Alzheimer’s Won’t Define Who I Am

Brian LeBlanc Talks About His Life With Young-Onset Alzheimer’s
MISSION: “TO PROVIDE OPTIMAL CARE AND SERVICES TO INDIVIDUALS LIVING WITH DEMENTIA — AND TO THEIR CAREGIVERS AND FAMILIES — THROUGH MEMBER ORGANIZATIONS DEDICATED TO IMPROVING QUALITY OF LIFE”

FEATURES

PAGE 4
AFA’s Washington Update

PAGE 7
Caregivers’ Guide to Making the Most of a Family Meeting

PAGE 8
On the Road Again

PAGE 10
Alzheimer’s Up Close and Personal

PAGE 12
A Walk In The Park

IN EVERY ISSUE

3 A MESSAGE FROM OUR PRESIDENT AND CEO
16 TO YOUR HEALTH
17 ASK AN AFA SOCIAL WORKER

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Front Cover: Brian LeBlanc
“An investment in knowledge pays the best interest.”

— Benjamin Franklin

Knowledge is an invaluable resource which should be accessible and available to everyone. That is a guiding principle for us here at AFA. Whether it’s through our National Toll-Free Helpline, National Memory Screening Program, research projects or other programs, we work every day to equip individuals with knowledge to help them deal with the challenges Alzheimer’s disease poses.

Our winter 2018 issue features stories about people and programs that are working to empower individuals living with Alzheimer’s disease, caregivers and all Americans through knowledge and understanding.

For our cover story, Brian LeBlanc shares his experiences living with young-onset Alzheimer’s to raise awareness, reduce stigma and help give caregivers a better understanding of how to help those living with the disease.

We discuss our Educating America Tour, which is once again traveling to states across the country to provide information and resources to families affected by Alzheimer’s disease, professional care partners and the general public.

A special feature tells the story about a first-in-the-nation Respite Care Relief Park, which gives caregivers and individuals living with Alzheimer’s disease a dementia-friendly place they can go to relax and learn about services available to help them.

Finally, you can learn about Emory University’s Alzheimer’s Disease Research Center’s grassroots outreach program which is helping connect underserved African-Americans with early detection services, support and research information.

We hope you enjoy this issue. If you have an idea for an article or would like to share a story of your own for possible publication in a future AFA Care Quarterly, please feel free to send it to us at info@alzfdn.org or mail it to our office at 322 8th Avenue, 7th Floor, New York, NY 10001. We look forward to hearing from you.

Take good care,

Charles J. Fuschillo, Jr.
President & CEO
Alzheimer’s Foundation of America
2017 was a busy year for Alzheimer’s policy. Despite a tumultuous and divided climate on Capitol Hill, the fight against Alzheimer’s disease remains bipartisan, with passionate champions advancing our cause on both sides of the political aisle.

We saw advancement on some issues, while others— including a possible increase in Alzheimer’s disease research funding for fiscal year (FY) 2018— are still being worked on as of the writing of this article.

The following is a summary of major action taken by Washington and what lays ahead in 2018.

WHAT GOT DONE:

New tax reforms
A new federal tax law was adopted which makes significant changes to tax rates, tax brackets, deductions, and the overall tax code.

For those living with dementia and their family caregivers, the law preserves the medical expense deduction which many rely on to help offset the significant costs associated with health care, supportive services, and senior living. The law also lowers the threshold needed to qualify for the deduction from 10% to 7.5% for the 2017 and 2018 tax years.

AFA will continue to monitor possible impacts to programs such as Medicare, Medicaid and Social Security should there be revenue shortfalls resulting from the tax code changes in future years.

New Postage Stamp to Raise Funds for Alzheimer’s Research
Over the last several years, AFA has been working with the United States Postal Service (USPS) and policymakers to issue an Alzheimer’s semipostal stamp. Semipostal stamps are first-class mail postage stamps sold above the regular first-class stamp rate to raise funds for designated causes. The net difference between the two rates is contributed to the specific cause. On November 30, 2017, the USPS unveiled a new Alzheimer’s semipostal stamp, with net proceeds going to the US Department of Health and Human Services (HHS) to fund Alzheimer’s research. The stamp will be sold for two years.

AFA is working with Reps. Waters (D-CA) and Smith (R-CT) and Sens. Markey (D-MA) and Collins (R-ME) on legislation (H.R. 2973/S. 2208) to extend issuance of the Alzheimer’s stamp to six years, enabling additional funds to be raised for Alzheimer’s research.

Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act
Both the House and the Senate passed the RAISE Family Caregiver Act (H.R. 3759/S. 2208), which was signed into law by President Donald Trump. Modeled on the National Alzheimer’s Project Act (NAPA), the law calls for development of a national strategy to support family caregivers. It will bring together stakeholders from the
private and public sectors to recommend actions, in a national comprehensive plan, that communities, providers, government, and others can take to make the responsibilities of caregiving a bit easier. AFA has long supported both measures and applauds our federal representatives for working together in a bipartisan manner to pass the law. The legislation was introduced by Reps. Gregg Harper (R-MS) and Kathy Castor (D-FL) in the House and Senators Susan Collins (R-ME) and Tammy Baldwin (D-WI) in the Senate.

HHS Releases Draft Strategic Plan for 2018-2022

HHS released its proposed strategic plan for 2018-2022 and solicited input from stakeholders, including AFA. The strategic plan is an “inspirational” document which defines the agency’s mission, goals, and the means by which it will measure its progress in addressing specific national problems over a four-year period.

AFA strongly advocated for greater access/opportunity for memory screening and increased implementation of person centered care models. AFA also called for HHS to increase dementia training for hospital personnel, encourage adoption of dementia friendly communities and step up efforts to increase participation in clinical trials.

WHAT’S ON THE HORIZON:

FY 2018 Federal Budget

In 2017, both the House and Senate Appropriations Committees approved separate federal budget packages that include large increases for Alzheimer’s disease research funding at the NIH. In the House, appropriators approved a $400 million increase for Alzheimer’s disease research in FY 2018. The Senate was slightly more generous, coming in with a $414 million increase. Current spending for NIH Alzheimer’s research is $1.4 billion, so passage of either of these FY 2018 appropriations bills will increase that level to at least $1.8 billion. AFA has asked for at least $2 billion in funding, the minimum amount leading scientists say is needed to achieve a cure or treatment by 2025.

Yet, various obstacles remain before Congress can vote on a FY 2018 budget. Among these is lifting budget caps put in place during the Budget Control Act of 2011. Failure to lift these caps could put the possibility of any future increase for Alzheimer’s disease research in jeopardy since spending in the FY 2018 budget package that has been agreed to by Congressional appropriators is above cap limits.

CHRONIC Care Act

In 2017, the Senate unanimously passed the Creating High-Quality Results and Outcomes Necessary to Improve Chronic (CHRONIC) Care Act. Of importance to those living with dementia, the Act extends the Independence at Home (IAH) demonstration for two years and increases the number of Medicare beneficiaries that can be included in the program from 10,000 to 15,000. The IAH demonstration provides shared savings incentive payments to medical teams providing high quality home-based care to Medicare beneficiaries with multiple chronic conditions, including dementia.

In the House, a similar provision extending IAH was approved by the House Energy and Commerce Committee as a “stand alone” bill. It is expected that the approved IAH measure could be incorporated in a future “must pass” health care bill. AFA supports the Act’s passage because it potentially enables people to remain in a home-care setting longer and improves efficiencies in care delivery.

AFA has long supported innovative, person-centered, team-based care models—like IAH—that provide better outcomes, increase efficiencies and save care resources for people living with dementia and their families.

AFA will continue to be a voice and strong advocate on Capitol Hill for advancing a policy agenda that will increase access of care and resources to all those living with dementia and their family caregivers.
Families are a vital part of the caregiving and support structure for someone living with Alzheimer’s disease. It's important for family members to be on the same page, have open lines of communication and work together to support their relative.

Family meetings are a valuable tool to bring the care team together to share information, collaborate on decision making and divide tasks among family members. They are also a way to keep the individual living with Alzheimer’s disease involved in decisions about their own personal care.

Meetings should be held regularly and, as needed, when there is a change in your loved one's condition or care plan. Utilize technology such as FaceTime, Skype, video conference or cell phone to connect family members living in other geographical areas. Whenever possible, try include the person living with Alzheimer’s.

To make the most out of your family meeting, start by setting realistic and attainable goals. Meetings are often most effective when they have structure; schedule start and end times and create an agenda beforehand. Limit topics to one or two items in order to keep the meeting on track. Encourage all family members to contribute ideas to the agenda and come prepared with relevant information to the discussion topics, such as doctor’s notes or legal documents.

