SPECIAL YEAR-END ISSUE

Alzheimer's TODAY®

The Official Magazine of the Alzheimer's Foundation of America

Children's Book Teaches About Alzheimer's and Love

VOLUME 18, NOS. 3-4

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Gardening with Grandma

An Alzheimer's Story for Children and Their Families

Created by the Alzheimer's Foundation of America

Illustrated by Mudassir M. Abid

Story by Linda Bozzo

"Even young children can and should be taught about dementia. *Gardening with Grandma* is a valuable tool for helping children understand brain change and empowering them with effective responses."

— Teepa Snow, MS, OTR/L, FAOTA
Founder of Positive Approach to Care®

"Love always remains, and this wonderful book reinforces that. It's a must read."

— Pam K., Wife, Mother,
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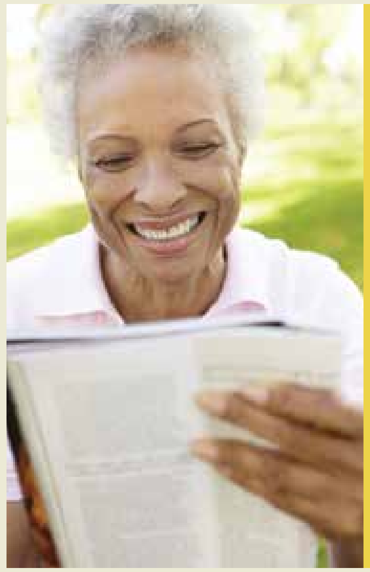

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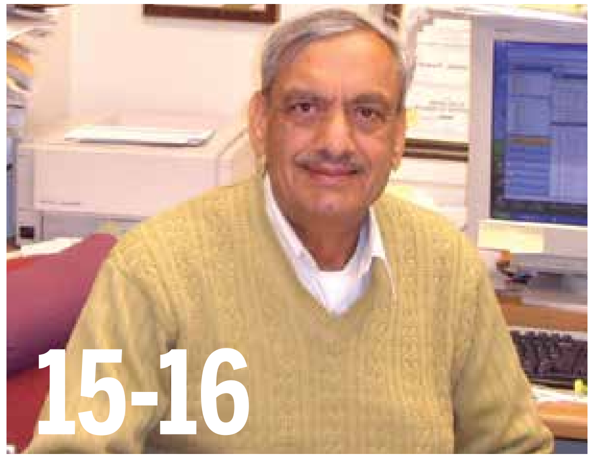

A MESSAGE FROM OUR PRESIDENT & CEO

CHARLES J. FUSCHILLO, JR.

As we mourn the recent passing of former First Lady Rosalynn Carter who lived with dementia in her final days, we are reminded once again of her wonderful legacy of advocacy, especially the Rosalynn Carter Institute for Caregiving (RCI). Established 35 years ago, the Institute champions family caregivers, promoting their health, resilience, and courage.

Carter reminded us of this truth: **"There are only four kinds of people in the world—those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregivers."** Like Rosalynn Carter, Alzheimer's Foundation of America founder Bert Brodsky's mission is to care for our caregivers, believing that no family should endure the Alzheimer's challenge alone.

We hope this special year-end issue of *Alzheimer's TODAY* serves you with support, inspiration, and resources. A few highlights:

- A new children's book, ***Gardening with Grandma*** (for ages 5-8), that can be used as a tool to start a conversation about Alzheimer's **(pp. 20-21)**. Says Jennifer Reeder, LCSW, SIFI, our director of Education and Social Services, "The best time to talk to children about Alzheimer's or any dementia-related illness is as soon as you can." The book's parent guide is new and much improved.

- **Dementia-Friendly Airport Travel (pp. 4-5)**: Teepa Snow, one of the leading educators on dementia care, in partnership with the Dementia-Friendly Airports Working Group, has created a video series to improve air travel for people living with dementia.

- An AFA member organization, **Lorenzo's House (pp. 7-8),** with a focus on helping younger families who are coping with an early-onset diagnosis. The nonprofit was founded by Diana Shulla Cose when her husband, Lorenzo, was diagnosed at 62 (her boys were 12 and 9).

- A conversation with **Dr. Sandeep Jauhar (pp. 15-16)** on his learnings when his father, a world-class scientist, was diagnosed with Alzheimer's.

- **What Are Neuropsychiatric Symptoms (NPS)?** The *behaviors* that accompany a dementia diagnosis, they are often the most difficult to manage for caregivers. In consultation with Dr. Jeremy Koppel, Medical, Scientific and Memory Screening Advisory Board member, we provide you with symptom and treatment types, and the important advice to take care of your own well-being.

We wish you and your loved ones a happy 2024.

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Making Airports More Dementia-Friendly

As one of the country's leading educators on dementia, Teepa Snow, the Founder of Positive Approach to Care™, has worked to enhance life and relationships for those living with brain change. One of her latest efforts is a partnership with the Dementia-Friendly Airports Working Group to create a series of short videos simulating a variety of travel scenarios. The mission of her partnering organization is to improve air travel for people living with dementia by developing and sharing dementia-friendly resources for travelers, air travel industry staff and security screeners.

Snow said about 25 airports internationally have adopted the dementia-friendly model. The number is growing because the effort is worth it. Airports can be difficult places for many people, but for those living with memory loss the confusion is far greater. Complicated security protocol, the unfamiliar environment, crowds and confusing signage can cause a person with dementia to become distressed, resulting in stress and delays for them, airport employees and other travelers. Episodes of physical harm or unnecessary calls to law enforcement or security often follow.

Snow mentioned the case of one woman who came out of the restroom and, thinking she had already been on the plane, went out to the parking lot to go home. The result was that the entire airport had to be shut down until she was found.

"It's bad enough for regular travelers who get stressed," Snow says. "The airports are supportive because they recognize that if they aren't, they pay the price."

Originally intended to train airport personnel, the free videos, which feature scenarios such as trying to check-in at an airport kiosk or purchase something in an airport store, have received positive feedback from individuals living with dementia, family caregivers, those who work in a variety of businesses at the airport, as well as those who plan trips for seniors, and the general public, Snow says. For airport personnel who don't always recognize the hidden disabilities of people living with memory loss, the videos have been enlightening.

"They say, 'I didn't know that was dementia. We get those people all the time.' It's not something they could figure out until they have the interaction. Without awareness, they just think the person is being unreasonable."

Many patients with memory loss travel alone, Snow said. "Some haven't been diagnosed yet and those who have been still want to go places and see people."

In dealing with distressed persons, the reaction is often to talk louder, which only upsets the person more. "But it's not a hearing problem," Snow says. "Sometimes the brain change problems are so hidden they won't show up until you stress me, like telling me to go to another gate. All of a sudden I can't compensate. 'What did he just say? Why did it change?' The sense of getting overwhelmed happens so rapidly. The brain doesn't have the flexibility it used to have."

The person can also become flustered when asked for something as simple as their ticket. "Their brain won't find the thing that is a ticket. It's a scary place to be. If I have someone on the other side of the counter who is trained, I don't have the meltdown."

Rather than give the person directions to the new gate, such as turn left at the end of this corridor and you will see it on the right midway down, which is too much to process, the trained worker will say, "I'm going that way. I'll take you."

TEEPA SNOW'S 8 TIPS

FOR DEMENTIA-FRIENDLY AIRPORT TRAVEL

- Choose supportive behavior. If the flight has been delayed and the person gets restless and keeps asking why they're not leaving, affirm them by saying, "Yes, you're right. We should have left by now," and take them for a walk to avoid just sitting in the waiting area.
- Wear a hat or clothes they will recognize in case they wander off and need to find you.
- Make sure you know where the exit for the restroom is, and that there is not more than one, so you can watch for them.
- Be aware of what your person is wearing so you can spot them in a crowd. "There may be a moment when you say, 'She was right behind me. Where did she go?'"
- Consider noise-cancelling headsets or earbuds because the hecticness of the airport can be upsetting.
- Choose their best time for traveling rather than for the best ticket price.
- Bring preferred snacks because you might not know what will be available. Bring snacks for yourself as well because it may be difficult to leave the individual to obtain your food.
- Watch the "Traveling with Dementia" videos that are available at Teepasnow.com/resources/pac-videos-about-dementia.

TSA Cares, Too

Teepa Snow explained why airports can be confusing and frightening places for people with memory loss illnesses and offers tips for those traveling with them. The **Transportation Security Administration (TSA)** has also been stepping up its efforts to assist.

Over the years, AFA has worked with the **TSA** to train frontline personnel about dementia-related illnesses, identifying signs that someone may have a cognitive impairment, and ways to positively interact and communicate with individuals who have dementia. And last year, the **TSA** presented AFA with its *Disability and Medical Conditions Community Award* in recognition of those collaborative efforts.

TSA TIPS FOR TRAVELERS

- If you will be traveling by air, know the security procedures so you can familiarize your person beforehand about what will happen at the checkpoint. **Go to tsa.gov/travel/security-screening to learn more.**
- Keep in mind, the TSA can assist with the screening process for certain dementia-related illnesses. For information, call the **TSA Cares Helpline at 855-787-2227 or email at tsa-contactcenter@tsa.dhs.gov**. Let the TSA know at least 72 hours in advance if you have safety concerns and special needs. You may request that a **Passenger Support Specialist or Supervisory TSA Officer** meet you at the checkpoint.
- Before making your trip, be sure travel is advisable by checking first with the person's doctor. People in the early stages of dementia may still enjoy traveling, but as the disease progresses it could become overwhelming.

AFA MEMBER SPOTLIGHT

Lorenzo's House: Building a Hub of LIGHT for Young-Onset Families

Alisha Stickney and Diana Cose

When Diana Shulla Cose's husband, Lorenzo, was diagnosed with young-onset Alzheimer's at the age of 62, their sons were 9 and 12. She realized quickly there were few resources for families like hers, younger with dementia, and younger children.

"To witness our son's experience brain change in their dad has been the hardest thing I've been asked to do in my life," Cose said. "Younger-onset is a diagnosis of the family. Its far-reaching impact is immeasurable."

Younger-onset Alzheimer's, also referred to as early onset, affects individuals diagnosed before 65. Children experience one parent leaving them because of their condition, and the other changing to navigate as primary care partner, single parent and often breadwinner.

"The stigma is thick for families living with this condition. We feel isolated and lost. Younger families are under-resourced and too often undiagnosed or misdiagnosed. I felt compelled to respond to all of it. I understood the resource gap and thought maybe I could help fill it and turn my own suffering into something that heals." Lorenzo Cose passed in August 2022.

Lorenzo, Justin at 12 (now 22), Diana, Lucas at 9 (now 18)

Cose imagined a place where families like her own could be seen, a hub of connection and light. So she built it, starting Lorenzo's House in her son's bedroom in 2021. Her 34-year career had been in urban education in Chicago, with 24 of those years as founder and president of one of Illinois' first charter schools.

"I learned about building something from an idea, and thought maybe I could leverage my experience and do this. It took a big leap of faith."

Continued on following page

AFA MEMBER SPOTLIGHT *cont'd from p. 7*

Cose created the tagline, “We Bring Light,” and the mission to empower younger families walking with dementia. She built a website, put together a nonprofit board with the goal to “shift the narrative” and turn isolation to connection, stigma to strength and darkness to light for younger families everywhere.

Today, just over two years in operation, this virtual organization (with one in-person music class in Chicago) supports more than 1,000 family members across 42 states and seven countries. Lorenzo's House receives more than 50 inquiries monthly from younger families, which can convert to more than 200 family members in need of community and support.

“Our growth has exceeded my expectations,” she says.

