

AFA Care Quarterly™

FREE

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

Winter 2017

We're Hitting the Road in Celebration of Our 15th Anniversary

Educating America Tour

Concepts in Care Educational Conferences

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“Individual commitment to a group effort—that is what makes a team work, a company work, a society work, a civilization work.” - Vince Lombardi

These words ring especially true as we kick off our 15th anniversary year. The commitment of the individuals who make up the Alzheimer’s Foundation of America’s dedicated board of directors, staff, member organizations, volunteers, and supporters has truly made this organization work. It is that group effort and commitment that:



- helped us grow our membership network to more than 2,600 organizations nationwide;
- has afforded us the opportunity bring our free Concepts in Care educational conference to thousands of people across the country;
- allowed us to expand the hours of our national toll-free helpline, and offer more support groups than ever before;
- helped increase our professional training offerings; and
- aided us in providing grants for important research toward treatments and a cure for this disease that has affected so many millions of people. See page 10 for just one example.

Fifteen years on, we remain steadfast in our commitment to providing optimal care and services to individuals living with Alzheimer’s disease and to their families and caregivers. One key way we do this is through education, which is a vital part of caregiving.

In 2017, we are introducing AFA’s Educating America Tour, a national tour featuring our Concepts in Care educational conference. This year, we will visit 15 states, sharing insights from dementia and caregiving experts, providing free, confidential memory screenings, and displaying panels from the AFA Quilt to Remember, the nation’s first large-scale quilt that pays tribute to individuals living with Alzheimer’s disease and their caregivers. Read more about the tour beginning on page 4.

And, of course, as with any new year, there will be changes to government programs, such as Medicare. An overview of what’s new in Medicare for 2017 can be found on page 6.

On page 12 are some fun and easy ways to help recharge almost any caregiving routine with activities to help care partners and individuals with dementia better connect.

Finally, on page 17 is the story of Master Gunnery Sergeant Willie L. Collins, shared by his daughter Retanya. It is a journey of the heart. When his wife passed away after a car accident in 1969, Collins gave up the military job he loved for a civilian job so that he could care for his five children. Diagnosed with Alzheimer’s disease in 2006, and now in the later stages of the illness, Collins’ sacrifice and love of his children is being returned via their coming together as a team and lovingly caring for him.

We will remain committed to the tremendous group effort of supporting, educating and caring for individuals living with Alzheimer’s disease and their families, and we thank you for helping us make it work.

Take good care,

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

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ALZHEIMER'S FOUNDATION OF AMERICA CELEBRATES 15TH ANNIVERSARY WITH 15-STATE EDUCATIONAL TOUR

In 1980, Anne Brodsky was diagnosed with Alzheimer's disease. At the time, there was little information on the illness and nowhere to turn for guidance and support. Years after she passed away, her son, Bert Brodsky, set out to ensure that families living with Alzheimer's disease did not have to face the illness alone. Brodsky founded the Alzheimer's Foundation of America's (AFA) in 2002—15 years ago—as a resource for individuals with Alzheimer's and related illnesses and their families. Today, AFA has grown to a network of more than 2,600 member organizations nationwide that are dedicated to providing optimal care and services to the more than 5 million Americans living with Alzheimer's disease and their families. In celebration of its 15th anniversary, AFA is kicking off the "AFA Educating America Tour,"

a 15-state tour that aims to help educate people about Alzheimer's and the availability of services and programs.

Each tour stop will include AFA's signature "Concepts in Care" Educational Conference for family and professional caregivers, individuals with dementia and the community. Attendees will learn from leading dementia and caregiving experts about topics such as clinical trials and research, access to healthcare, transitioning from home to a residential care setting, safeguarding one's space, long-term care, and perceptions of aging. The tour will also include community memory screening events, where people can take advantage of free, confidential memory screenings, and a display of the AFA Quilt to Remember.



“AFA is here to offer caregivers education, strategies and support to help them succeed at every step of their caregiving journey,” said Charles J. Fuschillo, Jr., AFA’s president and chief executive officer. “What better way to celebrate our 15th anniversary than to travel the country sharing our resources and bringing awareness of the need for greater caregiver supports, treatments and ultimately, a cure for this devastating illness?”

AFA’s 15th Anniversary Educating America Tour is made possible by the generous sponsorship of premier presenting sponsor, The Edward N. and Della L. Thome Foundation, Bank of America N.A., Trustee; gold sponsors, Allergan, Eli Lilly and Company and Merck; teal sponsor, CVS Health; and community sponsor, Kmart Pharmacy. **The tour will make the following stops:**



Location:	Date:
San Francisco, Calif.	February 22
Las Vegas Nev.	March 7
West Palm Beach, Fla.	March 27
Phoenix, Ariz.	April 5
Tri-State New York/New Jersey area	May 5
Philadelphia, Pa.	May 19
Tennessee/Kentucky	June 7
Charlotte/Raleigh, N.C.	June 20
Virginia/Washington D.C.	September 14
Long Island, N.Y.	September 26
Chicago, Ill.	October 19
Indianapolis, Ind.	TBD
Boston, Mass.	October 26

Currently, Alzheimer’s disease is the sixth leading cause of death in the United States and the only disease in the top 10 leading causes of death without a cure or meaningful treatment. Until there is a cure, education and advocacy are critical for people who are impacted by the disease.