Before the meeting starts, assign roles, such as who will lead the discussion or take notes. Some families prefer using an outside facilitator, such as a social worker, clergy member or other professional to help guide the meeting and ensure that everyone's voice is heard.

During the meeting, maintain a culture of respect and acceptance. Sticking to the facts of your loved one's care, such as a change in his or her physical abilities, rather than dealing in opinions is a good way to keep the meeting from becoming emotional or heated.

If a family member becomes angered or stressed, take a break to let them cool down and process their emotions. Being a caregiver for a loved one with Alzheimer’s is no easy task, and people deal with the stresses and emotions of that responsibility in different ways. Beyond doing your best, there is no "right" way of being a care partner. Acknowledge the strengths of others and try not to be judgmental of their limitations. Be open to compromise and willing to accept solutions that are “in the ballpark” of your expectations.

After each meeting, send a summary of the decisions and agreements that were made to everyone who participated. Clearly define everyone’s responsibilities, so that each family member knows his or her respective tasks. Utilize a family calendar which includes medical appointments, activities and important deadlines and outlines each individual’s responsibilities and commitments.

Finally, remember that not everything will be solved at once. Take things one day at a time, do the best you can to keep moving forward and support one another. You’re all on the same team working towards the same goal; ensuring your family member with Alzheimer’s receives the best care possible.

Have questions or need assistance? Connect with one of AFA’s licensed social workers by calling our National Toll-Free Helpline at 866-232-8484 or online through AFA’s website, www.alzfdn.org.
AFA’s national Educating America Tour is heading back out on the road again, stopping in 15 states in 2018. Launched last year in celebration of its 15th anniversary, AFA’s “Educating America” tour brings information about Alzheimer’s disease directly into communities across the country.

“The main goal of the Educating America tour is to connect people with information that will help them,” said Charles J. Fuschillo, Jr., AFA’s President and CEO. “So often, people don’t know where to turn to find information about Alzheimer’s disease, get caregiver support or have their questions answered. We want to make it easier by bringing it to them in their own communities, all under one roof.”

The success of the initial educational conference, which was held in New York State, confirmed the need for AFA to embark on a national tour. As part of its 15th anniversary, AFA wanted to take it to a whole new level by holding conferences throughout the US.

The 2017 tour provided services to thousands of individuals from California, Nevada, Florida, Alabama, New York, New Jersey, Pennsylvania, Tennessee, Kentucky, Washington, DC, North Carolina, Indiana and Illinois. At each stop, participants received updates on Alzheimer’s research from
some of the country’s leading experts. Free memory screenings were offered throughout the day. Workshops taught a variety of caregiving tips and strategies; in Indianapolis, participants learned about safety precautions they should take to help prevent individuals living with Alzheimer’s from wandering, a dangerous and potentially life-threatening behavior associated with cognitive impairments. The audience at the Chicago conference literally played a role in a session on improving communication, acting out common scenarios caregivers face on a daily basis and learning how to use the principles of improv to think on their feet and work with what their partner gives them to communicate effectively.

The conferences also featured a caregiving panel with moving talks from family caregivers who graciously shared their stories about caring for their loved one with Alzheimer’s. From the logistical challenges of organizing legal and financial affairs to the day to day stresses that all caregivers face, the speakers talked about the knowledge and lessons they learned as caregivers in order to help others who were going through similar experiences.

AFA looks forward to helping even more people through the 2018 Educating America Tour. We hope to see you on the road!
That’s how Brian LeBlanc of Knoxville, TN often begins his talks about living with young-onset Alzheimer’s. Since being diagnosed, he has been remarkably open about his life with the disease, aiming to raise awareness, reduce stigma and let families affected by Alzheimer’s know they’re not alone.

“Millions of individuals and their families across the United States and around the world are all dealing with the same challenges,” said Brian. “None of us are alone.”

Dementia has been a part of Brian’s life for years before his diagnosis. His maternal grandmother, maternal grandfather and mother all had Alzheimer’s disease, and his father lived with vascular dementia.

Several years ago, Brian started noticing a change in himself too. His personal “intervention” moment came when he got lost driving to his doctor’s office. He received help in getting to his destination and when he got home, he was told that this had been happening many times over the last several months, and given his family history, that he needed to see a doctor. On October 28, 2014, the diagnosis came back as young-onset Alzheimer’s. “For the first three days after my diagnosis, I stayed in bed feeling sorry for myself. Then I realized I had a choice; continue to wallow in self-pity or get up and make a difference. Choosing the second option was one of the smartest decisions I ever made.”

