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The Official Magazine of the Alzheimer's Foundation of America



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VOLUME 19, NO. 1



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A MESSAGE FROM OUR PRESIDENT & CEO **CHARLES J. FUSCHILLO, JR.**



As I'm writing this message, we are learning of the passing of Bruce Springsteen's mother, Adele, after a 13-year battle with Alzheimer's and the dementia diagnoses of Beach Boy Brian Wilson and Jay Leno's wife, Mavis. Alzheimer's and dementia continue to touch our lives in devastating numbers. For you, it may be a mother or father, a sister, a friend, or even yourself. An estimated 6.7 million Americans age 65 and older are living with it. And as the age of our population grows older, so will this number, which is expected to more than double by 2060.

Throughout 2024, AFA will continue working with officials in Washington, D.C. toward progress in dementia-care policies with a specific focus on caregivers. I'm excited to share that our first

AFA on the Hill Day will take place May 23. Please visit our website, alzfdn.org, to learn how you can participate.

Two stories in this issue address questions I routinely hear at our Educating America Tour conferences: **"Should I consider a clinical trial?" (p. 17)** and **"What's the difference between Alzheimer's and dementia?" (p. 25)**. The former article is based on a Fireside Chat that I had with Madhav Thambisetty, M.D., Ph.D., from the National Institute on Aging. The latter is an editorial written by AFA Medical, Scientific and Memory Screening Advisory Board member Nathaniel Chin, M.D. I hope you'll take the time to consider these important pieces.

Our inspirational stories are many: a wonderful feature about a therapeutic equine program, Connected Horse (**"Living in the Present," pp. 5-6**); a recap of tips and experiences from our caregiver panel at the **Women & Alzheimer's: The Empowerment Forum (pp. 8-9)**; and a fun **dementia-friendly entertainment series (pp. 11-13)**. We continue to focus on issues that address your needs: **palliative care (pp.15-16)**, **how to pay for in-home care (p. 21)**, and the **government's introduction of a new trial payment program for care providers (p. 19)**.

If you have topics or story ideas that you'd like to see us address in *Alzheimer's TODAY*, please send them to us at info@alzfdn.org. We love to receive your feedback.

On behalf of the individuals in your lives who are living with Alzheimer's and dementia-related illnesses, I want to say thank you. This journey is a challenging one. You are a blessing to them.

Check out AFA's 2024
Educating America Tour
schedule at
alzfdn.org/tour.



LIVING IN THE PRESENT TENSE

By Isabel Soloaga



When my Granddad Mitchell died of dementia at 86, he still lived alone on the East Bay ranch he'd won in a bet after returning home from serving in WWII. He always refused to leave. That was home: sitting on the front porch, watching his horses and the hummingbirds. His life and death remind

me to take my life into my own hands.

I remember him vividly: a small glass of sherry in one hand, my 4-year-old index finger in the other. He taught me the best things in life: hard work, wine and horses. Cocoa, my grandpa's black Tennessee Walking Horse with a white star on her forehead, became my first friend.

As my grandfather lived out his last years, I worked as a trail guide in Napa. There, I helped 13 thick quarter horses shepherd tourists around the vineyards. Day in, day out: horses groomed, heavy leather saddles swung up, cinched, winos and day-trippers strapped on, and away we went.

When my grandfather passed, I knew I needed a change. I missed a sense of fulfillment from my work. More than this, I knew horses to be teachers as well as friends.

A Google search brought me to a Stanford research article about an organization that brings hope to individuals living with dementia through horses. I was struck, not only because the issues landed so close to my heart but because the article described quantifiable benefits for participants on the scientific

Continued on following page



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LIVING IN THE PRESENT TENSE *cont'd from p. 5*

level. These included significantly lowered depression and anxiety in both people living with dementia and their care partners. I wanted to learn more.

