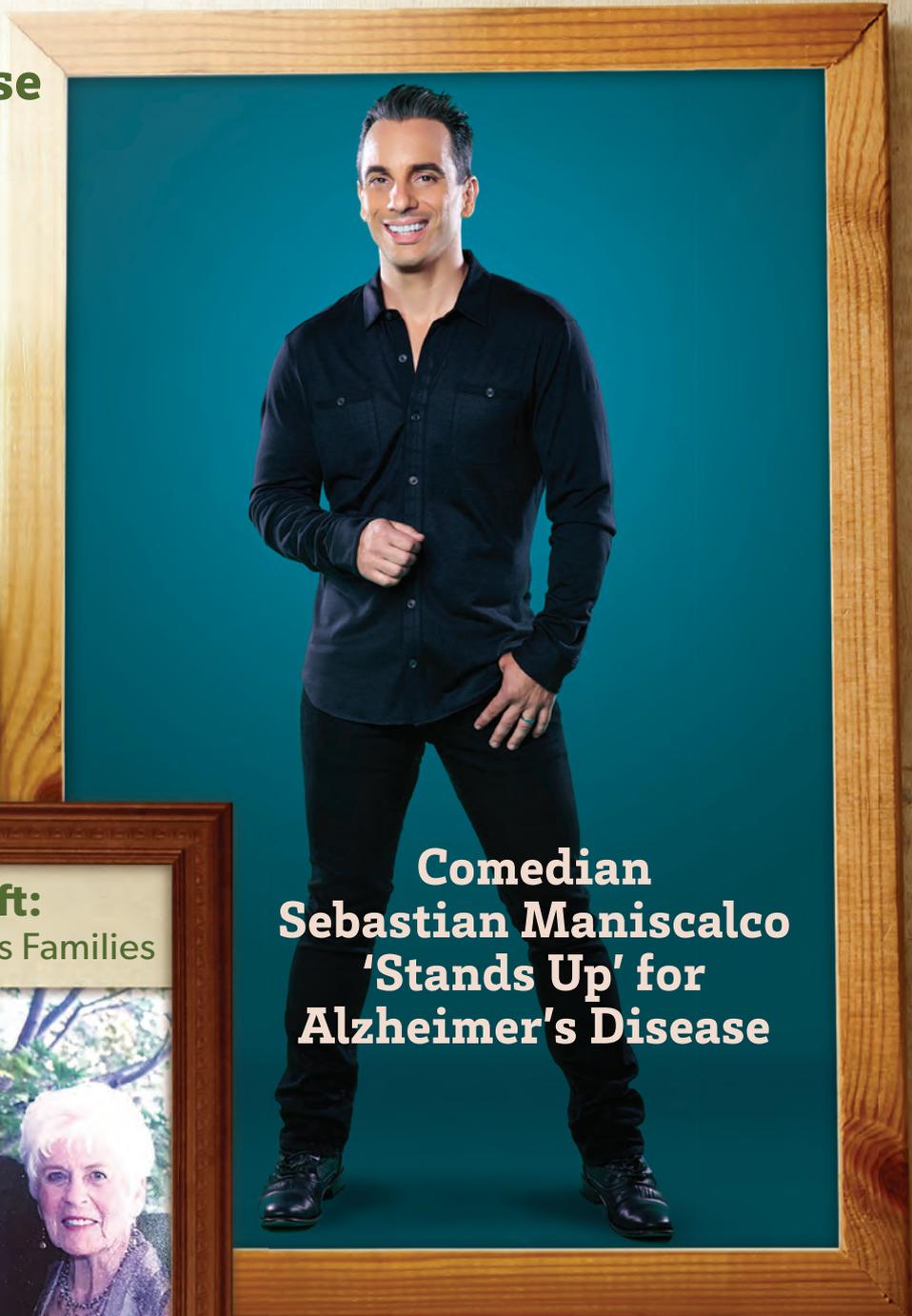


For caregivers of individuals living with **Alzheimer's Disease** and related illnesses
A publication of the **Alzheimer's Foundation of America**

Married Yet Widowed: Life As An Alzheimer's Spouse



**Comedian
Sebastian Maniscalco
'Stands Up' for
Alzheimer's Disease**

A Brother's Gift:
How Palliative Care Helps Families



Merrill Weiner, with her brother, Lou Reed and mother Toby Reed

Spring
2015

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MISSION: "TO PROVIDE OPTIMAL CARE AND SERVICES TO INDIVIDUALS CONFRONTING DEMENTIA, AND TO THEIR CAREGIVERS AND FAMILIES—THROUGH MEMBER ORGANIZATIONS DEDICATED TO IMPROVING QUALITY OF LIFE"

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GUEST COLUMN

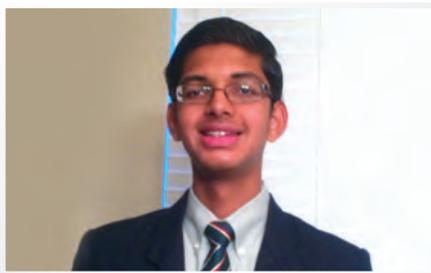
A brother gives his family the gift of palliative care



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'STANDING UP' FOR ALZHEIMER'S

Comedian Sebastian Maniscalco takes up the cause



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A TEEN'S PERSPECTIVE

Volunteering at an Alzheimer's care facility



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TOOLS OF THE TRADE

Training the next generation of dementia caregivers

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For more than 10 years, the Alzheimer's Foundation of America (AFA) has been providing this free, quarterly magazine for caregivers. I hope you have found the content to be helpful. I'd like to give you a little insight into how AFA got started and why we continue to advocate for, and educate, people with Alzheimer's disease and their families.

My mother lived with Alzheimer's disease from 1980 until 1992. At that time, no one understood the disease; no one knew how to deal with it. I found I would get frustrated and even angry when my mom would ask "When are you coming to visit?" after I'd just left, or ask the same question I'd answered only minutes before.

It took years for me to realize the scope of what was happening and how to deal with it. There was nowhere to turn with questions, no resources for support and very little regard for how the disease affects not just the individual, but his or her family as well.

After my mother's passing, I wanted to get involved—to help educate and support the families living with this disease. I wanted to give them what my family didn't have—tools and strategies for coping with their loved ones' condition. I wanted to help them understand what is happening to their loved one—to ask them to try to put themselves in their loved one's shoes—and to respond with patience and compassion. That is why I founded the Alzheimer's Foundation of America. And I'm so proud of how the Foundation has grown since it began in 2002.

Today, AFA serves nearly 2,000 member organizations across the country. Our social workers counsel tens of thousands of people. AFA provides funding for respite—or adult day—programs nationwide. Such programs are critical to individuals with Alzheimer's disease and their families. Respite care provides socialization and engagement for people living with the disease and a much-needed break for their caregivers.