Lorenzo's House, with Cose as its founding executive director, offers programs for younger people and their families:

- **Light Clubs** are virtual safe spaces to feel understood, share common stories, exchange mindfulness practices and build an alliance.
- **Summit** is an international youth-led event where young people (ages 8-35+) unite to grapple with topics of brain change, advocacy, stigma, mindfulness practices and more. The Summit started with 21 youths two years ago; more than 200 are expected next year.
- **Match** is one-on-one peer connection with someone walking a similar path to exchange techniques, share resources and cure isolation.

Cose says programs for children and young people of a parent with younger-onset are rare.

“We need to listen to our kids. They intimately understand this condition and their experience is often the hardest, yet their voice is the softest. Our mantra at Lorenzo's House is, our youth, our compass.”

More often than not, it's the first time they have met a peer walking their similar journey.

This connection can happen at a biweekly virtual hang-out called the **Light Club** for children and young people (ages 8 and up). Sessions open with community agreements to ensure a safe, judgment-free space, followed by a mindfulness breathing practice and a reminder of the positive scientific effects this has on the brain.

Next is a personal check-in and a youth-developed discussion topic, with time to reflect and journal. Closure is often sharing one thing learned, one word to describe how they feel and one thing they will do. “I feel like this Zoom is filled with a group of angels who understand me,” an 8-year-old said recently.

Alisha's Story

Alisha Stickney's mom was diagnosed with young onset when Alisha was 11 and died when she was 21. Today at 30 she continues to refer to herself as a daughter of Alzheimer's.

“It was so traumatic that the years of that experience, and many years after my mom passed, are just a blur.” She tried a support group but “everyone was in their 60s and I was, like, a teenager. I was alone with no group that catered to my needs. I wish I'd had Lorenzo's House.”

None of her peers understood. “I felt so isolated and ended up coping in unhealthy ways. I became involved with drugs and alcohol. I'm sober now, but it took a long time.”

It was not until she found Lorenzo's House at 28 that she connected with another young person walking her journey. Now working in TV and film production in Los Angeles, she volunteers at Lorenzo's House and has observed the Light Club sessions.

“I saw 8-, 16- and 30-year-olds able to relate to each other over what their family was going through. Even though my mom had passed almost 10 years prior, I started to unpack my experience in healthier ways.

“A lot of things go unspoken in a family walking with this condition. My family was trying to be strong for each other. We didn't want to weigh the other down with personal and emotional needs. And without the community and support found at a place like Lorenzo's House, I didn't have tools to self-regulate and tend to the trauma that I was experiencing.”

These tools will be valuable throughout the children's lives.

“Children and young people living with brain change in their home have a more profound understanding of this condition than anyone else,” Cose says. “Until a cure is found, these are the critical voices and leaders of the next generation who will inform the dementia spectrum.”

Photos courtesy of Diana Cose

Caregiver Creativity

Transforming Placemats into Smiles

The woman in a wheelchair seemed unaware of her surroundings. Arthritis left her hand clenched in a fist. Unable to open, it rested on her tray table. This was how she spent her time until one day someone put a placemat in front of her. The transformation was quick. Her eyes lit, she broke into a smile and opened her clenched fist to stroke the mat. Her niece was shocked.

This was no ordinary placemat, though. Her niece had heard about the “fidget mats” Li Cross was making from her Granbury, TX, home and donating to individuals and nursing homes. She wrote to Cross requesting a mat for her aunt who loved lady bugs, so Cross went in search of some in any form—pictures, stuffed animals—and sewed them onto a mat. That's how the long-clenched fist opened, and a vacant expression became animated.

“They change lives,” Cross said.

The retired accountant discovered this 10 years ago when a hospice volunteer gave her father, who was in his final days of living with Alzheimer's, a sensory mat made of different fabrics and elastic pulls. It made him smile for the first time in two years as he felt and smoothed the mat.

Inspired by his transformation, Cross and her mother began making fidget mats to donate. Somehow the word spread to Washington state where Interim HealthCare requested 100.

“I put a notice on Nextdoor for my immediate neighborhood. I said, ‘If you sew, I could use your help.'” She included a photo and a meeting time at a local coffee shop. Twenty women showed up. That was the start of what her husband would dub the Fidget Chicks, now a nonprofit that has donated more than 8,000 mats around the country since forming in 2017.

Now with 15 “solid” volunteers and “two ladies in their 90s who come every week” (one is her mother), they meet every Tuesday from 2 p.m. to 4 p.m. at Cross's house. They bring tote bags to fill with items bought at thrift shops and garage sales—small toys, baby clothes, large buttons, zippers—to take home to work on. Then they enjoy coffee, Cross' homemade baked goodies and each other; they've all lost a loved one to a neurological disease.

Paying for postage, which is more than $4,000 a year, is the biggest challenge. They hold a fundraiser each year and a garage sale, but mailing expenses are 10 times what is raised; Cross covers the rest. A bin at the community center collects donations of solid-color placemats (stripes are confusing).

Cross' mission is to inspire other groups to form around the country. She'll send a starter kit to get them going.

“My intension was never to cover the whole United States. We can't even cover Fort Worth, which is an hour away, but we try.” You can learn more at **licross.com**.

ACTING OUT FOR CAREGIVERS

The woman in New London, NH, was concerned about how she could take away her husband's car keys. His Alzheimer's was worsening, and she knew he shouldn't be driving but would resist losing his independence. She found the advice she was seeking in an unusual place, her local theatre.

Many caregivers have found help for their problems at the Barn Playhouse since it created "Improv for Caregivers" in February.

"Everybody likes improv but this is improv with a purpose," says Sage Tokash, the Barn's education director who started and oversees the program.

Tokash uses common caregiver problems, such as taking away car keys, and writes them, with professional guidance from VNA (the Visiting Nurse Association), as scenarios for actors to perform. At one point the action is stopped and the caregiver audience is asked how they would handle the situation. The actors then act out each solution. It's collective problem solving that is fun and helpful.

For the woman seeking to take away her husband's car keys, someone suggested she have her husband take the car in for repair and arrange for the mechanic to call in a couple of days to say it couldn't be fixed. Problem solved. Together.

The program, which was awarded a $4,000 Arts in Health grant this summer, is presented along with the Lake Sunapee Region VNA and Hospice in New London, NH. At every 90-minute session either a nurse, professional caregiver or healthcare provider is present to answer medical questions.

"It gives the community members and caregivers an opportunity to be in a safe place," says Marcia Goulart who was a caregiver for her mother who had Alzheimer's and now her youngest sister. "We hear from others about what to expect and what they're going through currently, so we don't feel so alone and question if what we are doing is right. It sparks discussion among community members, like 'Oh, that's what I should do' or somebody says, 'This is what I've done' and everybody says, 'That's a great idea.' We realize we can do this and do it together."

The notion of starting an improv group came from Gail Matthews, a theatre patron who had been a caregiver for her husband. She heard about a similar program in Rhode Island and approached Tokash who, with her B.F.A. in acting and M.F.A. in Theatre for a Young Audience, had a background in improv.

"We get a lot of suggestions from participants at the end," Tokash said. "One participant said it would be helpful to see a caregiver who was much smaller. All the actors had been the same size. The next week we brought in a smaller actor to see how to navigate those physical differences."

The program began with four sessions, for which caregivers paid $15 for each. Actors volunteered their talents. Thanks to the grant, the sessions are free, the actors are paid, and the experts provide practical advice on things like how to lift someone and proper nutrition and diet. In addition, the program will also follow the old showbiz tradition of taking it on the road, in this case to Claremont in January and Newport in April in 2024.

"There's such a high need in our area," Tokash says. "We have a large population with Alzheimer's and caregivers don't have enough resources. We're providing practical skills with a visual component example rather than just reading about strategies. We can stop and edit and get audience reaction."

And take requests. One woman told of the hurtful things her husband said to her. Members of the caregiver audience suggested various ways she could respond, and the actors took turns dramatizing the responses.

"The people in the audience had to come up with a whole new strategy."

Tokash says Improv for Caregivers would be easy to replicate "as long as you have someone who has an improv background and caregivers to come together."

She offered some advice for getting started.

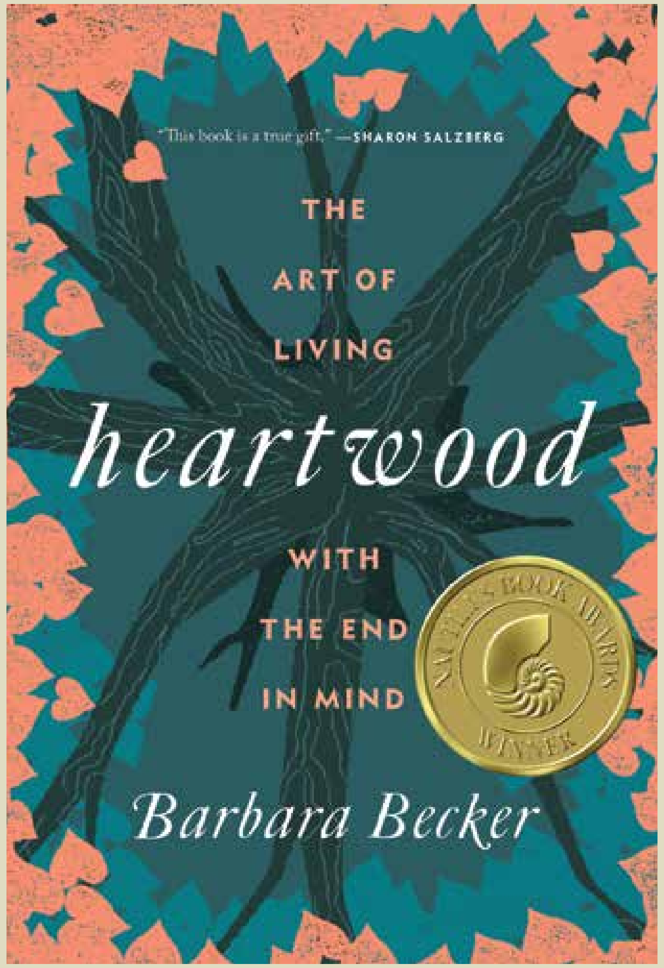
"The biggest thing is just to listen to the community and what they want. At the beginning I had a vision. I was going to teach improv skills because that's what I knew. I thought the caregivers would want to come up and participate, but they wanted to watch to see how it played out instead."

BOOK CORNER:

Heartwood: The Art of Living with the End In Mind

By Barbara Becker

Life was going along as usual, with "no insurmountable mountains to climb, no raging rivers to ford," writes Barbara Becker in her memoir, *Heartwood: The Art of Living with the End in Mind*. But she is quick to note that eventually everything changes. Within the space of a few months three close members of her family, including her father, a retired neurosurgeon, were diagnosed with Alzheimer's disease. She knew well what was ahead. Her two grandmothers, who had lived with her when she was a child, had died of Alzheimer's.



