Alzheimer’s Foundation of America

WALK IN THE PARK 2022

SATURDAY, SEPTEMBER 24
LONG ISLAND
Babylon Town Hall
Lindenhurst

SUNDAY, SEPTEMBER 25
(New site)
MANHATTAN
Battery Park City
Esplanade

NATIONWIDE
SEPTEMBER 24 OR 25
Walk wherever you are!

To register, visit:
alzfdn.org/walk

For more information, please contact:
866-232-8484

Together, we can help more people living with Alzheimer’s disease and support cutting-edge research that will help us find better treatments and get us closer to a cure.

Sign up today to walk with us!
A SPECIAL MESSAGE FROM OUR PRESIDENT & CEO CHARLES J. FUSCHILLO, JR.

Everyone needs to recharge themselves—especially during times of stress. When you are dealing with the different emotions of caregiving and need some inspiration, we hope that you’ll pull up a chair or find a comfortable place and open up the pages of Alzheimer’s TODAY magazine.

We have gathered some of the most inspirational and practical resources with you in mind—caregiving wisdom from the former governor of Wisconsin (p. 5) and a caregiver husband who shares how he dealt with neuropsychiatric symptoms of Alzheimer’s disease (p. 10). We provide tips to enhance self-care and mindfulness (p. 20) and combat caregiver depression (p. 7) as well as ways to support well-being with your person through meaningful experiences (p. 12). So important. Fun pieces provide a care partner activity (Cowboy Caviar, p. 14) and a woman who created the Doggies for Dementia Foundation (p. 19) so that families can heal, connect, and make new memories with their furry friends.

More than 6.2 million Americans are estimated to be living with Alzheimer’s, a disease with no known cure, and those numbers continue to grow every year. We hope you know that you are part of a community you can trust, and that you are not alone on this journey.

Reach out to our licensed social workers 7 days a week, at 866-232-8484. We are here for you.

My best to you and your family.

AFA is here for you.
alzfdn.org

CALL US
AFA Helpline, 7 days a week:
866-232-8484
Text us: 646-586-5283
Webchat: alzfdn.org
Webchat and text features available in 90+ languages.

CARE PARTNER THERAPEUTIC PROGRAMMING & ACTIVITIES
alzfdn.org/afatealroom

FOLLOW US ON SOCIAL MEDIA

alzfdn
Alzheimer’s Foundation of America

HELP US DO MORE! Give the gift of love, care & hope in our 20th anniversary year! All of this is made possible by the generosity of our donors.

If you’d like to make a charitable gift, please use the reply envelope inside this publication, go to alzfdn.org/donate or scan here:

CHAIRMAN OF THE BOARD
Bert E. Brodsky

BOARD OF TRUSTEES
Lee Brodsky, Vice Chair
Barry Berg, CPA, Treasurer
Gerald (Jerry) Angowitz, Esq., Secretary
Luisa Echevarria
Hon. Steve Israel
Arthur Laitman, Esq.
Nathan Halegua
Edward D. Miller, posthumous emeritus

President & Chief Executive Officer
Charles J. Fuschillo, Jr.

MEDICAL, SCIENTIFIC & MEMORY SCREENING ADVISORY BOARD
J. Wesson Ashford, M.D., Ph.D., Chair
Peter Bayley, Ph.D.
Soo Borson, M.D.
Herman Buschke, M.D.
Nathaniel Chin, M.D.
Jeffrey Cummings, M.D., Sc.D.
Margaret Dean, R.N., C.S.-B.C., N.P.-C.F.A.A.N.P.
Sanford J. Finkel, M.D.
Lori Frank, Ph.D.
Lee Hyer, Ph.D.
George Perry, Ph.D.
Richard E. Powers, M.D.
Allison Reiss, M.D.
Frederick Schmitt, Ph.D.
Peter Davies, Ph.D., posthumous emeritus

The content of this magazine is not intended to be a substitute for professional medical advice, diagnosis or treatment. Always seek the advice of a physician or other qualified health provider with any questions you may have regarding a medical condition. Never disregard professional medical advice or delay in seeking it because of something you have read in this magazine. The Alzheimer’s Foundation of America makes no representations as to the accuracy, completeness, suitability or validity of any of the content included in this magazine, which is provided on an “as is” basis. The Alzheimer’s Foundation of America does not recommend or endorse any specific tests, physicians, products, procedures, opinions or other information that may be mentioned in this magazine. Articles are provided for information purposes only and the views and opinions expressed in those articles are those of the respective authors and do not necessarily reflect those of the Alzheimer’s Foundation of America. Reliance on any information provided in this magazine is solely at your own risk.

The inclusion of advertisements in Alzheimer’s TODAY® is not an endorsement of the advertiser or its products or services. The Alzheimer’s Foundation of America does not investigate advertisers’ claims and is not responsible for these claims.

All rights reserved. This publication may not be reproduced in whole or in part without permission from the Alzheimer’s Foundation of America. www.alzfdn.org

©2022 ALZHEIMER’S FOUNDATION OF AMERICA
322 Eighth Avenue, 16th Floor, New York, NY 10001 | www.alzfdn.org | 866-232-8484
3-4
AN EARLY-STAGE DIAGNOSIS: 5 NEXT STEPS

5-6
TALK WITH ME AWHILE: A CONVERSATION WITH FORMER WISCONSIN GOVERNOR MARTIN J. SCHREIBER

7
9 TIPS TO COMBAT CAREGIVER DEPRESSION

8-9
HOW CAREGIVING FOR THOSE WITH ALZHEIMER’S IS DIFFERENT

10-11
NEUROPSYCHIATRIC SYMPTOMS: A CAREGIVER’S PERSPECTIVE

12-13
WELL-BEING THROUGH MEANINGFUL EXPERIENCES

14
CARE PARTNER ACTIVITY: COWBOY CAVIAR

15
20 YEARS OF MAKING A DIFFERENCE: NATIONAL MEMORY SCREENING PROGRAM

17-18
“UNDUE INFLUENCE”—AN ISSUE FOR EVERYONE

19
DOGGIES FOR DEMENTIA

20-21
FOR THE CAREGIVER: SELF-CARE AND MINDFULNESS

22-23
SUPPORTING THE LGBTQIA+ COMMUNITY IN DEMENTIA CARE

24-25
SHAPE BY MEMORIES: 3 TEENS SHARE THEIR ALZHEIMER’S STORIES
An Early-Stage Diagnosis: 5 Next Steps
By Linda Mockler, LMSW, M.Ed., and Susan Shipman, LMSW

Your loved one or dear friend has just been diagnosed with early-stage Alzheimer’s or a related dementia. Fortunately, they have been diagnosed at the beginning of the disease. It may seem inappropriate to use the word “fortunate” with such difficult news, but an early diagnosis can leave time for the person, often along with their caregiver, to make more personal choices about the next few years. Time is still among the most precious things we have.

