needed some sort of permission to go, a solemn indication that he was no longer required to suffer. Pop simply would not let go in the home that he shared with his loving wife for decades. Our family could see the pain in Gran that this realization instilled in her, but Pop's sincerity and love for Gran was most clearly demonstrated in this circumstance. It has been exactly one year since my grandfather passed. Through all the trial, turmoil and heartbreaking situations, my family has indubitably become closer than ever before. Some of my family lives in Texas, some in Austria and I in New Jersey, but we all came together for the sole purpose of taking care of our loved one, sharing the burden of a hardship and most of all, fortifying a support system for everyone involved. Pop's endless grin is engraved in all our minds, and his lifelong kindness and compassion haven't faded in significance through his passing. Pop was an incredible man who touched the life of every person he met. He had absolutely no enemies but the one raging inside of him, a merciless disease that eroded a good man's soul to the point of being unrecognizable.

This experience has taught me to make the most of every day I have, and touch the lives of as many people as I can. Health isn't something to take for granted, but my grandfather made the most of every day he had until he lost it. I can honestly say that if I were ever to encounter such a trial, I would remember Pop. Just as he did until the day he died, I would keep the biggest grin on my face that I possibly can.

**Gunnar Tyler Henning, 18, of Washington, N.J. (Tyler to his friends and family), is the grand prize winner of this year’s Alzheimer’s Foundation of America Teens for Alzheimer’s Awareness college scholarship competition. He is a recent graduate of Warren Hills Regional High School, in Washington, N.J. and was Salutatorian of his class. This fall, Henning will attend his “dream school,” Carnegie Mellon University, in Pittsburgh, Pa., where he will double major in business finance and computer science. He is the youngest of four siblings and though there are years between them, his family is very close.**
GONE ARE THE DAYS
By Shelby Rose Kwast

Gone are the days of cheerful holidays.
Of smiling pictures around the Christmas tree.
Of excited chatter at the Thanksgiving table.
Of Easter egg hunts in your backyard where Liz and I would fight over who got the purple eggs.
Gone are the days of visits,
Of “nice to see you Shelby,”
Of “what have you been up to?”
Of “where do you want to eat?”
And “oh, he’s a good looking boy, isn’t he?”
Those nice days where you would come up just to see us.
Where you would tease us,
Where we would laugh and have a good time.
Where the wonderful memories were made.
I miss those days.
Gone are the days of dance recitals,
Where you would come see us up on that stage in our little tutus and tap shoes.
Where we would have to follow the teacher who was dancing in the wings.
You didn’t care though, you just wanted to see us doing something we loved.
You would always make such a big deal out of it, even though we weren’t very good.
Did you know that this would have been my fifteenth year?
I’m much better now, I wish you could see me.
Gone are the days of “tell me about your next play”