For more information on AFA’s Educating America Tour, visit www.alzfdn.org or call AFA’s national toll-free helpline at 866- 232-8484.



WHAT'S NEW IN MEDICARE

AN OVERVIEW OF NEW COSTS FOR 2017

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Costs for Medicare coverage—whether Original Medicare or a Medicare Advantage Plan, sometimes called a Medicare private health plan—can change each year. Following is an overview of 2017 Medicare Parts A, B, and D costs, as well as tips for getting assistance with these costs.

MEDICARE PART B

Medicare Part B covers common types of health care such as doctors' visits; durable medical equipment; preventive care; lab tests and x-rays; outpatient physical, speech, and occupational therapy; outpatient mental health services; and home health care.

Part B Premium

The 2017 Part B premium is not the same for everyone. The base premium is \$134 per month for individuals who have an annual income of less than \$85,000 (\$170,000 for couples). People protected by the "hold harmless provision" in 2017 will pay a different amount.

A person is **protected by the hold harmless provision** if:

- S/he was entitled to Social Security benefits for November and December of 2016, and
- The Part B premium was or will be deducted from those benefits for November 2016 through January 2017.
- The majority of people with Medicare are protected by the hold harmless provision.

If protected by hold harmless provision, the 2017 Part B premium will go up the same amount that the individual's Social Security award increased as a result of the Cost of Living Adjustment (COLA). In 2017, the COLA is 0.3 percent. If, for example, an individual's Social Security award amount was \$1,000 in 2016, it will be \$1,003 in 2017. If a person's Part B premium was \$104.90 in 2016, then it will increase by \$3, the amount of the COLA, for a total Part B premium of \$107.90 in 2017.

The average Part B premium for people protected by the hold harmless provision is \$109, but the premium may be higher or lower. People should check their Social Security statement or contact the Social Security Administration (SSA) at 800-772-1213 to find out what their Part B premium is for 2017.

The **hold harmless provision does not apply**, and an individual will be assessed a base Part B premium of \$134 if s/he:

- is new to Medicare.
- already pays higher Part B premiums because s/he has a higher income.

- is enrolled in a Medicare Savings Program (MSP), government programs that help pay Medicare costs for people with limited finances. The MSP will continue paying the person's full Part B premium as long as s/he is enrolled, so s/he will not be responsible for the increased amount.
- was enrolled in a Medicare Savings Program in 2016 but lost the program because her/his income increased or he did not recertify.

Part B Deductible and Coinsurance

Individuals who have Original Medicare, will pay a Part B deductible of \$183 in 2017. They will continue to pay a 20 percent coinsurance for services covered by Part B. The amount people pay for Medicare Advantage Plan deductibles, copayments, and/or coinsurances varies by plan.

MEDICARE PART D

Medicare Part D provides outpatient prescription drug coverage and is available through private insurance companies. People who have Original Medicare get Part D through a "stand-alone Part D plan." For people who have a Medicare Advantage Plan, their plan usually includes prescription drug coverage.

Be sure to review Medicare Part D costs, benefits, and any changes in 2017. The national average for a monthly Part D premium in 2017 is \$35.63. Individuals who have an annual income above \$85,000 (\$170,000 for couples), may pay an extra amount in addition to their Part D premium. Other monthly drug costs may vary based on their plan and which Part D coverage period they are in:

- **Deductible period:** The period during which the individual pays the full cost of medications until she/he meets the deductible. While deductibles vary from plan to plan, no plan's deductible can be higher than \$400 in 2017.
- **Initial coverage period:** This period begins after an individual's deductible has been met (if her/his plan has one). During this period, individuals will pay a portion of the cost of their drugs (coinsurance or copayment: varies by the drug and by the plan), and

the plan will pay the rest. Most plans' initial coverage period ends after an individual has accumulated \$3,700 in total drug costs in 2017.

- **Donut hole/coverage gap:** The period when an individual's plan does not pay as much for his/her drugs. For most plans, this period begins when the amount paid by the individual and her/his plan on drugs for the year totals \$3,700, and ends when the individual has spent \$4,950 out of pocket on covered drugs (including costs before the coverage gap begins, but not including premiums). A person's costs during this period will often be higher than at other times.
- **Catastrophic coverage:** After an individual has spent \$4,950 out of pocket on covered drugs for the year, s/he reaches catastrophic coverage, the period when the individual will pay 5 percent of the cost of each drug, or \$3.30 for generics and \$8.25 for brand-name drugs—whichever is greater—in 2017.

MEDICARE PART A

Medicare Part A covers inpatient hospital services; skilled nursing facility services; home health care; and hospice care.

For people who have a Medicare Advantage Plan, that plan provides their Part A coverage. For individuals who have the same Medicare Advantage Plan in 2017 that they had in 2016, their plan should have sent them an Annual Notice of Change (ANOC) or Evidence of Coverage (EOC) notice explaining any changes for the coming year.