While Alzheimer’s often robs the individual of their ability to choose later in the disease, the first stage generally allows one to determine the quality of their future lives, including financial, medical, residential, palliative and end-of-life decisions. This can give the person with the dementia diagnosis a feeling of peace. The future will be dictated by them and their wishes, not by someone imagining what they might have wanted.

WHAT ABOUT THE CAREGIVER?
For the caregiver, many of whom are spouses or partners, the news is received as though the diagnosis is their own. And in many ways, it is. The many life plans they made with their loved one will need to be put aside in the future to make way for medical and health care planning and eventually comfort care and end-of-life planning. This is a dramatic change from the adventures, travel and activities they may be currently enjoying or hoped to enjoy during their shared lifetime.

Often the partner, who has been cared for during their lifetime, is called upon to be the caregiver for the person with dementia. This can be daunting. It’s a disease with many variables. It’s important to know there are many resources available to caregivers, both practical and supportive. And the more you take advantage of those centers of information and organizations, the more successful you can be at caregiving.

It is equally important to take care of yourself. Caregiving for a person with Alzheimer’s and related dementias is a marathon. A caregiver needs to be mindful that a person who overextends early in the endeavor will lessen the chances of being able to finish successfully and in good health.

ASKING FOR HELP.
Help in every area is recommended. Caring for a person whose cognitive ability is lessening a little each day is different than caring for someone who continues to be able to make decisions about their care. Don’t hesitate to ask for help, if only to confirm that what you’re doing is the best choice for the individual and yourself.

Continued on following page
Many organizations provide Alzheimer’s services and educational information free of charge. However, elder care attorneys and geriatric care managers and sometimes private ownership memory care residence location services, do charge after an initial consultation. It’s always good to confirm the costs at the beginning of the contact.

Below are 5 next steps caregivers should consider after an Alzheimer’s diagnosis.

1. FIND local services and supports.
   The Alzheimer’s Foundation of America (alzfdn.org) offers a 7-day-a-week, toll-free Helpline. You can speak with a licensed social worker via phone (866-232-8484), text (646-586-5283) or webchat at alzfdn.org; text and webchat are available in 90+ languages.

   Eldercare Locator (eldercare.acl.gov or 800-677-1116) guides you to your local Area Resource Agency on Aging, which offers services, resources, and information for care partners.

   Keep in mind, you’ll need to seek assistance as needs arise. This may include a support group, an adult day program, in-home care, as well as an aging life specialist, geriatric care manager, nutritionist, and physical and speech therapists.

   Looking for an activity to pass the time with your loved one? AFA provides daily therapeutic programming for care partners at alzfdn.org/afateatroom.

2. LEARN about Alzheimer’s Disease.
   The Alzheimer’s Foundation of America (alzfdn.org/caregiving-resources) provides caregiving resources, including factsheets about various topics; a monthly Care Connection webinar series and Educating America Tour conferences (see our events calendar at alzfdn.org/events); Alzheimer’s TODAY quarterly magazine; memory screenings, and more.

   The National Institutes of Health’s Alzheimer’s site (alzheimers.gov or 800-438-4380) provides caregiver resources, training, advocacy, and clinical trial information.

3. GET regular medical care.
   See your primary care doctor or specialist (neurologist, neuropyschiatrist, geriatric psychiatrist) regularly to keep up with ongoing changes in symptoms and behavior.

4. DO legal and financial planning.
   Many families are caught off guard by the legal, financial and estate consequences of an Alzheimer’s diagnosis, but you don’t have to be. Now is the best time to review and update financial and health care documents, such as your will and advance directives for health care, finances, and your estate.


   The National Elder Law Foundation (NELF at nelf.org) also provides advice as well as access to a directory of elder law attorneys in your area who will be able to provide counsel.

5. DO long term care planning.
   As Alzheimer’s progresses, long-term care, whether in the home or at an assisted living or memory care facility will be needed, including around-the-clock care. It’s important to review your family and financial preferences and abilities to pay. A good place to start is the U.S. Department of Health and Human Services Administration for Community Living (acl.gov/ltc), which provides information about future care and how to pay for it.

ABOUT THE AUTHORS
Linda Mockler, LMSW, M.Ed., and Susan Shipman, LMSW, are AFA Helpline social workers. The AFA Helpline can be reached 7 days a week at 866-232-8484, via text at 646-586-5283 or webchat at alzfdn.org. Webchat and text are available in 90+ languages.
**Alzheimer’s TODAY: Why was it important for you to share your story about Elaine this way?**

I started understanding if there is one thing worse than Alzheimer’s, it’s ignorance of the disease. My ignorance made my life and Elaine’s life worse. As I began to understand more about the disease, I realized that we had missed many moments of happiness.

I’ve been on this journey, I’ve been up the mountain, I’ve had this experience. I know, as a caregiver, you are going to have to make the same journey. I want to help other caregivers learn, cope, and survive.

**Tell us about your two Elaines.**

Elaine was my high school sweetheart. We met during freshman year, immediately fell in love, dated, went steady, got engaged, married, had four children and 13 grandchildren. She was my friend, my advisor, my wife. She was everyone in the world to me. When I’d run for political office, she was the hardest working campaigner. When I would lose, she never let me feel defeated.

But when she was in her mid-60s, like 64, she would get lost driving to and from places she had been driving to and from for the last 10 years. She was a great cook and then sometimes she would mess up recipes so badly she would cry. And the food would not be edible.

I had to learn to let go of the first Elaine, as difficult, challenging, and horrible as that was. Letting go of the first Elaine allowed me to hold, help, and embrace this new person.

**Your book includes ongoing excerpts from Elaine’s journal. How did that come to be?**

About four weeks before going to print, I found a series of notes and journals that Elaine kept since her diagnosis. Elaine and I prayed together and cried together, but I never understood the courage it takes to be diagnosed with Alzheimer’s, and to carry forward, until I read these notes. Nor did I understand how truly important I was in her life. I was her lifeline. Had I known, I would have understood that I needed to take better care of myself emotionally and physically—for her as well as for me.

**You are very open in saying there are things you wish you’d done differently. Can you share some?**

I wish I’d gotten help. And I wish I had understood more about this disease.

Alzheimer’s is not a “chicken casserole disease.” For example, if I’m home recovering from a broken hip or surgery, friends will bring me a chicken casserole.

But often with Alzheimer’s, friends don’t know how to act because they are ignorant about it and, maybe since I was too, I didn’t help them understand. As a result, they stay away; not out of malice or insensitivity, but because they simply don’t know what to do.