I signed up to volunteer with the organization, Connected Horse. In the presence of the horses, I watched individuals who couldn't speak when they arrived suddenly open up about their childhood experiences with horses. Shaky men and women living with dementia were leaving their walkers behind to groom, halter and lead horses. Somehow, the horses knew exactly what to do. They matched their hooved steps with their new leaders' and moved gently with the participants. The more I saw, the more I was convinced the program was not only a critical intervention in the struggle with dementia but transformative at every level.

The program, the first of its kind, fills a gap in existing healthcare options for people living with dementia and the people who care for them. Where personal relationships and medical needs collide, there remains a sincere need for professional support. This is where the lessons from horses prove so powerful.

Horses live in the present tense, highly attuned to their surroundings. Without language, horses communicate complex emotions, form tight herd bonds and remain connected to their family throughout their lives. They are living proof that experiencing joy together can happen throughout our lives, and that even after language skills might be lost to a disease, it is still possible to connect meaningfully to those around us.

"With Connected Horse, I could finally breathe, slow down and just be," says my friend Tammy, who lives with early-onset dementia. "The horses knew that I needed them."

Like my grandfather, Tammy is living life on her own terms. An avid traveler, she is planning to visit Italy as soon as she completes her participation in a six-month research study on the impact of a vegan diet and exercise on early-onset dementia.

"I refuse to let dementia define me," Tammy says. "I'm still just me."



Connected Horse (connectedhorse.org) is a therapeutic equine program for persons affected by memory loss and their caregivers that began with two lifelong horsewomen and a clinical research trial at Stanford University. Now a national program, Connected Horse is headquartered in the San Francisco Bay Area with programming to reach individuals around the US and the world.

Connected Horse offers free in-person workshops, programs for people at home or in adult daycare called "Barn At-Home," and training in skills building, coaching, certification and continuing education through its Training Institute. It is also expanding with the Connected Horse Facilitator Training Academy that trains individuals at pre-existing facilities in evidence-based methods of interaction between horses and persons with memory loss.

ABOUT THE AUTHOR

Isabel Soloaga (isabelsoloaga.com) is a documentary filmmaker based in the San Francisco Bay Area. Among her current work is *Unbridled Compton*, a short film in development about the healing power of horses in inner-city LA.

Photos courtesy of Isabel Soloaga



Alberto Dubini | Dreamstime

CAPITOL REPORT

By Ruby Dehkharghani, M.S., AFA Director of Public Policy

The Alzheimer's Foundation of America continues to advocate for legislative policies on Capitol Hill that benefit families impacted by Alzheimer's and dementia. Last year we saw encouraging strides.

One of the most encouraging steps was the increase in government funding for Alzheimer's disease research. Fiscal Year (FY) 2023 appropriations included \$3.74 billion dollars for Alzheimer's research, a \$266 million dollar increase from FY 2022. For FY 2024, that number grew by another \$228 million. These funds allow the National Institutes of Health (NIH) to accelerate investment in collaborations that speed discovery, groundbreaking prevention trials, and the testing of new therapeutics. Research funding investments are critical in the fight against Alzheimer's disease, and we are grateful that lawmakers from both parties continue to work together to deliver much needed funding increases.

To eliminate unnecessary administrative barriers that create challenges for caregivers, Senator Ed Markey (D-MA) and Senator Shelley Moore Capito (R-WV) introduced the Alleviating Barriers for Caregivers (ABC) Act. The bipartisan legislation, which AFA supports, would require the Centers for Medicare & Medicaid Services (CMS) and Social Security Administration (SSA) to reduce administrative challenges for family caregivers by reviewing processes, procedures, forms and communications and reporting back to Congress on their findings.

To provide further support for family caregivers, AFA joined AARP and other advocacy organizations in calling for reforms that would allow Medicare to pay health care practitioners for time spent training family caregivers.

