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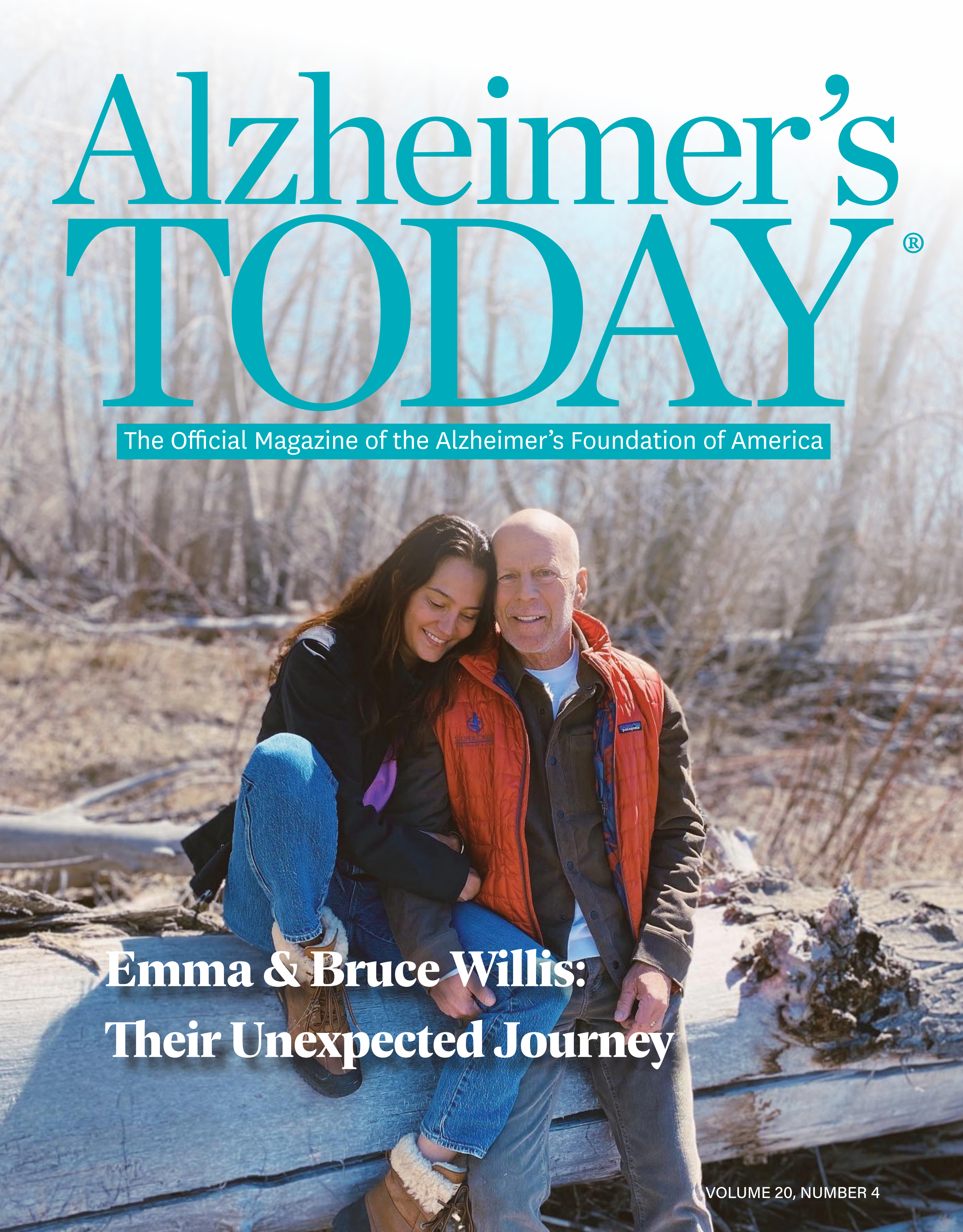
The Official Magazine of the Alzheimer's Foundation of America



Emma & Bruce Willis: Their Unexpected Journey

VOLUME 20, NUMBER 4

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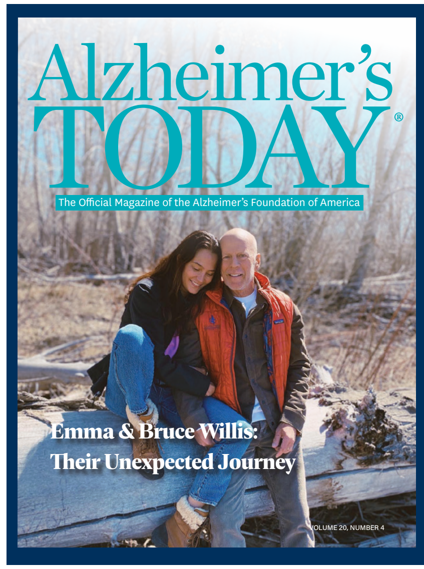

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Contents

A Message from Our President & CEO

CHARLES J. FUSCHILLO, JR.

As president and CEO of the Alzheimer's Foundation, I regularly receive inquiries from friends and acquaintances about someone in their lives experiencing memory changes, what it might mean and what they should do about it.

I'd like to share the advice of Dr. Nathaniel Chin, a member of AFA's medical advisory board and medical director of the Wisconsin Alzheimer's Disease Center and the Wisconsin Registry for Alzheimer's Prevention Study.

He says, "One of the key changes needed for us in this country is to talk openly about memory and thinking capabilities so that we can identify the earliest changes and have an intervention as soon as possible."

When you have concerns, make an appointment with your primary care provider. Determining what is going on, even if not serious, can take a little time. Sometimes these difficulties are mild cognitive impairment (MCI), a memory loss condition that precedes dementia. Sometimes MCI can be reversed or remain stable. Dr. Chin explains this in more detail in "Understanding Mild Cognitive Impairment (MCI)," pp. 22-23. I encourage you to check it out and share it with friends and family when they express concern about thinking changes.

Our cover story, "The Unexpected Journey" (pp. 9–10), features our interview with Emma Heming Willis, who has been navigating the challenges of her husband, actor Bruce Willis' life-changing diagnosis of frontotemporal dementia (FTD). Emma's story offers valuable lessons for all caregivers. When she asked experts across various fields for their single most important piece of advice, their answers were unanimous: *get help*. We can't travel this journey alone — and that's exactly why our founder and chair, Bert Brodsky, started the Alzheimer's Foundation of America.

We wish you, your family and friends a peaceful holiday season and all the best in good health and warm moments in the year ahead.

Warm regards,

2025: A Year of Service

In 2025, AFA **empowered families** through our Educating America Tour, Fireside Chats and Care Connections, equipping more than 10,000 families with vital knowledge and resources. We provided **caring support** to more than 5,500 families through AFA's Helpline, staffed by licensed, dementia-trained social workers. We **advanced research** with nearly $600,000 in grants to fund better treatments and a cure. We provided **educational training** to more than 2,500 professionals, raising the standard of Alzheimer's care. We **funded vital services in local communities** with more than $200,000 in grants to enhance lives. We opened the **AFA Barbara Rabinowitz Education & Resource Center** in Amityville, NY, and our newest **Respite Care Relief Park** in Port Washington, NY, reaching more families in need. We provided **memory screenings** to over 10,000 individuals to help them take better care of their brain health. Help us keep the support and fight going strong in 2026.

Make your gift before 12 midnight, December 31, to receive year-end tax benefits. We are grateful.

Donate today:
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Good for Your Brain

Living in "20-minute neighborhoods"

Living in a "20-minute neighborhood" — where shopping, dining, groceries, health care, parks, social spots and public transit are all within walking distance — can support better brain health, according to researchers at the University of Miami Miller School of Medicine.

In a study published in *Health & Place*, researchers examined 352 older adults from the *Healthy Brain Initiative* cohort and found that those living in more walkable areas had fewer white matter hyperintensities (WMHs) — small brain lesions linked to higher risk for stroke and dementia. While previous studies explored individual neighborhood features, this research was the first to assess their combined impact on brain health.