Of caring about even the smallest part like it’s the biggest,
Of “I loved seeing you as
The Fairy
The Tinman
The Juror
The Blind Girl”
Of being able to see every play I’m in.
I know you still want to.
Do you know you took me to see my first?
It was Cinderella, the same one I’m in now, but you won’t be able to see it.
I wish you could. I wish you could see me in the part I worked so hard to obtain.
Do you know I have you to thank?
You were always interested, always encouraging, always there.
But you can’t be now.
Do you know I don’t blame you?
How can I when it’s this disease that has plagued your mind.
You didn’t choose this, but no one ever does, do they?
I do miss the way things were before everything became so much worse.
Isn’t it amazing how we barely notice the change until it all comes crashing down on us?
It’s like a snowball rolling down a hill,
Slow, small at first, faintly there.
But all of the sudden its huge, racing downward taking all of your memories with it.
Gone are the days of you constantly worrying about us. Of the constant "make sure you have your coat" "do you have everything" and "you need to wash your hands". Those little comments that we would roll our eyes at. How much I would give if I could hear you tell us that one more time. Gone are the days of collecting, you always loved to hold onto everything. I never understood why you kept everything, why you would treasure them, Why you would never let them go. Those things, even the simplest ones, hold memories that are now long gone. They were your way of holding onto the good days that you cherished, I realize that now. Gone are the days of your memories. They are fleeting. No matter what I do I can't bring them back, though I wish I could. I wish I could keep you from forgetting. I wish I could stop this disease that haunts your mind. I wish I could stop it from gnawing away at who I am to you. But I can't. You need to hold on. You can't give up. Here are the days of confusion, Of blank stares and struggled speech, Of two word sentences that take so much work to get out. Of the evident loneliness even when you are surrounded by family. Here are the days of questions. Why is there no cure? For something that seems so common there should be a cure. They are trying, working so hard, but it's not enough. Why is nothing helping you? It isn't fair. You shouldn't have to suffer through confusion, there should be some relief. How long do you have? I know the statistics. I know they're not good. I know that once people with Alzheimer's are put in a nursing home they begin to feel useless. They give up on fighting, they accept that the thought that things can't get better. They lose the will to live, they let this disease cheat its way to victory, With its prize as another mind decaying into the darkness, Another soul that lost the battle for purpose, Another person who doesn't deserve this. They slowly fade away into nothing. You have to fight Nana, to the very end. You are too important not to. Will last time be the last time? I can only pray it won't be. I wish I could see you more often. I let there be too many excuses in the way. "I'm too busy." "I have too much homework this weekend." "It's too far of a drive to take by myself." "I'll go next time, I promise." I wish I had kept that promise. Will you even get to see me graduate? I hope you get to see all of my hard work pay off. I hope to see you surrounded by family as I walk across the stage. When will you stop remembering me?
I can tell you hardly recognize me, but its hard,
Hard to think that one day I will be a stranger to you.
Hard to think you will look at the pictures of me and have to ask,
“Who is that?”
Here are the days of not remembering who I am.
Of barely recognizing me, of not being able to put a name to the face.
It’s that hint of remembrance that keeps you going.
Sometimes I still hope it will somehow spark a lost memory and bring the rest back with it.
I know it can’t, but I wish it could.
Here are the days of struggle, of fighting for a say.
For an option.
For a chance at normalcy.
For a better treatment.
For your own decisions.
For a lost memory.
For the days before this disease took your freedom.

Here are the days of hoping.
For one more good day,
For one more good memory,
For one more smile,
For one more laugh.
It’s been a long time since I last heard you laugh.
I hope you find something to make you laugh one more time.
You don’t need to worry. The good days will always last in my memories.
We will remember for you. We will remember all of the little things you have done for us,
All of the good times, all of the smiles, all of the laughs.
You will be remembered not by your disease, but by the love you had for all of us.
You will be remembered by the days that are now gone.
By the holidays.
By the visits.
By the dance recitals.
By the “tell me about your next play” ’s.
By the collecting.
By the memories.
You won’t be forgotten, even if you forgot.
You will always be loved Nana.
I love you Nana.

Shelby Rose Kwast, of Muskegon, Mich., is first runner-up in this year’s Alzheimer's Foundation of America’s Teens for Alzheimer’s Awareness college scholarship competition. A recent graduate of Fruitport High School, Kwast will attend Ferris State University, majoring in pharmaceuticals and minoring in Spanish. After college, her goal is to take her knowledge and skills to the developing world in order to promote pharmaceutical knowledge.
I was in third grade when my parents told my brother and me that my mom had Alzheimer’s. She was only 46. As a young girl I had no idea of the impact that this diagnosis would have on my family and my future. The disease would be nearly forgotten by my young self until it really began to take its toll on my mom a few years later. Now, as I prepare to graduate high school, I can see not only the devastating effects of this disease, but also the incredible strength and patience it takes to care for a loved one who is affected.

My mom was a nurse who worked with newborn babies before they left the hospital with their families. She made all our meals and took care of the house when she was off work; mothering was like her second job. I remember how she used to tuck me in at night, and when I had trouble sleeping, she would come in every 15 minutes, at my request, to check on me until I fell asleep. She would watch cartoons with me as she folded laundry or teach me how to make origami fortune tellers. She picked me up from school each day and cooked dinner while I did my homework. But after that time in grade school, the memories change.