Legislation to increase early detection of cognitive impairment was reintroduced by Representative Linda Sanchez (D-CA) and Shelley Moore Capito (R-WV). The CHANGE Act would expand the cognitive impairment detection benefit during annual wellness

visits to require the use of validated detection tools and documentation of the results in the patient's medical record. Further, when a cognitive impairment is detected, physicians must refer the patient to an appropriate diagnostic service provider and other specified supports.

According to the National Institute on Aging, many people who are developing dementia or already have it do not receive a diagnosis. Studies found that more than 50% of patients with dementia had not received a clinical cognitive evaluation by a physician, and that physicians were unaware of cognitive impairment in more than 40% of their cognitively impaired patients. Delays in detection and diagnosis prevent individuals from accessing vital services and therapeutics that are more effective in the early stages of dementia.

AFA continues to advocate for legislation focused on Alzheimer's disease research and caregivers in the 2024 legislative session. Together with the aforementioned legislation, our current agenda includes supporting the NAPA Reauthorization Act, which emphasizes the importance of healthy aging, and the Connecting Caregivers to Medicare Act, which would make it easier for family caregivers to get the information they need to maximize their Medicare coverage benefits. Furthermore, we remain committed to learning more about the GUIDE program (Guiding an Improved Dementia Experience Model), created through an executive order from President Biden, which aims to support people living with dementia and their unpaid caregivers — see page 19 for more details. This is scheduled to go live in July 2024.

Throughout 2024, AFA will continue working with officials in Washington towards progress in dementia-care policies with a specific focus on caregivers. Our first AFA on the Hill Day takes place May 23. Visit our website, alzfdn.org, to learn how you can participate.

Caregiver Empowerment

Women are more likely to develop Alzheimer's; they're also more likely to serve as caregivers of people living with the disease. Such startling facts deserve attention.

That's why last November during Alzheimer's Awareness Month, AFA brought together women — professionals and caregivers, and many of them both — for Women & Alzheimer's: The Empowerment Forum at the Marriott in Melville, Long Island. The event, in its second year, provided personal, powerful and heartfelt sharing to help others better understand and manage the caregiving journey as well as practical tips and information to live a higher quality of life.



WOMEN & ALZHEIMER'S THE EMPOWERMENT FORUM

Charles J. Fuschillo, Jr., AFA president and CEO, served as host of the forum. Some excerpts of the conversation about caregiving follow.

CHARLES FUSCHILLO: WHAT'S ONE THING YOU WISH YOU KNEW?

"You have to pace yourself. You don't know how many years it's going to be. Sixteen years is a long time. I didn't see that coming....Stay on an even keel." –LORETTA WOODWARD VENNEY, inspirational speaker, author and LEGO Serious Play Facilitator; former caregiver for her mother, Doris

"If I don't make the effort to say 'I need help, I need information, I don't understand what's happening, I need a different drug,' it's not knocking at my door." –LORAIN CHRISTY KLIMAS, senior paralegal, National Grid USA; former caregiver to father, Frank, and Aunt May, who both recently passed away

"I wish I knew how long it was going to be so I would have planned better." We needed a "short, medium and long-term plan." Perla's mother's journey lasted more than 20 years.

–PERLA CASTRO, interim executive director, La Care Information Systems and project management professional; former caregiver to her mother, Lesbia, diagnosed with Alzheimer's in her fifties

"I wish that I understood what strength is....I thought my strength was in perfectionism, in doing. I didn't know my strength was in being."

–CHARLOTTE ALLEN, B.A., MSW, assistant professor, Department of Social Work, Coordinator of Gerontology, Malloy College, 2000-2014; caregiver to many friends and family, including mother, Neva

CHARLES FUSCHILLO: HOW DID YOU GET THROUGH THE CHALLENGES?