Sharing what it’s like to have Alzheimer’s, from the physical symptoms to the feelings, and everything in between, was the best way Brian thought would provide a voice for those who can no longer speak for themselves and help caregivers and their families understand what people with Alzheimer’s are going through, so they can improve the level of care and quality of life. So that’s what he did.

Using his talents as a former public relations and marketing professional, he started blogging and publicly speaking about his experiences so that others could learn from them.

“The best analogy to describe Alzheimer’s is a ‘fog,’” LeBlanc explained. “Imagine driving on a highway; on a clear day, you can see a crystal clear, picturesque landscape . . . then the fog rolls in.

“I have Alzheimer’s, but it doesn’t have me for I don’t allow it to define who I am!”
You can’t see anything in front of you. Everything slows to a slow crawl. That’s what it’s like in my brain; every day, a ‘fog’ rolls in that prevents me from remembering; it stays for varying periods of time, sometimes just for a few seconds, other times longer. When it leaves, everything is alright. But it always comes back.”

“Things change as the disease progresses. Unfortunately, there are things which I can no longer do, which I miss terribly. Having grown up in New Orleans, eating delicious food was a huge part of my life, but that has changed because of how the disease impacted my sense of taste and smell. Cooking remains a passion of mine, but I now have to follow a recipe.”

“Despite all that, I don’t view getting diagnosed as the end of my life, instead, it’s the beginning of my new one. And it can still be a good life; you just have to adapt.”

He also offers personal tips to help deal with the symptoms and challenges of the disease. For starters, Brian encourages getting up and getting out (“staying idle is no good”). Human interaction is extraordinarily beneficial; staying engaged socially and/or professionally is of the utmost importance.

Music and hobbies are two tools he advises using to stimulate the brain and provide normalcy and comfort. As an avid traveler before his diagnosis, he still tries to go to familiar destinations, such as Walt Disney World (his favorite), which brings back many warm feelings and fond memories.

Having a strong support system is not just a logistical necessity, it also provides a comforting feeling (“knowing that someone is a phone call away if I need help is extremely comforting”). Brian also recommends that individuals living with the disease have discussions with their loved ones and make decisions as early as possible relating to their health care, financial and personal affairs. By expressing their wishes, they are ensuring that they have a role in the process, rather than having someone else make those decisions for them without their input.

In addition to raising awareness, one of Brian’s main advocacy goals is to reduce the stigma of Alzheimer’s disease. As an example, he shares the frustration of once being out in public and having someone ask his care partner, “how is Brian doing?” as if he wasn’t there, despite the fact that he was standing directly beside her.

“Dementia-related illnesses unfortunately have a huge stigma associated with them, and it often affects relationships. Individuals with Alzheimer’s sometimes cannot speak for themselves, but they are alive inside and have a voice. The day before my diagnosis, I was forgetting things; just because my forgetfulness now has a name doesn’t change who I am.”

“People shouldn’t be afraid to talk and joke with me and treat me like they always have, because inside, I’m still me.”

He’s also been very candid about his own emotions. Having watched so many of his loved ones battle this disease, he “certainly doesn’t wear rose colored glasses when it comes to Alzheimer’s.”

“Alzheimer’s disease takes people away from us long before they are physically gone. It’s painful knowing that my family dynamic will continue to change, I may not be able to walk my daughter down the aisle or watch my son graduate college. We’ve talked about that but it makes you cherish each moment, each hug or kiss, no matter how small or insignificant, that much more.”

Alzheimer’s has presented Brian with many challenges and trying moments. But being able to channel those experiences into something positive and make a difference in the lives of others who are going through the same thing is something for which Brian is very grateful.

“I love being an advocate. Even though there is no payment, there are extraordinarily rewarding benefits. It’s the best job I ever had.”
Alzheimer's disease affects people of all races and ethnicities. More than 5 million Americans are currently living with Alzheimer's, including more than 50,000 Long Islanders.
Babylon Town’s First-in-the-Nation Respite Care Relief Park for Individuals Living with Alzheimer’s Disease and their Caregivers.

Located in the suburbs of New York City, the Town of Babylon is like many suburban areas; it’s got homes, small businesses and a tight-knit community. But the Town of Babylon now has something that no other place in America has; a park designed specifically for people living with Alzheimer’s disease and their caregivers.