—University of Miami Miller School of Medicine

Doing this after 70

Listening to music when you are over 70 years of age has been linked to a 39 percent reduction in the risk of dementia, according to a Monash University-led study of over 10,800 older people.

The study, which was published in the *International Journal of Geriatric Psychiatry*, found that always listening to music, compared to never, rarely or sometimes listening to music, was associated with the greatest reduction in dementia risk, with a 39 percent lower incidence and 17 percent lower incidence of cognitive impairment, as well as higher scores in overall cognition and episodic memory (used when recalling everyday events). Playing an instrument was associated with a 35 percent reduction.

— Neuroscience News

Shingles vaccine

A growing body of research provides some of the strongest evidence yet that some viral infections can have effects on brain function years later and that preventing them can help stave off cognitive decline.

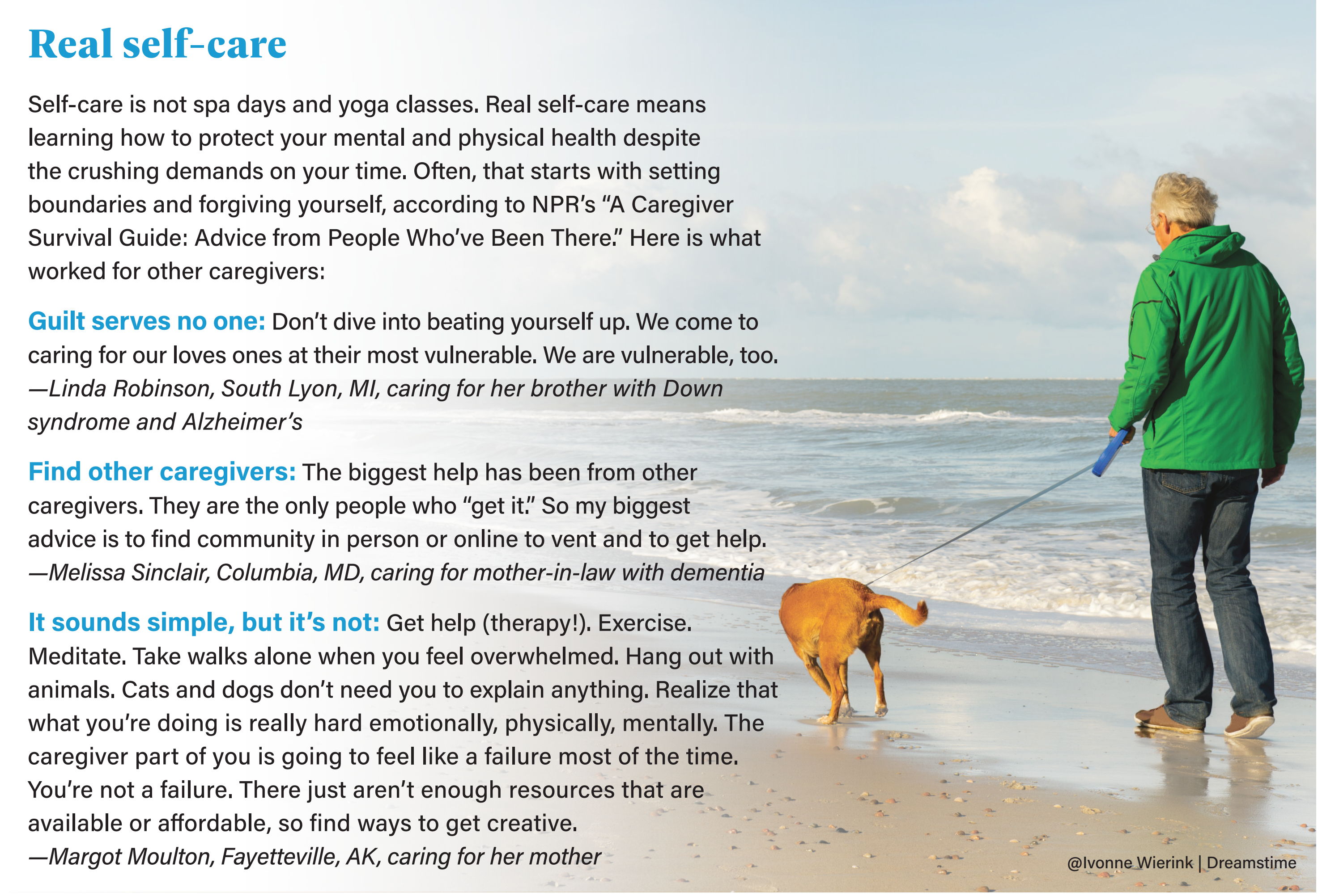
The study published in *Nature* found that people who received the shingles vaccine were 20 percent less likely to develop dementia in the seven years afterward than those who were not vaccinated. Whether the protection can last beyond seven years can only be determined by further research.

Dr. Paul Harrison, a professor of psychiatry at Oxford, told *The New York Times*, "If you're reducing the risk of dementia by 20 percent, that's quite important in a public health context, given that we don't really have much else at the moment that slows down the onset of dementia."

—The New York Times

Caregiver Life

Real self-care



Self-care is not spa days and yoga classes. Real self-care means learning how to protect your mental and physical health despite the crushing demands on your time. Often, that starts with setting boundaries and forgiving yourself, according to NPR's "A Caregiver Survival Guide: Advice from People Who've Been There." Here is what worked for other caregivers:

Guilt serves no one: Don't dive into beating yourself up. We come to caring for our loves ones at their most vulnerable. We are vulnerable, too. *—Linda Robinson, South Lyon, MI, caring for her brother with Down syndrome and Alzheimer's*

Find other caregivers: The biggest help has been from other caregivers. They are the only people who "get it." So my biggest advice is to find community in person or online to vent and to get help. *—Melissa Sinclair, Columbia, MD, caring for mother-in-law with dementia*

It sounds simple, but it's not: Get help (therapy!). Exercise. Meditate. Take walks alone when you feel overwhelmed. Hang out with animals. Cats and dogs don't need you to explain anything. Realize that what you're doing is really hard emotionally, physically, mentally. The caregiver part of you is going to feel like a failure most of the time. You're not a failure. There just aren't enough resources that are available or affordable, so find ways to get creative. *—Margot Moulton, Fayetteville, AK, caring for her mother*

@Ivonne Wierink | Dreamstime

Let go of difficult moments

The brain's memory system doesn't treat all events the same. The emotionally intense moments take priority — and awkwardness, shame or embarrassment tend to top the list.

"Our brains are wired to prioritize emotions, especially negative or uncomfortable ones," says Kristin Slyne, PsyD, ABPP-CN, neuropsychologist and neuropsychology program manager with the Behavioral Health Network at Hartford HealthCare. "This negativity bias has helped our ancestors survive by ensuring they wouldn't repeat mistakes."

That means you might forget what your boss said in your last meeting, but you're sure to remember tripping over your words during a presentation.

Here's how to help positive, important memories stick:

- Be present in the moment. Try to fully experience big life moments without distractions.
- Use your senses. What did it smell, sound, or feel like? Sensory input makes memories stronger.
- Talk about it. Sharing the memory out loud helps reinforce it in your brain.
- Write it down. Journaling gives your brain a second chance to process and store the experience.

"Memory is like a muscle — the more you use and revisit certain moments, the stronger they become," Slyne says.

Research Updates

Lithium link to Alzheimer's?

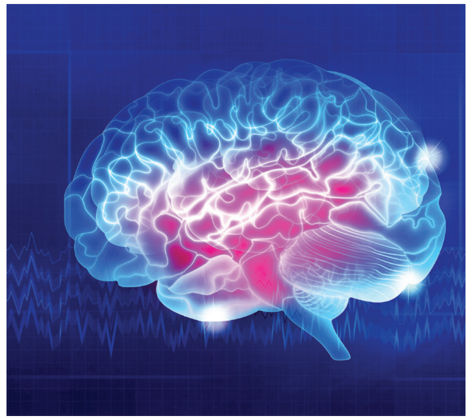
A recent study from Harvard Medical School asks whether the element lithium might be a key factor in whether someone develops Alzheimer's disease. Led by Dr. Bruce Yankner, professor of genetics and neurology at Harvard Medical School, the almost-decade-long study says it is the first to show that lithium is found naturally in the brain in small amounts and suggests that the element plays an important role in the prevention and treatment of cognitive decline.