In middle school, Alzheimer’s began to take hold in her, and she began to forget things. At first, it was little things. She and my dad started to go to doctors to try to help her remember things, and sometimes she would come home and cry because she knew she could not do it. At the time, she knew what was going on, not only from her earlier diagnosis, but also from her experience watching her own mother go through the disease. She would tell me stories about her mother chasing her angrily with a rake because she did not know who she and her siblings were. It was not until my own mom’s struggle with the disease that I realized it could happen to my family too. I was afraid.

Throughout the next few years, my mom’s role in the house diminished and my dad and I had to step up to keep up with the meals and housework. My dad worked for most of the day, and now that my mom had stopped going to work, she was home all the time. She stopped driving because she would forget where she was going and how to get there, and would end up miles down the road in the wrong direction. She could not remember what was going on or what she had to do. My grandma started coming to help her while my dad was at work. Eventually we hired caregivers to come and take care of her, but she did not remember who they were, and often came to my brother or myself to figure out what was going on.

A few months later my dad decided to move her to a care home where she could get the constant care that she required. She could not go to the bathroom or dress herself anymore, and eating was becoming a challenge. Taking her medicine was nearly impossible. But when she moved out of the house, it was too quiet in the house. There was one less place setting; one less person to reserve a table for. There were no constant questions or caregivers. Only silent emptiness. The heart of the home had finally moved out, and nothing felt right.

My dad visited her daily to make sure she was cared for and to see the woman he loved. My brother and I only visited occasionally. I think we were both trying to ignore the gravity of the situation and instead focused on our own lives with high school and marching band. When we visited, it was like seeing an entirely different person. The loving mother I remembered from growing up was not the confused and distant woman we saw at the care home. It made it hard to visit, knowing that she did not know who we were or why we were visiting. She understood we were important to her, but she could not quite place who we were. Sometimes there was clarity and she would talk about the disease and assure us that it would all be okay because she was going to
go to heaven. But most of the time she could barely remember her own name.

When the call came we were hosting people at our house. I remember my dad rushing out; he promised to call when he knew what was going on. I retreated to my room and cried in the darkness of my closet, having finally come to terms with the inevitable end to my mom’s struggle. It was a few days before she finally passed, and we visited often. I wanted more time. But on April 2, 2012, time ran out.

Over the next two years, both my uncle and aunt (my mother’s younger siblings) also passed away. It has been hard on the whole family, but two years later I can say with certainty that I have learned a lot, not only about the disease, but about myself and my family. My dad is amazing. He never stopped caring for my mom, and he always had patience for her. He was always strong, even when he knew she was close to passing away. He did his best to provide for the family for all those years, and made sure my mom got the best care possible. Although it was unimaginably hard for him to watch his wife pass away, he never let it get him down. My aunts and uncles and cousins are also strong, for being able to go through the same experience with their loved ones. I have learned patience, responsibility, and strength through this time in my life, and I know that even though it was hard, my faith and my experience have given me a new perspective on life and the importance of family.

Familial Alzheimer’s disease is a genetic form of early-onset Alzheimer’s, meaning that there is a chance that I, my brother, or any of my cousins may also have to experience what my mom, aunt, and uncle went through. Although I am unsure if I will be affected or not, I know that my family will always be there to support each other and that I do not need to live in fear of what may or may not come to pass.

Every day there is research into finding a cure for Alzheimer’s. Every year, thousands of dollars is raised for awareness and research. I can go on towards my future knowing that I am in good hands.

My story is not a pleasant one. It is not a fictional story with a happy ending or an embellished story to make the reality of the situation easier to swallow. It is a tragedy. I believe that it is important to tell my story and share the realities of Alzheimer’s disease without sugarcoating the truth. The truth is, Alzheimer’s is a disease that devastates the lives of people and families all over the world. Although there is a lot to be said about the strength and patience of family and the happy memories of those who have been affected by this disease, I believe that it is equally important to express the reality that this is a serious disease that is not just for elderly people and grandparents. With awareness and education, we can find understanding and diminish the fear and uncertainty surrounding this disease.

My mom was never afraid of her future and she never tried to run from her present. She enjoyed her life, and made the most of her situation. I know that she is proud of me and if she could, she would tell me once again, “I love you all the way to heaven.”