The Town and AFA partnered to create the park, which was funded through a grant provided by AFA, to give caregivers a special place where they can go to take a break, enjoy the outdoors and bring their loved one with Alzheimer’s.

“We wanted to make sure that our residents living with this devastating disease and their caregivers had a safe and comfortable place to visit outdoors that also provided them with information to help them in their time of need,” said Babylon Town Supervisor Rich Schaffer. “Working with AFA, we came up with this innovative, compassionate project.”
An estimated 50,000 Long Islanders live with Alzheimer’s disease, and as many as 200,000 more serve as family caregivers. Knowing the impact Alzheimer’s has on the community, the Town of Babylon has been working with AFA over the last several years on ways to make the Town more dementia friendly. They held memory screening programs...
for residents, provided dementia training for staff members and hosted educational events to raise awareness in the community. Creating the Respite Care Relief Park became the next step in those efforts.

“Socialization is critically important for individuals living with the disease and their caregivers,” said AFA’s President & CEO, Charles J. Fuschillo, Jr. “Staying isolated indoors is extremely detrimental; it accelerates both the progression of the disease and caregiver burnout. Caregivers sometimes find it hard to go out with their loved one to a public place and be able to relax. This park is designed specifically to give them that place.”

A picturesque, tranquil location was chosen; the site is nestled near a lake, children’s playground and Babylon Town Hall. With a parking lot nearby and an entrance right off a main roadway, the spot’s functionality and accessibility match its beauty.

Work began in August of 2017 and took approximately two months to complete. A wide brick walkway lined with decorative landscaping was created. The pathway leads to a gazebo equipped with USB port docking stations. This enables caregivers to plug in their phones and play music for their loved one to help aid in both relaxation and cognitive stimulation.

Educational signs were installed along the walkway, providing information about Alzheimer’s disease, respite care services, therapeutic activities for individuals living with Alzheimer’s and stress management for caregivers.

The Town of Babylon officially opened the park with a ribbon cutting ceremony on November 2, 2017.

Local residents came and loved what they saw.

“We’re always looking for someplace else to go,” said one caregiver who came with his father who has Alzheimer’s disease. “A lot of times, we just sit in the backyard. To be able to come to a place like this will be nice.”

In the short time since its opening, the Park has been widely embraced and utilized by members of the community. It is also a tremendous source of pride for the Town.

Babylon will not be the only place with a Respite Care Relief Park for long; AFA plans on using the Babylon model to create additional parks across the country.

“Our goal is to take what’s been done here and customize it for other communities throughout the US. Babylon’s park is the first, but it will not be the last,” Fuschillo concluded.

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CHOOSE ORGANIC INGREDIENTS WHEN AVAILABLE:

- 1 garlic clove, minced
- 1/2 large white onion, diced
- 1/4 teaspoon red pepper flakes
- 5 ounces fresh baby spinach
- 3/4 cup Arborio or sprouted rice
- 4 cups low sodium chicken or vegetable broth
- 2 large eggs
- 3 tablespoons fresh lemon juice
- 1/4 teaspoon dried dill

Greek-Style Spinach, Rice & Lemon Soup

Recipe and photo by Layne Lieberman, MS, RD, CDN, 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

Heat olive oil in a large saucepan. Add garlic and onion and cook over medium heat until slightly translucent. Increase heat to medium-high and add red pepper flakes and rice. Cook for about two minutes, then add broth. Bring soup to a boil, then lower heat to a simmer for 15 minutes, or until rice is barely tender. Allow soup to cool for at least 10 minutes.

Meanwhile, in a large bowl, whisk eggs then add in lemon juice. Whisk for 2 to 3 minutes. Add 1/3 cup of the cooled soup to the egg and lemon juice mixture; whisk vigorously. Whisk in another 1/3 cup of the cooled soup.

Add the egg mixture into the large saucepan whisking well. Add the spinach to the saucepan. Return the soup to a low simmer and stir for about 10 minutes. The soup will thicken slightly. Garnish with dill.

Bon Appetit!

Makes about 5 cups.

Note: You can use a “No Salt-Added” broth to further reduce the sodium in this recipe.

Nutritional Information:

Per serving: 179 calories, 4.1 grams fat, 74 milligrams cholesterol, 665 milligrams sodium, 25.5 grams total carbohydrates, 2 grams dietary fiber, 1.7 grams sugar, 9.7 grams protein.