Below are the Medicare Part A costs for 2017 for people with Original Medicare:

Original Medicare Part A Premium:

- \$0/month for people who have worked more than 10 years
- \$227/month for people who have worked between 7.5 and 10 years
- \$413/month for people who have worked fewer than 30 quarters (7.5 years)

Original Medicare Hospital Deductible

- \$1,316 each benefit period

Hospital Coinsurance:

- \$0/day for days 1 – 60 once the individual has met her/his deductible
- \$329/day for days 61 – 90 each benefit period
- \$658/day for days 91 – 150 (non-renewable lifetime reserve days)

Skilled Nursing Facility Coinsurance

- \$0/day for days 1 – 20 each benefit period (after a minimum 3-day inpatient hospital stay)
- \$164.50/day for days 21 – 100 each benefit period

GETTING ASSISTANCE WITH MEDICARE COSTS

There are a number of ways that people with Medicare get assistance with their Medicare costs:

- **Employer Insurance** - If the individual or her/his spouse is still working and has insurance through that job, it will work with Medicare to cover the person's health care costs.
- **Retiree Insurance** - Some employers provide health insurance to retirees and their spouses to fill in the gaps of Medicare coverage. Retiree insurance always pays secondary to Medicare.

- **Supplemental Insurance (Medigap):** If eligible, individuals can purchase supplemental insurance from a private insurance company to fill in the gaps in Original Medicare coverage. The Medigap may pay Medicare deductibles, coinsurances and copayments. Depending on where the person lives, there are up to 10 different Medigap plans to choose from: A, B, C, D, F, G, K, L, M, and N (plans in Wisconsin, Massachusetts, and Minnesota have different names). Each offers a different set of benefits. Premiums vary, depending on the plan and the company it is purchased from.
- **Medicare Advantage Plan (such as an HMO or PPO):** While premiums may be low, service costs may be higher than in Original Medicare for certain services. Medicare Advantage Plans must have annual limits on out-of-pocket costs. Although these limits are usually high, they should help protect an individual who needs a lot of health care from excessive costs.

A person who has limited income may also be able to get assistance through certain programs, such as:

- **Medicaid:** Individuals who have a low monthly income and few assets may be eligible for coverage from Medicaid to pay Medicare costs and for health care not covered by Medicare, such as transportation to medical appointments.

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- **Medicare Savings Programs:** Individuals who do not qualify for Medicaid, but still have problems paying for health care, may qualify for government programs that help pay their Medicare costs. All Medicare Savings Programs pay the Medicare Part B premium and the Qualified Medicare Beneficiary (QMB) Program covers deductibles and coinsurances as well.
- **Extra Help:** Assistance paying for the Medicare drug benefit: If an individual's monthly income is up to \$1,505 (\$2,022 for couples) and her/his assets are below specified limits, s/he may be eligible for Extra Help, a federal program that helps her/him pay for some or most of the costs of Medicare prescription drug coverage. Note: These income limits include a \$20 income disregard that the Social Security Administration automatically subtracts from monthly unearned income.

Even if a person's income or assets are above the limit, s/he may still qualify for Extra Help because certain types of income and assets may not be counted. For example, part of a person's earned income and her/his house will not be counted.

People who are enrolled in Medicaid, Supplemental Security Income (SSI) or a Medicare Savings Program (MSP) automatically qualify for Extra Help. They do not have to apply for this extra assistance.

OPPORTUNITIES TO CHANGE COVERAGE IN 2017

People who are dissatisfied with their Medicare Advantage (MA) Plan can switch to Original Medicare during the Medicare Advantage Disenrollment Period (MADP), which runs January 1 through February 14 each year. During this period, individuals can switch from their MA Plan back to Original Medicare and enroll in a stand-alone Part D plan, but they cannot switch from one MA Plan to another, and they cannot change their coverage if they already have Original Medicare.

For questions about changing coverage in 2017, contact the State Health Insurance Assistance Program (SHIP) at 877-839-2675, visit the SHIP website at www.shiptacenter.org, or call the Medicare Rights Center's National Helpline at 1-800-333-4114.

LEARN MORE

To learn more about Medicare coverage and costs, visit Medicare Interactive (www.medicareinteractive.org), the Medicare Rights Center's free online resource that has hundreds of answers to Medicare questions, or call the Medicare Rights Center's National Helpline at 1-800-333-4114.

Joe Baker, an attorney, has been president of the Medicare Rights Center since June 2009 and served as the organization's executive vice president from 1994 to 2001. Prior to that, he was deputy secretary for health and human services in New York State under Governor David A. Paterson. Baker also served as assistant deputy secretary for health and human services, directed the Health Care Bureau of the New York State Office of the Attorney General, and was associate director of legal services for Gay Men's Health Crisis.



Medicare Rights is a national, nonprofit consumer service organization that works to ensure access to affordable health care for older adults and people with disabilities through counseling and advocacy, educational programs and public policy initiatives. Medicare Rights is the largest and most reliable independent source of Medicare information and assistance in the United States.



UNCHARTED TERRITORY: EXPLORING A NEW RESEARCH PATHWAY

Dr. Peter Davies

In 1974, Peter Davies moved to Scotland to do research in schizophrenia. He found the work desperately frustrating because there is no pathology to that illness, and it is surrounded by diagnostic uncertainty. Not sure how to proceed, he consulted with neuropathologist, A.J.F. Maloney and shared his weariness with the subject. Dr. Maloney suggested he consider studying Alzheimer's disease. Upon seeing the characteristic plaques and tangles of the Alzheimer's, Davies was captivated. He began researching the illness in 1975, and published his first Alzheimer's paper in 1976.