Julianne Johnson, of Bermuda Dunes, Calif., is a recent graduate of LaQuinta High School and the second runner up in the 2015 Alzheimer’s Foundation of America’s Teens for Alzheimer’s Awareness college scholarship competition. She has faced a series of challenges thus far in her life, but prefers to look at them as victories. Johnson is an accomplished flautist, who sat first chair in her school’s Wind Symphony. She plans to attend Azusa Pacific University to study English.
CASTING A SAFETY NET TO PROTECT PEOPLE WHO WANDER

FORMER SWAT TEAM LEADER NOW LOCATES LOST LOVED ONES

By Mara Botonis

“I was putting dinner on the table one evening and heard frantic pounding on my door, it was a young lady with whom I had worked crying so hard she could barely speak the words to me, ‘Oh Ruth, Ron is in the middle of the road!’ This was 5:00 p.m. rush hour with 6 lanes of traffic going both ways. My pulse was racing while it seemed the whole world momentarily stopped moving. Ron, my husband more than 20 years, had been showing early signs of memory loss, but never in my worst nightmares did I think for a moment he would wander away, until the day that he did and my life changed forever.”

Ruth Boshart isn’t the only Alzheimer’s or dementia family caregiver to suffer the type of heart-pounding terror, described above, when a loved one goes missing.

“The very first time Ron wandered away was on an Easter Sunday. We had finished dinner and were having dessert in the family room when the phone rang, as I picked up the phone, Ron picked up the dishes and headed to the kitchen. I could hear him start the dishwasher. What I didn’t hear was the moment he slipped out the door. Off he went no hat, no coat, just disappeared!” Boshart recalls.

It was almost 6 hours before she found him. She went to every fast food restaurant in the area in case he was craving a familiar snack. Ron was a general contractor by trade, so she also went to every construction site in the area, driving for hours. Finally, Boshart went to the police station to report her husband missing. When they found him (about 6 miles from home) and brought him home, “he could not understand why everyone was so upset, was angry and seemed to be oblivious to what was happening.”

Few realize the emotional toll wandering takes on a caregiver. For Boshart, it was devastating.

“You fear for their safety, their well-being. It is the not knowing that is the most difficult to deal with. You have no idea if they are alive or dead, and you tend to fear for the worse. Cell phones are worthless. If he had the phone with him, he might not answer it when it rang. His wallet was usually on the dresser, so he carried little or no ID. I used to pin
his name and address into his shirt without him knowing so if someone found him they could call me."

Her worry was incessant. Afraid to sleep or let Ron out of her sight for any length of time, she notes, "I feel like I aged 100 years during that time!"

Nearly a decade earlier, some miles away from the Boshart’s upstate New York home, one man was inspired by a simple idea that he has since transformed into an internationally-recognized crusade: to find—and—safely return lost loved ones like Ron to their families.

In October of 1998, Gene Saunders, then a 33-year law enforcement veteran and commander at the Chesapeake Police Department in Chesapeake, Va., was becoming increasingly frustrated with the growing number of dementia-wandering incidents he and his team were receiving.

As the number of search and rescue calls involving people with dementia increased, he noticed that the success rate for locating them before an adverse event declined. At about that time, Saunders received literature in the mail about using radio frequency devices to track wildlife.

“It just dawned on me, wouldn’t it be great if we could outfit these people who wander with these radio frequency transmitters?” Saunders recalls. “When they wander, we could tune into that radio frequency and track them using a uniquely assigned radio signal for each individual. We could then locate them and bring them back home much more quickly and efficiently.”

Bringing wanderers back home is exactly what Project Lifesaver International (PLI), the non-profit organization Saunders founded is doing—and doing very well—every day.

The Project Lifesaver program relies on proven radio technology and specially-trained search and rescue teams. Citizens enrolled in Project Lifesaver wear a small wrist or ankle that emits an individualized tracking signal. If an enrolled client goes missing, the caregiver notifies his local Project Lifesaver agency, and a trained emergency team responds to the wanderer’s area. Most who wander are found within a few miles of home and search times have been reduced from hours and days to minutes.