Now, take an Alzheimer’s caregiver and someone who knows they are losing their memory. Add the fear, anxiety, worry, frustration, and despair, and, on top of all that, have your friends of 30 or 40 years desert you both because they don’t know how to act.

*Continued on following page*
One of the most important things that helped me, as a caregiver, was people just acknowledging what I was going through...That simple gesture is a relief. You know that you are not entirely alone.

And for the person living with Alzheimer’s, it’s important we know that we give them great comfort just by simply joining their world. Maybe a hug, maybe singing a song, or maybe holding their hand. What greater and simpler thing is there to do to make someone feel at peace?

**Did you take time for yourself?**

No, I didn’t and I should have. My children had an intervention and told me, “Dad, we know we are losing mom. But we don’t want to lose two parents. If you don’t take care of yourself, you might die before mom. We don’t want that.”

I was not helping Elaine at all by not taking care of myself. I was Elaine’s lifeline, helping her get through all of this. But I was fraying, and a frayed lifeline is a weak one, unable to do the job.

Elaine Ruth Schreiber passed away April 25, 2022, after living with Alzheimer’s for 18 years.

“Her world had become very, very small,” said Schreiber. “It would have been selfish for me to hold onto her longer. It was time.”

I was becoming more emotionally distressed, and irrationally irritable. I did not understand how critically important I was to her. She depended on me. How could I love my wife and at the same time not take care of myself? It didn’t make sense.

**Alzheimer’s is a difficult journey. Do you have hopes for our future?**

Until we find the answer, I want to offer caregivers a better life. I’m asking them to please understand this disease. Please, join the world of the person that now is. You can’t do it yourself. That’s really my hope for the short term.

I’m 83. I don’t know if Alzheimer’s will be solved during my lifetime, but until it is, the best, and only way to confront this disease is to understand it. The hope that at least we can understand the disease and help our loved ones live their best life possible. Alzheimer’s is bad, but ignorance of the disease is worse.
9 Tips to Combat Caregiver Depression

Depression is a serious and common challenge facing Alzheimer’s family caregivers. According to the Centers for Disease Control and Prevention, they are at greater risk for depression than caregivers of people with other conditions.

“Alzheimer’s family caregivers frequently put their family member’s needs ahead of their own physical and emotional needs—often to the point where they become overwhelmed. Many experience depression brought on by exhaustion, stress, and feelings of isolation and loss. When these feelings start to occur, they shouldn’t be reluctant to seek help or open up,” said Jennifer Reeder, LCSW, SIFI, AFA’s Director of Educational and Social Services.

“Everyone needs to replenish themselves, physically, mentally, and emotionally, and it’s important that caregivers find ways to do that,” she added.

Here are nine steps caregivers can take to help combat depression:

1. **Ask family members and friends for support.** Many may be eager to help but not know how. Be specific and let people know what you need.

2. **Try relaxation exercises,** such as meditation and yoga.

3. **Do physical activities.** The mind and body are interconnected.

4. **Take time for yourself.** Even something simple such as going for a walk can be relaxing.

5. **Look into respite care.** You’ll be able to find more time for the things you need and want to do. Respite care provides short-term relief for primary caregivers. It can be arranged for just an afternoon or for several days or weeks. Care can be provided at home, in a healthcare facility, or at an adult day center.

6. **Try journaling.** Express your thoughts, both positive and negative. By writing about what you are feeling, you may also become more aware of your stress and do something about it.

7. **Join a caregiver support group.** You will be with other people who understand exactly what you are going through and can share emotions and support, as well as practical advice and resources, in a safe and understanding environment.

8. **Get a good night’s sleep.** Speak to your doctor if you are struggling with sleep problems.

9. **Pay attention to nutrition.** A diet rich in fresh fruits, vegetables, and healthful fats, while low in processed foods, may help with symptoms of depression.

AFA offers telephone-based support groups and can provide support, services, and connections with local resources through the AFA Helpline.

Call **866-232-8484**, webchat at **www.alzfdn.org**, or text **646-586-5283** to speak with a social worker.
How Caregiving for Those with Alzheimer’s is Different

BY PAM OSTROWSKI

Many family members think caregiving for a loved one with Alzheimer’s is similar to caregiving for any other disease. It’s very different. The person you are caring for will not be able to help you and may even resist your care and requests. Alzheimer’s caregiving requires that you learn new skills, different communication techniques, and summon lots of patience and creativity while on this multi-year journey. Here are six of the biggest differences.

1) RESISTANCE TO THE DIAGNOSIS
It’s human nature to resist accepting a loved one’s Alzheimer’s diagnosis. Those with Alzheimer’s can otherwise appear healthy, so their diagnosis is harder to accept. In addition, we don’t really understand that our loved one is going to struggle with daily living tasks and forget the memories we’ve shared. However, if we, as family members, don’t accept the diagnosis and start learning about our new role, our loved one will be on the journey alone, scared and unable to help themselves.

2) MAINTAINING QUALITY OF LIFE
To maintain as much independence and quality of life as possible, the brain needs stimulation and engagement. Watching TV or doing a word search puzzle is not enough to keep the brain active. If you choose to live with your loved one, you’re the only stimulation they have and that’s exhausting and not very effective. It’s important that you take your loved one to a senior activity center two or three times a week (for both your sakes). As the disease progresses, memory care communities with staff trained in activities and stimulation ensure that your loved one is safe, happy, and maintaining as much brain function as possible.
3) LIVING AT HOME ALONE BECOMES IMPOSSIBLE
In the early days of dementia, a loved one may start repeating questions and can't remember where they placed things. They may be living at home, possibly alone. But as Alzheimer’s progresses, awareness of unsafe behaviors—such as throwing a towel on a hot burner or taking too much or too little medication—decreases. A loved one becomes a danger to themselves. In early to midstage, they’ll benefit from an in-home, dementia-trained caregiver. By late stage, they’ll need 24/7 “eyes on” care.

4) COMMUNICATING WILL BECOME MORE DIFFICULT
With most other diseases, caregivers are still able to communicate with their loved one. With Alzheimer’s, caregivers find themselves answering the same question many times over, which can get very frustrating. The words your loved one remembers on any given day may change. That means you have to get creative about how you ask questions and make requests.

“Go take your shower” may be met with a blank look. One option is to say, “Let’s go get washed up” and walk with them to the bathroom, turn on the shower, hand them a bar of soap and a washcloth and then observe whether they understand. In all communications, you must be respectful that your loved one is an adult who has lived a full life and deserves to be treated with dignity.

5) EATING AND DRINKING ABILITY CHANGES
It’s not unusual for a loved one with Alzheimer’s to gain or lose weight. They simply don’t remember if they’ve eaten and may not register their bodies’ level of fullness. In addition, in mid- to late-stages, sugary foods become a favorite, possibly creating other health-related issues. Another significant concern for all seniors is hydration. Most do not drink enough water and research shows that dehydration directly impacts brain function.