The study published in *Nature* this summer found a link between lithium deficiency in the brain and an increase in amyloid plaques and tau tangles — known contributors to the development of Alzheimer's disease. In trials on mice, researchers found they were able to reverse the disease, prevent brain cell damage and restore memory loss through a small dosage of a lithium compound called lithium orotate.

Experts told PBS News that it's premature to conclude from the results that people should use lithium as a treatment or prophylactic for Alzheimer's disease — but if the findings are confirmed through a randomized human controlled trial, measuring lithium levels could potentially help with early detection of the disease and provide a broader understanding of aging brains.

—PBS News

Vascular dementia



A recent study conducted by the Keck School of Medicine of USC has investigated a biomarker associated with vascular dementia across four distinct groups of middle-aged to older adults and offered insights into how cognitive impairment develops.

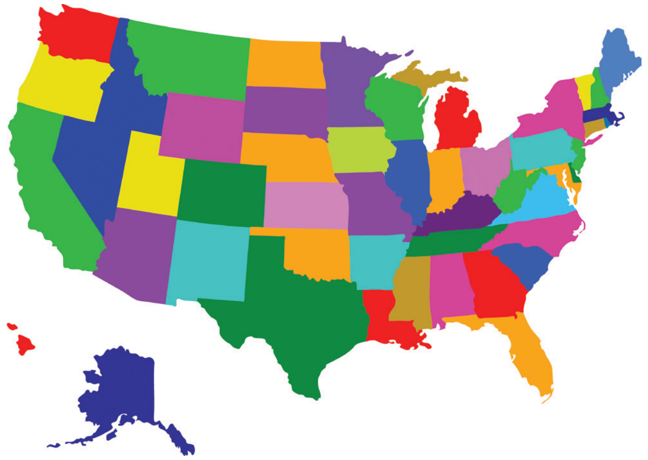
Vascular dementia is typically caused by cerebral small vessel disease (cSVD), which damages the brain's small blood vessels. However, the precise mechanisms connecting cSVD to dementia remain unclear. One prominent theory involves dysfunction in the glymphatic system, a network responsible for clearing waste from the brain. The researchers used a technique to determine how well the glymphatic system was functioning in each person based on brain scans and confirmed that glymphatic damage may be driving cognitive decline. The research findings have been published in *Alzheimer's & Dementia.*

—SciTechDaily

Where you live

In one of the largest and most comprehensive studies of its kind, a research team led at UC San Francisco has identified the regions of the country where dementia occurs most often among veterans.

Using the Mid-Atlantic as the basis for comparison, researchers found that dementia rates were 25 percent higher in the Southeast. The Northwest and Rocky Mountains were both 23 percent higher, and the South was 18 percent higher. The Southwest, which includes California, was 13 percent higher; while the Northeast, which includes New York, was 7 percent higher.

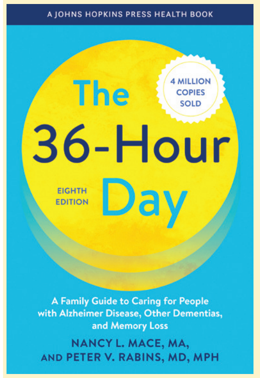


These differences remained when researchers accounted for factors like age, race and cardiovascular disease. This includes rural areas, where medical care may be less accessible compared to urban areas.

—UCSF News

Tip Sheet

Reducing overreactions



People living with brain diseases often become easily upset and experience sudden mood changes. Unfamiliar situations, confusion, crowds, loud noises, being asked multiple questions at once, or being given a task that feels too difficult can all trigger these reactions. The best way to manage these behaviors is to stop them before they happen, according to Peter Rabins, MD, MPH, and Nancy Mace, MA, authors of *The 36-Hour Day*. The things that trigger these outbursts vary, but as you learn what upsets your person, you will be able to reduce the severity and frequency of outbursts. Some of the most common follow:

- Needing to think about several things at once (e.g., all the tasks involved in taking a bath)
- Trying to do something they can no longer manage
- Being cared for by someone who is rushed or upset
- Not wanting to appear inadequate or unable to do things
- Being hurried (when a person is thinking or moving more slowly)
- Not understanding what they saw or heard
- Being tired
- Not feeling well
- Not being able to make themselves understood
- Feeling frustrated
- Being treated like a child
- Feeling sick and not knowing why

Familiar routines and surroundings can help calm someone with dementia and prevent distress. Keep things where they belong, follow daily habits, and use simple written reminders when possible. Because confusion often worsens when too much is happening at once, simplify tasks and give one instruction at a time. For example, during a bath, gently guide step by step: "I'm going to unbutton your shirt…that's all right…now step into the tub, I'll hold your arm." Calm, steady reassurance helps the person feel safe and in control.

Adapted from *The 36-Hour Day: A Family Guide to Caring for People with Alzheimer Disease, Other Dementias, and Memory Loss* by Nancy L. Mace, MA, and Peter V. Rabins, MD, MPH. Copyright 2025. Published with permission of Johns Hopkins University Press.

Communication Dos & Don'ts

People with Alzheimer's may struggle to find the right word when speaking and may forget what they are saying. Remember to be patient. Here are some dos and don'ts to keep in mind.

DO	DON'T
✓ Make eye contact and use the person's name.	✗ Exclude the person from conversations.
✓ Listen and be open to the person's concerns.	✗ Speak with an angry or tense tone.
✓ Allow extra time for the person to respond.	✗ Interrupt or argue with the person.
✓ Try using different words if the person doesn't understand what you say the first time.	✗ Ask the person whether they remember something or someone.
✓ Ask yes or no questions: "Would you like some tea?" rather than "What would you like to drink?"	

—National Institute on Aging

Photo courtesy of the Willis family

The Unexpected Journey

An interview with Emma Heming Willis on facing the challenges of husband Bruce Willis' life-changing diagnosis — with lessons for all caregivers.

Like everyone whose life is upended by a serious medical diagnosis, Emma Heming Willis had no understanding of the challenges that were coming her way after her husband, actor Bruce Willis, was diagnosed with frontotemporal dementia (FTD) three years ago. But she discovered she could develop the inner resources to meet those challenges. Now her goal is to help others do the same through her book *The Unexpected Journey: Finding Strength, Hope, and Yourself on the Caregiving Path.*

"The story is so much bigger than just Bruce and me. I want to normalize the conversation, to shine a light on caregivers. They are unsung heroes. They are unseen and unsupported, and we need to recognize them."

Willis talked about her experiences from the backseat of a car traveling through New Jersey following a meeting with caregivers in Ocean City, MD, and on her way to New York City to promote the book. It was mid-September and even though the book had only been out for a week and a half it was already No. 2 on the *New York Times* bestseller list. She attributes this to the millions of caregivers looking for help.

"Because I had the resources and access to be able to talk to the most incredible experts, I knew I was sitting on really important information other caregivers don't have. I wanted to share with others help for the long journey."

Information was something the Willis family didn't have when their journey began. FTD doesn't present itself like other memory loss conditions. Because it is marked by changes in language or personality and how the person relates to others, loved ones often assume the person is being rude, apathetic, irritable or depressed. These seem like behaviors of choice rather than symptoms of a disease.

Over time Willis watched her loving, easy-going husband change into a withdrawn man prone to arguments. She worried this could be troubles developing in their marriage until she began to suspect he might be experiencing some deep medical problems.

In early 2022, Bruce was given "a vague diagnosis of aphasia," a disorder affecting a person's ability to process and communicate language, but that didn't explain Bruce's changes in behavior.

More consultations with doctors followed until November 2022 when Bruce was diagnosed with primary progressive aphasia, which is a variant of FTD. He was 67. Willis advises loved ones to persist as she did until they receive a diagnosis that explains what their person is experiencing.

After his diagnosis, the couple was given a pamphlet on the condition and told to return in a few months.

"We walked out with no support and hope, nothing."