"Finally getting the diagnosis was a good thing. This was a disease that we could say out loud, there was no longer pretending it was something else....Talking to professionals and support groups helped." –LORAIN CHRISTY KLIMAS

"My church saved me. Having a community is important. Hopefully, you already have friends, neighbors, a church. I would not have survived without my tribe," Veney said. *"Who is in your tribe? Start thinking about it now."* –LORETTA WOODWARD VENNEY

"It's ok to ask for help." –All panelists chime in.

CHARLES FUSCHILLO: WHAT WAS YOUR BIGGEST LEARNING EXPERIENCE?

"She was still in there. You had to go and bring her out. So never give up." –LORETTA WOODWARD VENNEY

"The joy that you can find, the light that is there in the darkest hours, it's in them and it's in you." –CHARLOTTE ALLEN

"To meet her where she was....If she thought I was her mom, I was her mom." –PERLA CASTRO

"The ins and outs of Medicare, Medicaid and hospice. That I have as much compassion as I do." –LORAIN CHRISTY KLIMAS

CHARLES FUSCHILLO: WHAT ADVICE DO YOU HAVE FOR OTHER CAREGIVERS?

"Be present, take care of yourself. Eat healthy. Go to the doctor's. My father was in intensive care three times. Burnout is real." –PERLA CASTRO

"Use the community of support groups." –LORAIN CHRISTY KLIMAS

"One of my strongest motivations to stay healthy now for me is I have one son. I don't want him to spend years taking care of me." –CHARLOTTE ALLEN

"My mom was devastated when she found out she was in early-stage dementia. I promised mom that every day we would have joy. Instead of focusing on things she couldn't do, I would only focus on the things she could still do." –LORETTA WOODWARD VENNEY

CHARLES FUSCHILLO: HOW DO YOU RELIEVE THE STRESS AND NOT BURN OUT?

One of the "best gifts" her husband Tim gave her was their RV experience. When she and Tim met a group of women RVers on a trip, her husband said to them, *"If anything ever happens to me, you make sure she keeps RVing."* Six weeks later, her husband passed away. *"I credit those women for saving me. Nature is my thing. I'm always outside. I named my RV, Joy."* –LORETTA WOODWARD VENNEY

"I try to find space for yoga, and have schedules. I know someone will come, so I carve out the time to run to yoga." –PERLA CASTRO

"I go back to the phrase, 'If you want something done, ask a busy person.' This is how I live. I schedule myself and put me time in there....a standard walk in morning. I use exercise a lot for stress relieving. I'll call a friend for a 15-minute chat." –LORAIN CHRISTY KLIMAS

"I burnt out. I had three strokes....I had to bring myself back healthwise, emotionally, with yoga, meditation. I'm getting it all now. Thank goodness I had another chance." –CHARLOTTE ALLEN

CHARLES FUSCHILLO: AND HOW ARE YOU TODAY?

"I'm now on the road of grief — it's part of the disease. As the family goes through it, we are living a piece of that grief. It's anticipatory grief." –LORAIN CHRISTY KLIMAS

"I'm awesome today, and I think my mother would be proud of the legacy I'm trying to carry forward for her." –LORETTA WOODWARD VENNEY

"I'm still grieving. I'm proud that we were able to care for my mom at home. Proud of what we are trying to do with La Care." –PERLA CASTRO

"I'm filled with joy and gratitude and peace." –CHARLOTTE ALLEN

Women & Alzheimer's: The Empowerment Forum was made possible through the generosity of Eisai, Lilly and Merck.



Charlotte Allen



Perla Castro



Loraine Christy Klimas



Loretta Woodward Venney

The Card Squad

By Jack Cole



After Jack Cole's grandfather, Big Poppy, was diagnosed with Alzheimer's in December 2018, Jack started reflecting about all the time he had spent with him during his childhood. In 2019, he started writing down ideas and realized there could be a fun story from all his notes. The result is a young adult novel, *The Card Squad*, with engaging characters and dialogue and an intricate plot that is involving from start to finish.