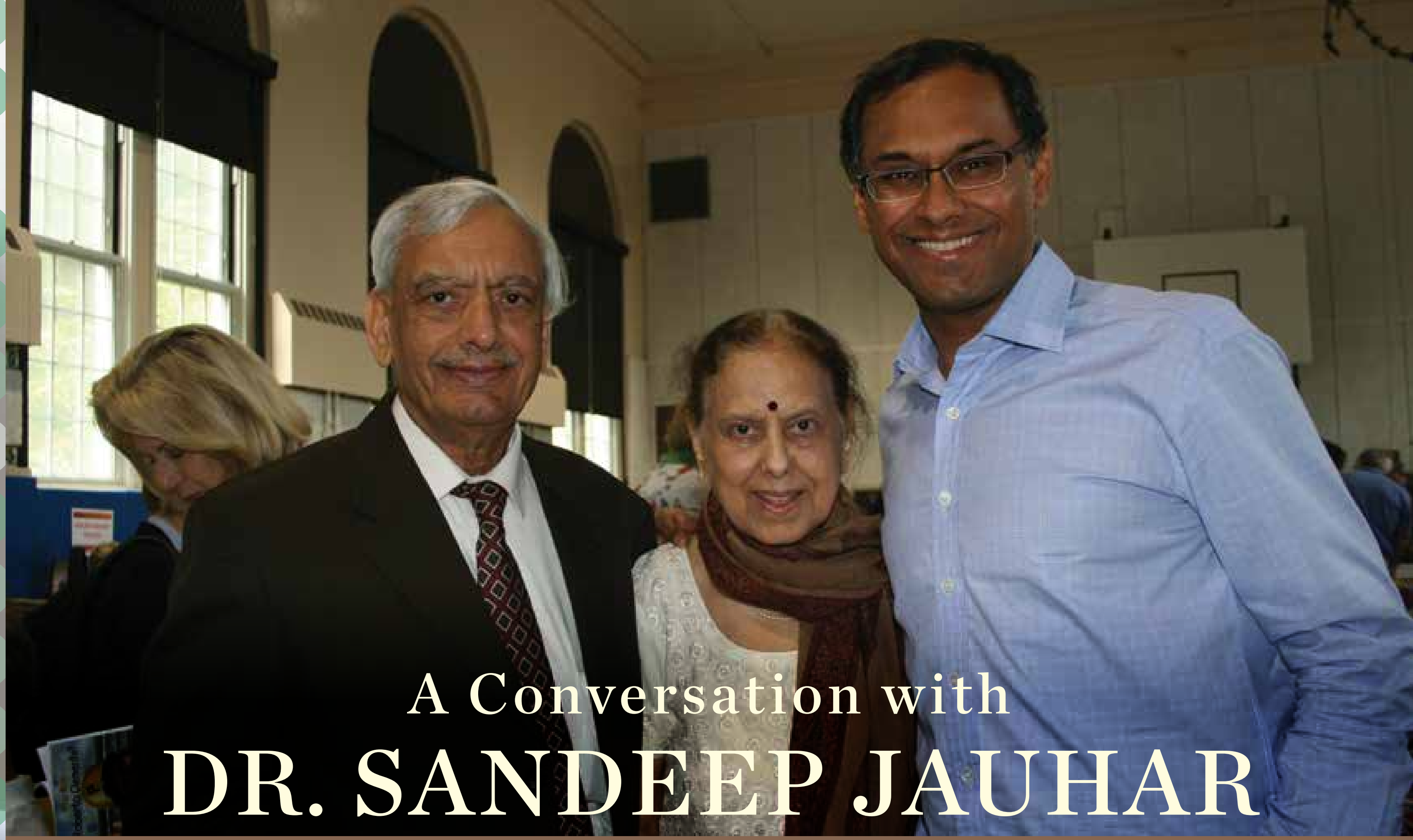
Becker, a writer, human rights activist and interfaith minister in New York City, shares her experience of Alzheimer's in "The Elders," one of nearly two dozen stories of loss throughout her life, which she tells through a spiritual lens, unearthing the love and strength present at the center of each experience. The title of the collection refers to the central core of a tree that is no longer alive yet it supports the more durable surrounding sapwood. She coins her own definition of heartwood as "a reminder to embrace the inseparability of life and death, the growth rings and the heartwood . . . a message of wholeness."

After her father's diagnosis it was her mother-in-law, Laura, and then her Aunt Bev. She concentrated on focusing on the things she considered "bigger than Alzheimer's"—her father's tenacity, Laura's love of nature and how Aunt Bev had been like a third parent.

> *"The care of one human being for another—even when one person may not recognize the other—is bigger than Alzheimer's, I thought. And what about love? Isn't love bigger than Alzheimer's?"*

In addition to crafting stories of her loss of family and friends, she also pays tribute to those who inspired her, one of whom was her mentor, Ann Dunham, who "had an infectious way of believing in people." Both women were working in programs to alleviate poverty. Dunham was the mother of former President Barack Obama, who was a lawyer in Chicago at the time Becker met her.

"Heartwood is about strength in what remains and the virtue of listening to our innermost source of stability and stillness. It is about how trusting the natural cycle of life and loss can help us to better live our lives."



A Conversation with

DR. SANDEEP JAUHAR

Author of *My Father's Brain: Life in the Shadow of Alzheimer's*

Alzheimer's TODAY: You've written a beautiful memoir that blends humor, compassion and family drama. You've said you wanted to write the book you had needed, considering the history, science and bioethics surrounding dementia so caregivers can understand what is going on in their loved one's brain. Was it hard to reveal so much about your personal struggles?

I believe if you're going to write a memoir you must be honest. This is my fourth memoir. Yes, it was hard to relive some of the struggles. It's hard to be so transparent and show your vulnerability, weakness and foibles, but it's important not to whitewash it and to present it all, in the way it happened, with all the pain and struggle.

You address the ethical issues involved in caring for someone with dementia. What were some of the issues you faced?

In Alzheimer's, the number-one issue is honesty, the conflict between validating a patient's false perspective versus orienting them to the caregiver's reality. I had to decide whether to tell my father that my mother was dead—and tell him again and again because he would forget—or validate his perspective that she was still alive. It's honesty versus therapeutic deception.

You mention that dementia has been called the worst of all diseases. What is your opinion of that?

To say dementia is the "worst" is a tough assessment but probably true. In some ways, neurodegenerative illness is more difficult than physical disease like cancer. A person's selfhood, memory, autobiographical history, and shared history with loved ones get defaced. People have a harder time accepting it. It's a psychological disease. It's so much more difficult because it affects what we think of as our most intimate possession—*who we are*.

As you look back now, what advice can you give to family members who disagree about caring for their loved one?

Finding consensus is important. If one family member's views are not listened to, it may create resentment and disagreements become bigger than they have to be, and relationships may become fractured.

Continued on following page

Prem Jauhar was a world-class scientist and a fellow of the American Association for the Advancement of Science. He passed away March 12, 2021.

Jauhar with grandson, Mohan, 4.

A CONVERSATION WITH DR. SANDEEP JAUHAR

cont'd from p. 15

You are a doctor so you knew what was happening to your father's brain but that didn't stop you from becoming exasperated. You write: "I wish I could say that we were more patient than the world outside, but we weren't. I wish I could forget how we scolded him when he'd ask questions, telling him that it was pointless when he could not remember the answers. There was little to deter us, even as we regretted it, again and again, after the fact. We knew our father was more than just his damaged brain. We knew it, but we struggled to believe it." Many people will relate to this. What advice can you offer them in retrospect?

Those kinds of responses are born out of frustration and ignorance of what is going on. My advice is to *learn* about what is actually happening in the brain so you can have a sort of blueprint of what to expect.

I thought dementia was a disease of the memory so why is my father so angry and ungrateful for all the work I'm doing. When we understand the trek of the disease, how it works its way through the brain, we understand better the cognitive manifestations. We can understand that it's not a disease of the person; it's a disease of the brain.

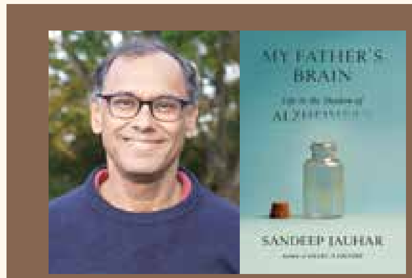
Two major things are going on in the brain. The most characteristic change is accumulations of a brain protein called beta amyloid that has undergone structural changes, becoming sticky and forming microscopic collections called plaques in between brain cells. The other abnormality is fibers inside neurons that become abnormal when a protein called tau misfolds, twisting the fibers into tangles, thus interfering with brain cell function. Together these abnormalities cause brain cells to die and the brain to atrophy, thus losing its ability to function normally.

Many people will also understand the conflicted feelings between you and your siblings about lying to your father, to either go along with his delusions or try to set him straight. What do you think about that now?

It took me a long time to understand the difference between lying for your own benefit or someone else's. White lies for mental peace validate the person's perspective. It's a way of conferring dignity in a way that brutally honest talk may not. Patients often need the therapeutic deception.

What do you hope people will take away from reading this book?

Caregivers will hopefully get some solace from reading about my personal struggle, understanding that other people have been through it and come out the other side. I also want them to have a clearer understanding of the science, what goes on in the brain. And hopefully they will find it an engaging story. ■



Dr. Sandeep Jauhar is the bestselling author of three acclaimed books, *Intern*, *Doctored*, and *Heart: A History*, which was a *PBS NewsHour*/*New York Times* book club pick. A practicing physician, Jauhar writes regularly for the opinion section of *The New York Times*. His most recent book, *My Father's Brain: Life in the Shadow of Alzheimer's*, is an intimate memoir about caring for his father as his disease progressed.

Katarzyna Bialasiewicz | Dreamstime

TRANSITIONING TO LONG-TERM CARE

For many people caring for a loved one with memory loss, the time will come when they must transfer that person into long-term care. This is rarely easy.

"It is important to understand that a care transition removes your loved one from a familiar and reassuring environment and routine to a new and challenging environment," says AFA social worker Linda Mockler, LMSW, M.Ed. "Let your loved one know you know this change is difficult for them; listen and empathize. Assure them you will be there for them throughout the process."

No one size fits all.

Melanie Budd, RN, MS, Dementia Alliance of NC, says there is no one-size-fits all solution for making the transition to long-term care.

"It depends on what's really going to be most important to your person. Ask them what they like best about their home."

If they say they like being able to go outside, look for a place where they can do that safely. If they are physically active, make sure the facility's security is good so your person can't get out without being noticed.

"I'm a big believer in talking to people who are part of your community," Budd says, mentioning support groups, primary care providers or members of a faith community. "That's how you start to screen where you're going to look."

Much depends on the person's level of awareness.

"Some people living with dementia have a tremendous amount of insight." In those cases, start the conversation by suggesting that living at home is no longer working. "Be gently out front."

"For other people those conversations don't work. If I don't have awareness that I need help, then explaining that I need help is only going to make me mad at you.

"My approach would be a conversation. 'What would your preference be now that you can't live here?'" Ask them whether they want to live near family or near where they are currently living.

If possible, start the conversation early, framing it as an "if something happens" situation. "Do it more theoretically."

Challenges of moving.

It's a challenge to go from the familiar to the unfamiliar where "this place is scary because I don't understand it." Other challenges include adjusting to living with many people after living with just a spouse or alone, and "we underestimate the challenge of routine. How do we replicate that routine as much as possible? Some things are so automatic we don't realize how embedded they are."

Other factors are loss of independence and being in control. "In a group setting your individual control is lessened. It might be as simple as you don't like the music."

And then there's the loss of memories made in their home, such as where they had family dinners. "The loss of the places where those memories are anchored can be really hard."

For family care partners the challenge often involves guilt and, in some cultures, shame, Bunn says. "It's the uncertainty of what's going to happen. Is this the right decision? Is it going to go well or be chaos?

"For many families things from childhood resurface and family dynamics start to come out."

Continued on following page

TRANSITIONING TO LONG-TERM CARE

cont'd from p. 17

Some family caregivers place their loved one in a facility because they are exhausted by the care responsibilities. Once they've had a break and catch up on sleep, Budd says, they begin to doubt their choice and consider bringing the family member home.

"I encourage people to journal through the decision-making process. If they start having doubts they can see, 'I do remember it being that challenging.'"

As for whether to involve your person in the decision-making, Budd says people with a good level of insight can be included, but people without may become confused by the choices.