Caregiver connecting.

At first, Willis "spent so much time in isolation trying to fix, hide, control." Then she started researching online before beginning a sweeping effort to consult dozens of leading experts on FTD and other forms of dementia.

"I have a platform. My husband has such global resources. For me to twiddle my thumbs and not do anything would not serve anyone."

Wanting to share what she had learned, she felt compelled to get it out in a book, weaving in the perspective of her life with Bruce "not to sensationalize or fuel tabloid gossip" but to connect through stories.

Connecting is crucial for finding support, she says, which is why she encourages people to join support groups in-person or online. "Be in the room with other caregivers. Some are a few steps ahead of you and you can learn from them. You're able to share stories and lean on one another."

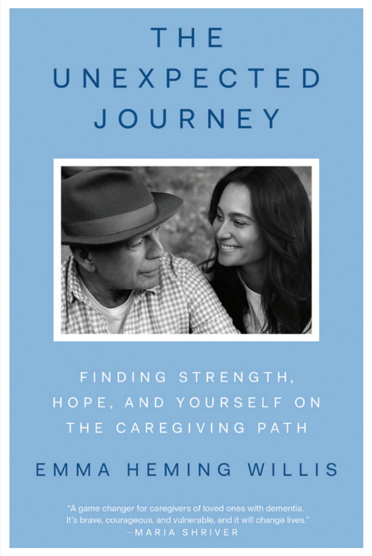
The Unexpected Journey addresses the many chapters of every dementia caregiver's journey with honesty, depth and heart — dealing with your person's brain changes, building community, taking care of your emotional and brain health, parenting, letting friends and family take care of you and even reframing the journey (when you can).

@ Belathee Photograp

The young family: Emma and Bruce with daughters Evelyn and Mabel.

Here is a sampling of insights from Emma Willis, excerpted from *The Unexpected Journey*:

- ***Get help.***
  When I asked experts for their top piece of advice for care partners, no matter their field of expertise, they said to get help. And when I asked about the biggest mistake care partners make on this journey, they say it's not getting that help soon enough.
- ***Try to connect with a person who has had a similar experience.***
  One of the most important members of your community is the person who is walking a few steps ahead of you on the caregiving journey, because they can provide insight but aren't so removed that they can't empathize with what you're currently going through.



- ***Be informed.***
  In time, I've been able to dig into my ongoing education. This has provided me with so much comfort and helped settle my nervous system to some degree. As Teepa says, "Knowledge is the key to stress reduction." For me, that means reading a lot and asking the doctors, specialists, and other experts about what is happening and what's to come. [Teepa Snow is the founder of Positive Approach to Care.]
- ***Let friends and family take care of you.***
  This book is here to give you permission to prioritize your own well-being.

Six Tips for Keeping Joy in the Season

With the holiday season in full swing, AFA offers tips to help care partners celebrate safely and comfortably.

"Dementia doesn't prevent someone from feeling the warmth, love and laughter of the holiday season, but it can change how they experience it," says Jennifer Reeder, LCSW, AFA's educational and social services senior director. "Being proactive, adaptable and inclusive of the person's wishes and abilities are the best ways to help them have a happy and joyful experience."

AFA offers these six tips for creating a dementia-friendly holiday season:

- **Keep decorations festive, but simple.** Decorating is part of the holiday fun, but many flickering lights, noisy items or major changes to the person's environment can be overwhelming and potentially cause the person to wander. Choose a few favorite items and phase in decorations over a period of days, so changes to the person's environment are less confusing.
- **Eliminate dangerous decorations and safety hazards.** Avoid fragile decorations that can shatter or ones that look like food or candy. Be mindful of potential tripping hazards, such as wires for decorations. Memory loss can cause changes in vision, depth perception and gait.
- **Adapt past traditions.** If your person always sent cards or baked cookies and still wants to, help them accomplish this. You can also start new traditions that center on activities and events the person enjoys and can do, such as touring neighborhood holiday lights. Ask your loved one what traditions are most important, if possible. Feeling some sadness about changes and losses, especially during a holiday, is normal. Acknowledge these feelings and then move on to new ways to celebrate.
- **Take cues from your loved one.** Use a strengths-based, person-centered approach, incorporating what the person *can* do and chooses to do now, rather than dwelling on what they used to do.
- **Prepare a quiet, calm space before a holiday gathering.** Create a space where your loved one can sit comfortably and guests can visit in small groups or one-to-one. Provide familiar comfort items, such as a favorite blanket, sweater or stuffed animal. To the greatest extent possible, maintain the person's normal routine; disruptions in routine can be difficult for someone living with memory loss.
- **Accept help from others.** Many parts of the holiday season — shopping for gifts or hosting a holiday gathering — can be stressful even without the additional responsibilities of caring for a loved one with memory loss. Relatives and friends might be eager to help but do not know how. Accept their offers and be specific about what would be helpful: running errands, bringing a dish to the celebration or spending time with your loved one so you can complete holiday tasks. **Happy Holidays!**

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Songs of Love for People with Memory Loss

When songwriter John Beltzer was cut out of a record deal in 1995, he was devastated. "I was left out in the cold," he recalls. But two weeks later, inspiration struck: "I could create a charity that helps sick children."

With no nonprofit experience but strong determination, he launched an organization to create free personalized songs for gravely ill children. His first call was to St. Jude Children's Research Hospital, which sent him six children's names, photos and stories.

Two weeks later, five-year-old Brittany, who had cancer, called to thank him for her song. "It was the cutest voice," Beltzer says. "I cried my eyes out. I knew then that's what I was meant to do for the rest of my life."

The nonprofit he created is the Songs of Love Foundation. Now, 30 years after his life-changing epiphany — and more than 46,000 songs later — Beltzer, inspired by his mother's experience with Alzheimer's, has launched Memory Request, a new project that creates personalized songs for people with memory loss.

Request your song

Caregivers can request a free song by filling out a form on **songsoflove.org/memoryrequest** with details from the person's life — first name, children or grandchildren's names, former occupation, pets of the present or from long ago and any favorite things and experiences. Their life story will be related in each lyric. Songs are delivered preloaded on an 8 GB USB file drive.

Beltzer reached this point with help from more than 1,000 singers and songwriters — most volunteers, some paid only a small stipend. But creating songs for seniors presented a challenge: how to offer songs in the style of their era — big band, Motown and swing. That music would normally cost between $5,000 and $10,000 to orchestrate in a recording studio.

He sought help from the AI music platform Suno, whose CEO, Mikey Shulman, offered his company's full support.

"This is a really *big* deal as we will be scaling big time as a result," Beltzer says. "This is a revolutionary partnership that will, for the very first time, help provide personalized songs for seniors with dementia all over the world."

By mid-September, after starting the initiative in the spring, he had created more than 100 songs. "It's the music they grew up with, but we take it a step further. We weave in their entire story to keep their memories alive as long as possible. It's almost a little biography in a song." And it's something loved ones can cherish forever.

Concetta M. Tomaino, DA, LCAT, MT-BC, executive director/co-founder of the Institute for Music and Neurologic Function, sees significant benefit to this new venture: "We have just started to partner with them and look forward to studying the impact of these very special songs in helping people stay connected with their sense of self and memory of the important people in their lives."

Roche

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1. Elecsys® Method Sheet: ms_08821941190, ms_08846693160, ms_08846685190
2. Cummings, J., Apostolova, L., Rabinovici, G.D. et al. Lecanemab: Appropriate Use Recommendations. J Prev Alzheimers Dis (2023).
3. World Health Organization. Risk reduction of cognitive decline and dementia: WHO guidelines. Published January 1, 2019.