This Mediterranean-style soup, typically served in Greece, is one of my favorites! In Greece the name is Avgolemono. The eggs give the soup a velvety texture and the lemon adds a punch of tanginess. If you follow a vegetarian diet, choose vegetable broth instead of chicken broth. This soup makes a satisfying meal, sprinkled with Parmesan cheese and served with crusty wholewheat sourdough bread.
Question 1:

My neighbor has Alzheimer’s, but her husband is in denial of her disease and care that would help her. He has become dependent on myself and other neighbors for support. I do not mind helping, but I want to create boundaries and help him to get care in his home. Any suggestions?

Denial is a psychological process whereby humans protect themselves from anxiety by blocking out the reality of an unpleasant truth. As a result, your neighbor may be shutting out the reality of needing to seek help so that he doesn’t have to accept his wife’s illness. This can be a common occurrence in care partners, and broaching the subject of accepting assistance can be a complex process. Your friend’s husband may also find it difficult to talk about this matter as it will mean admitting his wife has this disease, something which can cause feelings of fear, anxiety, grief, regret and a host of other emotions. As your friend’s husband experiences this denial reaction, you may want to be sensitive with him.

Although he is resisting connecting with resources, he has been relying on his neighbors and friends which can be his way of showing his need for help. It seems like the neighbors and friends are his anchors of support right now and he needs you more than you know. Although it sounds as though you have reached your limit with helping him, know that just your presence and support is an invaluable gift. You can start out by letting him know you are concerned and want to help him seek out support for his wife.

That being said, it is also important for you to be aware of your own limits and limitations, and find ways for you to effectively communicate these limits to your friend’s husband. While it can be challenging to say “no” in response to requests for help, if you become clear on what you can and cannot do, it will be easier to express and set those boundaries with your friend’s husband. For example, once you become clear on the kind of role that you want to take in your friend’s care, you can approach him and perhaps say, “I am happy to help out with your wife as much as I am able, but I have other responsibilities in life that also require my attention. I can only imagine how stressful of a situation this must be for you and...
want to be there for you and your wife, but it is important to me to have respect for my own boundaries. Can we sit down and discuss a schedule that will work for both of us?” This kind of communication will hopefully set the stage for a more open dialogue around what your friend requires and the role that you are able to play in her care. After giving voice to what you can and cannot do, it may be helpful to suggest that your friend’s husband look into community services. You can try saying, “I know how much you rely upon me and our other neighbors and we are here to help, but it may be useful to connect with community services to provide you and your wife with extra support. I’ve done some research and would be happy to help you connect with these resources.”

In efforts to help your friend, her husband and bring you all support, I would like to inform you about a couple of available options that may be beneficial for your neighbor. Many care partners benefit from obtaining respite care. Respite refers to rest and relief, a break from the caregiving responsibilities to create space and time to care for themselves. This can include in-home assistance, like an aide, or having their person attend an adult day program. In addition, he may like to be part of a support group.

A good starting point would be for you to refer him to AFA’s helpline. At AFA we have licensed social workers that can speak to your friend’s husband. By speaking to the social worker, who is not a friend or family member, he may feel more comfortable to open up about his emotions, feelings related to denial and get information for respite care. We can be reached at 866-232-8484 and are happy to assist.

**Question 2**

*As a family caregiver, I’m glad I can be there for my loved one, but at times I feel extraordinarily stressed trying to tend to their needs while also handling additional personal responsibilities, such as my other family members and my job. What can I do?*

The pressures of being a care partner can lead to feelings of being overwhelmed and stressed; often this feeling is referred to as “caregiver burnout.” Caregiver stress can be caused by anything that requires you to adjust to a change in your environment and family situations. For example, with this disease there are many new tasks and plans of care that need to be arranged and explored. Having these new additions to your already busy schedule can leave you feeling pulled in one too many directions. As we know, there are only 24 hours in a day and often those hours do not match all we have to accomplish. We all have our own ways of coping with all these added responsibilities and each person will respond differently.

Persistent stress can affect the body’s immune system, leading to physical, mental and
emotional distress. Coping with stress starts with pinpointing the cause and source of stress, then learning healthy ways to treat it. When you are not sure of the exact cause of your stress, it may be helpful to know the warning signs. Emotional changes can include depression, anger and anxiety. Physical changes like trouble sleeping, headaches, and weight gain or weight loss can occur as well. Keep in mind, these are not exhaustive signs or symptoms but just a few to be mindful of. Once you can identify these signs, you can learn how your body responds. Then you can take appropriate steps to reduce the stress.