A person with insight can be taken to the facility before moving, but not on your first visit. When you do take them, arrange for them to have lunch or join an activity so they can "not just look but experience" rather than go on formal tour.

Moving forward.

How much notice to give the person that they are moving also depends on their awareness level.

"I'm not a big believer in tricking people. I don't feel that sets people up to feel safe in an environment."

Do "a lot of validating," Budd says, giving an example, "'I understand this is not what you want to do and I feel the same way.' I use a lot of 'ands,' not 'buts.' When you use a 'but,' you wipe out everything you've just said. 'I know you don't want to do this, but you have to for your safety.'"

Begin looking for placement possibilities early.

"I want everybody to have a back-up plan from diagnosis when it's not an emergency."

If, when the time comes, you're feeling anxious, it may be better to have a secondary person like a doctor or lawyer tell your person they are moving because people with dementia pick up on emotions and can become anxious themselves. "Authority figures yield a lot of power for the older generation."

Budd is uncomfortable with facilities that advise families not to visit for the first weeks while their person adjusts.

"The last thing they want is for their person to feel deserted."

A plus is that relationships can deepen through separation.

"You're the only person who's got memories of the person. Other people can do tasks. If you're busy doing tasks, it's hard to be in a relationship."

The new living space can benefit your person in another way.

"There's a forgiveness about being in memory care," Budd says. "The rules are more fluid and there's a wider range of acceptable behavior. If I make a mistake, it's not always identified as a mistake. It's just something that happens." ■

Kriangsak Koopattanakij| Dreamstime

FALL PREVENTION

The risk of falling increases with age and can be a serious problem affecting older individuals. This may be due to a range of factors including medical conditions, medication, balance difficulties, visual or cognitive impairment and environmental issues.

Falls can cause serious injury, and loss of independence. Prevention is important.

13 tips to help reduce the risk of falls:

1) **Clear Pathways** — Make sure all pathways inside and outside of the house are clear of clutter and other obstacles, such as package deliveries or snow in the winter.

2) **Install handrails** — Stairs are one of the most common causes of falls in elderly folks. Install handrails in stairways and ensure they are securely anchored. Grab bars can also be used in the bathroom. Consider gating the top and bottom of staircases to prevent access.

3) **Watch out for rugs** — Rugs can bunch up or become folded, presenting extra risk for falling. Avoid this by removing the rugs altogether or switching to non-slip rugs. Outside the bath or shower, use a bathroom rug/bathmat during bath time, but leave it on the side of the tub when finished.

4) **Corral the chords** — Chords from TVs, lamps and other devices present a fall risk. Ensure that cords are neatly kept or tucked behind furniture and not strewn across the floor.

5) **Make everything clear** — Clearly mark all rooms with signs, to avoid wandering and confusion.

6) **Keep the important items close** — Keep everyday items, such as food or personal care products, within reach.

7) **Use nightlights** — Nightlights can be especially helpful in areas that are frequently visited at night, such as the bathroom or hallways.

8) **Minimize glare** — Alzheimer's disease can change the way a person perceives and sees light. Lights that produce glare may hinder vision for someone with dementia. Minimize glare from windows and mirrors. Use shades and furnish your home with glare-free lighting, along with circadian lighting or light bulbs that mimic natural night-day patterns of blue lights. These can be helpful to improve sight, state of mind, and sleep quality.

9) **Monitor medications** — Some medications can cause dizziness that can lead to falls. Ask the individual's doctor or a pharmacist about prescription and non-prescription medication side effects.

10) **Utilize vision and hearing aides** — Ensure the individual wears eyeglasses and hearing devices, if needed. Sensory issues can contribute to falls.

11) **Look into assistive devices** — Consult with a physical or occupational therapist about assistive devices (e.g., walker, cane, etc.)

12) **Use comfortable and secure shoes** — Evaluate the feet for pain and ensure the individual wears comfortable, well-fitting shoes with non-skid soles.

13) **Eat healthy and exercise** — Consult with a physician about appropriate diet and exercise. A healthy diet can help build bone strength. Strengthening exercises, such as chair rises and tai chi, may help strengthen leg muscles and improve balance.

Talking to Young Children About Alzheimer's

When a family member or important friend has Alzheimer's disease, it affects everyone close including children, who may have trouble understanding the changes they see, as well as dealing with their feelings about them.

"The best time to talk to children about Alzheimer's or any dementia-related illness is as soon as you can," says Jennifer Reader, LCSW, SIFI, AFA's director of educational services and social services. "This conversation is about nurturing and maintaining the bonds between the family members while also helping to eliminate the fear of the unknown for children."

***Gardening with Grandma*, AFA's latest children's book, offers help in starting these conversations.** AFA developed *Gardening with Grandma* as a tool to help start a conversation with a child about Alzheimer's. This book and AFA's beloved first book, *Dancing with Granddad*, are available at shop@alzfdn.org.

How to start.

If the person with Alzheimer's is able to and feels comfortable doing so, have a conversation with them and the child together. Having the child hear from their loved one directly about what they are experiencing can be helpful.

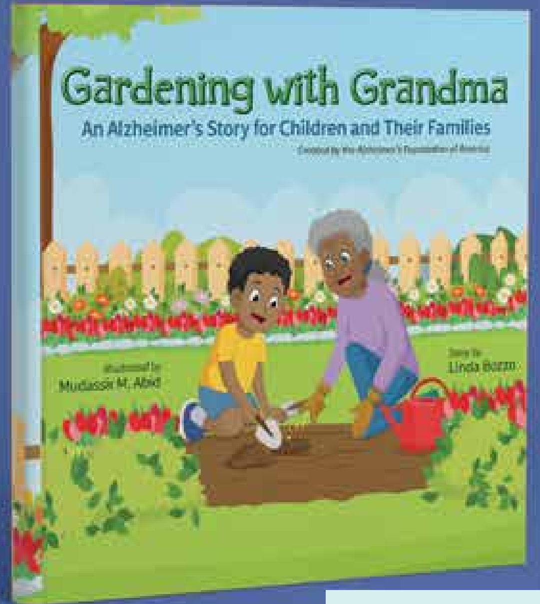
- **Set time aside for the conversation in a comfortable setting.**
- **If possible, invite feedback from the person living with Alzheimer's about what they are experiencing.**
- **Encourage questions from your child to address with your loved one. For instance, "What can I do for you when you can't find something?" or "If you seem sad, is there anything I can do to make you feel better?"**

Be mindful that this type of conversation is more effective when the person is in the earlier stages of Alzheimer's and may not be possible in the later stages. If the person is unable to have this conversation, or feels uncomfortable doing so, do not force the issue.

Children are highly intuitive. No doubt they have been picking up on these changes in their loved one, but they may not feel comfortable asking questions about them. It's important to welcome questioning.

Share information at a level appropriate for the age and maturity of your child. Explain that Grandma has Alzheimer's, an illness that affects memory and speaking. She may forget words and ask the same questions over again.

There may be a time in the Alzheimer's journey when a person with memory loss won't know the child or remember their visits. This may be difficult for the child and make them feel worried about how to engage with their loved one. Reassure the child that although their loved one may not remember a visit or a conversation, they can still hold on to the emotions they experience, carrying with them the happy and joyful feelings they felt during their time together.



"Grandma, I thought you said you didn't know where the watering can was."

"Did I say that?" Grandma said.

Luke didn't want to make Grandma feel bad that she didn't remember what she said. He gave Grandma a big hug.

5

Luke knew it wasn't good to argue with Grandma. It would only upset her. He remembered it was best to do something that would make her happy instead.

So, Luke turned on some music.

Together they sang as Grandma washed the dishes and Luke dried them. Then he went home.

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"We can visit her often," Dad assured Luke.

"We can even plant a new garden together!" Grandma added.

Luke's heart leapt at the idea that he would still be able to garden with Grandma.

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About *Gardening with Grandma*

(for ages 5-8)

One of the things 8-year-old Luke liked best about spring was heading next door to help his grandmother plant her garden. She taught him about different types of flowers and plants, and they loved watching them grow. He was unprepared as things began to change. First Grandma mistook a packet of seeds, thinking marigolds were tomatoes. When she became confused about other things, Luke told his parents he was worried about her.

Gardening with Grandma follows Luke's learning experience as he finds new ways to connect with his grandmother who has Alzheimer's disease. Grandma, who is early in her diagnosis, is able to share with him that even though she has a disease that affects her memory and behavior, she still loves him. The story unfolds as Luke adjusts to her move to a new home with more support. *Gardening with Grandma* also ends with a special message to adults to help them have meaningful, age-appropriate conversations with a child when a special person in their life has Alzheimer's.

***Gardening with Grandma* is available at shop@alzfdn.org.**

STORIES, INSPIRATION AND WISDOM FROM AFA SCHOLARSHIP WINNERS

AFA's annual Teen Alzheimer's Awareness Scholarship Contest asks high school seniors to describe how Alzheimer's disease has impacted their lives, what they have learned about themselves, their families, and their community in the face of this disease, and what their plans are for bringing awareness to Alzheimer's in the future. Students can submit entries as essays or videos. This year AFA awarded almost $70,000 in college scholarships to 103 students from across the country who were chosen from more than 1,500 entries. Since its inception in 2008, the program has awarded more than $430,000 in scholarships.

VINCENT YAO, Malvern, PA, FIRST PLACE (essay contest), $5,000 scholarship. Attending University of Pennsylvania.

"Whenever my elementary school teachers asked, 'Who is your hero?', my classmates often mentioned Spiderman, Tom Brady, or Barack Obama. But for me, my hero was my grandfather, Yeye....Over the few years that Yeye struggled with Alzheimer's, my mother and I devoted more and more time to taking care of him.... Now, I'm working hard to learn more about Alzheimer's....As an incoming freshman at the University of Pennsylvania, I plan to join the Penn Alzheimer's Buddies, a club that pairs members with nursing home residents experiencing dementia....I hope to pursue research into the field of Alzheimer's through the Joseph Wharton Scholars Program....Most importantly, I hope to help other children, just like me in middle school, cope with their loved ones suffering from Alzheimer's. As a student who loves writing and hopes to pursue a hobby as a journalist, I plan to submit articles that raise awareness about Alzheimer's and dementia to *Penn Today* and *The Daily Pennsylvanian*, two student-run newspapers at the University of Pennsylvania. What initially began as a way to connect with my grandfather has become a passion and an integral part of my identity."

CLARICE NGUYEN, Gilbert, AZ, SECOND PLACE (essay contest), $2,500 scholarship. Attending Arizona State University.

"As I enter college, I continue to find little ways to connect and assist my grandmother before I leave. I also find ways to help other senior citizens, be it playing piano with my music school at senior living centers or writing letters and making art for those in nursing homes. I look to find more opportunities like these at university, or perhaps even start them myself. One thing I am sure of is even if there is little to someone's memory other than their name and little to their abilities other than a small smile, their emotions and feelings are still so real, and that is worth any effort to bring hope and joy to their lives."

Continued on following page

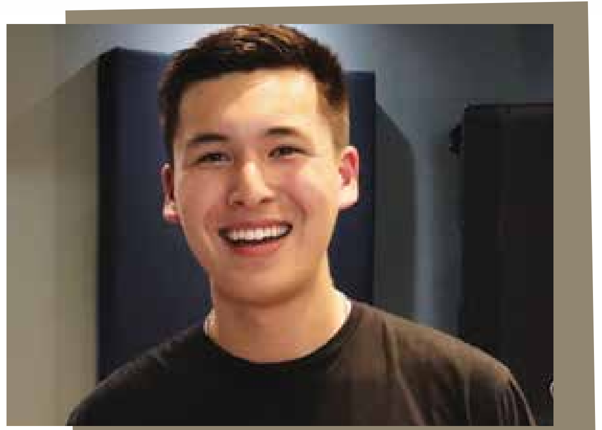
STORIES, INSPIRATION AND WISDOM FROM AFA SCHOLARSHIP WINNERS

cont'd from p. 23

AN LI, El Paso, TX, THIRD PLACE (essay contest), $1,250 scholarship. Attending University of Texas, Austin.