In fact, the program has been so successful, that more agencies are requesting training and more family caregivers are enrolling their loved ones in the program daily. What started as an idea to help people with dementia has been found to be just as useful for individuals with autism, mental health issues, brain injuries and other conditions that may render them at risk of wandering without the ability to self-initiate a return to safe and familiar surroundings.

Upon enrolling a loved one in the program, Project Lifesaver International’s local agency meets with the at-risk individual and his caregiver to learn more about their unique needs, wandering triggers, past wandering history, and what the at-risk person may find calming or comforting. The team also obtains a current picture and physical description. The at-risk person is fitted with his own, unique tracking device. The device—a
water-resistant ankle or wrist bracelet—offers peace of mind in that it is almost impossible to remove and the knowledge that loved ones who wear this device are 95 percent more likely to be found safely than those who do not. In fact, Project Lifesaver International’s member agencies have achieved an impressive average rescue time of less than 30 minutes.

Saunders feels that the technology is only half of the program. The other half is the organization’s commitment to providing the training member law enforcement agencies need to best utilize the equipment and to understand the unique challenges facing people living with cognitive impairment and their caregivers. To that end, Project Lifesaver International established highly-specialized training programs, certified by the Department of Justice, to aid officers in gaining proficiency with the technology and program.

Back in upstate N.Y., Boshart began looking for something, someone that would help her keep her husband safe. She researched a popular national program that issues identification bracelets, but found it was useless to her. “Someone would have to approach him, notice he had the bracelet, get him to allow a stranger to get close enough to read the phone number on the bracelet, and then call me,” she said. “It was much easier for me having the cooperation of our local police and fire departments. Having all of us looking, and looking with the added benefit of Ron’s homing signal guiding us to his location seemed a much more efficient way to reach him quickly.” Boshart was instrumental in bringing Project Lifesaver into her area. In fact, her husband was the first client with a PLI transmitter in her county, which now has more than 90 Project Lifesaver bracelets in use.

Boshart recalls those first few nights and weeks after Ron was a part of the Project Lifesaver program, “For the first time, I had peace of mind knowing that if and when he wandered, I would have their assistance in finding him. They became family, and Ron looked forward to seeing them every time they came to visit. He always called them ‘My Guys.’ He would touch his bracelet and say ‘My Guys.’ He knew if he got lost his ‘Guys’ would be there to help him. Many times they found him and brought him home safely.” Though Ron’s disease has now progressed to the point that he no longer lives at home, and his decreased mobility means he is not at risk of wandering, Boshart never forgot the positive impact that Chief Saunders’ program had on improving the safety and quality of her years with Ron at home. She is now a Project Lifesaver activist, educating others about this program alongside the team at the sheriff’s department whom she considers family.

Project Lifesaver International, the idea that began with one man on a mission, has now helped successfully locate more than 3,000 persons to date. It has grown to more than 1,400 police, sheriff, fire, public safety departments and other emergency responders in 48 states, as well as Canada and Australia. The program has received more than $1 million in grants from federal, local and private sources to help continue its life-saving work. Project Lifesaver is also mentioned by name in pending legislation in several states seeking to make its technology more accessible to the most vulnerable citizens.

Chief Saunders, now regarded as the father of—and subject matter expert on—electronic tracking of at-risk persons has earned a number of law enforcement and family caregiver honors, including a nomination for the Presidential Citizen’s Medal.

Mara Botonis of North Hutchinson Island, Fla., spent 30 years working in the senior housing industry before her life and career trajectory was forever changed when a close family member was stricken with Alzheimer’s. She is the author of the best-selling book, “When Caring Takes Courage: An Interactive Guide for Alzheimer’s and Dementia Caregivers,” and recently received the Jacqueline Kennedy Onassis Medal—the nation’s highest honor bestowed upon an individual whose public service makes a notable and widespread impact.

DETAILS
To learn more about Project Lifesaver or to download it’s free safety checklist, visit: www.projectlifesaver.org or call: 1-772-446-1271.
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“Who are you?” I ask the cheeky cherub gazing out from the sepia photograph. “My mother or my child?” The resemblance to Mom is still there, moon face, thin lips, little ski nose. But, more often than I care to face, so is a child’s mind.