"I was fascinated the minute I started researching Alzheimer's disease, and have not wanted to do anything else since," said Davies, who is now a Ph.D., and director of the Litwin-Zucker Research Center for the Study of Alzheimer's Disease, at the Feinstein Institute for Medical Research (part of Northwell Health).

Davies' latest research is in an uncharted area. He and his team, which includes geriatric psychiatrist, Jeremy Koppel, M.D., and a staff of 22 others, are exploring the underlying causes of some of the more disturbing behaviors associated with Alzheimer's disease—agitation, hallucinations and aggression—as a means for identifying ways to treat them.

"Our research has suggested that these symptoms are actually a part of the disease pathology in likely half the people who have the illness," said Davies.

These behaviors are a major cause of families moving a loved one from home to a residential healthcare setting.

"When your wife of 40 years starts yelling at you, hitting you and telling you to get out of the house, it is a very difficult and emotional situation," Davies said. "Families struggle so much."

Currently, the only medications used to treat these symptoms are the powerful antipsychotic drugs used for schizophrenia. In the elderly, even small

doses of that kind of drug can have a very dulling effect on the individual, and yet do not address the issue. These drugs are also associated with a higher rate of mortality, cardiovascular disease and stroke in older individuals.

The team seeks to fill a huge gap with this research. Almost no one researches psychosis in Alzheimer's disease because it is very difficult to work with individuals exhibiting these symptoms. As such, few have seen firsthand what this illness can do.

"People tend to tune out because they don't know what the problem is and what it's like to live this scenario every day," said Davies.

The Alzheimer's Foundation of America (AFA) recently awarded Davies and his team a \$500,000 grant to support the study.

AFA board member, Luisa Echevarria; Dr. Peter Davies; AFA board chairman, Bert E. Brodsky; and AFA president and CEO, Chuck Fuschillo



RECHARGING THE ROUTINE

Enrich Daily Life with Easy, Engaging Activities

By Deborah Shouse

How am I going to stay connected with my mom throughout her dementia journey? That was a key question for me, one that I explored throughout our time together.

I wanted to find new ways for my mom to enjoy her life. I also wanted activities we could do together. I tried many ideas, including simple cooking projects, singing, and sitting outdoors. In the years since her death, I have continued this exploration. I've interviewed dozens of innovators from all over the globe. These experts use art, music, gardening, technology, nature, and more to foster creative and emotional connections.

Studies show that doing activities together benefits both partners. Each person can look forward to more energy, reduced anxiety, and chances to express themselves in new and meaningful ways.

HERE'S EVEN MORE GOOD NEWS: THESE ACTIVITIES ARE ADAPTABLE FOR ALL AGES AND ABILITIES, AND NO SPECIAL TALENTS ARE REQUIRED. HERE ARE A FEW IDEAS TO TRY AT HOME:

Cook up a Connection

People want to be useful, and fixing a meal or a treat offers a hands-on and delicious way to enjoy time together.

Here are some tips for connecting in the kitchen.

- Look through a favorite family cookbook or recipe box. Use the pictures and recipes as a conversation starter. Ask open-ended questions, such as, "What does that brownie recipe make you think of?" Or, "What do you like about baking?"
- Select a special recipe to make together. Choose simple and safe tasks for your partner, such as measuring, adding ingredients, stirring, and tasting.
- Have fun sampling your work when the cooking is done.

Helpful hint: even if people living with dementia can't help prepare food, they can still enjoy sitting in on the action.

Tune into Favorite Songs

As usual, Henry was slumped in his wheelchair, eyes closed, hands in his lap. His care partner put headphones on Henry and turned on an iPod, which contained Henry's favorite tunes from the 1940s. When the music started, Henry suddenly raised his head and opened his eyes. He smiled, snapped his fingers, and tapped his feet, echoing his old dance steps. Such responses fueled the international Music and Memory movement, started by Dan Cohen from Brooklyn, N.Y.

Today, thousands of people living with dementia are waking up their creative spirits through music. And thousands of care partners are also benefitting from



this program. You can start by just slipping on a favorite CD and listening together. Then you can enjoy building your playlists together.

Listening to music and singing were ways I stayed engaged with my mom. I always felt happy after we sang together. A recent study from Dr. Teppo Sarkamo in Helsinki, Finland, explains why. Dr. Sarkamo's research found that regular musical activities help maintain cognitive ability and improve mood and quality of life for people living with dementia. Singing is also a relaxing activity for both partners.

Dr. Jytte Lokvig, from Santa Fe, N.M., facilitates sing-along groups in memory care communities. She believes that music is a doorway to creating connections.

"Even when I do an art activity, I start with a few songs to knit us together," she says.

Sharing daily musical activities with your loved on is a simple way to connect.

Laugh Often

The meeting room was packed with people pretending they're having cell phone conversations and laughing heartily. This role-playing session was one of thousands of "Laughter Club" meetings worldwide. People came together for the purpose of happiness and healing through a series of playful, easy to-do laughter exercises.

"Laughing is a skill anyone can master and laughter yoga is ideal for people living with dementia," says Madan Kataria, M.D., from Mumbai, India, the founder of the Laughter Yoga movement. "It's an aerobic workout that helps lift your mood within minutes by releasing endorphins from your brain cells. You often remain energized, relaxed, and in good spirits throughout the day."