And, of course, there is this, our quarterly magazine, which includes practical tips, strategies and articles that help people to understand that they are not alone in their journey. With this, our first issue of 2015, we are pleased to debut our new title: AFA Care Quarterly. I hope you will continue to turn to the Alzheimer's Foundation as a resource for your caregiving needs.

Take good care,



A handwritten signature in black ink, appearing to read "Bert E. Brodsky".

Bert E. Brodsky
Chairman, AFA Board of Trustees

Don't you just love spring? It seems as if everything gets a fresh new look and our spirits are renewed. This spring, change is in bloom at AFA. As our founder mentioned in his column, we've given this magazine a makeover. We are also in the process of redesigning our website to make it an even better resource to our community. And, we are fortifying our existing programs and services and bolstering our social services team to serve even more people.

But perhaps our most extensive undertaking is being spearheaded by Kristen Cribbs, M.P.H., AFA's deputy director of educational services. Kristen has a true passion for elder care and brings enthusiasm and creativity to everything she does both here at AFA and in her daily life.

In her current role, Kristen oversees our Dementia Care Professionals of America (DCPA) division and has been working tirelessly for the better part of the past year to revamp our professional training program. It's no secret that there is a shortage of healthcare professionals who are trained in dementia care. AFA introduced its DCPA division more than a decade ago to help fill this gap.

Our new training film will provide healthcare professionals not only a foundational knowledge of dementia, it also will promote relationship-building in dementia care; reinforce that people with dementia should be treated with dignity and respect; and provide practical strategies for communication, collaboration, facilitating care transitions, ensuring safety and security, and navigating end of life.

Learn more about the training program, which will be available later this spring, in the article "Tools of the Trade," on page 19.

Kristen also manages our Excellence in Care (EIC) program, which sets a nationwide standard for the highest quality dementia care. She is currently in the process of overhauling the tools used to evaluate care settings. The new evaluation criteria are more inclusive of elements such as person-centeredness and collaboration among the care team (staff, physicians and families). In addition, the evaluation tools themselves will be customized for the different types of care settings (e.g., skilled nursing, adult day, assisted living). Our goal is to increase the number of EIC care settings across the country to help families take the guesswork out of finding quality facilities and programs for their loved ones.

I'm so proud of the work we do here at AFA and I hope that you'll take advantage of the many services we have to offer. Please don't hesitate contact me at 866-232-8484 or info@alzfn.org.

Sincerely,

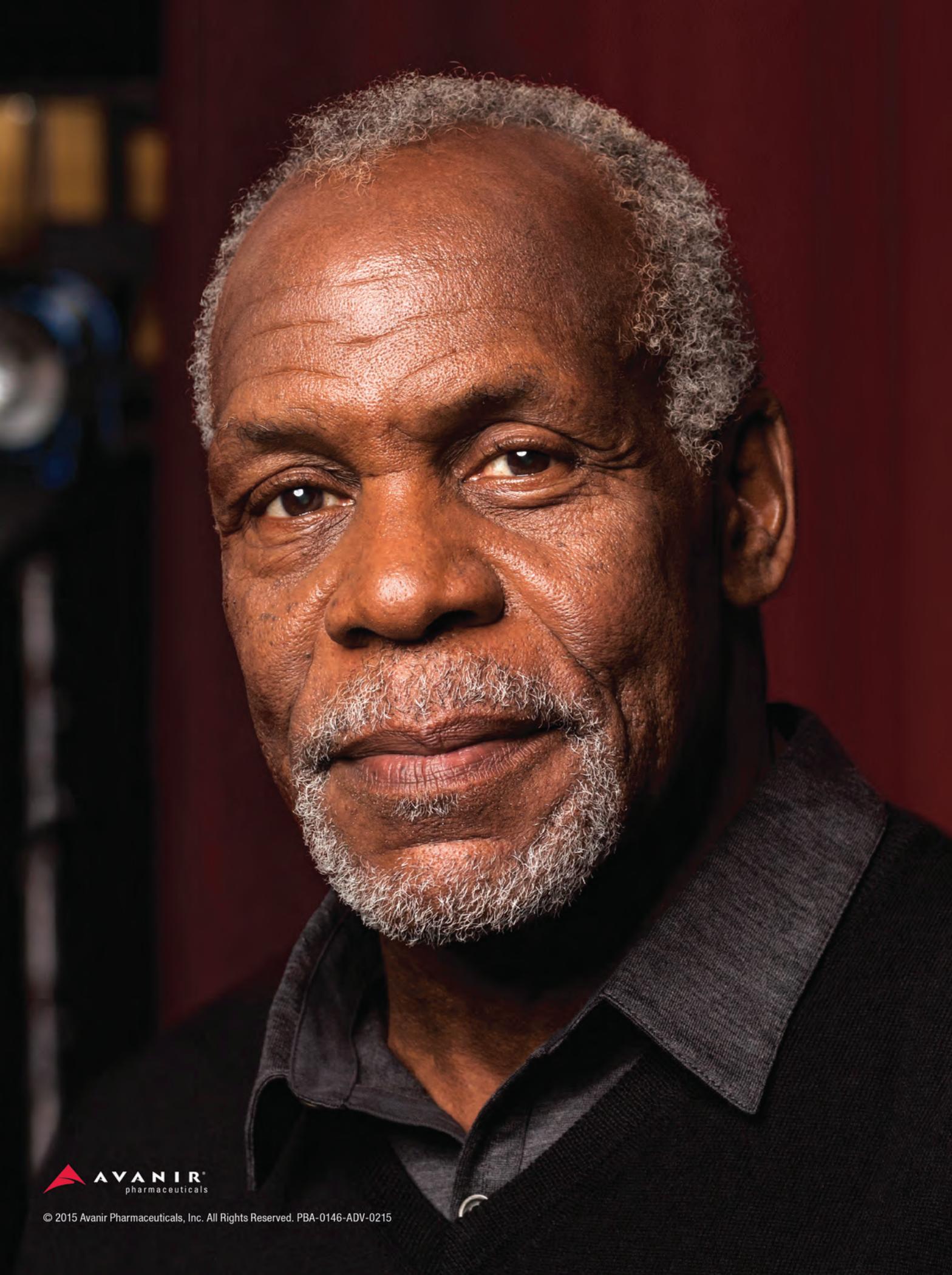


A handwritten signature in black ink that reads "Charles J. Fuschillo, Jr." in a cursive script.