6) LENGTH OF THE DISEASE’S IMPACT
Those with Alzheimer’s disease live an average of four to eight years after diagnosis. Most live with mild cognitive impairment for several years before their diagnosis. From the time that I noticed issues with my mom to the time she passed, we went through 14 years of learning how to evolve our skills to accommodate her disease progression and diminished abilities.

Note that how Alzheimer’s disease affects your loved one is very individual and unique. The disease progresses over different amounts of time and impacts different parts of the brain, so no journey is exactly like another. Creating a plan early on for how Alzheimer’s can and will affect your loved one’s life and yours is critical for the best experience possible.

ABOUT THE AUTHOR
Pam Ostrowski is the CEO of Alzheimer’s Family Consulting (AlzheimersFamilyConsulting.com) and the author of It’s Not That Simple: Helping Families Navigate the Alzheimer’s Journey.

Making a Real Impact for Patients
Alzheimer’s can be devastating for families and fatal for patients. We’re working to make a real impact for those impacted by this disease.

Applying our 35+ years of protein dysregulation experience and legacy of foundational discoveries, we’re directly addressing the root cause of this disease, misfolded proteins.

Learn more at www.prothena.com
David German and his wife, Linda, were a team. When they left the doctor’s office after Linda was diagnosed with young-onset Alzheimer’s disease in 2014, David reminded her that whatever lay ahead, they would face it together as they always had. Neuropsychiatric symptoms were among the challenges they encountered during their seven-year journey.

“Early on, Linda started out with sundowning, which wasn’t too hard to handle. As the disease progressed, things became tougher,” German said. “She had trouble performing everyday activities like brushing her teeth or getting dressed and would get agitated whenever I tried to help her. There were times where she would get violent because she no longer understood what was going on. At the end stages, she would periodically just yell or scream out.”

The Germans’ experience is a familiar one for families affected by Alzheimer’s and other dementia-related illnesses. Approximately 90 percent of individuals with dementia will experience at least one of five major behavioral and psychological symptoms—agitation, psychosis, depression, apathy, and sleep disturbance—according to Dr. Jeffrey Cummings, Director of the Chambers-Grundy Center for Transformative Neuroscience at the University of Nevada, Las Vegas. These are among the greatest challenges caregivers encounter.

“With agitation, there is distress and fear about not knowing how to control the person, what they are going to do, or how to help them. With sleep disturbances, if the person is up during the night, the caregiver likely is, too,” said Cummings, an AFA Medical, Scientific, and Memory Screening Advisory Board member. “There are so many different demands of care that can add to a caregiver’s stress.”
What can caregivers do?

REDIRECT
When a person is disoriented and irritable or having a psychotic episode where they see something disturbing, there’s a natural tendency in others to try and insist that whatever the person is “seeing” isn’t there. Confronting them is usually ineffective, according to Cummings, who advises caregivers to accept the person’s reality rather than insist on their own.

“Telling the person their reality is wrong doesn’t change it. Instead, try to enter and work around their reality. Acknowledge it by saying something like ‘Yes, I see that’s distressing—let’s go over here and do something you like to do.’ Redirecting the person into something that’s more acceptable to them—like taking a walk or having a cup of tea—can help get them beyond that episode.”

The strategy worked well for David.

“There would be times where Linda would say ‘I smell something terrible,’ so I would respond ‘OK, let’s go for a ride in the car, maybe there’s something wrong in the house,’ even though I knew there wasn’t. Switching the subject to something she enjoyed—she really loved car rides—brought her to a comfortable place whenever she was outside of reality or feeling depressed or anxious.”

“Entering her reality was a challenge, I don’t like to downplay it. But as challenging as it was, I really felt I was doing good for her,” added German.

AFFECTION
Affection is another resourceful tool Cummings encourages families to use.

“I’ve found my patients could always distinguish, no matter how late in the disease progression, between familiar and unfamiliar. A husband holding a wife’s hand or hugging her feels different from someone else who didn’t have a lifetime with her doing the same thing. Even if they no longer remember their spouse’s name, that familiarity can still be extremely reassuring to the person in advanced stages.”

“Being a caregiver does change things, but it doesn’t change the love and doesn’t change how much you can do positively,” German said. “Even at the end, when Linda couldn’t remember who I was, I would get a smile or a response when I held her hand or hugged her. That made me feel I was accomplishing something.”

FORGIVE
Even while using these and other techniques, every caregiver will have stressful moments where they lose their composure, which is why Cummings reinforces the significance of self-forgiveness.

“It’s an important aspect of caregiving because you cannot be perfect all the time. Things are going to happen, you’re going to get frustrated, and you may raise your voice in a way you never intended. Forgive yourself and get back on track because your loved one needs you.”

German knows firsthand that it can be hard but agrees it’s necessary.

“My father had Alzheimer’s many years ago—long before we knew what we know today—and I yelled at him and felt terrible about it for a long time. But nobody can be a saint 24/7. You must be able to forgive yourself,” he said.

Building off his past experiences, he used a constructive technique during challenging moments with Linda.

“When I would get frustrated, I would leave the room so I could release my frustrations away from her, without her knowing,” said German. “I encourage everyone to try that.”

Above all, remind yourself that you’re making a difference.

“One of the things that helped me get through this was that I really felt I was making a difference, and that was really gratifying,” said German. “As difficult as life was for Linda, I was making it better than it could’ve been.”

Adapted from the AFA Fireside Chat series, Episode 4.
View AFA Fireside Chat episodes at www.alzfdn.org/firesidechat.
SUPPORTING WELL-BEING (& REDUCING DISTRESS) THROUGH MEANINGFUL EXPERIENCES

BY DR. JENNIFER CARSON

Leisure is more than fun and games; it’s more than diversional activities or a therapeutic means toward a functional end. “Leisure is the celebration of freedom at its crowing point,” said Charles Sylvester in the Philosophy of Therapeutic Recreation. The right to leisure is a universal human right (Universal Declaration of Human Rights, Article 24). Like all citizens, people living with dementia have a right to leisure wherever they may reside.