"Each time a vulnerable moment was shared with me, or I had found a new opportunity to inspire change, I am reminded of my grandpa's legacy. Although I lost him, I will never lose what he instilled within me: the ability to persevere through any hardship. Pocky's slogan—to share happiness—has become my ultimate mission in life. (Pocky is a Japanese chocolate-covered biscuit stick.) I hope to continue channeling these same essences in my future career as a reformer, where I'll work to bridge the gap between the inaccessibility of dementia resources to willing families and caregivers."

MATTHEW AASEN, Chantilly, VA, FIRST PLACE (video contest), $5,000 scholarship. Attending Belmont University.



"The biggest thing that has stuck with me is the music she [my grandmother] inspired in me and gave me the confidence to make. In the future I'd like to bring more awareness to how music can help bring those with Alzheimer's peace, comfort and happiness just like it did with my halmeoni [grandmother]. I've learned that when everything is forgotten music can remain. Now I'm planning a music business degree as well as a career in the music industry, and I wouldn't be at that point without my halmeoni."

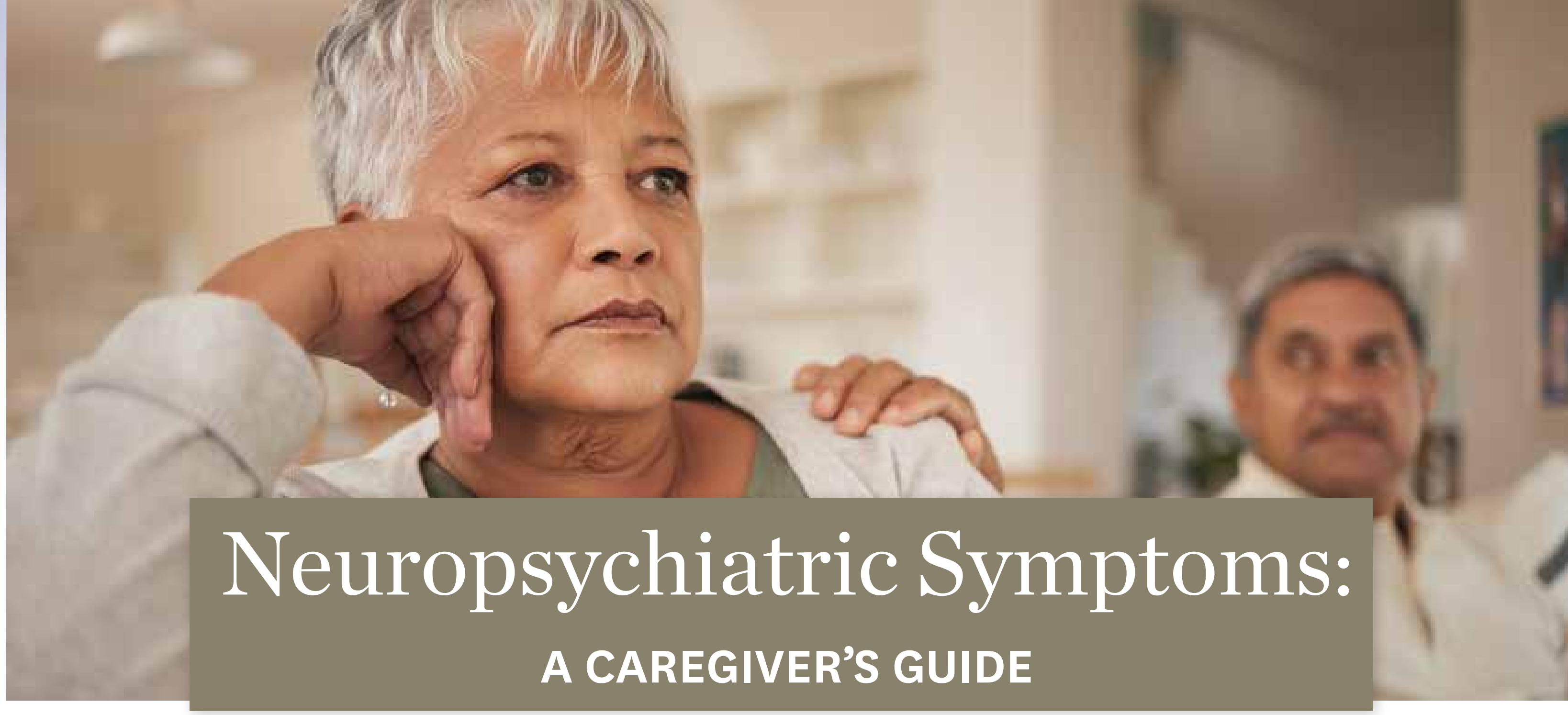
CHARLES BLACK, Portland, OR, SECOND PLACE (video contest), $2,500 scholarship. Attending MIT.

"Grandma has been an important part of my life and it is now time for me to help her. Through this process I've found my calling to pursue medicine and help others partly because of my grandmother. I'm infused with a passion to study neuroscience and finding a cure for dementia. I have great potential and plan to do biomedical research in neuroscience and become a physician scientist to help find a cure for this devastating disease. My biggest contribution, I believe, will be through my career and love of my grandmother."

MADELYNN COY, Avon, IN, THIRD PLACE (video contest), $1,250 scholarship. Attending Kelley School of Business, Indiana University.

"I have really seen first hand what it takes to take care of Alzheimer's patients. Watching my mom be their [my grandparents] primary caregiver is really difficult for me because I don't understand why there aren't more resources provided. I plan to be an Indiana senator and I believe that being in local government I'll be really able to input so many resources and programs to provide for the elderly community that we all kind of set aside. The more resources we have and the more funding we have the more likely that someone else won't lose their best friend." ■

To learn more about AFA's Teen Alzheimer's Awareness Scholarship, go to **ALZFDN.ORG/SCHOLARSHIP.**



Neuropsychiatric Symptoms:

A CAREGIVER'S GUIDE

Studies show that nearly every person living with dementia will eventually develop some form of Neuropsychiatric Symptoms (NPS), the non-cognitive, behavioral manifestations of dementia. Just as those living with Alzheimer's and other forms of dementia may develop a range of impairments that affect their capacity to remember, communicate effectively and reason, they also may experience changes in mood and personality leading to troubling and disruptive behaviors.

It is important to be aware that behavioral changes can be prodromes, symptoms that begin prior to the onset of a diagnosis of a neurocognitive disorder. In fact, they can be the first symptom of dementia.

SYMPTOM TYPES

Jeremy Koppel, MD, AFA Medical, Scientific, & Memory Screening Advisory Board Member, describes common symptom types associated with NPS. They include:

- **Apathy** — Sitting for prolonged periods, disengaged from normal activities, lack of expression of pleasure. This is the most common and enduring symptom, with nearly nine in 10 manifesting this, especially in late stages.
- **Depression** — Enduring sadness or irritability, loss of interest, changes in sleep and appetite, thoughts of not wanting to be alive. It occurs in nearly half of people over the course of the illness. It may resolve and return episodically.

It is important to distinguish apathy from depression (apathy is loss of interest, depression is change of mood). Rates of apathy tend to increase as illness progresses; rates of depression tend to drop.

- **Irritability** — Easily frustrated, persistent negativity, rejection of help, saying "no." Up to a third of people experience this. It's a persistent symptom that if left untreated will worsen.
- **Agitation and Aggression** — Yelling, cursing; sometimes pushing, shoving, spitting, biting, especially when someone is trying to provide care. More than a third of people manifest this confrontational behavior over the course of illness. If left untreated, verbal abuse can progress to physical abuse.
- **Psychosis: Delusions** — Preoccupations that someone is stealing or disloyal, intends harm; their home is not their own, relatives from the past are still alive or present, people are not who they say they are. Nearly half will experience psychosis. Peaks at the moderate stage of Alzheimer's and gradually reduces in frequency in later stages. Occurs in many who are exhibiting violent behavior.
- **Psychosis: Perceptual errors and hallucinations** — Hearing voices or people talking when no one is nearby; seeing people who are not present; seeing things that are not there. They are less common than delusions.
- **Motor activity and wandering** — Inability to sit still, sitting down and getting up, pacing, wandering, shadowing loved ones; rummaging, collecting and hoarding. Nearly half will experience increased motor activity with greater prevalence during later stages.
- **Sleeping and eating disorders** — Disrupted sleep, such as trouble falling asleep, going to sleep too early, reversed sleep cycles (sleeping during the day, up at night), attempting to leave the house or initiating daytime activities at night (dressing, eating, cooking), as well as decreased appetite. Experienced by most over the course of the illness. Both will increase in severity and frequency as the illness progresses.

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TREATMENT OPTIONS

The first step in accessing an intervention is the engagement of a qualified dementia health care provider for a complete evaluation. This could be a geriatric medicine specialist, a neurologist or a geriatric psychiatrist.

Non-Pharmacological approaches

For mild cases, non-pharma approaches should be tried first: music therapy, aromatherapy, exercise or physical therapy, pet/animal therapy and, for some, psychotherapy. If these fail or if symptoms are persistent or severe, medications may be necessary.

Pharmacological approaches

All medications carry risks that need to be discussed and weighed against possible benefits. Dementia-focused providers, especially geriatric psychiatrists, may recommend medications from the antidepressant class (selective serotonin reuptake inhibitors, SSRIs) or from the atypical antipsychotic class. Though often effective, use of antipsychotics is generally a last resort and should be approached with caution, as these have been associated with an increased risk of death. Use of sedative hypnotics should generally be avoided as they often worsen confusion and cause falls.

Clinical trials

Experimental non-antipsychotic medication clinical trials are ongoing. Information about where these are offered and how to begin the process of enrollment can be found at **clinicaltrials.gov**.

CAREGIVERS NEED CARE

Although these behaviors—collectively referred to as NPS—contribute directly to caregiver stress and burnout, often they can be successfully addressed by working with professionals using a variety of intervention approaches.

Seek support, guidance and resources by contacting the AFA Helpline, staffed by licensed social workers trained in dementia care, available 7 days a week by phone (866-232-8484), text (646-586-5283) or webchat at alzfdn.org.