Dr. Kataria created a unique routine that combines laughter exercises with yoga breathing.

In California, Carmela Carlyle is a dementia care specialist, certified laughter yoga teacher, and the creator of the training DVD, "Laughter Yoga with Elders." She has seen how the practice lights up people who have advanced dementia.

"Sometimes people laugh for the first time in years," she says. "Laughing brings out memories of happy times with friends. We are social beings. People with dementia can connect through laughing and being around laughter."

But just how can one put that into practice with, for example, activities of daily living? Carlyle suggests the following:

"When helping a partner dress, you might say, 'The left leg is going into the pants. Ha. Ha. Ha. Right foot going into the shoe. Ha. Ha. Ha.'"

When driving to medical appointments, Carlyle likes to laugh during red lights. She recommends looking at the clock and saying, "Let's see if we can laugh for five seconds straight!" Make it a game throughout the day. You can also include laughter into your visits with family and friends.

"Even if your partner doesn't laugh right away, that's fine," Carlyle says. "You help yourself when you laugh and your partner benefits from the sound of laughter."



Hold onto Hobbies

When Mara Botonis' beloved grandfather was diagnosed with dementia, she was determined to help him continue to enjoy his life-long passions, which included golf and playing cards.

Botonis, author of *When Caring Takes Courage*, understood the care partner's tendency to let creative time slide in favor of practical matters: dressing, feeding, and bathing.

"I wanted him to have the best possible life, so I learned to put having fun ahead of laundry and dishes," said Botonis.

Here are some ways she kept her grandfather involved in his passions:

For a time, he walked the golf course and played with caring friends. When he could no longer play, he still enjoyed being driven around the course. He loved the scent of freshly mown grass, the rolling green lawns, and the sound of a well-hit ball. At home, the family set up an indoor putting green and watched golf tournaments on television with him.

Family gin rummy sessions were another favorite. When her grandfather could no longer track the game, Botonis asked herself, "What is important about these family competitions?"

She realized the game was an excuse for talking, laughing, and eating potato chips and dip. Even when her grandfather couldn't play, he still liked sorting the cards by suits and sitting around with his family.

To adapt hobbies, think: "what is most important about the activity?" For example, for gardeners, is it the feel of their hands in the soil? Is it producing flowers or harvesting vegetables? Is it having something to nurture and care for? For those who like quilting, is it the finished product or making the squares? Is it the social aspect of being with other quilters? Or the feel and colors of the fabric? You can then use that information to adapt the hobby to the person's abilities.

Seed the Conversation

Lately Colin, who was living with dementia, seemed bored and depressed. His wife Angela was having a hard time staying cheerful. Then she remembered the list she'd made at a recent care partners' workshop—a collection of her own favorite memories, sayings, and simple pleasures.

"When the care partner is worn out, their partner senses that," says Karrie Marshall, author of *Puppetry in Dementia Care*. "Creating cards with quotes, ideas, and fond memories can lift your spirits."

Care partners can use these cards when they need a personal boost or a topic of conversation. Some care partners paste an inspiring quote, a shared memory, a line from a favorite song, or a family joke on each card. They then can share the card with the person living with dementia, using it as a conversation trigger.

After breakfast, Angela might hand Colin a card that says, "Our weekend at the lake," and tell him:



"I've been thinking about the time we went to the lake and you decided to swim across to the other side."

Colin nods silently; she knows he doesn't remember.

"It was before we were married," she says. "We took a picnic and you swam across the lake and back while I watched you."

"I was a good swimmer?"

"You were and you are. You swam all during high school and kept it up all your life. In fact, we're going to the pool tomorrow."

Angela smiles as she talks to Colin. Even though he's not saying much, he's listening. And she's enjoying talking about their shared adventures.

Getting the Most Out of Creative Activities

When selecting creative activities, keep in mind that a good activity should be easy, fun for both the individual with dementia and the care partner, and suited to both care partners' abilities. In addition, it should be meaningful and pressure- and deadline-free. Here are some tips to get started.

- ✓ Choose a quiet space free of distractions. Select a time of day when both the individual with dementia and the care partner have enough energy.
- ✓ Choose a project both partners enjoy and prepare any supplies in advance.
- ✓ Approach the activity with a spirit of playfulness. Take risks and try new things. Celebrate whatever happens, whether it's an amazing watercolor scene or yellow marks on a plain white paper.
- ✓ Allow the project to unfold at its own pace. Offer support and encouragement along the way.
- ✓ Give notice when winding down the activity and offer an easy transition into whatever is next.
- ✓ Thank the person with dementia for doing the activity with you.

Why not try recharging the caregiving routine with some of these suggestions?

Deborah Shouse is a writer, speaker, editor and dementia advocate. Deborah's newest book, "Connecting in the Land of Dementia: Creative Activities to Explore Together," features dozens of experts in the field of creativity and dementia. Portions of this article are excerpted from her book. To learn more, visit DementiaJourney.org



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TO YOUR HEALTH

The cooler weather months are an ideal time to enjoy root vegetables. Because they grow underground, root vegetables absorb many of the nutrients found in the soil. They are high in antioxidants and fiber and low in calories. They come in a wide array of colors sure to brighten even the darkest winter days. Roasting is an easy way to prepare and enjoy root vegetables.