"It was an interesting process because a lot of the characters are loosely based off of people I have known," Jack says. "So I kept asking myself, 'What would these people do in this situation. What would they say?' And from there, the book kind of created itself from the characters."

The central character is 11-year-old Jake who begins to suspect his cousins, Max and Alexandra, are trying to steal their grandfather's rare baseball card collection. Without the watchful Jake, they would have had no trouble because Grandpeter has developed Alzheimer's and doesn't remember his once-prized possession. With the help of his friends Brit, Rowdy and Noah, Jake works to uncover their intricate scheme.

The first-time novelist, now 17, was 15 when he wrote most of the book, which he finished in 2021. "I am definitely thinking of another mystery/adventure book but maybe for slightly older kids," he says.

His grandfather died shortly after he finished the book, but he had enjoyed having it read to him while Jack was writing it.

"He was still pretty cognizant when I started writing it, and he would tell me his childhood stories again and again. I would read him my chapters, and he would start laughing. It was worth writing it just to hear him laugh."

Jack did a great deal of research and spoke to a few doctors about how young people would most easily digest information about the disease "because it's kind of scary when you think about your memory going away."

Some may be concerned that the book's ending is unrealistic but

Jay M. Izes, M.D., F.A.A.P., appreciates the unconventional conclusion.

"We all dream of a world where there is effective treatment for Alzheimer's. This story leaves us with hope."

That's part of what Jack had in mind for his book, which is available on Amazon.

"It was never meant to be anything but a fantasy of what could have been from the perspective of a child. That was my reaction to my grandfather's diagnosis. What if we could somehow reverse this? What if we could go on some crazy adventures together?"

Jack, a junior at Pine Crest High School in Fort Lauderdale, FL, received his first royalty check in January and plans to donate it to AFA. "I can't imagine how hard it must be for people who are facing this diagnosis for themselves or for a loved one if they don't have resources. You provide that, and I am so grateful you do."

Although unsure of what college he will be attending, he hopes to incorporate writing into whatever he does while focusing on environmental studies. For now, he says the book was a good way to preserve the time he and his grandfather shared.

"It made me think that this was the best way to honor him, to create a book based off all these memories and adventures. It was also really important for me to reach out to other kids to let them know that this is happening to a lot of families and that they aren't alone."

Enjoying Travel Despite a Diagnosis

From canoeing adventures in the Alaskan wilderness and trips to antique car museums to glass bottom boat trips in the Caribbean or enjoying some new foods during high tea, Elite Cruises and Vacations offers a wide variety of trips, just with a different guest in mind than usual vacationers. These trips are designed for people with memory loss conditions and their caregivers.

"Many of our clients feel because of their diagnosis they have to be confined," says Kathryn Speer Shoaf, a registered nurse with 40 years of executive experience in senior living and the owner of Elite. "A diagnosis does not condemn you to spending your life in front of the TV. There's definitely a way to live life well with a diagnosis. There's no one we won't take. We can make it happen."

Elite cruises combine conferences for caregivers with activities for their loved ones living with memory loss. Shoaf attends every cruise, which lasts between seven and 12 days. The ships are mid-sized, big enough to have plenty of activities but not to be overwhelming. Between 20 to 40 guests attend. This year, for the first time, Shoaf will lead a cruise to Europe, lasting 14 days. They have a regular travel family of experienced volunteer caregivers and RNs who accompany them and provide as much support as needed for all travelers on and off the ship. They can arrange for private duty caregivers and accompanied flights for those who need that extra level of support.

Shoaf takes a personal approach for every guest, talking with family members and caregivers beforehand to learn as much about the person as possible to help plan activities specific for them.

The hardest part is the getting to the ship and getting back home, Shoaf says. Travel is often stressful for people with memory loss conditions, but when traveling by ship they can sleep in the same room each night and eat in the same dining room at the same table.

On arrival, staff members take the loved one and leave the caregiver to unpack.

"Then they can come down and listen to music and feel the relaxation they don't get until they are at that level. They get all the fuss done and then enjoy a five-course meal."