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Through Teens’ Eyes

AFA’s annual Teen Alzheimer’s Awareness Scholarship contest invites high school seniors to share their stories about how a loved one’s Alzheimer’s or dementia-related illness has impacted them and what they have learned about themselves, their families and their community. AFA also asks them to offer their plans for bringing awareness to Alzheimer’s in the future. This year, more than 1,200 students submitted either an essay or a video, of which 55 winners were awarded nearly $50,000 in scholarships. **Learn about AFA’s 2026 Teen Alzheimer’s Awareness Scholarship at alzfdn.org/scholarship.** Here are excerpts from the winning submissions:

AFA Teen Alzheimer’s Awareness Scholarship

2025 Essay Winners

Brianna Jefferson

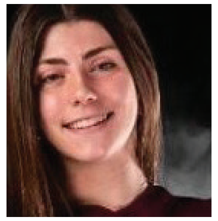
Miami Gardens, Fla.
FIRST PLACE
Attending North Carolina Agricultural & Technical State University

“Growing up in a low-income neighborhood in Miami, I was acutely aware of the lack of resources available to families like mine. This realization made me feel even more strongly about the need for awareness and support in underserved communities. As I watched my grandmother’s condition worsen, I began to think about how I could help others facing the same challenges. That’s when I decided I wanted to raise awareness and advocate for better care and resources for Alzheimer’s patients and their families in my community. I plan to start a program in the same neighborhood where I grew up, focused on educating families about Alzheimer’s disease and dementia....Alzheimer’s disease has taught me about the power of family, the importance of empathy and the need for better healthcare access. While the journey has been difficult, it has shaped me into a more compassionate, resilient and motivated individual.”

Jack Cole

Fort Lauderdale, Fla.
SECOND PLACE
Attending Harvard University

“We, the families of Alzheimer’s patients, know there may be a time when we are deleted from our loved one’s memories, but for my family that loss of recognition never happened. Big Poppy ultimately passed away from a stroke, but how he passed or whether or not he recognized me in the end wouldn’t have mattered. Our relationship would have persisted. I will remember his words, his kindnesses, his impact on the world. I will carry his imprint on the world and know that Alzheimer’s cannot take the memory of who he is to me. My grandfather passed away the week [my young adult novel] *The Card Squad* was published, and I like to think of it as his legacy living on when he couldn’t. I know he would be so proud that...his stories [are] being read around the country, but also that the royalties I receive are being donated to the Alzheimer’s Foundation to help fund awareness. Perhaps even more importantly, I know I did what he would want me to — make the best of the situation handed to me.”



Mallory Beal

Glenside, Pa.
THIRD PLACE
Attending West Chester University

“I remember one specific moment that hit me the hardest: I walked into his room, and he looked at me with confusion in his eyes and asked, ‘Who are you?’ It was like being punched in the gut. My uncle, who had been such a constant figure in my life, didn’t even recognize me anymore. I was still a teenager, trying to figure out my own life, and suddenly, my world felt different. But even through all the heartbreak, I realized something important: My uncle, even though he was going through so much, was still showing us how to live with grace. He wasn’t giving up, even when it felt like his mind was slipping away from him. And if he could keep going, even on his hardest days, then maybe I could too. I started getting involved in Alzheimer’s awareness campaigns, both online and in my community.”

Continued on following page

AFA Teen Alzheimer's Awareness Scholarship

2025 Video Winners

Valencia Imperi

Novi, Mich.
FIRST PLACE
Attending University of Michigan

"My nonna's health declined, her memory faded, her spark dimmed. She was diagnosed with Alzheimer's. Visiting her in the nursing home was heartbreaking. She looked at me with confusion and she spoke only in Italian. Slowly I saw her connections slip away. It was as though we lost her before she was gone. Feeding people physically and spiritually with my nonna's bread [from the family-owned business] has translated into my desire to heal and care for others through a career in medicine. I'm also eager to join the Michigan Neuroprosthetics Club to encourage the design of memory aides or the use of technology, specifically for Alzheimer's patients. My nonna's bread is no longer just about survival. It's become a symbol of my purpose, a reminder to live a life that nourishes others."

Henry Pitts

Bexley, Ohio
SECOND PLACE
Attending Miami University

"In 2019 my maternal grandfather passed away from Alzheimer's disease while weeks later my paternal grandfather was diagnosed. It was hard for me to watch two of the most important people in my life slowly lose their memories. If there was one thing important to my family it's that we were going to do something about it. My family organized three community events. As events grew and I became more capable I became the director of operations. I was managing over 100 volunteers, which included serving on our board where we came up with new ideas to make our events bigger, more sustainable and, of course, maximize how much money we raised. [We have] raised more than $200,000 for Alzheimer's research."

Samuel Poppen

San Clemente, Cali.
THIRD PLACE
Attending Miami University

"My grandpa was my hero, my guide and my best friend, but Alzheimer's took hold of my grandpa. I watched the vibrant, loving man I adored slowly slip away. The day he forgot me, was the day I began mourning someone who was still alive. It shattered me, but in that heartbreak I also found a sense of purpose. I turned to painting as a way to process my emotions. Selling my art at farmers' markets allowed me to connect with others who had lived through similar pain. I founded Care for the Caregivers. I'm proud to say I've sold my art, organized benefit concerts and have raised over $50,000 for Alzheimer's research and caregiver support. I've learned that even in the face of unimaginable loss we're stronger when we come together, that small acts of kindness, a care package, a shared story or a simple smile can change lives."

Kylie Klaiber

Marion, Ohio
FOURTH PLACE
Attending Ohio State University

"I loved having my grandma live with us, seeing her everyday but watching her memory fade away first-hand was heartbreaking. Someone always had to stay with her so our family had to make adjustments. We weren't able to go on vacation. Alzheimer's didn't just change her life but it changed all of ours. A couple of years ago I learned I have one of the four varient genes for developing Alzheimer's. Knowing this motivated me to learn how I could take better care of myself. I'm majoring in psychology and after that I will be applying to the graduate program in neuroscience to study even more about the brain, with the goal of researching new treatments and cures for diseases like Alzheimer's."

Legal Brief

Planning for Aging and Dementia

Before sharing important legal advice about how people can maintain control of their finances, health care and other personal matters, the speaker offered a simple, easy-to-understand piece of advice: "Don't wait; stuff happens."

"Your options and choices get much more limited in a crisis," said Richard A. Courtney, a principal at Courtney Elder Law Associates PLLC, addressing legal planning for long-term care at AFA's Educating America Tour in Jackson, MS, earlier in the year.

"When you plan ahead, there are more options, and proactive planning is much less expensive."

Courtney mentioned three things people don't like about aging: change, conflict and loss of control. Legal planning aims to avoid these things as much as possible, he says.

"We're not going to avoid change but we're going to deal with it. We'll address situations to avoid conflict and loss of control at different life transition points." Planning ahead will make finances secure and protect the person's assets.

"Lots of people, like adult children, come in and say, 'We want to try to save Mama's assets from the nursing home.' Sometimes I interpret that as, 'We want to save our inheritance from the nursing home.'"

Courtney makes it clear that only the mother, if she is mentally sound at the time, has control of her assets.

"She's my client — and I can only have one. I'm not here to worry about who inherits what; my responsibility is making sure she has what she needs for a good quality of life. That's what I'm supposed to do as her lawyer."

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Power of Attorney

For decision-making about finances the Power or Attorney "is probably the most important document to have properly done when you're planning for someone who's got dementia, gets incapacitated or maybe is headed there. You need your Power of Attorney in place."

Courtney says this document doesn't mean you are giving up your rights to make decisions about your property, money and other assets.

"It means if I can't do it, I've given someone else the legal authority to do it for me. It's not a cookie-cutter document. We can also put in a safe-guard provision that says my agent shall have no authority to make loans or gifts from my assets to other people. It's a personalized document for what you want the rules to be if somebody steps in to manage assets for you."

Courtney said the mother, for instance, can designate the child to speak for her in a Power of Attorney legal document. Otherwise, the mother retains power over her assets, even if she later develops a memory loss condition, in which case family members will need to go to court for guardianship or conservatorship.

A Will

Courtney describes a Will as "who gets my stuff" when I die.

"I can give it outright or put it in a trust for them so somebody else will be the trustee and manage it for them if I don't think they can manage it themselves. It won't be subject to their divorce or their debts. It's not in their ownership."

Advanced Healthcare Directive

One of the major concerns Courtney hears from older clients is who will make health care decisions for them if they are no longer able. He recommends the Advanced Healthcare Directive (AHCD), which allows the person to make clear all their health care decisions and prevents the adult children from hiring a different lawyer to make changes.