Roasted Root Vegetables *Serves 6*

Ingredients:

- 3 cups parsnips, scrubbed or peeled, then sliced on the bias into ½-inch-thick pieces
- 3 cups carrots, scrubbed or peeled, then sliced on the bias into ½-inch-thick pieces
- 1 cup rutabagas, peeled and cut into wedges
- 1 cup turnips, peeled and cut into wedges
- 1 cup beets,* peeled and cut into wedges
- 1 teaspoon chopped fresh thyme or rosemary
- 2 teaspoons cold-pressed extra virgin olive oil
- 3 Tablespoons freshly-squeezed lemon juice
- ½ teaspoon freshly-ground black pepper
- ½ teaspoon salt

Method:

- Preheat oven to 375° F.
- Place vegetables in a steamer basket. Add an inch of water to a large saucepan pan and insert the steamer basket. Bring the water to a boil over high heat, then cover and reduce heat to medium. Cook for 6 to 8 minutes, or until half-cooked, **OR** place vegetables in a loosely-covered microwavable dish with ½ inch water and microwave for 4 minutes.
- Drain vegetables and evenly toss with thyme or rosemary, olive oil, lemon juice, pepper, and salt.
- Spread vegetables on a non-stick or foil-lined rimmed baking sheet and roast for 35 to 40 minutes, until vegetables are fork-tender.

**Smaller beets tend to be sweeter than larger ones. Save the beet greens and steam them for another meal.*

Nutrition Facts per serving (based on 6 servings): 115 calories, 2 grams fat, 280 mg sodium, 642 mg potassium, 23.8 grams carbohydrate, 6.3 grams dietary fiber, 2.3 grams protein. Excellent source of vitamins A and C.



Recipe and photo by Layne Lieberman, M.S., R.D., C.D.N., culinary nutritionist and award-winning author of "Beyond the Mediterranean Diet: European Secrets of the Super-Healthy." For more information and recipes, visit www.WorldRD.com.

SHARE YOUR STORY

MY STORY

Submitted by: **Retanya Collins**



From left: Mamie Collins & Master Gunnery Sergeant Willie L. Collins, Retanya Collins, Ruby, Michael and Myia Collins

My life changed forever September 17, 2011, when I received the call that my stepmother, Ruby, who was 10 years younger than my dad, had passed from a massive heart attack. You can imagine how shocking this news was when she had never been sick!

My two children and I moved in with dad that evening. Since he had dementia, he could not be left alone. Ruby was my dad's primary caregiver. Even though many of his five children offered to help and to try and relieve her, she always turned down the offer.

Dad has had dementia since 2006 and it escalated into Alzheimer's in 2011, after Ruby's passing. He is currently in the later stages of the illness and can no longer communicate; however, he indicated in both his will and his health directive that he wanted to stay in his home for as long as possible.

Fortunately, we are able to fulfill this wish with the help of many caregivers and siblings and grandchildren to this day. Dad—Master Gunnery Sergeant Willie L. Collins—dedicated 21 years of his life to service in the U.S. Marine Corps. After we lost our mom in a car accident in 1969, dad had to leave what he loved the most, the U.S. Marine Corps., because he would have had to go overseas. As the only parent of five children, he chose to get a civilian job to care for his kids. Knowing the sacrifices Dad made, made it easy for me to make the decision to move in with and care for him. He cared for us when we lost our mom.

Dad is 85 years young and enjoys watching golf, the Chicago station, (he is from St. Louis, not sure where watching this station comes from), Los Angeles Lakers, and any football game! His eyes light up when you serve him ice cream. His favorite is black walnut or pistachio nut. Dad is like my third child; however, he eats well, and for the most part sleeps well.

We all make sure he is well cared for and show him all the love we can. He has taught my children what love is and how you do not abandon your family in their time of need. Both my kids have developed more kindness and forgiveness, and they are not afraid to show their love for their grandfather.

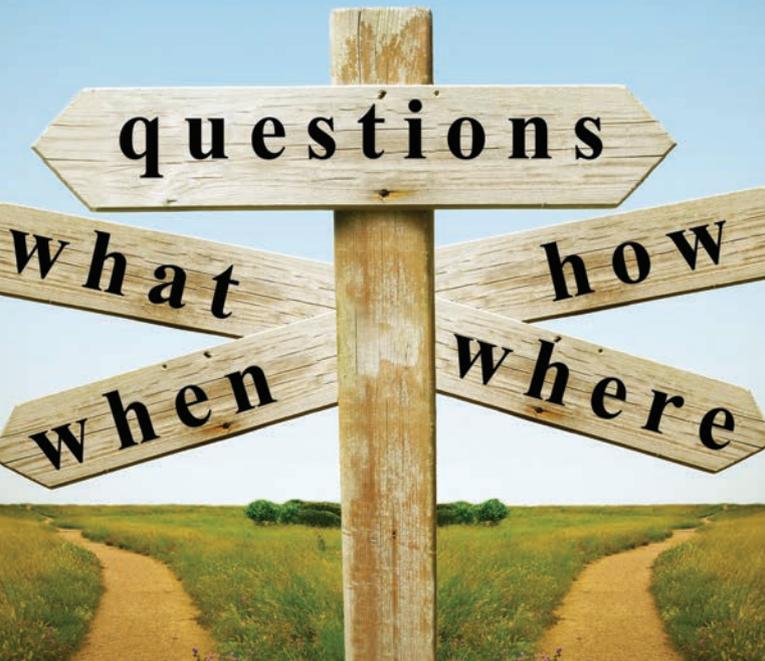
I asked Dad if he wanted me to write his military story before the disease progressed and he said yes. I had the book published last year and he recognizes his name on the book cover and keeps a copy of the book on his nightstand. The name of the book is: "Top A Proud Marine."