It’s hard to believe that parents are growing old, but it’s almost impossible to accept that they’re becoming children again. And the journey can be a roller-coaster ride, with twists, turns, dark tunnels, and, yes, even thrills.

Take this phone conversation. For the first time in months, Mom and I had a genuine mother-daughter talk, one where the daughter cries her hurt or laughs her joy and the mother simply listens.

I hadn’t confided in Mom for so long, and I’m not sure why. Was it because I thought she didn’t want to hear my problems anymore? Was I afraid her mind wouldn’t follow along? Did I fear becoming impatient when I had to repeat myself? Whatever the reason for holding back, I was troubled, so I poured out my heart, and she listened. And she was Mom again.

“Well, sweetheart,” she said as we ended our conversation, “I’ll say a prayer that things work out for you.”

“Thanks, Mom. I love you.”

“I love you, too, honey. Good night.”

As we hung up, I was smiling, not mumbling. She was the mother—and I was the daughter—the way it should be!

But hopes can quickly nose-dive, as in a later phone conversation. In the middle of our conversation, Mom blurts, “Aunt Gert’s coming over to take me to the doctor.”

Her beloved Aunt Gert passed away years before. I spend a few minutes trying to convince Mom that she wasn’t sick and that Aunt Gert, who never drove, wasn’t coming to take her to the doctor. I feel I have succeeded when she asks for the umpteenth time, “What’s today?”

“Well, today is Wednesday,” I reply, slowly forming each word.

“Well, I’m supposed to go into the hospital for an operation tomorrow, and no one will take me.”

“Mom, you’re not going into the hospital for an operation,” I snap, immediately feeling guilty for the edge in my voice.

“I’m not? Lenore, are you sure?”

Her tone of voice makes me feel like a child again. “Yes, Mother, I’m sure.”

That’s what gets me about this thing—senile dementia, hardening of the arteries, Alzheimer’s, whatever. I’m never quite sure which person I’m dealing with. The child who doesn’t know any better. Or the parent who does, and wants to be treated like she does.

And as a parent’s mind becomes foggier, a grown child’s nightmare often becomes reality.

Mom’s going into a nursing home today. I sit across from her as she fiddles with the buttons on her floral jacket, my gift to her last Christmas. Those hands once sewed my mint-green graduation dress and crocheted the lace tablecloth that covers my dining room table.

She braces her hands on the side of her dark velvet sofa, slowly rises halfway, then sways. I jump up and steady her. I remember those once strong legs walking my sister and me to Golde’s Department Store to pay on the dolls she had in layaway for us.

Yes, Mom’s hands and legs and mind can’t do the things they once could. And that’s what’s hardest—and scariest.

“Mom, it’s time to go.” I coax.

Grabbing her neck, she moans, “Oh, my neck, my neck, it hurts so bad.” Plopping down, she clasps her chest and gasps, “Something’s wrong with my heart. I can’t breathe! I can’t breathe!”

Feeling her fear, I struggle to calm her. She looks up at me and then raises her arms like a child begging for a hug. As I lean down to hug her, she sees the tears trickling down my cheeks.

“Oh, honey,” she soothes, “don’t cry.” Brushing away my tears and pulling me to her breast, she repeats “Don’t cry, honey.”

We sit on the sofa comforting one another until Mom squeezes my hand and slowly rises. “You know,” she says, “it’s really hard, making a change like this in the middle of your life. Or maybe I should say at the end of your life.”

Then, arm in arm, we walk out of her apartment.
This delicious salmon recipe is perfect for summer.

It provides an abundance of beneficial omega-3 fatty acids for brain and heart health. Grilling it in a foil pouch seals in flavor and requires hardly any clean-up!