For more information about Elite Cruises and Vacations, go to elitecruisesandvacationstravel.com.

Photos courtesy of Elite Cruises and Vacations



SHOAF'S TIPS FOR DEMENTIA-FRIENDLY TRAVEL

- "Do not leave a full suitcase where [your person] can find it. Ninety-five percent will unpack it. I learned the hard way." Shoaf said her mother had gotten into the suitcase and took out all her clothes, which Shoaf didn't realize until they were unpacking at their destination.
- Organize each day's needs and put them into clear plastic bags. "Give yourself time to organize ahead of time so you still feel in control."
- "Bring wipes, gloves, supplies and a change of clothes." One morning on the last day of a cruise, a gentleman had "an accident." His clothes had been packed and sent off the ship. "Always be prepared with back-up clothes, even if they're just sweats. Bring incontinent supplies even if they're not incontinent. They're in a different environment with different food." Shoaf says she learns something new on every cruise.

Spying for Fun

Although long retired, Gary's help was requested in solving a case of sabotage involving material for an atomic bomb. It was clear by the look of joy on his face that Zooming into Washington, D.C. to face this challenge was exactly what he wanted to do. His eyes twinkled as he answered every question put to him.

This is how Gary spends one afternoon each month, listening to stories of intrigue as part of Spy with Me, a free one-hour program offered by the International Spy Museum for people with memory loss and their care partners.

The program is the brainchild of Shana Oltmans, manager of museum programs and experiences, who had been working with Iona Senior Services, a D.C.-based nonprofit, to develop programing for their community. When the pandemic hit seniors especially hard, Oltmans realized she could reach a wider audience if she created a virtual program. Spy with Me was first offered to the public in 2022, using music and museum artifacts to explore favorite spy stories.

The programs, which are kept small to encourage participation, start with introductions so people can share where they are located — participants are from around the country.

Every month Oltmans creates a different theme, which she builds around a PowerPoint presentation. Participants don't need to know about the content beforehand. For January she chose "Spies in the Snow," starting off with Frank Sinatra singing "Let It Snow," to which Gary was smiling and snapping his fingers. She incorporated snow-related artifacts that included a photo of a parhawk, the fictional hybrid paraglider/snowmobile used in a James Bond movie to land in snowy mountains.

She then showed a photo of a thermos and mittens and asked, "Which of these items has a secret spy purpose?"

Gary guessed the thermos, which did indeed have a bottom that screwed off to reveal a camera. But the mittens also had a purpose: Secret messages were sewn into the lining.

The real-life story she was building focused on a World War II sabotage mission in Norway. A photo of the building shows a brutal environment. "What would be the challenge to this building," Oltmans asked. "The mountains," Gary said.

At the conclusion of the exciting story, Oltman played Gary's favorite group, the Beach Boys, singing "Frosty the Snowman," to which Gary again smiled and snapped his fingers.

The program is promoted as being for people with memory loss, but Oltmans doesn't "ask about someone's potential condition." Most participants have a caregiver with them, which can be helpful for the technical portions but also to create a shared experience. Oltmans has received wonderful feedback.

"Our goal isn't necessarily to teach intelligence history. It's to create fun."



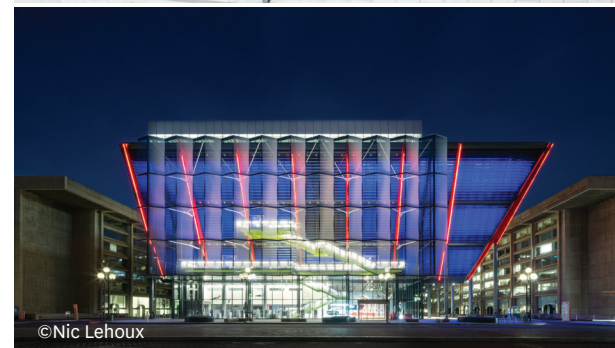
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For more information about Spy with Me, visit the International Spy Museum's calendar on the website at spymuseum.org. The program is free, but space is limited. To register, email Shana Oltmans at soltmans@spymuseum.org with your preferred date from the listings on the website.