Charles J. Fuschillo, Jr.
President & CEO
Alzheimer's Foundation of America



Kristen Cribbs



“Sudden outbursts of crying or laughing can be a sign of fine acting. But for people with Alzheimer’s, it could be **PBA.”**

—*Danny Glover*

People with brain injuries or certain neurologic conditions like Alzheimer’s disease or dementia, may experience frequent outbursts of uncontrollable crying or laughing called **P**seudo**B**ulbar **A**ffect (**PBA**).

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

‘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.

Learn more and talk with your doctor.

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



*PRISM was a nationwide registry of adult patients with brain injuries or certain neurologic conditions, including 1799 who have Alzheimer’s disease. PBA symptoms were defined as a Center for Neurologic Study Labillity 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.



CONNECTING YOUR QUESTIONS AND OUR ANSWERS

A Q&A WITH **HEATHER SAPOSNICK, LMSW, QDCS**, A SOCIAL WORKER AND PROJECT COORDINATOR AT THE ALZHEIMER'S FOUNDATION OF AMERICA

QUESTION: *My father has Alzheimer's disease and is being cared for by my stepmother. Our family has a long tradition of attending college football games and my father and stepmother still do so. After our last football game, my stepmother approached my wife and said that my father got into altercations with fans around him at both games they attended this year.*

She suggested to my wife that I sit with my father during the game because she thinks I would be better able to control him. My stepmother did not say a word to me about this; my wife informed me about it after we had parted ways with her and my father.

On the way home from the stadium after the last game my father said that he didn't want to go anymore because he "couldn't even tell you who won the game." He did not appear happy—and most of the time even appeared angry—during our tailgating at both games we attended this season. I think it's time for him and my stepmother to stop going to games.

ANSWER: For many families, going to sporting events is a popular pastime. They come together to cheer on their favorite team, and enjoy each other's company and the camaraderie of other fans. In many cases, it becomes more than the game, rather, an all-day outing.

However, for an individual with Alzheimer's disease, no matter how much he or she may once have loved the experience, it may now be too much, for a variety of reasons. First, the arena is a large space with crowd noise, music and other loud sound effects. There is also constant movement, with fans getting up and down to cheer, or to visit the restroom or the concession stand. Attending a game also means frequently having to maneuver through packs of people.

This can be overstimulating and disorienting to anyone, let alone someone with Alzheimer's disease. A person with Alzheimer's disease may become quite frightened and agitated due to this overstimulation. That may be part of the reason your father got into an altercation with another fan. He may have been unable to interpret the fan's verbal and body language, and perhaps, misinterpreted the fan as being abusive toward him and thus, got agitated.

Although, as your stepmother suggested, you are probably able to help de-escalate your father's reaction, it is always best to try to prevent triggers that can cause behavioral problems.

It would be wise to take a cue from your father, who stated he does not want to attend games anymore. With that noted, he can still enjoy watching the games in the comfort of his own home. Bring the tailgate to his living room, with a small group of family members. Set up a table with his favorite snacks, get him a shirt with the team logo, and bring fan paraphernalia to help him feel part of the action. In this setting, he will be able to enjoy himself without having to contend with everything around him, which can be a win-win situation for everyone.

QUESTION: *My sister's husband has mid-stage Alzheimer's disease and isn't ready for institutional care; however, his care is a strain on my sister. I would like to know if anyone has ever tried anything like a babysitting co-op, in which one person would care for her own loved one and another person's loved one for a few hours in exchange with another caregiver.*

ANSWER: Caring for an individual with Alzheimer's disease at home can become overwhelming to the caregiver. This disease not only affects cognitive abilities, but behavior and communication as well. It also can result in a greater need for supervision. The combination of these issues can leave the caregiver feeling at his or her wits' end.

In fact, research has shown that caregivers are at increased risk for burnout if they do not have a support network in place. A caregiving co-op would be a form of respite, which is a scheduled period of relief from the responsibilities for caring for someone with this disease. Caregivers need this relief in order to maintain their physical, emotional, and mental well-being.

The idea of having a caregiver co-op, in which each caregiver takes turns watching multiple individuals with Alzheimer's disease, can be a creative solution that could benefit everyone involved. Given the fact that in most instances home care is an out-of-pocket cost, a caregiver co-op could be an

alternative for financially-strapped caregivers to have a much needed break. However, careful planning is essential to ensure a safe and positive experience for all.

The first step is identifying the right caregiver to share the care. Some places to consider networking and recruiting include support groups or local places of worship. It is important for all parties to feel confident that each caregiver is responsible, reliable and trustworthy, and has the skills to work with his or her loved one. Also, unless your sister knows the other caregiver well, it would be wise to screen him or her, by running a criminal background check, and asking for employment history, and references.

Another potential benefit to a caregiving co-op is the opportunity for socialization among the individuals involved. Therefore, it is important for the

individuals with Alzheimer's disease to meet one another ahead of time to get a sense of whether it would be a good fit. Some factors to consider include: the stage of the disease in each individual, as well as temperament, personality and shared interests.

Once you identify a potential care partner, it is important to develop an agreement, detailing the dates, times and locations each person will be providing care, a set routine or schedule, and emergency plan in the event an issue should arise. Creating and signing a contract that each caregiver agrees to can help to clarify or prevent misunderstandings or issues.

Your sister might also benefit from exploring more traditional types of respite care, including in-home aides, adult day programs, companion care and overnight respite.

RESEARCH CLIPS

Nature • November 2014

For the first time, researchers have cultivated what they're deeming "Alzheimer's in a Dish." Rudolph E. Tanzi and colleague Doo Yeon Kim of Massachusetts General Hospital in Boston, Mass., grew human brain cells in a petri dish and gave the neurons genes for Alzheimer's disease. This resulted in the development of the characteristic amyloid plaques of Alzheimer's disease. This research could potentially accelerate the testing of new drug therapies aimed at treating the disease.

Neurology (online) • November 19, 2014

People whose jobs require more complex interactions with other people, such as social workers and lawyers, and those who work with data may have longer-lasting memory and thinking abilities compared to people who do less complex work, according to a new study. The study tested the memory, processing speed and general thinking abilities of 1,066 Scottish people with an average age of 70. Researchers also gathered information about the jobs participants held and assigned scores based on the complexity of the work.

Neurology (online) • November 26, 2014

According to a new study, the majority of people with dementia have never seen a doctor about memory and thinking problems. In the study, 845 people age 70 and older were evaluated for dementia. For each participant, a loved one or other close contact was asked whether the participant had ever seen a doctor for any concerns about memory or thinking. Of the 297 participants who met the criteria for dementia, just 45 percent had seen a doctor about their memory problems.