**BEST FOR LAST**

**EASY GRILLED APRICOT-GLAZED SALMON**

**Ingredients**

1 1/3 pounds salmon fillets (wild salmon when available)
1/4 teaspoon freshly ground black pepper
1 Tablespoon extra-virgin olive oil
1 clove garlic, minced
1/3 cup apricot fruit spread, 100 percent fruit
1 Tablespoon Dijon mustard
1/2 cup low-sodium vegetable broth

Serves 4

**Method:**

- Preheat grill to medium heat.
- Pat salmon dry with a paper towel and cut into four equal servings. Season the skinless side of salmon with pepper.
- Place each piece of salmon on a double layer of foil with skin side down. Fold the sides of the foil up so that the cooking liquid will not run out.
- In a small bowl, whisk together the rest of the ingredients. Pour the liquid over the four pieces of salmon so that the glaze is distributed equally.
- Seal each foil packet by folding as if you were wrapping a gift. Slide the foil packets onto the grill and close the lid.
- Cook until the salmon is cooked through, about 10 minutes. Let it rest for 2 minutes and then unwrap and serve salmon over a bed of greens. This dish can be served hot or at room temperature.

**Serving Suggestion:**

Salmon goes well with almost any grain. I like to serve such a rich-tasting fish with a hearty grain like brown rice.

**Nutrition Facts Per Serving (213 g):**

304 calories, 13 g fat, 130 mg sodium, 14.3 g carbohydrates, 30.4 g protein.

Recipe and photo adapted from the book: “Beyond The Mediterranean Diet: European Secrets Of The Super-Healthy” by culinary nutritionist and award-winning author Layne Lieberman, M.S., R.D., C.D.N. The book was recently named one of the best independent books of 2015.
HERE’S WHAT’S HAPPENING!
The Alzheimer’s Foundation of America (AFA) and the Long Island Alzheimer’s Foundation (LIAF) have something for everyone!

RAISE YOUR VOICE FOR CARE COLLEGE TOUR
September 15, 2015 -- Washington University (Missouri)
October 7, 2015 -- Adelphi University (New York)
October 23, 2015 -- Loyola University (Maryland)

AFA GOLF CLASSIC
September 28, 2015 -- Fresh Meadow Country Club, Lake Success, N.Y.

CONCEPTS IN CARE EDUCATIONAL CONFERENCE FOR CAREGIVERS OF THOSE LIVING WITH ALZHEIMER’S DISEASE AND MEMBERS OF CONGRESS
October 1, 2015 -- Washington, D.C.

FOR THE LOVE OF JOSEPH DISANTO – AN EVENING OF COMEDY WITH SEBASTIAN MANISCALCO
October 28, 2015 -- Gotham Comedy Club, New York, N.Y.

LIAF COPING & CARING EDUCATIONAL CONFERENCE
October 22, 2015 -- Hilton Long Island/Huntington, N.Y.

CARE CONNECTION TELECONFERENCE
AFA’s free teleconference is designed for both family and professional caregivers of individuals with dementia. For more information, http://www.alzfdn.org/AFAServices/careconnection.html

August 13, 2015 -- 1:00 p.m.-2:00 p.m. ET -- Sherry L. Dupuis, Ph.D., professor, Recreation and Leisure Studies, and co-principal investigator, Partnerships in Dementia Care Alliance, faculty of Applied Health Sciences, University of Waterloo, Waterloo, ON, Canada will present on “Creating Meaningful Experiences for People with Dementia through Leisure”

September 10, 2015 -- 1:00 p.m.-2:00 p.m. ET -- Jenny Miller, M.S.W., C.M.C., president of Senior Care Concepts, Inc., Warwick, RI, will review “The Role of a Geriatric Care Manager in the Care Planning Process”

October 8, 2015 -- 1:00 p.m.-2:00 p.m. ET -- Renee Kinder, M.S. C.C.C.-S.L.P. R.A.C.-C.T., clinical specialist at Evergreen Rehabilitation, Louisville, KY., will present on "Abilities Based Dementia Approaches for Cognitive and Language Changes”

November 12, 2015 -- 1:00 p.m.-2:00 p.m. ET -- Tim R. Johnston, Ph.D., manager of education and training for SAGE (Services and Advocacy for LGBT Elders), New York, N.Y. will present on “Supporting LGBT Families with Alzheimer's Disease”

December 10, 2015 -- 1:00 p.m.-2:00 p.m. ET -- Karol Tapias, L.M.S.W. is the director of training and innovation at LiveOn NY, N.Y. and will present on the topic “What You Need to Know: Intimacy, Sexuality and Alzheimer’s Disease”