Our family has been affected by this terrible disease; however, it has brought us closer together and we never lose sight of how important it is to care for our dad, my hero! I pray for a cure ASAP so that my children and their children will not have to endure what their grandfather has endured.

Want to see your story here? In honor of our 15th anniversary, we'll be celebrating the triumphs and challenges, laughter and tears of caregiving. Feel free to send us stories, poems, essays, anecdotes, and photos, and you may just see them in a future issue of AFA Care Quarterly.

Send your stories to: Amanda Secor, Alzheimer's Foundation of America, 322 Eighth Avenue, 7th Floor New York, NY 10001 or e-mail asecor@alzfdn.org.

ASK AN AFA SOCIAL WORKER



A Q&A WITH LAUREN SNEDEKER, L.M.S.W., A MEMBER OF AFA'S SOCIAL SERVICES TEAM



QUESTION: *I am a social worker new to this field. Although I receive great guidance and support from my colleagues at the hospital, I am the only social worker working directly with a neurologist and individuals living with dementia and their families. Is there any additional support for professionals like me?*

ANSWER: Caregiving, in its different forms, can be taxing. It sounds like you are facing challenges in feeling fully supported by your colleagues due to a lack of shared experiences. You may share a story about working with a family who is reacting to the news of a new diagnosis and your colleagues, friends and family may not understand the accompanying emotions you are feeling. And, while your experience may not be the same as that of the family caregiver in that situation, it is,

nonetheless impactful. AFA recognizes the need for support across the entire caregiving spectrum—for the individual who is living with the illness, for the family of that individual and also for the care professionals serving the individual and family.

From your letter, I can see that you recognize that self-care is vital, and I encourage you to continue to look for opportunities to get support. You may be interested in joining AFA's new telephone-based support group, which is geared specifically toward professional caregivers of individuals with dementia. The group, which kicks off February 2, will provide a shared connectedness and an opportunity for individuals to learn more about best practices in dementia and self-care.

QUESTION: *My wife has been diagnosed with dementia. I am her caregiver, and although my children and other family are supportive, I don't feel comfortable telling them EVERYTHING that I am feeling. Can you help?*

ANSWER: It is understandable that you may want to shield your children and friends from some of what you are feeling about your wife's diagnosis. For example, you may be thinking "this wasn't part of our plan," or "sometimes, I just get so frustrated, I want to scream." Perhaps you feel that sharing your emotions or asking for help may burden your children and family or be perceived as complaining. Maybe you also feel pressure to always wear a smile in the presence of others. Keep in mind that you have the right to feel all of these things and express only what you choose.

That said, I encourage you to explore other outlets that will give you a space to express your emotions and feelings about your and your wife's new life chapter. Whether it's enlisting a family member or friend to spend time with your wife so you can run an errand, meet a friend for coffee or play a round of golf, it is important that you honor what you are feeling and take time for yourself. Doing so will help you be a better caregiver.

In addition, attending a support group may help you become more comfortable sharing and also help you gain tips and strategies from other spouses who may have similar caregiving experiences and emotions. AFA offers an ongoing telephone-based, support group for spouses of individuals living with Alzheimer's disease. It takes place Thursdays from 7-8 p.m. ET.

If you'd prefer to speak with someone one-on-one, AFA's national, toll-free helpline (866-232-8484) is staffed by licensed social workers who are available Monday through Friday, 9 a.m. to 9 p.m. ET and Saturdays from 9 a.m. to 1 p.m. ET.

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HAVE A QUESTION?

Please feel free to call AFA's national toll-free helpline at 866-232-8484 if you have additional questions or need further support, information, clarification or referrals to local resources.



Introducing the All New

AFA EXCELLENCE IN CARE DEMENTIA CARE PROGRAM OF DISTINCTION

In 2006, the Alzheimer's Foundation of America (AFA), developed the Excellence in Care (EIC) Dementia Care Program of Distinction to establish a nationwide standard of excellence for care settings that provide care to individuals with Alzheimer's disease or related illnesses. During the past 10 years, best practices in dementia care have evolved significantly, and so has EIC. AFA is proud to introduce the all new AFA Excellence in Care Dementia Care Program of Distinction.

A Commitment to The Highest Quality Care

Through comprehensive on-site assessments and personalized consultation, AFA-trained EIC specialists work with participating facilities to enhance their dementia programs by targeting crucial facets of care, ranging from staff education to the physical environment to meaningful living and active engagement.

Facilities across the country have achieved the status of Alzheimer's Foundation of America

Excellence in Care Dementia Program of Distinction, demonstrating their commitment to quality care and meaningful living for their community members.

Who Can Participate?

Assisted living residences, skilled nursing facilities, continuing care residential communities, adult day programs, group homes, and senior centers that provide care to individuals living with dementia are eligible to participate in EIC.

AFA is also looking for individuals who would like to be trained as EIC specialists to help with the evaluation process.