Neurology (online) • December 10, 2014

New research suggests that people who have sleep apnea or spend less time in deep sleep may be more likely to experience the type of changes in the brain that are associated with dementia. The study found that people who don't have as much oxygen in their blood during sleep, which occurs with sleep apnea and conditions such as emphysema, are more likely to have tiny abnormalities in brain tissue, than people with higher levels of oxygen in the blood. These abnormalities are associated with the development of dementia. Previous studies have also shown a link between sleep stages and dementia.

Neurology (online) • January 14, 2015

A new study suggests that depression and other behavior changes may be evident in people who will later develop Alzheimer's disease even before they experience memory problems. Study participants had no cognitive problems at their first visit to one of the Alzheimer's disease centers used for the study. Individuals who developed dementia also developed behavior and mood symptoms such as apathy, appetite changes, irritability and depression sooner than the people who did not develop dementia. In addition, the people who developed dementia were more than 12 times more likely to develop delusions than those without dementia.

JAMA Internal Medicine • January 26, 2015

A recent study suggests that taking high doses of certain over-the-counter drugs, including those found in allergy medicines and sleep aids—or using such drugs long-term—may increase the risk of dementia, including Alzheimer's disease.

THE DISH ON DINING

THE SITUATION

Living with Alzheimer’s disease can make it difficult for individuals to get the nutrition they need. Symptoms of the disease may lead to lack of interest in eating, loss of taste and smell, difficulty swallowing or an inability to feed oneself. In addition, people with Alzheimer’s disease may forget whether or not they have eaten.

Further, it is important to keep in mind that conditions such as diabetes and obesity are also risk factors for dementia.

THE SOLUTION

- **Consult a professional.** Work with your loved one’s physician and a registered dietitian to address dietary concerns while being mindful of other elements of his or her care plan. The care team can help raise flags about foods that may interact with certain medications.
- **Stick to the seasons and think locally.** When possible, strive to purchase local, in-season and organic foods to ensure freshness and reduce the ingestion of synthetic chemicals, pesticides and added hormones.
- **Think Variety, Think Color.** The outside color of a fruit or vegetable can be a good indicator of its nutritional content.

OUTSIDE COLOR	NUTRIENTS	EXAMPLES
Red	Fiber, minerals, vitamins A and C	Tomatoes, peppers, cherries, red grapefruit
Orange	Vitamin A, fiber, potassium, iron, zinc	Carrots, oranges, peaches, yams
Yellow	Vitamins A and C, folic acid, fiber, minerals	Bananas, pears, pineapple, corn
Green	Fiber, potassium, vitamin A, B vitamins	Broccoli, cabbage, green beans, kale
Blue/Purple	Vitamin C, fiber, antioxidants	Blueberries, eggplant, beets, acai

SOURCE <http://www.fruitsandveggiesmorematters.org/maximize-the-benefit-of-eating-fruits-and-vegetables>

- **Go fish! Eat seafood twice a week.** Choose varieties that are high in beneficial omega 3 fatty acids like salmon, mackerel, sardines and trout. Buy from reputable sources to help conserve our oceans’ resources and ensure our seafood supply is safe and sustainable. Visit <http://www.seafoodwatch.org> for a list of safe seafood.



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Layne's Chocolate Tofu Banana Mousse

Serves 4

- 1 banana, broken into chunks
- 12 ounces firm tofu, silken preferred
- 1/4-cup maple or agave syrup
- 2 tablespoons black strap molasses (optional-but adds a nice flavor)
- 5 tablespoons unsweetened cocoa powder
- 3 tablespoons low-fat milk or soymilk
- 1/4-teaspoon ground cinnamon

In a blender, combine banana, tofu, syrup, molasses, cocoa powder, milk and cinnamon.

Cover the blender and blend until smooth.

Pour into individual serving cups or one shallow bowl and refrigerate for at least one hour before serving.

Per serving made with soymilk and including maple syrup and molasses (164 grams): 184 calories, 4.8 grams fat, 32 milligrams sodium, 32.4 grams carbohydrates, 3.9 grams dietary fiber, 9 grams protein



- **Grab a handful of nuts.** Research published in the May 2012 issue of "Neurology" suggests that eating foods that contain fatty acids found in nuts may be associated with lower blood levels of a protein related to Alzheimer's disease and memory issues. Strive for one serving of nuts per day. One serving equals 24 almonds, 18 cashews, 12 hazelnuts, 8 Brazil nuts, 15 pecan halves, 14 walnut halves or 2 tablespoons of nut butter. Always choose unsalted raw or dry-roasted nuts. Nuts are a good source of protein, fiber, vitamin E, trace minerals, and healthy monounsaturated fats with good amounts of fatty acids similar to those found in seafood. When choosing nuts, go for dry-roasted or raw varieties.
- **Steer clear of saturated fat and trans fat.** A diet high in saturated fat and trans fat can clog arteries, restricting blood flow and impacting both heart and brain health. Instead, choose monounsaturated fats such as olive oil, safflower oil and canola oil, or foods like avocados.
- **Shake the salt habit.** Season food with pepper, dried and fresh herbs, lemon and other citrus juices. Check the nutrition labels on grocery products. On average, the ratio of calories to sodium should be one to one. Choose low-sodium varieties of packaged foods like soup and tomato sauce.
- **You're sweet enough!** To avoid empty calories, cut back on refined sugars like table sugar and artificial sweeteners. Use small amounts of natural sweeteners like maple syrup. Otherwise use fruit purées, applesauce and dried fruits to replace sugars.

Contributed by Layne Lieberman, M.S., R.D., C.D.N., an award winning, internationally recognized culinary nutritionist and author of "Beyond The Mediterranean Diet: European Secrets Of The Super-Healthy." This recipe is adapted from her book.



Merrill Weiner, Lou and Toby Reed

© rangizz, Shutterstock, Inc.

A BROTHER'S GIFT

BY MERRILL WEINER

The world recently mourned the death of Lou Reed, remembering him as one of the greatest artists of his generation. My loss was more personal—Lou was my beloved big brother, my one and only sibling. He left to the world his music, his art, his talent. To our family he left many memories but there is one that stands out as the greatest gift he could have given. It came in the form of a physician specializing in palliative care. Lou's gift to our family was Dr. Sean Morrison.

Palliative care is focused on providing patients relief from the symptoms, pain and distress of a serious illness, even when it is not currently life threatening. The goal is not necessarily to cure, although it can and does exist alongside curative treatments, but to provide quality of life for both patient and family.