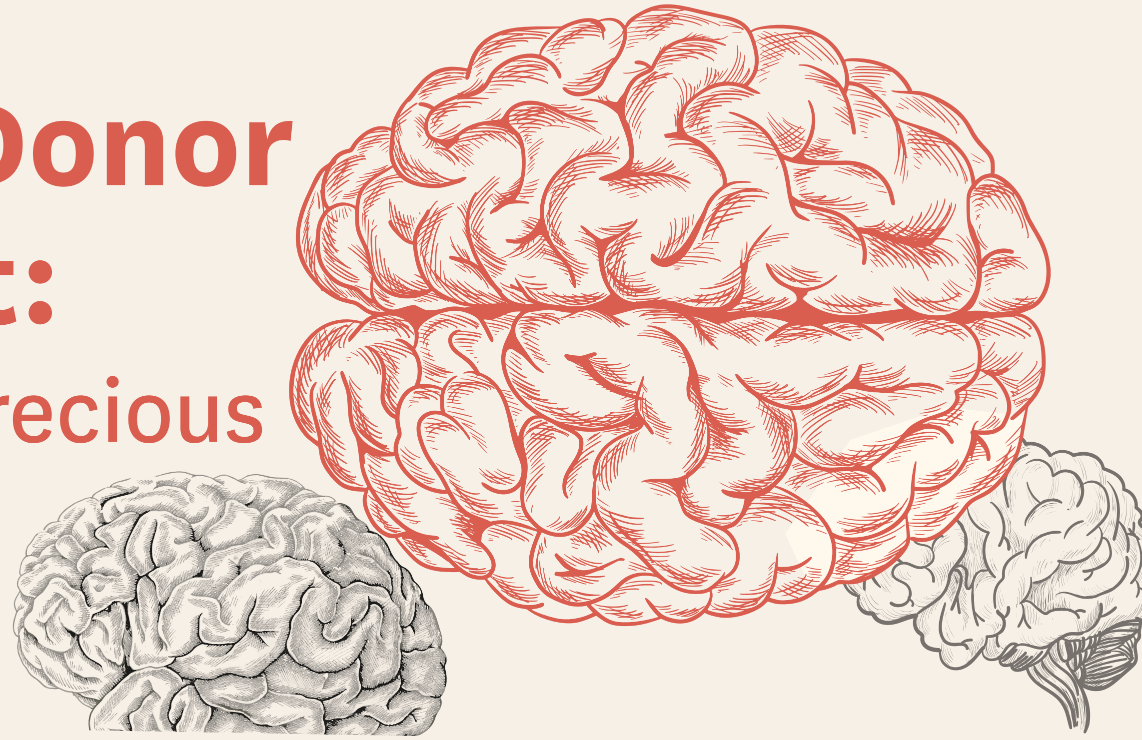
ABOUT THIS ARTICLE

This article is based on a brochure, "What Are Neuropsychiatric Symptoms? A Caregiver's Guide," written in consultation with Medical, Scientific and Memory Screening Advisory Board Member Jeremy Koppel, MD, co-director of the Litwin-Zucker Center for the Study of Alzheimer's Disease, Feinstein Institutes for Medical Research.

Interested in receiving a copy, please contact the AFA Helpline, at 866-232-8484, text at 646-586-5283, or webchat at alzfdn.org.

Brain Donor Project:

Leave a Precious Final Gift



Your final act could very well advance the science of brain disease. It starts with completion of a simple online form. Go to **braindonorproject.org** to learn more. Soon you're referred to a brain bank, given instructions to share with your family, and when the time comes, plans are in place to leave a precious, final gift.

Tish Hevel says most people plan carefully for what will happen to their belongings, their property and their money when they die, but she wants to make sure they include their most important asset, their brain. She formed a nonprofit, The Brain Donor Project, to help them do just that.

"Dementia illnesses are out of control right now," she says. "Our chances of being diagnosed increase as we age. We're all living longer. It's easy to see where this is leading, where the urgency lies. We're desperate for answers."

Researchers are looking for those answers. The most effective way to find them is through examining human brain tissue.

"Access to tissue is a stumbling block for a lot of science to get done," says Dr. Walter Koroshetz, director of the National Institute of Neurological Disorders and Stroke/National Institute of Health (NIH). He said brain disorders are the leading cause of disability in the United States.

Tish Hevel and her dad Gene Armentrout

Traditional methods of studying the brain are insufficient.

Neurological disorders "affect the brain at a very, very fine level so there are all kinds of very small structures in the brain, neurons and the connections between the neurons, that we cannot visualize with imaging, that we can't study without actually looking at the brain tissue," Dr. Joshua Gordon, director of the National Institute of Mental Health/NIH, said.

Tish Hevel has made it her mission to raise awareness of this need. For this former journalist and public relations professional her quest arose from her personal experience with her father's Lewy body dementia. It started with many internet searches to try to understand the disease. Which led to more questions.

"We didn't even know what brain donation was. It kept coming up."

Her father was already a full-body donor, so Hevel assumed

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Hevel, her dad, and sister Annie McManis

BRAIN DONOR PROJECT *cont'd from p. 27*

assigning his brain for separate research would not be a problem after he died in 2015. She was wrong.

"It was super complicated at the time. I wanted to see if I could do anything to help."

She reached out to NIH for advice and turned her personal quest into The Brain Donor Project, which she started in 2016. Her mission was twofold: to raise awareness of the critical need for donated brain tissue and to simplify the process of becoming a brain donor.

Hevel said NIH heard from researchers that they had problems getting access to human brain tissue because most brain banks imposed some level of barrier. So the NIH created the NeuroBioBank to make the tissue more readily available. The Brain Donor Project supports NIH's NeuroBioBank.

Many people think if they check the box on their driver's license everything will be taken care of, Hevel says, but that's not the case because unlike other organs the brain isn't transplanted so it is overlooked.

"There are too many misconceptions," she says.

Fear that brain donation will be costly for the family is another misconception.

"We're only working with the brain banks of NIH so there's no cost."

A third misconception is that the removal will be disfiguring but the brain is taken from the back of the head, so an open casket funeral is still possible.

Close to 20,000 people have taken the first step to donation by registering on the Project's website, **braindonorproject.org.** Thirty percent of them are people with unaffected, healthy brains. Because of privacy reasons, Hevel doesn't know the exact number of donations that have resulted, but estimated it to be "well over 1,000." She cites two big motivations.

"For some it's altruistic. If we can spare some future family, we'll give this gift on our way out the door when we're finished with it. It's comforting to know something positive can come from it. We felt that way too."

Another motivation is that the NIH brain bank will supply a summary of its neuropathological findings based on an autopsy of the brain.

"That's really important for families to have," Hevel says. "It's key information for children and grandchildren because soon there may be avenues for editing or repairing their genes.

"People assume dementia is a natural part of aging, but that's not necessarily true."

Hevel still draws inspiration from her father, a former president of a regional brokerage firm who died at 78.

"We really miss him, but doing this work I feel his presence. He's with me."

Photos courtesy of Tish Hevel

Dementia Risks in the LGBTQ+ Community

LGBTQ+ is an acronym that brings together many different gender and sexual identities that often face marginalization across society. It stands for: lesbian, gay, bisexual, transgender, queer, questioning, intersex, asexual and the "+" holds space for the expanding and new understanding of different parts of diverse gender and sexual identities.

Although there is greater social acceptance of LGBTQ+ identities in cities like New York and San Francisco, this does not hold to be true in many parts of this country and the world. Sixty-four countries have laws criminalizing homosexuality. Among the penalties are death and forced psychiatric treatment.

"Recent data suggests that social acceptance of LGBTQ+ people in the United States has plateaued and may even be reversing," said Jennifer Reeder, LCSW, SIFI, AFA's director of education and social services.

"Aside from the here and now, it's important to take into consideration the long history of discrimination experienced by LGBTQ+ people," she said. "There is no federal law that explicitly protects LGBTQ+ people from discrimination, and not all state and local nondiscrimination laws include protections based on gender identity.

"This lack of protection from their federal, state and local governments creates great mistrust in systems that have already proven to be discriminatory. This can impact a person's willingness to share their true identity, as well as seek support before there is a medical crisis."

An older LGBTQ+ adult who is experiencing symptoms of dementia has already likely experienced stigma and discrimination for most of their life from healthcare and social services providers. It is terrifying to become vulnerable and reliant on these providers, Reeder says.

When LGBTQ+ older adults do access services, their history of experienced stigmatization can affect their willingness to disclose their identity. Forty to 60 percent of older LGBTQ+ adults in their 60s and 70s say their healthcare provider does not know their sexual orientation.

HEALTH DISPARITIES

According to the CDC, health disparities are preventable differences in the burden of disease, injury, violence or opportunities to achieve optimal health. These disparities are inequitable and are directly related to historical and current unequal distribution of social, political, economic and environmental resources.

"Historically, LGBTQ+ adults have lower rates of health insurance coverage,

Continued on following page

Lindsay Snow | Dreamstime

DEMENTIA RISKS IN THE LGBTQ+ COMMUNITY

cont'd from p. 29

which can delay access to healthcare and treatment," Reeder says.

CHRONIC PHYSICAL CONDITIONS

LGBTQ+ older adults have higher rates of chronic health conditions that can lead to an overuse of medications such as opioids for chronic pain. These drugs impact brain health, leading to cognitive decline. A major cause of these chronic conditions is from avoiding medical care due to fear of mistreatment, Reeder says.

This can also cause delayed screenings for certain illnesses like heart disease, breast cancer and colon cancer. Many of these chronic conditions are risk factors for dementia and cognitive decline.

SOCIAL ISOLATION

Recent research shows that social isolation can lead to a serious decline in a person's health, especially for those with dementia. This can lead to premature placement into a care setting and early death. LGBTQ+ older adults are at greater risk of social isolation due to bullying, harassment, hate crimes and family rejection.

"Many LGBTQ+ older adults are more likely to be self-reliant and put off care to be protective of their home as a safe space," Reeder says.

WHAT TO DO

When supporting an LGBTQ+ person, as with anyone who has dementia, it is important to remember that everyone is unique. Take a person-centered approach.

"It is also important to be aware that the individual and their partner or caregiver may still be experiencing discrimination and harassment in their neighborhood, biological family, place of residence and with service and medical providers," Reeder says, "so we must be aware of realistic reasons why they may be resistant or fearful of healthcare, home health aides and sharing their identity."

Reeder says we should acknowledge their fear.

"Helping anyone with dementia, especially those who have experienced trauma, feel safe and secure is the overarching goal in dementia care."

This article was adapted from AFA's continuing education workshop "Supporting the LGBTQ Community in Dementia Care."

Shining Colors|Dreamstime

Project Lifesaver Finds Missing Loved Ones

The 89-year-old woman in Pennsylvania County, VA, had Alzheimer's and had slipped away from her caregivers one night. While they had no idea where she had gone, her rescuers were hot on her trail. They tracked her across an open field, a roadway and midway through a tobacco field that was thick with mud from days of rain.

They found her by stumbling over her in the dark. She was covered in mud but physically unharmed and was reunited with her loved ones. As in the case of at least 5,000 other people with neurological disorders who went missing, recovery started with a phone call—thanks to a registered tracking device the woman was wearing and the special Project Lifesaver training of local police and fire employees.

"One of the beauties of the program is that it's quick, simple and it works," said Chief J.E Gene Saunders, Project Lifesaver International's founder and CEO.

HOW DOES PROJECT LIFESAVER WORK?

A family member needs to register their loved one with a local Project Lifesaver agency to receive a monitoring bracelet. The system relies on pulse-carrier wave radio frequencies (assigned by the FCC for medical purposes) that are emitted as a constant tracking signal from a client's personalized bracelet.

Each wristband has a unique radio frequency enabling trained search and rescue teams at local police and fire stations to positively locate and identify a missing person. Recovery time is cut from days to minutes.

An important element in the success of the program is the relationship building that occurs during a necessary monthly change of battery in the bracelet the person wears. An officer may pick up on the possibility of straying if the person starts talking about "going home." If all goes well, the responder doesn't see the person for a month, until the next battery change. If all doesn't go well, however, the family has the security of a contact number for their public safety agency.

Saunders said the tracking devise in the bracelet is based on technology developed in World War II to help the United States locate spies.

"It's not new. It's not complicated with a lot of moving parts to go wrong like GPS. It's simple and it works."

Started in 1999 while Gene Saunders was with the Search and Rescue Company of the Chesapeake, VA, Sheriff's office, Project Lifesaver is the premiere search and rescue program operated internationally by public safety agencies. Its mission is to educate and equip these employees in the protection, search and safe recovery of wanderers, also known as the eloped. It has more than 1,800 member organizations across all 50 states and in Canada and Puerto Rico.