Learn More

To learn more about AFA's Excellence in Care program, visit www.excellenceincare.org or contact Molly Fogel, AFA's director of educational and social services at 866-232-8484 x131 or mfogel@alzfdn.org.



Alzheimer's Foundation of America's **FREE** Concepts in Care Educational Conference

February 22 • 8:30 a.m.-2:30 p.m.

The Bently Reserve-Banking Hall • 301 Battery St • San Francisco, CA 94111

Discussion topics include:

Unraveling Alzheimer's Disease

Access to Healthcare: Meeting the Needs of a Diverse Population

Caregiver Stories

The FrameWorks Project: Aging

Music as Therapy



Loren Alving, MD
UCSF Fresno
Alzheimer's &
Memory Center



Dillon Campbell,
son of
Glen Campbell

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**For more information, or to register,
call 866-232-8484 or visit www.alzfdn.org**

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THE HARDEST CROSSWORD

ACROSS

- 1 **Pat** lived with these for much of her life
 5 Pear or apple, e.g.
 9 **Pat**'s friend who was a frequent visitor to her home
 14 Calculus calculation
 15 Like some postgrad exams
 16 St. Theresa's city
 17 While in a car, **Pat** reads aloud every ___ sign she sees
 18 Chances of **Pat** recognizing her son
 19 A brother of **Pat**
 20 **Pat**'s father's middle initial
 21 Either of two masses near the pharynx
Pat's middle name
 23 Hard to fathom
 24 Suffix with ethyl
 26 **Pat** would be paranoid about the bathroom being ___
 29 Title for McCartney, a member of **Pat**'s favorite band
 31 **Pat**'s favorite dish
 35 **Pat** couldn't serve a ___ she had prepared because the olives had shifted out of place
 38 Look ahead
 40 Come down in sheets
 41 **Pat** preferred ___-conscious products
 42 **Pat** was born here
 45 **Pat** once went out to her mailbox and was found wandering ___ blocks away
 46 "The Lion King" lion
 48 King-size
 49 **Pat** and her husband at Thanksgiving dinner, traditionally
 51 **Pat**'s favorite restaurant

- 53 "Tell Dad I'll meet him at the ___" (message **Pat** never passed along)
 54 **Pat** went to church on this day, thinking it was Sun.
 55 Crude oil qty.
 57 ___ ghanouj (Eastern dish **Pat** didn't like)
 61 Craven who directed **Pat**'s favorite horror movie
 64 Groups of species
 66 Weekday when **Pat** forgot a doctor's appointment: Abbr.
 67 Like **Pat**'s late father, in her delusions
 69 Homecoming attendee
 70 Inaugural Ball, e.g.
 71 **Pat** couldn't remember how to apply eye ___
 72 **Pat** used to carry a can of this for protection
 73 Reason to rent a tux, perhaps
 74 Along with mountain's **Pat**'s favorite things in nature
 75 **Pat** used to sing "The Look in Your ___" by Maze
 76 Bastes, e.g.

DOWN

- 1 Gave a hoot
 2 Cropped up
 3 Make sport of
 4 How forgetfulness made **Pat** feel
 5 To help **Pat** remember, her husband made a ___ with names and pictures of her children and grandchildren
 6 Fabric created by DuPont
 7 **Pat** and her husband spent their honeymoon here
 8 Trees common in McNairy County, where **Pat** spent a holiday
 9 Hardwood sources
 10 May ___ (Rd. near **Pat**'s house in Richmond)

1	2	3	4		5	6	7	8		9	10	11	12	13
14					15					16				
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72							73				73			
74							75				76			

- 11 Pop singer Ora
 12 Secluded spot
 13 Bring home
 22 "___ to shower" (**Pat**'s frequent request after taking a bath)
 25 Pro bono TV ad
 28 Bit of body art, for short
 30 **Pat**'s friend from her old neighborhood
 31 **Pat**'s son would stay in the right ___ so **Pat** could read road signs
 32 Understands
 33 Politico Gingrich
 34 "Famous" cookiemaker

- 35 "___ my greetings to the neighbors" (message **Pat** forgot to pass along)
 36 **Pat** liked this trendy berry
 37 Hang in the hammock
 38 Good quality
 39 **Pat** would do this between sentences
 43 Number of **Pat**'s siblings
 44 "Caught ya!"
 47 ___-country (music genre)
 50 Sun or moon, poetically
 52 Boring tools
 53 Holds liable
 55 Secure, as a ship's line
 56 **Pat**'s husband

- 58 Initially, **Pat** was ___ of her problems, and tried to cover them up
 59 In the cargo hold, say
 60 **Pat** saw a sign that read "___ Steel Co." and mentioned that her father worked in steel 55 years before
 61 Where **Pat**'s 5-Down hung
 62 Director Kazan
 63 **Pat** would clean this several times a day
 65 **Pat** couldn't remember her mother's ___
 68 Churchillian gesture
 70 **Pat** couldn't drive home without one

Can't find the answers?
 Neither can Pat.

This crossword is based on the true story of how Pat Y.'s life has been impacted by Alzheimer's disease.

Learn how the Alzheimer's Foundation of America can provide help for individuals living with dementia, as well as for their families and caregivers.



Call our national toll-free helpline at 866-232-8484 or visit www.alzfdn.org