Our mother, Toby, suffered, as do millions of elderly Americans, from the ravages of dementia. Lou and I watched as her body was steadily robbed of sight and hearing, ultimately unable to walk or to communicate. From a docile, sweet

woman, she had become what some at her assisted living facility called "stubborn, entitled, a diva." We reached out for help—to the staff at the facility, to the in-house psychiatrist, to a well-regarded geriatric center for an evaluation. We wanted someone to help us understand what was happening and what to do and they left us frustrated and confused at every turn. As caregivers, we were experiencing what so many others have discovered—the excruciating dilemma of finding humane and appropriate care for the individual suffering from dementia.

We had come to a breaking point. Toby had been unceremoniously evicted—without concern, without humanity—from her assisted living facility after living there for seven years. They gave us two days to move her. “Find me the best doctor in New York City for Toby,” I asked Lou.

Through friends, Lou located Dr. Sean Morrison, an expert at the Mount Sinai Medical Center in the little known specialty of Palliative Care. The gift had begun. What a difference palliative medicine made. I’ve never told Dr. Morrison what that first evaluation was like for me. We had been treated callously by other physicians, left adrift. And as the world knows, Lou and our parents had lived a tortured relationship. He had forgiven my mother but she never forgave herself for the mistakes she felt she made. So imagine for me, the baby sister, sitting with the kindest, gentlest of doctors with my mother in the room, and I am leaning on my big brother, holding his hand, as the two of us came full circle as a family trying to help my mother. In that moment, I felt Dr. Morrison had allowed

my family to heal. He didn't know that but I am telling him now.

Dr. Morrison gave us our very first accurate diagnosis, that of frontotemporal dementia, a rare form of dementia characterized by loss of personality and inhibition. He helped by giving us much-needed context for Toby’s outbursts, and strategies to reduce her distress and make her comfortable. He saw her as an individual with a specific disease, not just a generic dementia patient.

That meant changing the treatment strategies that had been deemed appropriate by the facilities—less socialization, for example, because of the stress this placed on her lowered inhibition capacities. With the explanations he provided, I educated the staff and the aides who dealt with her. What a difference it made!

As Toby lost more and more of her function, Dr. Morrison was there at each step with innovative care not to prolong a life she did not want, but simply to improve what time she had left. When Toby’s local physician gave up on how to help with her torturous scratching at her skin, his advice was, “call Dr. Morrison.” Dr. Morrison not only didn’t give up, he looked at the reasons a person scratches. He adjusted medications and came up with simple solutions that brought her—and us—months of relief. And anyone with a loved one in this situation knows that a day without crisis is a good day.



Toby Reed, Queen of the Stenographers, 1939



Lou and Toby Reed

That thoughtful and humane approach to care known as palliative care is available to all patients with a serious illness—but the family must know to ask for it. We certainly didn't! And therein lies the problem. People don't know to ask. They don't know that they can do better for their loved ones. Palliative care is the fastest growing medical specialty in the U.S., yet not a single medical professional or social worker had ever mentioned palliative care as an option for Toby.

I hope that sharing our story will equip others with the knowledge to find the care that their loved ones need, the care that their loved ones deserve. I believe in my heart that we as a society must not just prolong life; we must make it bearable and dignified for those who are suffering. Dr. Morrison and palliative medicine allowed my mother some dignity towards the end and helped me to feel peace in my role as a caregiver.

With timing that can only be described as mystical, just 10 short days after her adored son, Lou, passed away, so did our mother. I had told her he had passed and it appeared to me she understood. She sat bolt upright, opened her eyes and spoke an unintelligible sentence with great passion. Toby, I believe you knew and you went to join Lou, to accompany him and thank him as well for this precious gift. Lou, you know I will always love you and I thank you as well. May you both rest in peace.

Palliative Care 101: Understanding the Basics

When he began medical school at the University of Chicago, R. Sean Morrison chose the field of geriatrics because he liked its focus on enhancing quality of life and helping families. Upon entering his residency in New York during the height of the AIDS epidemic, Morrison soon realized that the medical community was not doing enough to stop suffering and enhance quality of life for people in throes of AIDS and other serious illnesses. And so began his interest in the then-developing field of palliative medicine.



Today, Dr. Morrison is director of the Lilian and Benjamin Hertzberg Palliative Care Institute and the National Palliative Care Research Center, where he is committed to helping improve care for people like Toby Reed and her family and to raise awareness of palliative care in the U.S.

"People with advanced dementia are the most marginalized and vulnerable population of people in the United States," Morrison said. "Palliative care should be the standard of care in dementia."

Five Things to Know About Palliative Care

1. *Palliative care is team-based care that involves physicians, nurses, social workers, and chaplains who are focused on enhancing quality of life for people with serious illnesses.*
2. *Palliative care benefits patients, caregivers, family members and loved ones.*
3. *Palliative care treats pain and other distressing symptoms, utilizes skilled communication to set goals of care, help with decision-making and help to coordinate care across settings.*
4. *Palliative care is performed at the same time as traditional care.*
5. *Palliative care is appropriate at any age and at time of diagnosis of any serious illness.*

Palliative care varies depending on the stage of the illness. For people in mid-to early late-stage dementia, Dr. Morrison suggests families ask their physician for a palliative care consultation. People can also look for a palliative care program at their local hospital.

Many skilled nursing facilities will consult with hospice for palliative care of people with end-stage dementia. According to Dr. Morrison, this provides an added layer of support and personal care to the individual with the disease and to his or her family.

For more information or to find a palliative care provider, visit www.getpalliativecare.org.



Clare & Allan Vann

AN ALZHEIMER'S SPOUSE...

Married, yet Widowed

Written by ALLAN S. VANN

My wife, Clare, and I met right after our sophomore year of college, became engaged during our junior year, and married a week after graduation. We were best friends before our marriage and have been best friends and deeply in love for nearly 50 years since.

However, our life as a couple is very different now. Clare has Alzheimer's disease, and in September 2013, she began living in the dementia wing of an assisted living residence. Clare is now confused all the time and both her long-term and short-term memory have long since faded away with two exceptions: She still remembers who I am and still recalls the words to songs.

Due to Clare's worsening illness, we obviously no longer have the same relationship we once had. In many respects, our relationship now is more akin to parent/child rather than husband/wife.

I visit with Clare at her new home after dinner almost every day. We still go out for dinner each week and still get together with friends. We still go to sit on benches on the boardwalk at the beach on nice days, and we still go to the theatre to see musicals on occasion. Clare often falls asleep in my arms in the theatre, but “in the moment” while she is still awake she enjoys singing along with the music. And we still kiss and hug, and say “I love you” to each other every time we are together.

But I have reached the stage now where so many Alzheimer’s spouses find themselves—still married, yet in a very real sense widowed at the same time.

Clare’s roles as my best friend, my lifelong partner, my lover, my wife, our children’s mother have already faded. I have had to learn how to do more things by myself now, alone in the house we had lived in together for more than 40 years. Going to sleep in an empty bed was incredibly difficult that first night after Clare moved into the assisted living residence.