Ten years ago, in an effort to uphold and promote this right, researchers from the University of Waterloo’s Murray Alzheimer Research and Education Program (MAREP)** collaborated with people living with dementia to better understand the meaning and nature of leisure within the context of dementia. As a PhD student, I was one of those researchers. Our team conducted more than 200 surveys and interviews with people living with dementia in a variety of settings, asking questions about what brings leisure, meaning, and well-being into their lives. According to our findings, when people have regular opportunities to engage in the meaningful experiences shown in Figure 1, they can live well with dementia:

Our partners living with dementia described these meaningful experiences as follows:

- **Being Me**: Opportunities for self-expression and for simply being, including experiences that are personally meaningful and connected with current and/or past interests
- **Being With**: Opportunities to be with other people, pets, and/or nature that foster a sense of connection and/or community
- **Seeking Freedom**: Opportunities that provide a break from the norm; an escape from the stress of daily tasks and responsibilities; an escape from restrictive relationships and/or environments
- **Finding Balance**: Opportunities to find or create a sense of balance between relaxation and keeping busy—too much or too little of either is not good
- **Making a Difference**: Opportunities to fulfill a sense of purpose, to contribute and feel helpful and valued
- **Growing and Developing**: Opportunities to grow and develop by challenging the mind and the body, learning new things, and/or having novel experiences
- **Having Fun**: Opportunities to feel pleasure, enjoyment, happiness, playfulness, and to share a sense of humor
CELEBRATING & LIVING LIFE THROUGH LEISURE

Since partnering on this research, I have continued my work and commitment to supporting the well-being of people living with dementia as a researcher, educator, professional care partner, and beginning in 2016, as a family care partner when one of my parents was diagnosed with Lewy body and vascular dementia. As I’ve continued in these roles, I have come to appreciate, more than ever, the vital role meaningful engagement plays not just in supporting well-being but in reducing or eliminating expressions of distress. I’ve learned that most expressions of distress represent an unmet need of some kind, or a threat to a person’s well-being. Instead of treating ill-being through reactive pharmacological and/or nonpharmacological interventions, everyone’s primary goal should always be supporting well-being. When a person living with dementia does their best to communicate that they are in distress, care partners should do their best to identify and meet the unmet need.

Here’s a way to apply this learning:

Think of a person living with dementia you know well. Maybe the person is you, or maybe the person is a family member or friend. Consider whether or not this person seems generally more content or distressed. Now imagine that each meaningful experience theme is represented by a glass (see image to the right). What is the amount in each glass? For example, is this person’s glass of “Being With” full, empty, or somewhere in between? How about the glasses of “Seeking Freedom,” “Finding Balance,” or “Growing and Developing”?

As you reflect on each of the seven glasses, jot some notes about your assessed levels. Are any glasses full or brimming over? If so, then consider the root cause of that success. What’s working well to support that particular meaningful experience? These are strengths you can build upon as you find ways to fill any glasses that are low or empty. Consider what opportunities exist for improvement. The good news is that all of the glasses are all refillable.

As a care partner, I have found this way of reflecting on and supporting well-being invaluable; it’s part of my daily practice. For a more in-depth exploration of related ideas, I recommend Dr. Al Power’s book, Dementia Beyond Disease (2014). Please note, it is always best to engage the person living with dementia as a partner in this exploration of well-being to the fullest extent possible. Each person is the expert of their own experience. Effective, empathetic care partners open equitable spaces for the inclusion and engagement of people living with dementia in the decisions that affect their life, including decisions about how to best promote well-being. Committing to a care partnership is big part of supporting well-being.

**One more tip before I close: You can’t pour from an empty glass. As a care partner, I use the meaningful experiences framework to reflect upon and foster my own well-being. When my well-being is supported, I show up more present, centered, and capable of supporting the well-being of the people living with dementia in my life—just another example of what is good for people living with dementia is often what’s good for everyone. May your cups run over.**

ABOUT THE AUTHOR
Jennifer Carson, PhD, is the Director of the Dementia Engagement, Education, and Research (DEER) Program at the School of Public Health, University of Nevada, Reno; and a family caregiver.


COWBOY CAVIAR

A cross between a bean salad and a salsa dip, Cowboy Caviar is a popular, healthy recipe all year round that’s fun to make and eat. A care partner can prepare the ingredients beforehand then invite their person to combine them in a large bowl or tray, one at a time, and help mix. Enjoy!

INGREDIENTS
3 Roma tomatoes, seeds removed, diced
2 ripe avocados, diced
1/3 cup red onion, diced
15 oz. can of black eyed peas, rinsed and drained
15 oz. can of black beans, rinsed and drained
1 ½ cups frozen sweet corn, thawed
1 bell pepper, diced
1 jalapeno pepper, seeds removed, diced (opt.)
Serve with tortilla chips

DRESSING
1/3 cup olive oil
2 tbs. lime juice
2 tbs. red wine vinegar
1 tsp. sugar
½ tsp. salt
½ tsp. pepper
¼ tsp. garlic powder

DIRECTIONS
Combine the diced avocado and the lime juice in a large bowl or serving tray.
Add the black beans and black-eyed peas, diced tomatoes, bell peppers, corn, onion, jalapeno (optional) and cilantro.
For the dressing, combine the olive oil and red wine vinegar. Then add the sugar, salt, pepper, and garlic powder. Mix well with a whisk.

HOW TO USE
• As a side dish with dinner
• Spooned on top of scrambled eggs
• As a chunky dip with tortilla chips
• As a topping for tacos
• Sprinkled over a green salad

Source: Spend with Pennies.com

Jackie Gatto, MS, Manager of Therapeutic Programming at AFA, leading a Teal Room community class on “cowboy caviar” recently in our Education and Resource Center.
Many people visit their doctor for annual checkups and regularly get screenings for things like blood pressure, cholesterol, and cancer. But how often do they get checkups on one of the most important parts of their bodies—their brains?

That’s why memory screenings—simple and safe “healthy brain checkups” that test memory, language, and other thinking skills—are so important. Administered by qualified professionals, screenings consist of a series of questions and/or tasks that take approximately 10 minutes to complete. While they do not diagnose any particular condition, memory screenings can indicate if someone might benefit from a comprehensive medical evaluation and are a significant first step toward detecting a potential memory problem—especially for someone experiencing signs of memory loss or declining cognitive ability.

To encourage early detection and educate individuals about healthy aging, AFA created a nationwide initiative to connect people with screenings. Launched on November 18, 2003 as part of Alzheimer’s Awareness Month, AFA’s “National Memory Screening Day” provided free, confidential memory screenings to individuals at hundreds of screening sites nationwide. Goals of the initiative included promoting the importance of screenings and early detection; educating the public about Alzheimer’s, brain health, and healthy aging; raising awareness; and removing stigma.

Following years saw National Memory Screening Day grow exponentially. By 2013, there were thousands of screening sites, including doctors’ office, hospitals, care settings, senior centers, libraries, and pharmacies.

In 2015, National Memory Screening Day grew into National Memory Screening Week, taking place the first week of November to kick off Alzheimer’s Awareness Month. Continued growing demand for the service led AFA to create the National Memory Screening Program, which provides free memory screenings at community-based sites throughout the year.