Meet Me at MoMA

A dozen art lovers sat on stools in front of five bronze Matisse sculptures, listening as their instructor shared information about the artist and drew out their reactions to the various depictions of the head of his friend known only as Jeannette. It was a busy afternoon at The Museum of Modern Art (MoMA) in New York City, but this group was fully engaged.

"The thing about art is it doesn't require memory," said Francesa Rosenberg, director of Access Programs and Initiatives. "We can look at Vincent van Gogh's 'Starry Night' and all be together and have a reaction, enjoying the colors and brushstrokes."

That was what the museum had in mind in 2006 when it created Meet Me at MoMA, a free 90-minute monthly program for people with memory loss and their caregivers. "Our access team is dedicated to thinking about people with disabilities. We were paying attention to the staggering number of people with dementia."

Many of the people following teaching artist Riva Blumenfeld on that January afternoon were regulars, some arriving nearly an hour early in their excitement. One man who used to bring his mother has continued coming even after her death because it makes him feel close to her and because he loves the company.

Rosenberg said one of the teaching artists was even asked to speak at the funeral of one of the regulars because folks at the museum knew the man in a different way from his family and caregivers. "We were honored," she said.

The memory loss visitors and their caregivers are divided into two groups of 12. The museum's teaching artists are trained by doctors on how to better understand how the brain is impacted by neurological disorders and which parts of the brain function better than others so they can tap into those areas with their creativity and learning. Participants wear nametags so they can be referred to personally.

"The key is to ask good questions to draw them out," Rosenberg said. "We do get to know them."

As January's group observed the various depictions of the unfinished head sculptures, Blumenfeld explained that Matisse would have started with clay. "Why would he not want to complete Jeannette's head," she asked.

"He ran out of material," someone suggested. Blumenfeld said that was possible but maybe he wanted us to just focus on certain features. She encouraged everyone to walk around to look at the heads from all sides. Several questioned whether they all portrayed the same person because they looked different. Blumenfeld said Jeannette had posed for the first two while the other three were from memory.

"As we all know, memory is always the question," she said.



All photos ©Jason Brownrigg, The Museum of Modern Art

To find out more about MoMA's program and to sign up for Meet Me at MoMA, a free program for individuals with Alzheimer's disease or other forms of dementia and their family members or care partners, please email AccessPrograms@moma.org or call [Access Programs at 212-408-6447](tel:212-408-6447).

MoMA also offers training resources intended for use by arts and health professionals as well as caregivers on how to make art accessible to people with dementia. MoMA's teaching methodologies and approach can be applied to most settings and situations. Please visit moma.org.



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Arnegoon | Dreamstime

Palliative Care Through a Dementia Lens

Seventy-five percent of people with dementia in the United States will spend time in a nursing home, most typically in the moderate and advanced stages of their condition. Ann Wyatt, MSW, has been observing the treatment they receive for years, and it has turned her into a champion of palliative care.

“There are some treatments available that will help some people with Alzheimer’s for a time, but there is no treatment yet that will prevent or cure the disease,” she says. “In this absence the best medicine is good care.”

The World Health Organization defines palliative care as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual.”

Wyatt embraces this approach.

“Now the understanding is that basically from the point of diagnosis there may be, and is likely increasingly, a need for a palliative approach along with any treatment that is available and effective. That means that you could do both at the same time. Palliative care means that you may have a life-threatening illness, but there are things that you can do to be more rather than less comfortable.”

“Comfort is not something that caregivers decide. It’s something that’s conveyed by the person in a variety of ways. People with

dementia do communicate comfort and discomfort through their actions. The goal here is to really work on figuring out what is the cause of the discomfort and help somebody become comfortable.”