It’s now more than 18 months since Clare’s placement and coming home to an empty house and an empty bed is still difficult for me on some nights. I miss not having her by my side.

When we are together, I do almost all of the talking now for both of us. We can no longer discuss anything for more than a few seconds before Clare gets very confused. It is the rare afternoon when she can express a complete sentence of more than a few words or at least a sentence that I can understand. I miss not having real conversations with Clare.

We can no longer play games, travel, do sports activities, or share virtually any of the experiences we used to engage in as a twosome. I miss all of that, too.

I still find myself crying at my loss—our loss—of the social, emotional and physical parts of our once close marital relationship, and of the once bright future we had as young retirees that Alzheimer’s disease brought to an unexpected abrupt and premature end.

Part of me already wants to rekindle such a relationship with someone else. But while our love still flourishes and Clare is still able to tell me she loves me, how can I seek a close relationship with another woman without feeling tremendously guilty? How can I “date” another woman for that companionship I miss so dearly, let alone have a physical relationship with another woman while Clare is still alive?

Although Clare and I have not had sexual relations in several years, I could still have sex with her if I wanted to because I believe she would do anything for me. But if I were to take advantage of her willingness to please me in bed when she no longer expresses a desire for anything more than kissing and hugging, I would feel terribly guilty. Instead of enjoying mutual sex as we both did for so many wonderful years, I would feel as if I were “using” Clare to satisfy my own physical desires.



Clare & Allan Vann

I am an Alzheimer’s spouse. I am married to the love of my life, but except for a few hours each day when we are together, I now live most of my life as a single man. I grieve for what was and what is. I already mourn. In a very real sense, I am already widowed.

As Clare fades faster and faster, I know that it won’t be too long before Clare no longer recognizes me or knows who I am at all. Maybe then I will feel more comfortable about seeking a serious relationship with another woman.

However, even then, I know that I could not enjoy a sexual relationship with another woman. While Clare is still alive, regardless of condition, personal feelings of love for Clare, sadness about what is happening to her, and guilt about doing anything to tarnish our wonderful marriage will prevent me from doing that.

I know about other changes yet to come. I know that the time is coming closer when Clare’s Alzheimer’s disease will lead to her death. I know all that. I am an Alzheimer’s spouse ... married, yet widowed, at the same time.

IMAGES

Written by **LINDA STURGILL**

Sitting alone in the small room
Faces flash across your inner eye
Familiarity dances at the corner of your memory
Then fades beyond your grasp.
Amid the frustration, a cry comes from within.
"I am Joyce. Do you remember?"

We remember ...
Images of your light curls shimmered in the sunlight
As your long lean legs bicycled on dirt roads.
The softball soared over Hickman's apple tree.
With a smile, you ran the path of bases worn in the grass.
We held hands in the light rain,
Laughing with glee as the puddles washed over our feet.
Darkness embraced us as we ran to kick the can;
Calling "Olly, olly, oxen free," to bring all teammates home.
Your hands playfully led a sibling to the Saturday matinee,
Our dimes held tightly in sweaty palms.
Your adept fingers touched the ivory keys
And effortlessly filled the house with music.
Your lips moved silently in bedtime prayers.
We remember.

In the small room
Voices echo through the corridors of your mind
Then become a cacophony of confusion.
Your once bright, dancing eyes
Now stare vacantly back at us.
Your head slumps as if burdened
By all the nothingness.
Yet again comes the cry.
"I am Joyce. Do you remember?"

We remember ...

This is an excerpt from the poem "Images," by Linda Sturgill of Chillicothe, Ohio. She wrote the poem for her sister, Joyce Smith, who passed away in April 2013, after an eight-year battle with Alzheimer's disease. Sturgill read the poem at Smith's funeral.



Joyce Ellen Barker Smith (left) and her sister, Linda Barker Sturgill (right).

10 Questions with Sebastian Maniscalco

Comedian Sebastian Maniscalco grew up in Arlington Heights, Ill., a suburb of Chicago, and moved to Los Angeles in the early 2000s to follow his dream of doing stand-up comedy. He paid his comedy dues by night, playing his brand of comedy in bars and bowling alleys while working as a waiter at the Four Seasons Hotel in Beverly Hills. He eventually broke into the national spotlight with a 20-city tour in support of his one-hour Comedy Central DVD special. Now, Sebastian has a Showtime stand-up special, entitled “Aren’t You Embarrassed?” and a forthcoming memoir and he is currently touring the country performing. Sebastian is a strong supporter of the Alzheimer’s cause and knows first-hand the toll the disease takes on families. We recently caught up with Sebastian between tour stops.



Courtesy: Anders Krausberg/EB Media PR

Care Quarterly: **How did you get started in comedy? Was there an “aha” moment for you?**

Sebastian Maniscalco: Growing up, whether I was at home or at school, I always enjoyed making people laugh. I can remember making family laugh around the kitchen table. And, where a lot of people are afraid to speak publicly, I actually preferred it to small groups. The “aha” moment was probably in second grade. The teacher went around the room, asking all the kids, “what do you want to do when you grow up?” Most kids gave the usual responses: a fireman, a doctor ... me? I said, “a comedian.”

CQ: **Coming from Chicago, were troupes such as Second City a big influence?**

SM: I studied at Second City and although I enjoyed improv, I gravitated more toward stand-up. I really like coming up with ideas and performing in more of a solo, stand-up setting.

CQ: **You’ve had a pretty intense schedule lately—a Showtime special, a tour and a newly-inked book deal. What’s a typical day like for you?**

SM: I don’t really have a specific day-in, day-out routine. I don’t like doing the same thing every day; that’s why I got into comedy. I like that my day could change at any minute. My schedule allows me to be flexible—both with my career and socially.

Today is Monday; I just did a public service announcement (PSA) on Alzheimer’s disease [Editor’s note: the PSA can be viewed at www.alzfdn.org]. I’m preparing for the week ahead. I have a show coming up in San Francisco, so will be doing some press interviews around that. I do a weekly podcast with another comedian. I go on auditions—I have one tomorrow.

In addition, I’m writing book. I have a deal with NBC for a scripted show, and also am working on an unscripted show that kind of correlates to the book.

CQ: **Tell us about your book.**

SM: The book is a kind of autobiographical collection of funny stories—from childhood through now—through food experiences.

I grew up in an Italian-American family where food was always the conduit to conversation. Today, my wife, Lana, and I enjoy dining out—the restaurants, the culture of food.

Food sparks memories of what we were doing at a specific time while eating certain dishes and it has always left an imprint on my life. For example, my wife is Jewish, so a chapter about our dating may be called “Matzoh Ball Soup.”