When the COVID-19 pandemic prevented in-person screenings, AFA made screenings available virtually through secure videoconference technology so that individuals could continue accessing this important service.

To date, these collective efforts resulted in more than 5 million people receiving free memory screenings. AFA looks forward to increasing that number in the years ahead!

Interested in getting a free memory screening through AFA’s National Memory Screening Program?

Contact AFA at 866-232-8484 or visit alzfdn.org.
At Otsuka, our purpose is to defy limitation, so that others can too.

We have an unwavering belief in going above and beyond—under any circumstances—for patients, families, providers, and each other. This deep-rooted dedication drives us to uncover answers to complex, underserved medical needs, so that patients can push past the limitations of their disease and achieve more than they thought was possible.
Press stories have highlighted “undue influence” lawsuits involving large estates of millionaires or billionaires, but anyone can be a target, especially if they have a cognitive condition, such as Alzheimer’s or another dementia.

According to Sanford Finkel, MD, a geriatric psychiatrist with 34 years’ experience as an expert in will contests, “Dementia, as well as delirium, can make a person especially vulnerable to ‘undue influence’—excessive or inappropriate manipulation where someone uses deception to gain assets without a person’s true consent. And, unfortunately, relatives, friends, professionals, and caregivers are all in a position to exercise undue influence.” Finkel is Clinical Professor of Psychiatry at the University of Chicago Medical School and a member of AFA’s Medical, Scientific, and Memory Screening Advisory Board.

Money is not the only covetable asset that someone may try to obtain through undue influence, notes Finkel. Someone without a lot of cash in their bank account may still own a home that significantly appreciated in value from the purchase price. “I’ve done a number of cases involving farms in North Dakota which are now more valuable because oil and mineral deposits were discovered on them,” he said.

What is legally required to change a will?
Wills are vital legal tools to ensure a person’s wishes about who inherits their assets (i.e., the money and property that they own) are carried out appropriately. This living document can be updated and amended as the person’s wishes change.

However, executing or changing a will relies on the person having “testamentary capacity.” This means that they possess the mental ability to know that they are making a will; understand the nature and extent of their assets; have a plan to distribute them; and know the individuals designated as beneficiaries and their relationships to them.

Having a dementia-related illness does not automatically mean loss of this capacity. Someone living in the early stages of dementia, for example, may retain the legal ability to make decisions. But as the illness progresses, and loss of memory and cognitive function becomes more severe, testamentary capacity is more compromised.

Another serious disturbance in cognition that can also affect capacity is delirium. Caused by medications, dehydration, anemia, infections, and anesthesia, delirium can contribute to the development of dementia and vice versa, and affects someone’s ability to have testamentary capacity.

For a person’s own protection, someone lacking testamentary capacity cannot legally execute a will. Determinations about whether a person has testamentary capacity are made by a court, usually as part of litigation contesting a will or estate. The party contesting the will and alleging undue influence must prove that the person did not possess testamentary capacity.

Continued on following page
WARNING SIGNS OF UNDUE INFLUENCE

Red flags that someone living with a cognitive impairment may have been subjected to undue influence can include:

- A “new” beneficiary appears in the will, someone in a position of power that the person is/was dependent upon (financially or for care, such as access to medications, doctor’s appointments, food, or activities of daily living).
- The person is/was increasingly isolated or sequestered from others by someone who stands to benefit.
- “Changes” in the person’s wishes are radically different than anything previously expressed.
- Someone who stands to profit from the changes in the will had the opportunity and access to get the person to make them, possibly by bringing in their own attorneys or legal documents.
- Suspicious circumstances surround the will changes (i.e., “deathbed revisions” or someone new suddenly standing to benefit).

Undue influence is not just limited to wills and estates—someone may try to manipulate the person into signing over control of their finances, transfer assets, or make purchases while they are still alive. Money is almost always a factor, of course, but not the only one.

“Wills are not just legal documents conveying asset distribution; they can also convey love or rejection,” Finkel said. “When siblings stand to inherit unequal amounts, the one getting less may wonder if the parent loved them less. Correcting this ‘inequity’ can motivate them to try to get their parent to change the will or to contest it after the parent’s death.”

What can caregivers do?

Discussing your loved one’s wishes with them and other family members together, openly and honestly, and ensuring they are documented legally is the best way to help protect everyone. Litigation can become costly and contentious, especially when it’s between family members, so it’s best to get everyone on the same page as soon as possible to reduce the chances of having to go to court at a later time.

If you suspect that someone manipulated your loved one with dementia into giving them assets, contact an elder law or estate planning attorney.
Healing and connection through storytelling and photography are Carmen Davailus’ passion. After four decades in nursing, her desire to raise dementia awareness by sharing the stories of families affected by it, while simultaneously giving them new, cherished memories, inspired her to create the Doggies for Dementia Foundation.

The Doggies for Dementia Foundation, a Texas-based nonprofit organization, gifts compassionate photography sessions to individuals living with dementia, showing them together, candidly, with their loved ones and their family pet (or one of the foundation’s dogs if they do not have their own). They also invite families to share their own photos and stories with them. Images and stories are then shared on social media to raise dementia awareness and decrease stigma, isolation, and loneliness for those impacted by dementia-related illnesses.

Davailus got the idea while photographing families for her book Just See Me: Sacred Stories from the Other Side of Dementia. For three years, she followed families and learned even more about their fears, their joys, and how they learn to love while grieving their family members when facing dementia. People approached Davailus expressing their sadness for not getting pictures taken of their loved ones before it was too late. Spurred by a sense of urgency, Davailus founded Doggies for Dementia in 2018.

“I was a nurse and nurse practitioner for over 40 years and saw the pain associated with loneliness and stigma for those impacted by dementia. I also saw how people paid attention to stories—especially when dogs were pictured. We use the arts of photography and storytelling to capture priceless family memories and raise awareness,” Davailus said.

Participating families receive two photo sessions, professional matted prints, digital images, and two video slideshows. Photos, together with the family’s story, are then shared on the foundation’s social media pages to raise awareness.

“Families enjoy a low-stress time with a photographer familiar with dementia, their loved one and family pet, usually a dog, to create candid, fun experiences. Dogs are also popular in the media and help our stories be heard as we teach the world about dementia in a kind and beautiful way,” Davailus said. “Families love knowing their stories help others with dementia. They describe their experience and photographs as ‘priceless.’”

For more information, visit doggiesfordementia.org. The Doggies for Dementia Foundation is an Alzheimer’s Foundation of America member organization.
FOR THE CAREGIVER:
Self-Care and Mindfulness

By Cindy Maria Bautista-Thomas, PhD, LCSW

Caring for a loved one living with Alzheimer’s can be filled with so many mixed emotions. Let’s normalize the challenges that come with caregiving. Some days it’s a blessing and full of joyful moments. Other days, caregiving is filled with heartache and many disappointments. Caregivers give unconditionally, and sometimes they give from an empty cup.