To find a Project Lifesaver member agency in your community where you can enroll a family member or loved one, visit projectlifesaver.org/about-us/where-we-are.

PROJECT LIFESAVER FINDS MISSING LOVED ONES

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Sample RF transmitter wristband.

Project Lifesaver radio-frequency tracking device

MORE THAN SEARCH AND RESCUE

"What I've heard many, many times from families is that it means they have peace of mind," Saunders said, adding that this is because they know trained professionals are looking for their loved one. People with neurocognitive disorders who go missing are in danger of dying from exposure to weather conditions they are not dressed for, and they are unable to understand the danger they are in. And the dangers have increased, Saunders says.

Sauders rose to the rank of chief during his 33 years of service with the Chesapeake Police Department where he founded the SWAT Team, which he commanded for 23 years. He served on AFA's board of trustees for eight years.

With his law enforcement background, he knew public safety agency employees need to have a basic understanding of neurocognitive conditions, so he created community policing courses within Project Lifesaver to give searchers the tools to respond, assess and effectively manage the safe return of the missing person, as well as ways to interact with caregivers.

The visits that are most beneficial are the ones in which the public safety person connects with the bracelet wearer as well. Saunders remembers a time when he was working search and rescue. A caregiver's daughter mentioned to her father that Saunders had been a ranger in the army. That launched a three-hour—one way—conversation during which the man talked about his years in the military. The daughter had never heard him utter a word about those days.

"He couldn't remember what he had for breakfast, or if he even had breakfast, but he remembered his war experiences. That opened him up," Saunders said.

Saunders says most responders know someone with a neurocognitive disorder. Because finding the person is only half the job, with the other half getting them home safely, training includes information about these disorders but "not deeply medical. It's about understanding behavior. That's the aspect they will be dealing with. It makes them feel great when they can return someone."

Rescuers are told to always be in uniform because the person might still have long-term memories and the uniform could bring a feeling of safety. Training includes how to work with the person who has been found. Techniques include reassuring the person by saying who they are and what they are doing, using simple phrasing, avoiding complex questions, and keeping their voice low so the person must "de-escalate" to hear what is being said. Officers are also required to spend eight hours in a memory care facility observing the residents and nurses.

Saunders says he has learned that the term eloped, used in the autism community, is more appropriate than wanderer.

"They don't wander," he says. "There's a purpose to them going, you just may not know it. We call it a mission. They may be going to work. They may have retired 30 years ago, but in their mind they're still working. These are the kind of things you learn as you go on."

Photos courtesy of Project Lifesaver

AN ESSAY:

Alzheimer's, My Dad and Me

BY JENNY ADAMS

Jenny Adams with her dad, Lee

I looked for it under a tree. But in the end, I found it near the bushes lining the edge of his condominium yard. I wish I could say that it was hidden. It was not. It stood out, a solid brown mass of poop in plain sight.

Unlike my dad's quite visible accident, the disease that caused it is as stealthy as a diamond thief. The first signs — lost keys, lost wallet, confusions about dates — are imperceptible. Can't remember a name? Forgot that you already bought peanut butter? Confused about the day of the week? Sure, these could be early signs of dementia. Or they could just be life.

Grown children often fail to recognize signs of dementia in their aging parents. When I was little, my dad amazed me with what he could do. He could cook a French dinner. He could ride a bicycle with enviable ease. He knew all the lyrics to the musical "Oklahoma!" How could this same person, a man who could parse a *Law Review* article in one minute and reel off Joe Montana's touchdown completion stats the next, poop under a tree and not fully remember it?

You might think I would look at this drying lump and have an epiphany. But epiphanies about Alzheimer's don't often happen. Like the disease itself, understanding and then acceptance of Alzheimer's come slowly, less like a light bulb and more like a slow tide on Nauseta Beach making its way in.

My limited grasp started only when my dad lost so much of his memory that even I could not fail to notice. Shortly after the incident, my dad mentioned how much he was enjoying his visit to Massachusetts. I laughed. He seemed confused, so I reminded him that he moved to Northampton in 2018.

He looked stunned. Then he started to cry. This was the closest I came to any sudden realization. As I watched my dad, I finally realized that in his mind, he was out to see me and my family for a quick visit. A few weeks later, he once again talked about his visit "out East." Then called me "Joan," his sister's name. And, a few weeks later, he asked, "Joan, are our parents still alive?"

All of this sent me scurrying to various websites. The more I read, I learned that Alzheimer's is a disease, not an intrinsic part of

Continued on following page

AN ESSAY: ALZHEIMER'S, MY DAD AND ME

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aging. Most older people might have some memory loss, but not Alzheimer's. I also began to understand its symptoms and trajectory. Researchers stage Alzheimer's in different ways. All list specific behaviors to help caregivers wrap their heads around what they're seeing. Learning these stages let me map where my dad had been and where he is headed.

Most importantly, seeing where he was going motivated me to act. In late 2021, when my dad landed in the hospital for a medical issue unrelated to his dementia, I used his multi-week recovery to sell his condo and relocate him to an assisted living facility. When the rehab facility discharged him, I brought him to his new "home."

He raged, swore, and cried, and so did I. But I remained firm because I now knew what the disease had done to his brain and what was coming next. Indeed, my dad spent only 18 months in assisted living before I had to move him to a memory unit. Now he is in a skilled nursing facility and hospice.

With all this understanding has come empathy. I stopped sniping at my dad for his tantrums or his forgetfulness. My childhood grievances became muted then replaced by compassion for his suffering.

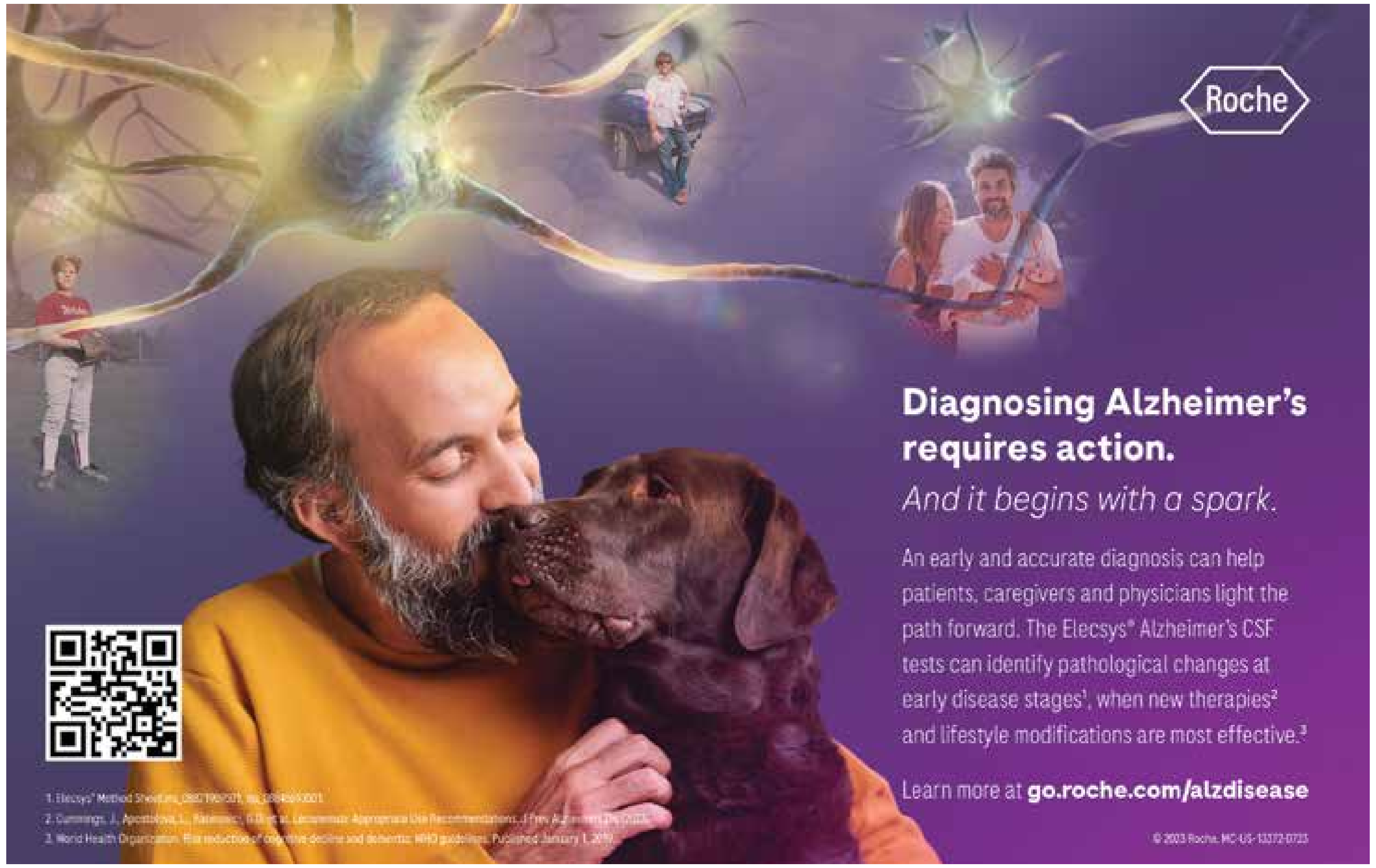
He never asked to be in this position. Sure, people can reduce their chances of Alzheimer's by modifying their diets, stopping their smoking, curbing their drinking and getting physical activity. (And please, for the love of Pete, do these things.) Yet even people who do everything right can still succumb to it.

Even with his condition my dad continues to inspire me. He often laughs at his own forgetfulness, and this lets me know that part of him is still self-aware. He continues to ask about his granddaughters and loves any updates about them, even as he moves into the late stages of the disease. He hugs me easily these days and thanks me for helping him. In return I can more easily hug him and thank him for all he's done for me, too.

The thinking part of my dad's brain remembers none of these moments. But his joy at each of them is gratifying and a reminder that life, love and happiness do not have to stop with this disease.

ABOUT THE AUTHOR

Jenny Adams is a professor of English at the University of Massachusetts Amherst. She lives in Northampton. This essay was adapted from a longer one published in the *Daily Hampshire Gazette*.



Dementia Linked to Air Pollution

Higher rates of new cases of dementia in a population over time — known as incident dementia — are linked to long-term exposure to fine particulate matter (PM2.5) air pollution, especially from agriculture and open fires, according to a study funded by the National Institutes of Health and published in *JAMA Internal Medicine*. Scientists found that 15 percent of older adults developed incident dementia during the average follow-up of 10 years.

Compared with those who did not develop dementia, participants with incident dementia were more likely to be non-white, have less formal education, less wealth and higher surrounding PM2.5 levels at their address. While agriculture and open fires had the strongest air pollution-dementia associations, road traffic, non-road traffic and coal combustion for energy production and industry were also associated with incident dementia.

Alzheimer's TODAY asked Nathaniel A. Chin, MD, an assistant professor (CHS) at the University of Wisconsin-Madison, department of medicine, geriatric division, for advice on how to minimize damage from air pollution exposure. Chin is a member of AFA's Medical, Scientific & Memory Screening Advisory Board.

"Wearing masks can be helpful. It may not be as feasible or practical for most people, but it could help, particularly when one wears an N95."

When this topic comes up in his clinic, Chin suggests the following:

- **Check the daily air pollution forecasts in your area. This became a particularly common practice with the Canadian fires.**
- **Avoid being outdoors during high air pollution levels. Try not to exercise outdoors when air pollution levels are high, or even moderate.**
- **Limit time in congested traffic areas.**
- **Avoid fires. Avoid burning wood or trash.**
- **Spend more free time in remote or rural parts of your state. Spend less time in dense areas or near factories.**
- **Write to your local representatives and state representatives expressing your concern because this is a public health issue and requires public health interventions to protect all of us.**
- **Make sure your indoor air is as clean as possible too.**

◂ Sunrise over downtown Los Angeles.