"You can indicate your choices on the form itself," he said. If no surrogate has been appointed to speak for an incapacitated person, medical decisions can be made by the following, in this order: a spouse if they are not legally separated, an adult child or majority of children, parent, sibling or a person who shows concern and is willing to make decisions based on the person's values. In the latter case, the nursing home or hospital may require written evidence that the person "is one of these types of people."

Courtney said his firm publishes the free *Essential Elder Law and Dementia Planning Guide*, which can be requested at www.elderlawms.com or by calling 601-987-3000.

Caregiver Hero

Life Continues, in a Good Way

By Ann Berlam

Photos courtesy of Ann Berlam

My wonderful husband, Bob, was diagnosed with Alzheimer's in 2020. We were facing a new future and a different lifestyle from the one to which we were accustomed. Living in Naples, FL, we were fortunate to have the services of the Alzheimer's Support Network, a nonprofit organization "to make the lives of care partners easier and enrich the lives of those living with Alzheimer's." Bob attended a weekly group session with other individuals living with some form of cognitive impairment. These sessions were filled with activities, games, art projects, music and food. They provided me with a three-hour window to take care of myself, a time to rejuvenate.

As Bob's Alzheimer's progressed, we decided to look for a community where we could face the future together and where our needs, physical and emotional, could be met. I investigated continuing care retirement communities (CCRCs). Some did not accept new residents who were diagnosed with Alzheimer's, and other communities had multi-year wait lists. After investigating many we found The Woodlands at Furman in Greenville, SC. The Woodlands was an attractive choice as it offered independent living but also health care options with a memory care component available when needed.

Relocating to The Woodlands in August 2023, I began searching for services for Bob like those available to him in Naples, but there were no enrichment programs for Bob and no respite care programs for me in one package.

I began discussions with the management team at The Woodlands about creating a program on campus. I shared with them the programs that were available to us before and the positive impact they had on both our lives. I suggested The Woodlands develop such a program for those residents in independent living apartments with one partner experiencing brain change. Sadly, Bob passed away before any action was taken. However, I continued to pursue this initiative with management.

They explored options, discussed how a program could operate and identified staffing and other needs. In partnership with The Woodlands management team, I helped bring Club Berlam to life on January 31, 2025: a heartfelt initiative born from personal

Continued on following page

> **“We appreciate Ann’s dedication to Bob and our community.** Her voice helped create a new program that will impact the lives of residents at The Woodlands for years to come. Club Berlam will serve as a shining example of how communities and residents can partner for the greater good.”
>
> –Donald R. Lilly, COO,
> The Woodlands at Furman

loss but driven by a fierce commitment to serve others.

Club Berlam offers a warm, non-threatening environment for residents experiencing brain change, filled with music, exercise, arts and crafts, brain games and shared meals. Just as important is what it offers to care partners: respite. For three hours every Friday, they get a much-needed break to rest, recharge or simply take time for themselves.

The ripple effect is growing. Several residents have stepped up to volunteer, some with no direct connection to dementia, but with a strong desire to be part of something that brings comfort and dignity to others.

I miss Bob every day. But through Club Berlam, I’m keeping his legacy alive. So, life does continue. It may be bittersweet, but good things can arise out of difficulties.

Quick Tips to Initiate Program Change at a Care Community

(from Ann Berlam)

- Identify the need for services for those living with brain change.
- Get advocates to work together to develop a program that provides a service.
- Obtain commitment from management in the community to support the program.
- Seek support in the community to promote the program — financial support, staff, volunteers.
- Select the location for your program, build component parts of the program, advertise and invite participants to join.
- Engage higher functioning individuals in establishing the program to create buy-in from all levels of participants.
- Start the program and the ripple effect to spread will follow.

AFA Member Close-Up: Scottsdale Arts, Ariz.

Where Forgetting is Welcome

As a woman walked out of Scottsdale Arts Memory Lounge after participating in a 90-minute improv workshop, she summed up the feelings of many who attend the twice-a-month programs: “I haven’t laughed so much in so long. It was wonderful to have fun and forget about the forgetting.”

These workshops are for people with mild to moderate memory loss and their care partners, conducted by professional artists. Recent workshops have featured improv group Second City, international musicians Samite and Okaidja, local visual artists, ballet and flamenco dancers, pianists and actors.

“We tailor the workshops to be simple, fun, casual, while also being designed for care partners,” says Natalie Marsh, learning and innovation director. “When someone is diagnosed, it can be isolating and lonely for not only them but also for the care partners. We make sure it’s a couple’s workshop where they can come together, work together, and make memories together.”

The Alzheimer’s and other dementia-related illness program began in 2008 through a Scottsdale Arts partnership with Banner Alzheimer’s Institute and other local arts organizations. It was revitalized in 2016 through a grant from the Arizona Commission on the Arts. Both projects addressed the need for dementia-friendly interventions because, at the time, Arizona had the second-highest rate in the country. The project was intended to provide care for both the care partner and care receiver.

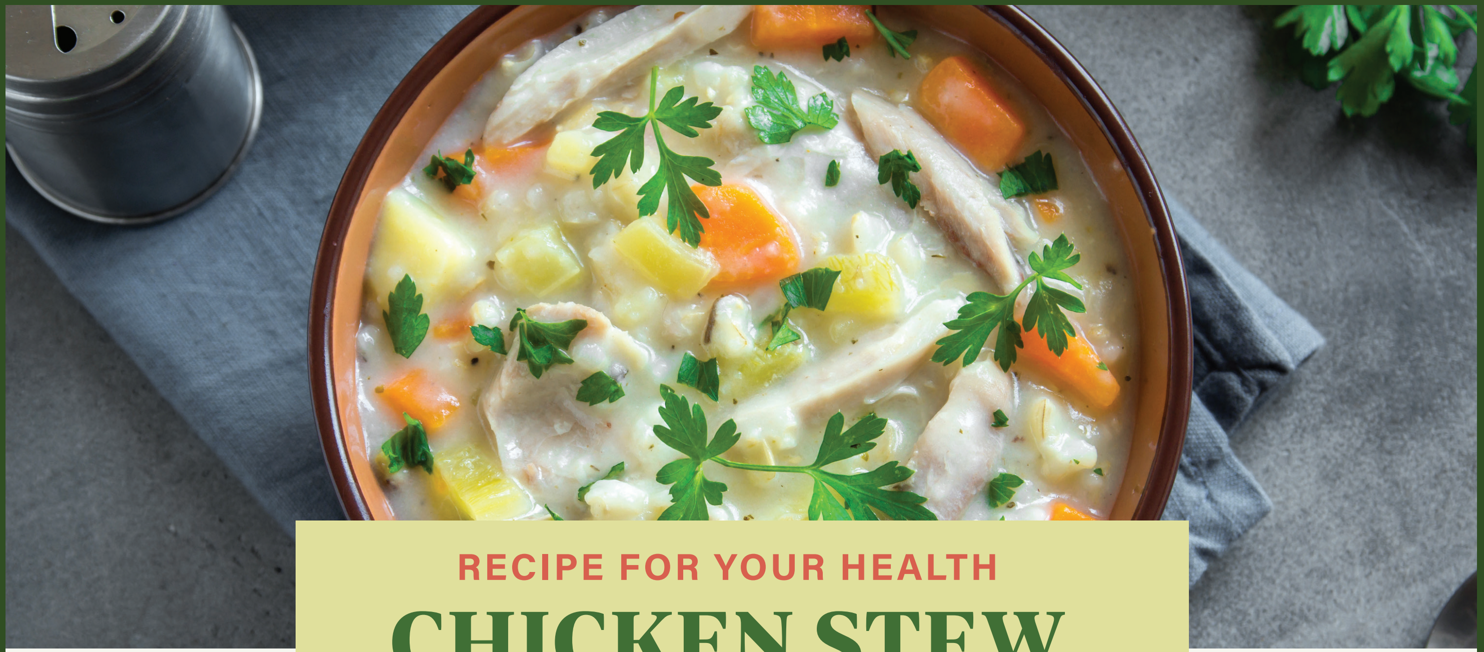
Basket making at Scottsdale Arts

As one Memory Lounge care partner said, “Spending time with my mother in an atmosphere free of daily stressors — where she lives, why she can’t drive, having difficulty expressing herself in words — has been a joy for both of us.”