My mother was diagnosed with Alzheimer’s in 2016. I lived with her, and her Alzheimer’s symptoms increased steadily. My family and I could not care for her. A few months before the global pandemic, my mother was approved for the Nursing Home Transition and Diversion (NHTD) 1915(c) Medicaid waiver program, which provided 24-hour home health aide support. It was devastating and overwhelming to manage all her needs and my life at the same time. I had a full-time job, I was a PhD student, an entrepreneur, a mother of two teenagers, and a wife. At some point, I was giving from an empty cup and experienced burn out.

You can’t give from an empty cup. As caregivers we often provide support from a place of exhaustion and overwhelm. Running on fumes and not caring for oneself should not be worn like a badge of honor. Giving from an empty cup is a harmful act against oneself, as you are giving from a place of deficit. It can cause resentment and burnout. Our physical, mental, and psychological health can decline, resulting in illness. If you are not in good health, how can you possibly provide the optimal level of care for your loved one? You can’t. It’s not sustainable. You will eventually crash and burn.

So, what do we do to avoid the crash? We practice self-care.

Self-care are activities that you engage in on a regular basis that promote wellness and enhance your body, mind, and soul. Practiced over time, self-care activities can help support your bounce back muscle and help you manage obstacles in a healthier way. Engaging in self-care will help you give from a place of overflow. When you operate in overflow, you are thriving and can share your gifts, talents, and abilities with the world in a more profound way.

In 2021, my mother died of COVID-19. While losing her was heartbreaking, I attribute my resiliency to consistent self-care and mindfulness practices. As I grow through the grief daily, I am also able to experience joy and connection.
Below are self-care tips that will help support your mind, body, and spirit wellness as a caregiver.

**Practice Mindfulness.** Mindfulness is a form of self-care that is for everyone. It’s when you become aware of your thoughts, feelings, actions, surroundings, and bodily sensations in the absence of judgment. Mindfulness helps to settle your brain and has been associated with a reduction in pain, anxiety, and stress. Choose a mindful activity that you can do every day—meditation, journaling, walking, yoga, and breathing exercises are all examples. Even starting with two minutes a day or practicing it while doing something else (i.e., meditate while taking a shower), goes a long way!

**Treat Attention Like Money—Be Careful How Much You Pay.** Paying attention to things that are calming, soothing or joyful can enhance those areas and promotes positive feelings. The reverse is also true; spending too much attention obsessing about stressors can cause anxiety and other mental health challenges. Don’t ignore challenges but spending all your attention dwelling on them without making time for enjoyable things is detrimental.

**Celebrate the Wins.** Make time regularly (i.e., daily, weekly, etc.) to celebrate the wins or progress you experience, regardless of whether it’s related to caregiving, whether big or small.

**Seek Support.** Seeking support is a form of community self-care. Sometimes we don’t ask for support because we think people will say no. Don’t make choices for other people. Make a list of the things you need support with and then make a list of close family and friends. They may be able to take some things off your to-do list or even take care of your loved one while you engage in something fun and restful. Asking for help is vulnerable and empowering as it will make room for those things that will help you thrive and be a better person and caregiver!

What if you took care of yourself the same way you took care of your loved one? As you consider all the ways that you provide care to your loved one, think about how much more present and connected you would be if you prioritized you!

---

**ABOUT THE AUTHOR**
Cindy Maria Bautista-Thomas, PhD, LCSW, is the cofounder of Velocity Visions, Inc. and a former Alzheimer’s family caregiver.

---

**Do you or someone you love have symptoms of early Alzheimer’s disease?**

**Consider participating in the study if:**
✓ You (may) have early Alzheimer’s disease.
✓ You are between 55 and 85 years old.
✓ You have a study partner (a next of kin or someone you have a close relationship with), who is willing to take part in the study and share information about you.

The study doctor will explain any potential risks to you and describe the study procedures before you decide whether to join the study.

To find out more about participating in the evoke and evoke+ studies, please contact:
1 (844) 420-2857
https://evokeadstudy.com/Alztoday

---

**If you or someone you love is increasingly becoming forgetful, experiencing difficulties in planning and problem solving, or getting lost in familiar places, these could be signs of early Alzheimer’s disease.**

Contact us today to find out more about the evoke/evoke+ clinical studies.

---

**If eligible, you will be one of over 3500 participants worldwide on this 3-year journey and will receive regular clinic visits, health checkups, and medical testing. You will get access to expert guidance and facilities during the study.**
Supporting the LGBTQIA+ Community in Dementia Care

Alzheimer’s disease and other dementia-related illnesses impact every ethnic and cultural group, but they do not impact all those groups in the same way. Using a “one size fits all approach” to dementia care is ineffective. Groups may have different barriers or difficulties resulting from their own historical experiences, challenges and trauma. The LGBTQIA+ community is an example of a group that necessitates a “culturally competent” approach to caregiving, one that is sensitive and responsive to their unique experiences and challenges.

LGBTQIA+ is an acronym for lesbian, gay, bisexual, transgender, queer (questioning), intersex and asexual, with the plus sign symbolizing other sexual identities not listed. Each are individual terms used to describe a person’s sexual orientation or gender identity. More than 2.4 million Americans ages 65 and over identify as lesbian, gay, bisexual, or transgender, according to the American Psychological Association (APA), and researchers from the University of California, San Francisco (UCSF) estimate that 350,000 of them are living with a dementia-related illness.

Challenges facing older Americans in general impact LGBTQIA+ elders as well, such as lack of financial resources or access to health care, but there are additional challenges which uniquely impact them.

Older LGBTQIA+ individuals often spent decades hiding their true identities and/or feared having their “true selves” revealed; experienced trauma, such as bullying or harassment; and often have a lack of familial support systems compared to elders who are straight and cisgender (meaning their gender identity matches their biological sex), according to Laurel Gumpert, MPH, AFA’s Educational Program Coordinator.

“The LGBTQIA+ older population is unique because many lived a large portion of their lives where the very nature of their sexual orientation or gender identity was considered illegal and immoral,” said Gumpert. “As a result, many faced significant hardships: from discrimination and stigmatization to forced institutionalization and incarceration, in some cases, simply because of who they are.”

One major barrier to care that must be overcome is that LGBTQIA+ older adults frequently have a deep mistrust of traditional institutions, often stemming from past discrimination or harassment. Changes over the last several years, such as the 2015 U.S. Supreme Court ruling legalizing same-sex marriages
nationwide, have made progress, but this has not erased the fact that many remember when homosexuality was illegal in certain states, classified as a medical condition by the APA, and grounds to be fired from a job or dishonorably discharged from the military.