Monkey Business Images|Dreamstime

The Role of Light Sensitivity

New Alzheimer's research from UVA Health suggests that enhanced light sensitivity may contribute to sundowning, the worsening of symptoms late in the day, and spur sleep disruptions thought to contribute to the disease's progression.

The new insights into the disruptions of the biological clock could have important potential both for the development of treatments and for symptom management, the researchers say. The altered circadian rhythms experienced by people living with Alzheimer's affect caregivers as well as they struggle with the erratic sleep patterns of their loved one. Light therapy, the new research suggests, might be an effective tool to help manage that.

Further, better understanding Alzheimer's effects on the biological clock could have implications for preventing the disease, the researchers say. Poor sleep quality in adulthood is a risk factor for Alzheimer's, as our brains at rest naturally cleanse themselves of amyloid beta proteins that are thought to form harmful tangles in Alzheimer's.

"Circadian disruptions have been recognized in Alzheimer's disease for a long time, but we've never had a very good understanding of what causes them," said researcher Thaddeus Weigel, a graduate student working with Heather Ferris, MD, PhD, of the University of Virginia School of Medicine's Division of Endocrinology and Metabolism. "This research points to changes in light sensitivity as a new, interesting possible explanation for some of those circadian symptoms."

Ferris and her collaborators used a mouse model of Alzheimer's to better understand what happens to the biological clock in Alzheimer's disease. They essentially gave the mice jet lag by altering their exposure to light, then examined how it affected their behavior. The Alzheimer's mice reacted significantly differently than did regular mice.

The Alzheimer's mice, the scientists found, adapted to a six-hour time change significantly more quickly than the control mice. The scientists suspect this is the result of a heightened sensitivity to changes in light. While our biological clocks normally take cues from light, this adjustment happens gradually, causing jet lag when we travel great distances. Our bodies need time to adapt. But for the Alzheimer's mice, this change happened abnormally fast.

The researchers' results ultimately suggest there is an important role for the retina in the enhanced light sensitivity in Alzheimer's, and that gives researchers a promising avenue to pursue as they work to develop new ways to treat, manage and prevent the disease.

"These data suggest that controlling the kind of light and the timing of the light could be key to reducing circadian disruptions in Alzheimer's disease," Ferris said. "We hope that this research will help us to develop light therapies that people can use to reduce the progression of Alzheimer's disease."

Robert Kneschke|Dreamstime

Get UP

The benefits of exercise on our physical and cognitive health have been well documented. New research backs this up once again, finding that sitting for long hours increases a person's risk of developing dementia. A study by researchers at the University of Southern California and the University of Arizona, which was recently published in JAMA, found significant increase in dementia risk among adults who spend more than 10 hours a day engaging in sedentary behaviors. The researchers noted that the average American spends about 9.5 hours sedentary each day.

The Power of Healthy, Older Brains

As an expert in neurocognitive disorders, Marc E. Agronin, M.D., knows the statistics for Alzheimer's cases and how drastically the numbers are expected to increase. The chief medical officer of the Frank L. and Lynn Scaduto MIND Institute and Behavioral Health in Miami also knows that older, healthy brains have strengths, and that significant decline is not inevitable.

The author of *The End of Old Age: Living a Longer, More Purposeful Life*, says, "We have what is called crystalized intelligence—our skills, our knowledge, our experience. These basically remain stable or even increase over time. We tend to build more vocabulary and our overall knowledge increases."

What changes is our processing, Agronin says. Our fluid intelligence—problem-solving, reasoning, logic, pattern recognition—begins slowing in our 20s and 30s. People have more of those tip-of-the-tongue experiences, lapses where you can just almost taste what you're trying to remember. Luckily, slower doesn't necessarily mean worse or less. It depends on the skill we're talking about, he adds.

Brain and cognitive reserves, neuroplasticity.

Over time your brain continues to gain more experiences. You're continuing to learn, building up what Agronin calls **brain and cognitive reserves**. Put together, these consist of the total brain connections, intelligence, skills and experiences that we accumulate over time.

Brain reserves "refers to the stuff, the connections." Cognitive reserve "is all the skills and abilities."

"In some ways it's like putting money in the bank over time. The bigger reserve you have in your brain means the more connections you have protected as you got older.

"In addition, our brains have the ability to adapt and sculpt themselves in the face of change and even injury. This is called neuroplasticity."

Older vs. younger brains.

To compare the workings of a young brain and an older brain, Agronin said to imagine an auditorium full of people with an aisle down the middle. He said to think of each person as a brain cell, or neuron, with the aisle as a separator of the two sides, or hemispheres, of the brain.

"If you're a 30-year-old brain and I put a problem on the board and point to one or two of you and say, 'solve it,' you know what to do: You solve it quickly and efficiently, end of story.

"The older brain is a little different. In this case I'm going to point to maybe five of you on one side and eight of you on the other side and I'm going to say, 'get together to solve this problem.' The older brain may need to recruit more from more areas of the brain. It might take a little longer, but there are strengths in the numbers, and this speaks again to the ability of older brains to bring in more circuits, more experience, more skills, more abilities. You can imagine there's great strength in that."

If you were to ask older adults when they've made better decisions, when they were 18 or now, most would say now, he points out.

"In part it's because you're using more brain circuits on both sides of your brain, so that adds an important element."

Continued on following page

THE POWER OF HEALTHY, OLDER BRAINS

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Agronin identified three different valuable *approaches* that aging provides.

- **Post-formal thinking.** Scientific data shows older brains tend to be more pragmatic and practical. "They're less reactive, rigid and impulsive."
- **Socioemotional selectivity.** "Older minds tend to prefer more positive experiences and gravitate toward more meaningful goals and activities."
- **Developmental intelligence.** As we get older, our brains are able to take all of our cognitive abilities, emotional experiences, judgment and social skills and put them together in a more balanced and integrated whole.

This really is wisdom and it speaks to the strengths that older brains get.

"We know that people who have higher ratings of wisdom feel better, are more satisfied with life, have better family relationships and marriages. They adjust better to aging. They have lower levels of depression. So wisdom is a key currency of aging and it's something we can focus on."

Adapted from AFA's Care Connection webinar featuring Marc E. Agronin. Part Two of his talk will be featured in the next issue of *Alzheimer's TODAY*.

AFA Opens More Respite Care Relief Parks

Ribbon cutting at AFA Respite Care Relief Park in Eisenhower Park

The quiet parks overlooking the water with their gazebos are a welcome refuge from the busyness of the world. AFA opened new Respite Care Relief Parks in May and November, two of only three of their kind in the country, as dementia-friendly places where caregivers can bring their loved one with memory loss to enjoy a peaceful outdoor setting. The gazebos are surrounded by placards detailing facts about Alzheimer's, tips for caregivers as well as activities for those living with the disease.

"It's incredibly important that people who have been afflicted with Alzheimer's and dementia have a place like this, and that their caregivers have a place to bring them to enjoy nature, peace and solitude in a gorgeous setting," said County Executive Bruce Blakeman, of Nassau County, NY, which partnered with AFA on a new Respite Care Relief Park within Eisenhower Park in East Meadow, NY. Eisenhower Park is the largest park in Nassau County and even bigger than Central Park in New York City.

"This allows people living with Alzheimer's and those caring for them to pause and reflect in a peaceful setting. The educational resources here will advise them and give them a sense they are not alone in this journey," said Mayor Mike Spano of the City of Yonkers, NY, which worked with AFA to build a Respite Care Relief Park along the Hudson River waterfront **(above)**.

The need for dementia-friendly places is critical because caregivers often have a hard time finding a public space where their loved one feels comfortable or where they feel comfortable bringing their loved one. Isolation is one of the biggest challenges for people with Alzheimer's and their caregivers. It can accelerate

Continued on following page

MORE RESPITE CARE RELIEF PARKS *cont'd from p. 39*

Ribbon cutting at Yonkers Respite Park

the progression of the disease and contribute to caregiver burnout. The parks give Alzheimer's caregivers a chance to get out of the house, enjoy a peaceful setting, socialize, and receive helpful information—all in a place that is welcoming to them with their loved one.

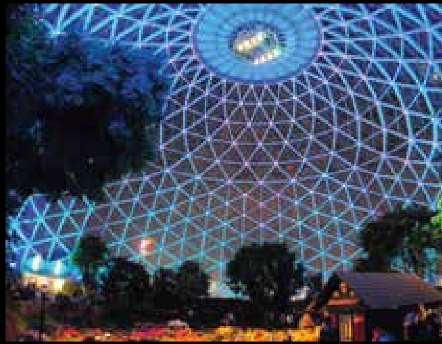
"When it's a spouse, it's very close to your heart," Jeff Ray, a first-time park visitor shared with CBS News. Jeff Ray and Arthur Dozier, also a caregiver for his wife, met for the first time at the East Madow park's gazebo. "We can come and talk. It's almost like a support group," Ray said.

The East Meadow park was largely funded through a grant AFA received from the Mother Cabrini Heath Foundation. Grant funding from the Mother Cabrini Heath Foundation and the Thomas and Agnes Carvel Foundation helped fund the Yonkers park.

"We are proud to support the AFA and such an important project that will benefit caregivers, individuals and families dealing with Alzheimer's, as well as many other park-goers in the surrounding community," said Daniel Frascella, chief programs and grants officer for the Mother Cabrini Health Foundation.

AFA works with municipalities to build Respite Parks in their communities. AFA's first opened in Lindenhurst, NY, and was built with the Town of Babylon. Contact AFA at 866-232-8484 to learn more about our Respite Care Relief Park program. ■

AFA Respite Care Relieve Park in Eisenhower Park, East Meadow, NY; Alex Wolff/Concierge Photography



What's Inspiring Us

LANDMARKS "LIGHT UP IN TEAL" TO SHOW SUPPORT FOR THE MILLIONS OF PEOPLE IMPACTED BY ALZHEIMER'S

More than 1,000 landmarks in all 50 states and 13 foreign countries inspired hope as part of AFA's Light the World in Teal annual awareness campaign on November 2 this year, part of November National Alzheimer's Awareness Month.

"Every site that participates in this global initiative is making a difference in the fight against Alzheimer's disease—and the more that join, the more awareness we will raise about Alzheimer's," said Charles J. Fuschillo, Jr., AFA's president and CEO.

Skyscrapers, office and government buildings, bridges, tourist attractions, concert halls and sports complexes all took part. These include the Empire State Building and One World Trade Center in New York City to LAX Airport, Met Life Stadium in NJ, the General Motors Building in Detroit and the Governor's Mansion in Baton Rouge. Internationally, participants included the Clock Tower at Banbridge Town Hall, Northern Ireland; the Sky Ribbon Bridge in Australia; and the Emirates Spinnaker Tower in the UK.

To see the complete list of participants, go to **lighttheworldinteal.com**. Organizations interested in participating next year can learn more here as well or contact the Alzheimer's Foundation of America at 866-232-8484. There is no fee for sites to participate in the program.

AFA®
ALZHEIMER'S FOUNDATION OF AMERICA
322 Eighth Avenue, 16th Fl.
New York, NY 10001

MORE THAN 6.5 MILLION individuals are living with Alzheimer's.

Each year, **MORE THAN 16 MILLION** Americans provide more than 17 billion hours of unpaid care for family and friends with dementia.

The number of people in the U.S. living with Alzheimer's is projected to more than double to **14 MILLION BY 2060.**

Source: Centers for Disease Control and Prevention

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