That’s what Scottsdale Arts had in mind.

“We really wanted to get a space where people could come together, have a memory that’s not in a doctor’s office and get together not only with their care partners but also with others who are going through similar situations,” Marsh says. “Brain health is crucial. When you work in the arts — listen to music, create a painting, go to a museum — you keep your brain active in all phases of life. We know the arts won’t cure the disease, but, at the very least, we can make the quality of life for caregivers and care receivers the best it can be.”

Photo courtesy of Scottsdale Arts



RECIPE FOR YOUR HEALTH

CHICKEN STEW

This one-pot chicken breast recipe is heart-warming for the winter months, offering a delicious blend of flavors that add brightness and comfort. You can cut the chicken into bite-sized pieces instead of serving whole breasts. You may need to reduce the cooking time for the chicken if the thickness is 1 inch or less. Cooking time varies, so use your best judgment.

INGREDIENTS

(use organic ingredients when available)

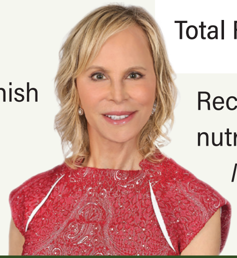
2 Tbsp. olive oil
1 ½ lb. boneless, skinless chicken breasts
3 medium carrots, peeled and sliced into coins
3 stalks celery, chopped
1 medium sweet onion, finely chopped
2 cloves garlic, minced
1 ½ Tbsp. flour
3 sprigs fresh thyme
1 bay leaf
¾ lb. baby potatoes, quartered
3 cups low-sodium chicken broth
1 Tbsp. lemon juice
Freshly ground black pepper to taste, optional
Freshly chopped flat-leaf Italian parsley, for garnish
¼ cup pomegranate seeds (optional)

DIRECTIONS

- In a large skillet over medium-high heat, add 1 tablespoon oil, brown the chicken breasts for 5 minutes per side. Keep pan half covered to avoid splatter. Remove to a plate with a slotted spoon.
- Heat the remaining tablespoon of oil then add carrots, celery, onion and garlic. Cook, stirring often, until vegetables are tender, about 5 minutes.
- Add flour and stir until vegetables are coated, then add thyme, bay leaf, potatoes, lemon juice and broth. Use a spatula to deglaze the pan (release any pan droppings into the broth mixture). Bring mixture to a high simmer and cook covered for 20 minutes, until the potatoes are tender.
- Add the chicken breasts back into the skillet and simmer for an additional 5 minutes, or until chicken is thoroughly cooked. Cut the pieces into bite-size pieces, if you wish. Season with optional pepper to taste.
- Garnish with parsley and optional pomegranate seeds before serving. Serve stew with a mixed green salad. Serves 4.

NUTRITION FACTS PER SERVING

Calories: 400
Carbohydrates: 27 g
Protein: 45 g
Total Fat: 12 g (2.2 g saturated fat)
3 g dietary fiber
155 mg sodium
124 mg cholesterol



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

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AFA Educating America Tour

Bringing Vital Resources Nationwide

Next year marks the 10th year AFA has toured the country to offer half-day programming that brings together medical, scientific, legal and financial experts to provide critical resources and hope to individuals and families impacted by Alzheimer's and other forms of dementia. No other organization is doing this type of free educational conference nationwide. Our goal for each Educating America Tour (EAT) is to empower with education and to ensure that no person faces Alzheimer's alone.

"It started as a way to educate caregivers about the services of AFA and how we can provide support to those who don't know where to turn," says Stephanie Evans-Ariker, AFA's external relations director. As the conferences have evolved, they are also about making connections that will last. "When we leave at the end of the day, we want people who attended to know who their local experts are. AFA is the connector. We are truly bringing together the caregivers with the professionals in their states. People often don't know where to start. We give them the starting points to plan for the journey they are going on."

2026 AFA Educating America Tour:

Alzheimer's & Caregiving Conferences

alzfdn.org/tour

February 11	**Houston, TX**
March 18	**Portland, OR**
April 15	**Las Vegas, NV**
May 20	**Wichita, KS**
June 17	**Providence, RI**
July 15	**Burlington, VT**
September 16	**Manchester NH**
October 21	**Little Rock, AR**
November 18	**Nashville, TN**

The Educating America Tour was launched in 2017 as part of AFA's 15th anniversary. The conferences are open to families, healthcare professionals, individuals living with a memory loss condition and anyone interested in learning more about Alzheimer's, brain health and care partnering.

The conferences present three speakers — one from the medical profession to offer an overview of Alzheimer's and dementia, a legal or financial expert to discuss the legal and financial implications of the disease, and a care partner "to bring some experiential expertise to the conference," Evans-Ariker says. Topics presented cover a wide range, such as developments in the fight against Alzheimer's, advance planning, building a long-term care team and home safety.

Conferences also include resource vendors, such as AFA member organizations, other agencies, and businesses in the host city, to connect attendees with information about local services. The EAT team works with state and municipal agencies such as offices on aging, aging and disability resource centers and academic institutions affiliated with our speakers or member networks.

Locations are chosen by where resources are lacking. Marketing is done through direct mail, social media and newspaper ads. Most conferences are standing-room-only and have grown every year since returning to the road after the pandemic.

When AFA's team visited Charleston, WVA, in October, Evans-Ariker said someone asked them why people were coming to them from New York City, telling them "no one ever comes here."

"That's exactly why we're there," she says.

> *"Our friend was just recently diagnosed, so I came with my wife to learn more. The future is uncertain for our friend, but we want to help. Hopefully, we can learn to best support her. Thank you AFA for helping."*
>
> –Joseph B., Charleston, WV

Brain Health

Understanding Mild Cognitive Impairment (MCI)

Forgetting names or having a hard time recalling a fact is common for everyone, but as people get older, they worry that this is a sign they're developing a memory loss condition. It may or may not be, says Nathaniel Chin, M.D., member of AFA's Medical, Scientific and Memory Screening Advisory Board. That is why it is so important that we do cognitive testing early. Chin is also the medical director of the Wisconsin Alzheimer's Disease Research Center and the Wisconsin Registry for Alzheimer's Prevention Study.

Sometimes these difficulties are mild cognitive impairment, or MCI. This is a memory loss condition that precedes dementia in some cases, but sometimes it can be reversed or stay stable, Chin says.

"We describe MCI as someone having a memory or thinking complaint representing a decline from their baseline (i.e., from what they have been accustomed to). However, their day-to-day activities still are very much intact; we see no functional impairment," says Chin. "But when we do a cognitive test, we find that the person has an impairment or low score.

"With MCI, it's entirely possible that you will have MCI going forward. It doesn't get dramatically worse, and you will pass away with MCI. It's also possible that you will progress to dementia, but it's also possible that you will get better and have a diagnosis of being cognitively healthy again."

Chin said it's hard for clinicians to know the underlying causes of MCI and whether it will remain or advance to dementia. Among the factors that can bring on MCI that can be corrected are reactions to medication, sleep apnea, thyroid issues, hearing or vision loss or mood disorders such as depression.

"This is why it's important to get routine follow-ups regarding your cognitive health," Chin says. "One of the key changes needed for us in this country is to talk openly about our memory and thinking abilities so that we can identify the earliest changes and have an intervention as soon as possible."

MCI early symptoms

Chin emphasizes that the earliest changes are thinking changes, not your ability to perform daily functions. "That's the key part of having MCI. You are still functionally intact."

If you are experiencing a memory change, it typically involves forgetting events or conversations, repeating stories, or misplacing items. If language happens to be the first part of your brain affected, then you might experience difficulty finding words, problems understanding words, problems reading, or writing. Visual or spatial problems, such as getting lost or not recognizing familiar faces, can also occur, particularly in cases of diseases that may later be diagnosed as Parkinson's or Lewy Body disease.