Stand-up is rapid fire, but I have a lot of stories that take a while to set up, and this book is another creative outlet that lets me share some of those longer stories.

CQ: What inspires your material?

SM: Comedian Joe Rogan once said: "You want material? Go live your life."

And that's what I do. I draw from life experiences—whatever is going on in my life at the time. I'll take an everyday experience like going to the tech support counter at the computer store and think: "How can I bring this to life in a funny way?"

CQ: How did you get interested in the Alzheimer's cause?

SM: I spent the last 17-18 years getting to this point in my career—all me, me, me. Now, my life is at the point where I thought, "Enough about me, how can I give back?" I have some time to devote to raising awareness and Alzheimer's is a cause that really means something to me.

My grandfather, Joseph DiSanto, had Alzheimer's disease. He lost his wife in 1998, and then a year later, they found him wandering, so my mother took him in. He lived with us until his passing in 2005, and it truly affected the whole family. My raising awareness of Alzheimer's disease is in homage to my grandfather and my mother, who was his primary caregiver.

I'm still learning about the disease—prevention, genetics, etc. There are a lot of questions out there and people shouldn't be afraid to ask those questions.



Josephine and Joseph DiSanto

CQ: What helped you to cope with your grandfather's illness?

SM: As a family, there was always something that was funny throughout the experience. Humor helped us cope with a lot of hard times. And I thought, if I can help shed light on the disease and also bring some laughter, why not?

CQ: What advice do you have for other caregivers?

SM: Alzheimer's disease is a family thing and the whole family has to get behind it. Living with Alzheimer's disease, as a family, really tests your patience. The person with the disease doesn't know what's happening; he or she may have moments of clarity but more moments of disorientation. As a family, you really have to come together and not have one person take on the brunt of it.

CQ: What do you hope people will take away from your shows?

SM: With all that's going on in today's world, the news is all bad, people are looking for a way to detach. If someone comes to the show and forgets their problems for an hour and gets to laugh, and they can leave and share what they saw with other people, that's it, that's the takeaway.

My shows have become a place where multiple generations of family can come and hang out and forget their problems. It's a two-way street: I make them feel good and they do the same for me.

CQ: What's next for you?

SM: My goal was to make a living doing stand-up. Anything else is gravy. I'm always trying to find different avenues to share my comedy. I would like to have my own TV show. I was married a year and a half ago and my wife and I want to start a family. I'm just enjoying the balance of working and spending time with the people I love.

I have no master plan. I'm not trying to take over the world; I'm just trying to make people laugh.



Sebastian (center) with sister Jessica Dadon (l), mother, Rose Maniscalco and father Salvo Maniscalco

My Experience with Volunteerism and Alzheimer's Disease

BY ABHI RAO

My first day volunteering at an Alzheimer's care facility near my home, I felt as if I had stepped into a different world. As my care facility director led me down the hall, I was overwhelmed by uncertainty. It seemed as if time had stopped, and I instantly found myself in a place that seemed devoid of sound. Acclimating to such an environment proved to be a difficult task.

The patients seemed like shadows of their former selves, forgotten by their community. I had heard of Alzheimer's disease before, but to me, it was still information in a textbook. On my quiz bowl team, I was responsible for biology, so I knew terms related to Alzheimer's disease like "tau protein" and "beta-amyloid plaques." I failed, however, to understand that Alzheimer's disease tears apart millions of families across the U.S. Alzheimer's disease places immense stress on relationships. I could hardly imagine the anguish of failing to recognize my family, and the inability to communicate.

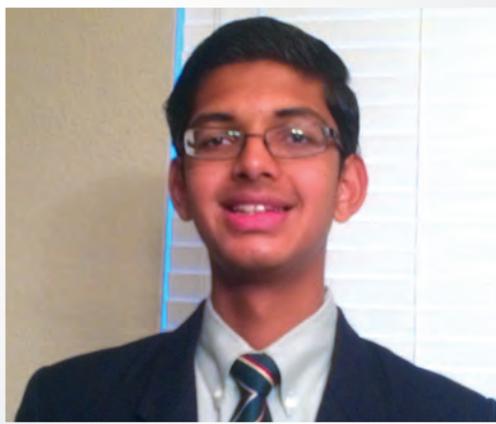
My volunteer coordinator helped me realize that Alzheimer's disease has a vast, but hidden, social cost. Often, family members must sacrifice a job in order to care for a loved one, and some individuals living in a nursing home experience intense grief and anxiety due to separation from their families.

I soon learned that one of the best ways to lessen the devastating social impact of the disease is to soften the pain of alienation that many individuals with Alzheimer's feel. I found that, music, rather

than language, is a useful way to improve patients' alertness and incite emotion. For example, gathering a group of musicians for a performance at a care facility can engage a large group of people.

Some other ways people can get involved include:

- Reading to residents
- Going for walks (within the facility)
- Hosting a social event, such as a dance
- Playing mentally stimulating games, such as crosswords and bingo.



Abhi Rao is a junior at Ronald Reagan High School in San Antonio, Texas. He is on the AFA Teens National Advisory Board. He is also a Hugh O'Brian "young leader."

I was able to organize a group from my middle school band to visit the facility during the holiday season, and perform holiday songs for the residents. I was astonished by the instant transformation the music brought. The residents were so cheerful; some tapped their feet while others clapped their hands.

Youth volunteers can leverage the Alzheimer's Foundation of America's Young Leaders program to rally friends to support the cause. Volunteering at a young age encourages

community involvement, foster a sense of unity, and can help raise awareness of Alzheimer's disease. In addition, youth volunteers can really help lift the spirits of and provide comfort to individuals with Alzheimer's disease.

Combating such a far-reaching, devastating disease requires a collaborative effort, on multiple fronts. While scientists and researchers continue to do their part to work toward a cure, it is important that others take the first step in lending a hand.

AFA Teens was founded by a teenager to help unite teens nationwide in raising awareness of Alzheimer's disease and to engage, educate and support teens and their families. Along with AFA on Campus, AFA Teens is part of the Young Leaders of the Alzheimer's Foundation of America division.

For more information, visit www.youngleadersofafa.org.

Training Healthcare Professionals to Provide Optimal Dementia Care

A solid knowledge base about dementia is essential to any dementia care provider's toolbox, but just being armed with the basics is not enough. Today's professional needs a host of other skills and sensitivities to make a difference in the quality of life of people with dementia and their families.