A good first step is setting up an evaluation with your primary doctor and letting him or her know all the ways stress has been impacting your life. The doctor then can help you with setting up a plan of care that’s right for your health needs. Since each person is different, the physician will offer different recommendations, but common recommendations include exercise, a change in diet, and sleep hygiene techniques. The doctor also might make a referral to a specialist such as a counselor to receive emotional support.

In terms of relaxation, there is no single technique that is best for everyone. Because we’re all very different, keep in mind what things might help you relax, what your body can handle, and your reaction to stress. The right relaxation technique is the one that will fit your lifestyle and is able to focus your mind and body to slow down. In many cases, you may find that combining different techniques will keep you motivated and provide you with the best results. For example, if you prefer solitude, solo relaxation techniques such as meditation will give you the space to relax your mind and recharge your batteries. For those who like to have social interaction, a spin class or dinner with friends may be helpful.

The best way to start and maintain a relaxation practice is to make it part of your everyday life. You can start by incorporating methods at your work, with family, and other social engagements. If possible, schedule a set time to practice each day. For example, if you commute to work, listen to soothing sounds and practice deep breathing. Techniques such as tai chi and yoga can be practiced in your home or during a lunch break in your office at work. To learn more about the wide array of techniques, perhaps visit a local yoga or meditation studio and take an introductory class.

It’s important to set realistic goals and go slow—life is not a marathon, rather, it is a journey. Take each day as it comes with the mind frame “Today I will be good to my body, mind and soul!”
Trust and understanding are the foundations of all good relationships. That’s what Emory University’s Alzheimer’s Disease Research Center (ADRC) has been working tirelessly to build in an effort to help African-Americans get the education, care and support they need when it comes to Alzheimer’s disease.

Located in Atlanta, Georgia, the Emory ADRC holds the National Institutes of Health’s (NIH) highest status an institution can receive in Alzheimer’s research and care. It is the only NIH designated ADRC in the Southeast, making Emory ADRC a major hub for patients, research and educational resources.

Alzheimer’s affects people of all races, ethnicities and genders in growing numbers, but African-Americans are especially affected by it. A Centers for Disease Control (CDC) study released in May of 2017 found a staggering 99 percent increase in the death rate from Alzheimer’s among African-Americans between 1999 and 2014. Emory ADRC states that Alzheimer’s is now the fourth leading cause of death among older African-Americans and that African-American seniors are two to three
times more likely to develop Alzheimer’s disease compared with Caucasians.

Part of the reasons for this stem from social factors, according to Emory ADRC. They contend that African-Americans have a higher distrust of medical providers than many other ethnic groups, often stemming from experienced and perceived discrimination and disrespectful treatment. As a result, African-Americans are more reluctant to see a physician about memory loss or other symptoms which could signal the onset of Alzheimer’s disease or another dementia-related illness. That reluctance often means they miss out on early detection, when treatment can help slow the disease’s progression, and are not diagnosed until the later stages of the disease, when a significant amount of neurological damage has already occurred.

Emory ADRC saw the problem first hand, especially in terms of how underrepresented African-Americans were in research participation. African-Americans make up approximately one-third of the Atlanta-metropolitan area’s population (where Emory is located), yet they accounted for just two percent of Emory’s research cohort in 2008.

Understanding the problem, Emory ADRC began developing a solution. It started with building trust with the African-American community.

Under the direction of Clinical Core lead Dr. James Lah, Minority Engagement Core lead Dr. Monica Parker and Education Core lead Dr. Ken Hepburn, Emory ADRC launched an extensive outreach program to break down the barriers that inhibit or discourage African-Americans from getting Alzheimer’s-related education and services.

They started reaching out to trusted leaders in the African-American community, such as senior pastors and health ministers, and partnered with them to connect people with services and education. Working in close partnership with these stakeholders, Emory ADRC began hosting public outreach events where African-Americans could acquire information and services in a setting that was more inviting because a trusted community figure was involved.

At each forum, participants are able to get information about Alzheimer’s disease and other dementia-related illnesses, learn about ways to potentially reduce the risk of developing cognitive impairment and understand the warning signs of a potential memory problem. Memory screenings are also offered on-site so that individuals can take advantage of early detection services.