To deal with the symptoms of MCI, Chin recommends using compensatory strategies such as sticky notes, a calendar or whiteboard and putting your keys and wallet in the same place whenever you come home.

Risk factors for developing MCI

Men are more likely to develop MCI, individuals with less education and those carrying the Alzheimer's gene APOE4. Other risk factors are vascular conditions such as diabetes, high blood pressure, being overweight, having high cholesterol and smoking. Having mood conditions, particularly if they are untreated, is also a risk factor.

"These are all things that we can start working on and addressing. We just need to know to do that, which takes talking to your primary care provider," Chin says.

More than MCI

We define dementia as a thinking *syndrome*. At least two areas of a person's thinking ability are now considered impaired (such as articulating *and* understanding what they hear). This is leading to difficulty in communicating, focusing and making sense of information.

"Now there's an impairment in their day-to-day function, even with a set of compensatory strategies such as sticky notes and phone alerts. They can't do something they used to be able to do (e.g., grocery shop, balance their checkbook, cook from a recipe, dress themselves). That's a key defining feature," Chin says.

"We don't think of underlying medical problems and psychiatric illnesses as causes of dementia. It's the accumulating *brain* changes that are causing these functional changes," Chin says.

Getting a cognitive evaluation

Chin says an evaluation is important, but this doesn't happen in just one doctor visit.

"It's a multi-step process that should start with your primary care provider, but you will likely need to see a specialist too," Chin says. "That's why it's important for people to get in as early as possible, which means as soon as they are experiencing these changes. A clinician will want to get a thorough history. It's also essential that the person brings someone they know and trust with them. The information family members and friends can provide can be extremely helpful."

The clinician will need to consider when the problems started, what kind of symptoms the person is experiencing and how they are impacting the person's day-to-day abilities.

Clinicians will also want to know if the symptoms started after a fall, a new medication or a stroke.

"We need to know your medical history because we want to know what risk factors you have. Eventually, blood work will be ordered, and that's to look for those reversible factors."

Chin says dementia is chronic and persistent and usually caused by a brain disease or brain injury. "Early assessment and support improve outcomes. I can't emphasize this enough," Chin says.

"One of the key changes needed for us in this country is to talk openly about our memory and thinking abilities so that we can identify the earliest changes and have an intervention as soon as possible."

-Nathaniel Chin, M.D.

Memory screening

Individuals concerned about declining thinking abilities can schedule a virtual memory screening (via phone or computer) with the Alzheimer's Foundation of America. Visit the AFA website at alzfdn.org, click on "Find Help" for memory screening information, or call 866-232-8484 and ask for the memory screening department. A memory screening does not provide a diagnosis, but it will determine if additional evaluation is necessary. You can also explore cognitive symptoms via IQ Code and AD8 forms; both are available online.

Adapted from the AFA's Care Connection webinar "Mild Cognitive Impairment: What Is It? And How Does It Relate to Alzheimer's Disease?" which can be found at alzfdn.org/webinar_archive/ in addition to other resources.

Caregiver Voice

Calling For Care

All of a sudden, I am a caregiver of a person with brain change.

Considering everything, it really shouldn't have jolted me to hear the cardiac nurse say she couldn't do much more with my person that day, "because of the dementia." Somehow, that medical word hit me hard.

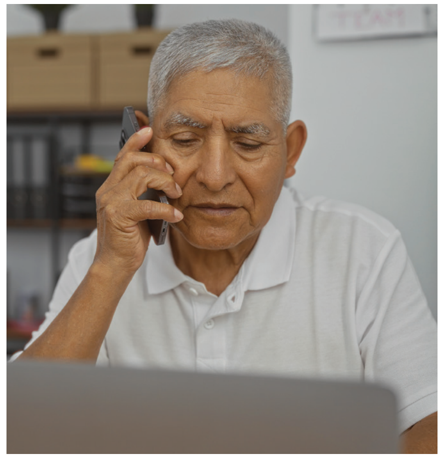
What to do? Who to tell? What next? All these questions and more sprang to mind. Writing helps, so I turned to *Alzheimer's TODAY*. Could I write a piece about this?

Turns out that the Alzheimer's Foundation of America (AFA) has, for over 20 years, offered a Helpline at 866-232-8484. I spoke recently with one of the eight licensed social workers who staff it, an LMSW. It operates daily. All calls are confidential, and people can connect with someone 9 a.m. to 9 p.m. ET, 7 days a week. The AFA Helpline staff fields an average of 500 queries per month.

The social worker helped me with my immediate questions: Who should I tell about the diagnosis? (Definitely any facility where my person may eventually move, if and when that becomes necessary.) Who else? (Up to me; such decisions are individual.)

Anyone dealing with any issues relating to dementia can call. There's no cost. What other queries does the Helpline get? Common questions relate to finances, behavioral challenges, family stress, what to do following recent diagnosis and whether to tell the person who's been diagnosed. Callers can also learn about joining support groups.

I also learned that holidays raise questions about how to accommodate the loved one at gatherings. Is it possible to provide a separate room so they can get away from unaccustomed noise? How to handle questions from fellow guests who don't know about the diagnosis. How the caregiver can still enjoy the festive season, if the loved one cannot (or will not) participate.



Photos: @ Aaron Amat | Dreamstime

If nothing else, my call to the Helpline assured me I'm not alone. Talking to a licensed professional who's been discussing dementia for years is a comfort this caregiver recommends.

Need a Helpline chat? Call 866-232-8484 or visit the AFA website, alzfdn.org. General questions can also be answered by AFA's new virtual Helpline assistant, Allison, whom you can access 24/7 on the website's opening page.

Editor's note: The writer has chosen to forgo a byline to protect privacy.

AFA
ALZHEIMER'S FOUNDATION OF AMERICA

Dear AFA Friend,

Together, we've made real progress: supporting more families, improving care for those living with Alzheimer's, guiding and educating families and professionals and driving research towards better treatments and a cure.

But there's still so much more to do. Your gift today can bring support and hope to families who still need it most.

Remember, please give before 12 midnight, December 31, to receive your year-end tax benefit and you'll be helping us keep the fight going strong.

With gratitude,

Charles J. Fuschillo, Jr.
President & CEO

Donate today.
alzfdn.org/donate

Make a **Meaningful Impact** Today:

$35
$35 Supports a subscription to *Alzheimer's TODAY*

$75
$75 Funds an hour of guidance from a licensed social worker.

$120
$120 Supports therapeutic programs like music and pet therapy.

$500
$500 Delivers a college scholarship to a high school senior who has been impacted by Alzheimer's.

Any Amount
100% of all donations designated for research goes towards funding scientific projects.

Maximize Your Impact with Tax-Wise Giving:

Donor-Advised Fund (DAF)
Make a grant to AFA and help fund crucial research and education initiatives.

IRA Gift
If you're 70½ or older, you can contribute directly from your IRA (up to $100,000) and avoid paying taxes on the distribution.
Learn more at alzfdn.org/stocks

Stock Gifts
Donate appreciated securities to reduce capital gains taxes while advancing our mission.
Learn more at alzfdn.org/stocks

Tribute Gift
Leave a lasting tribute to someone special with a commemorative brick, tree, or other naming opportunity at the new AFA Barbara Rabinowitz Education & Resource Center
Learn more alzfdn.org/tribute/

Workplace Giving
Many employers offer payroll deductions, corporate matching or giving campaigns. Double your impact through workplace giving.
Learn more at alzfdn.org/workplace-giving/

AFA is proud to hold Charity Navigator's highest 4-star rating, ensuring that your donation will be used efficiently and responsibly, maximizing its impact in the fight against Alzheimer's.

Charity Navigator ✦✦✦✦ FOUR-STAR

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The mission of the Alzheimer's Foundation of America (AFA) is to provide support, services and education to individuals, families and caregivers affected by Alzheimer's disease and related dementias nationwide, and fund research for better treatment and a cure.

Everyone loves someone with Alzheimer's.

As 2025 comes to a close, please make a tax-deductible gift to the Alzheimer's Foundation of America. **Your support means everything**.

Donate today.
alzfdn.org/donate

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