In recent years, there has been a significant shift toward a culture of dementia care that is person-centered and that values the uniqueness of each individual rather than applying a "one size fits all" approach to care. This philosophy involves interdisciplinary collaboration among care providers and places individuals with dementia and their families at the center of decision-making processes to ensure that care plans reflect their needs and preferences. A tall order? Yes. But one that is critical to promoting wellness and health and improving the delivery of dementia care across the board. In fact, the National Plan to Address Alzheimer's Disease, which was released in 2011 and updated annually since, counts "Enhancing Care Quality and Efficiency" as its one of its goals.

In an effort to better equip today's health care professionals with dementia-specific education, AFA's Dementia Care Professionals of America (DCPA) division has recently revamped its training program. The new, comprehensive training film underscores the importance of relationship-building in dementia care and, in addition to instruction, provides opportunities for self-reflection within each topic area.

"We are proud of this innovative training program, which goes beyond the basics and encourages participants think critically about their work," said



Teepa Snow visits an adult day program.

Kristen Cribbs, M.P.H., AFA's deputy director of educational services. "It is our hope that the film's emphasis on relationship building, as the cornerstone of high-quality dementia care, will cultivate a more skilled and empathetic workforce that is prepared to meet the unique needs of this growing population."

The film features a variety of health care professionals, including renowned industry experts James Galvin, M.D., M.P.H., professor of neurology and psychiatry at New York University's Langone Medical Center; Mark Lachs, M.D., professor of medicine and co-chief of the division of geriatrics and gerontology at Weill Cornell Medical College; Richard Powers, M.D., a geriatric psychologist and neuropathologist and member of AFA's medical and scientific advisory board; and dementia care consultant and educator Teepa Snow, M.S. O.T.R./L., F.A.O.T.A.

In addition, critical perspectives and insights are provided by individuals living with dementia, their families and other care providers, including direct care workers.

Participants who complete the training can take an exam to illustrate their proficiency in the subject matter and become an AFA-Certified Dementia Care Partner. This certification, renewable each year, will require that individuals earn continuing education credits in dementia care-related core competencies.

The new training program will be available later this spring. For more information, contact Kristen Cribbs at 866-232-8484 or e-mail kcribbs@alzfdn.org.



Care planning meetings and activities are highlighted in the film.

DIG IN!

Gardening Sows Seeds for Engagement

Gardening is an activity that many people look forward to each spring and summer; however, this popular activity can pose challenges to individuals with Alzheimer's disease and related illnesses. Heat, mobility and balance issues, and the time it takes for a seed to grow into a plant or vegetable can all make it difficult for someone with dementia to enjoy this once beloved pastime.



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But with a few modifications, gardening can again be an enjoyable and even therapeutic activity for loved ones with Alzheimer's disease.

1 *Keep it simple*

Forego the vegetables and opt, instead, for flats of flowers and herbs.

2 *Elevate the work area*

Use raised gardening beds or window planters to prevent unnecessary bending.

3 *Think small*

The smaller size window planters require less effort and the project can be completed in a shorter time—something to be considered if a shortened attention span or fatigue is an issue for your loved one.

4 *Buy big and bright*

Look for almost fully-grown flowers from the local nursery or market and

choose ones with large, vivid blooms and good color contrast. This makes it easier for them to be seen. Red geraniums planted among large-headed yellow marigolds are a good choice.

5 *Tempt the senses*

Consider filling one window planter with herbs that can be used for cooking and also for their aromatherapy properties.

6 *Prepare the work area*

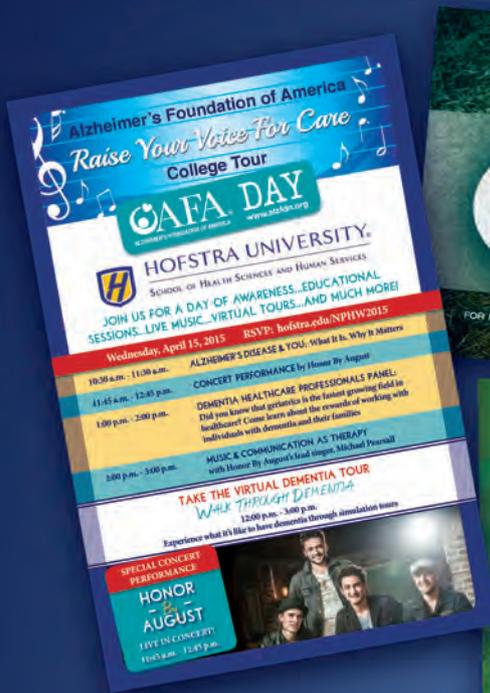
Have your loved one sit outside at a table with all the needed implements at hand. Invite him or her to place the flowers into the boxes. Prompt him or her gently, as necessary during the process, to provide direction. Next, distribute the soil and allow your loved one to tamp it down.

Once the planting is done, your loved one can follow up with the watering and pruning of the plants on an ongoing basis as part of his or her after-breakfast routine.

Contributed by Judith A. Levy, Ed.M., O.T.R., author of "Activities To Do With Your Parent Who Has Alzheimer's Dementia." Levy has been a practicing occupational therapist for over 40 years. She now finds herself in a new role as the child of a parent with Alzheimer's dementia. In this book, she makes use of her personal as well as past work experiences to support others who find themselves in a similar situation. This activity is adapted from her book.

HERE'S WHAT'S HAPPENING!

The Alzheimer's Foundation of America and the Long Island Alzheimer's Foundation have something for everyone!



RAISE YOUR VOICE FOR CARE COLLEGE TOUR - Hofstra University
 Wednesday, April 15, 2015 || 10:30 a.m. - 3:00 p.m. || RSVP: hofstra.edu/NPHW2015

CARE CONNECTION TELECONFERENCE
 Thursday, May 14, 2015 || 1:00 p.m.-2:00 p.m. ET
 Thursday, June 11, 2015 || 1:00 p.m.-2:00 p.m. ET
 Thursday, July 9, 2015 || 1:00 p.m.-2:00 p.m. ET
 Thursday, August 13, 2015 || 1:00 p.m.-2:00 p.m. ET

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>

LIAF CELEBRATING WOMEN WHO MAKE A DIFFERENCE
 City Cellar Wine Bar & Restaurant || Wednesday, May 6, 2015 || 12 noon-2:00 p.m. ET

CONCEPTS IN CARE EDUCATIONAL CONFERENCE - New York Hilton Hotel
 Friday, May 15, 2015 || 8:00 a.m.-3:00 p.m. ET || To register: <http://alzfdn.org/registration>

LIAF GOLF CLASSIC - Sands Point Golf Club || Monday, June 8, 2015

AFA GOLF CLASSIC - Fresh Meadow Country Club || Monday, September 28, 2015

THE ALZHEIMER'S FOUNDATION OF AMERICA'S NATIONAL MEMORY SCREENING PROGRAM IS EXPANDING!



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](http://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