Those who attend can also speak one on one with Emory ADRC researchers to learn about the importance of taking part in research studies, what it entails and what some of the current studies hope to accomplish. Currently enrolled research participants also share their personal experiences with those in attendance, both in one-on-one and group settings, so that people can get a greater understanding of what it’s like to take part in a study.

Emory’s efforts have been paying off. African-Americans’ participation in Emory ADRC’s research cohort went from just two percent in 2008 (when the program was first launched) to 32 percent in 2016.

Last September, AFA awarded Emory ADRC a $50,000 grant to expand the program, so that it could reach even more people.

“Emory ADRC is doing tremendous work and has gone to great lengths to connect people with Alzheimer’s related educational, training, health and research programs, all aimed at improving life for those living with the disease. We wanted to support their work and help them make an even bigger difference,” said Bert E. Brodsky, AFA’s Founder and Board Chairman.

The funding enables Emory ADRC to double its outreach events and activities, including community forums, memory screenings, trainings, resource navigation and one on one interaction with medical providers. Thus far, the results have been tremendous. 900 people attended outreach events in September, October and November alone, with more than 100 of them getting memory screenings. Emory ADRC has a number of additional events planned for 2018.

Emory ADRC is working towards the goal of having African-Americans account for 50 percent of its research cohort by 2020. Using the bridges they are building, they have a strong chance of getting there.

For more information about Emory ADRC, please visit alzheimers.emory.edu.
This issue’s Giving Corner highlights a way that AFA is channeling philanthropic support into resources for families affected by Alzheimer’s disease.

One of the initiatives AFA is most proud of is helping families keep their loved one with Alzheimer’s disease safe from wandering through its partnership with Project Lifesaver International.

Wandering is a very common, and dangerous, behavior among individuals living with Alzheimer’s disease; some of our readers may have experienced this in their own families. When someone who is easily disoriented, unable to call for help and may not even remember their own name wanders away, they are at significant risk of injury or even death. Fortunately, there are tools available which can help first responders quickly locate these individuals and return them to safety.

The Project Lifesaver program does just what its name says; it helps save lives through state of the art technology which protects individuals who are prone to wandering. The program enables someone living with Alzheimer’s disease to voluntarily wear a bracelet that emits an individualized radio frequency signal. If they go missing, local emergency responders can utilize the technology to quickly locate them and return them to safety. Project Lifesaver reduces search and rescue times from hours or days to a matter of minutes.

To date, AFA has provided hundreds of thousands of dollars in funding for Project Lifesaver and emergency response agencies throughout the country to offer this valuable safety tool to families affected by Alzheimer’s disease. With 5 million Americans living with Alzheimer’s disease, there is a vital need to do more.

One of AFA’s goals for 2018 is to provide funding for at least 100 more units to emergency personnel to protect individuals affected by Alzheimer’s. Not only will this help deliver a valuable safety tool to families, it will also give them peace of mind knowing that their loved one with Alzheimer’s is protected.

If you’d like to learn more about Project Lifesaver, contact AFA at 866-232-8484.

HOW YOU CAN HELP BE A LIFESAVER AND MAKE A DONATION TO SUPPORT THIS PROGRAM:
1. Visit www.alzfdn.org/donate
2. Call AFA at 866-232-8484
3. Mail a check  
   (payable to Alzheimer’s Foundation of America) to  
   322 8th Avenue, 7th Floor, New York, NY 10001
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- Continuing education and certification opportunities available.

Visit www.alzfdn.org or call AFA at 866-232-8484 to learn more.

AFA is an approved provider of continuing education for social workers by the National Association of Social Workers and the New York State Education Department’s State Board for Social Work.
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The Alzheimer’s Foundation of America (AFA) believes that when Alzheimer’s disease or a related illness enters someone’s life, they should have access to professionals who are specifically-trained in dementia care. That is why when you call AFA’s national toll-free helpline, you will speak with a dementia care-trained licensed social worker, who will provide answers to your questions, offer caregiving tips and strategies, and provide referrals to services and supports in your area. If someone in your life is living with Alzheimer’s disease or a related illness, call AFA today. We are here as your partner in care.

www.alzfdn.org

Support AFA!
Make a donation online at www.alzfdn.org/donate, call AFA at 866-232-8484 or clip this card and mail it to AFA at 322 8th Avenue, 7th Floor, New York, NY 10001 with your check enclosed.

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