Loneliness and isolation are additional barriers. Gumpert noted that among the LGBTQIA+ community there are increased rates of loneliness and isolation which can stem from feeling or suffering rejection from family members or society at large because of who they are, all of which can increase a person’s risk for dementia. Since same-sex marriages and same-sex adoptions were only legalized nationwide within the last ten years, many elder LGBTQIA+ individuals are less likely to have a spouse or children as compared to straight individuals.

“We are doing communities a major disservice when we don’t look at their history, experience, and past traumatic events and how that may impact their health in the future,” said Gumpert.

So, what steps can care partners take to be supportive?

1) **Provide more culturally competent and inclusive care.**

   Having the ability to understand, appreciate, and interact with people from cultures or belief systems different from their own is an essential caregiving tool. Take time to learn about a person’s background and build empathy. Failing to do so can potentially lead to misunderstandings or even discrimination.


2) **Create a welcoming and supportive environment.** Post nondiscrimination statements, amend in-take forms to include a “transgender” option and the term “partner” in addition to spouse, and educate staff to be comfortable in discussing sexual orientation, gender orientation, and sexual practices.

3) **Provide visual cues of allyship.** Display LGBTQIA+ symbols (such as rainbows) or posters of ethnically and racially diverse transgender and same-sex couples. Images such as these reinforce a welcoming, inclusive setting for the LGBTQIA+ community. Keep in mind, elders from this community often spent decades keeping who they really are a closely guarded secret.

4) **Reach out.** There are LGBTQIA+ organizations, such as SAGE, a national nonprofit service and advocacy organization for LGBTQIA+ elders, which can offer guidance and advice on additional steps you can take to make a care setting or practice LGBTQIA+ friendly, as well as provide training to staff.

---

**To help dementia-care partners become more culturally competent in serving the LGBTQIA+ community, AFA’s Professional Training and Education Division developed a new course, “Supporting the LGBTQIA+ Community in Dementia Care.” Learn more by visiting alzfdn.org and clicking on the Professional Training & Education tab.**

---

**Eisai**

**CREATING HOPE THROUGH INNOVATION**

At Eisai, everything we do is guided by a simple principle: patients and their families come first. We spend time with them. We listen and we learn about their lives, their desires and their greatest needs. We call this human health care or hhc, giving first thoughts to patients and their families and helping increase the benefits health care provides.

Our hhc mission is what drives us to discover innovative solutions and therapies that help address unmet needs within the communities that we seek to serve.

**TO LEARN MORE, PLEASE VISIT WWW.EISAI.COM/US**

CORP-US2790 ©2022 Eisai Inc. All rights reserved. May 2022
Anyone can positively influence the lives of others, regardless of age.

In recognition of making a difference for individuals living with Alzheimer’s disease and other dementias, 117 recent high school graduates received nearly $90,000 in college scholarships through AFA’s 2022 Teen Alzheimer’s Awareness Scholarship contest. Each shared their story of how Alzheimer’s touched their lives.

First-place winner Mary Willis of McDonough, Georgia, described her close relationship with her grandmother, Frances, who was diagnosed with Alzheimer’s when Mary was nine years old. Despite the difficult challenges, it taught her much about herself and helped her “realize my best memories of [my grandmother] were the ones that shaped me into the person I am today.”

“My work ethic in every aspect of my life represents the two jobs she worked to send my mother to college. I strive to be the best student and teammate possible as I remember what my grandmother gave up to give my mom her best shot. My drive to be the best person I can be, not just for myself, but for those around me, reflects the type of person she was. My grandmother inspires me daily to change the world even if it starts small,” she wrote in her essay, which earned her a $5,000 scholarship toward her education at Auburn University in Alabama.

Influenced by her experiences, Mary started the Passion Project, a local initiative that brings students from different schools and backgrounds together to make the community a better place. The initiative allows her to share how Alzheimer’s affected her life and inspires her to want to help others impacted by it.

Photo courtesy of Mary Willis
Second-place winner Julius Josephson of New York, New York, who received a $3,500 scholarship toward his education at the University of Pennsylvania, described memories of his paternal grandparents, Papa Stanley and Grandma Sheila, as they battled Alzheimer’s, including weekly family dinners where he, his siblings, and parents would spend time reminiscing with Papa and Grandma over old photos and familiar stories. As the disease progressed, and Papa Stanley and Grandma Sheila moved into assisted living, Julius described how he continued to make the best out of the situation and their time together.

Jonathan Marx of Birmingham, Michigan, whose third-place essay focused on his relationship with his paternal grandmother, Mame’ Paulette, shared how her Alzheimer’s diagnosis inspired him to study neuroscience.

He describes childhood memories of playing with Mame’ at her home in France, and nearby park, and breaking through the language barrier by connecting through music and laughter. Following her Alzheimer’s diagnosis, Jonathan discovered the Brain Bee, a neuroscience competition, where he started learning about the brain and took a specific interest in music’s cognitive impact, based on his own experiences with his grandmother.

“Music is important to me, and it plays a central role in my heritage and culture. Even now, when my grandmother might not recognize my face, she recognizes the tunes of her past, opera songs, and the hits of yesterday,” Jonathan wrote. “Paulette often enjoys such attempts at bringing her past to life again, and during such moments, I feel as though we can still connect. I would never have felt the same drive to learn more about music and its effect without her influence.”

Jonathan further pursued his passion by joining the International Youth Neuroscience Association (IYNA) and learning about topics such as neuroethics, deep brain stimulation (DBS), and closed-loop DBS. Jonathan will continue studying neuroscience at the University of Michigan this fall and received a $2,500 AFA scholarship to support his efforts.

“In my struggle to cope with not just Alzheimer’s but other neurological disorders and diseases, I have found peace in knowledge. I still attempt, and will continue, to try and connect with my grandmother. If it had not been for my familial connections to neurological disorders and diseases, I would not be in the same spot I find myself in today.”

Visit alzfdn.org/scholarship to view the complete list of winners and learn more about AFA’s Teen Alzheimer’s Awareness Scholarship.
The mission of the Alzheimer’s Foundation of America (AFA) is to provide support, services and education to individuals, families and caregivers affected by Alzheimer’s disease and related dementias nationwide, and fund research for better treatment and a cure.

Order AFA’s children’s book Dancing with Granddad (for ages 5-8) at shop.alzfdn.org or call 866-232-8484—available in English and Spanish!

“Both children and adults will connect with the tender relationship between Nia and Granddad as they use this special book to begin or continue the often challenging conversations about Alzheimer’s.” —DALE V. ATKINS, PHD, PSYCHOLOGIST