She said it’s usually not dementia that causes the distress.

“It is the dementia that prevents the person from expressing the cause of their distress. Most of the time it means that somebody is in pain or has some other discomfort. Dementia just means they can’t explain what it is.”

In many care facilities the distressed person is prescribed antipsychotic drugs, which “may remove the person’s only means of communicating and still not be responsive to the underlying problem.” They will still have the pain, but they will not be able to let anyone know.

“Care settings often expect the person to conform to the needs of the setting, which means not only that the person’s needs may not be met adequately or in a timely manner but the setting itself may be causing the person’s distress.”

THE COMFORT APPROACH

Wyatt shared an example of a man who was admitted to a nursing home she worked with. He had been in a couple of other homes and a psychiatric unit. His wife was “at her wit’s end. She was terrified he’d be discharged from this home as well.”

Fortunately, the staff sat down with her to talk through what may be going on with him. They learned that at home he had been in the habit of staying up until 4 a.m., then having a snack, going to bed and sleeping until around noon or 1 p.m.

“It was only when people tried to get him to go to bed before he

Continued on following page

PALLIATIVE CARE THROUGH A DEMENTIA LENS *cont'd from p. 15*

was ready and then wake him out of a sound sleep in the morning when he was finally getting some rest that he became upset.”

The nursing home worked with the family, changed his schedule “and these behaviors disappeared.” He was also no longer on the antipsychotics that he had been taking when he arrived there.

LOOKING AT COMFORT FROM A DEMENTIA-SPECIFIC PERSPECTIVE

Wyatt says she’s regularly asked if the palliative care approach takes a great deal more time.

“My answer is to consider how much time it takes to try to get someone to do something they don’t want to do. It may take a little more upfront time to get to the root of the problem, but more often than not it will save time in the long run.”

She points to Beatitudes Campus, a retirement home in Phoenix, AZ, which about two decades ago revamped its dementia unit with a comfort approach. “Resistance to care there is rare. People eat, sleep and wake as they desire. Staff at Beatitudes are always assessing what’s working for the person, understanding that people with dementia, like everyone else, are experts on their personal comfort.”

This kind of detective work to understand an individual’s needs involves a process, with weekly interdisciplinary meetings bringing together nurses, nursing assistants, social workers,

activities staff and all involved. Each might have a different observation and perspective. The process should also include a comprehensive assessment at the time of admission to understand the person’s history in terms of care needs, habits and comforts.

Wyatt cites an example of one woman who was regularly being written up for aggression toward other residents. When the staff began observing her closely, they realized she was trying to hug the other residents. The staff then began giving her frequent hugs throughout the day and the problem was solved. The woman wasn’t aggressive; she was loving.

Facilities that take the time to practice the comfort method report higher staff satisfaction, Wyatt said.

For help in finding facilities that are comfort-focused, Wyatt recommends downloading the free booklet *Finding Comfort: Living with Advanced Dementia in Residential Care*, which is also available in Spanish, from caringkindnyc.org. It will help family members develop questions to ask when they are looking for a home. Another free booklet, *Palliative Care for People with Dementia*, is also available as well as a newsletter featuring topics such as trauma, pain and how music can help.

This feature is adapted from the AFA Care Connection webinar “Palliative Care Through a Dementia Lens.”

What is agitation that may happen with dementia due to Alzheimer’s disease?

Actor portrayals



To identify the symptoms scan the QR code.

Learn more at AgitationInAlz.com

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When AFA hits the road for its Educating America Tour, questions from audience members routinely come up about clinical trials. In response, Charles J. Fuschillo, Jr., AFA president and CEO, devoted one of AFA’s Fireside Chats to the topic, talking with Madhav Thambisetty, M.D., Ph.D., senior clinical investigator and chief, Clinical and Translational Neuroscience Section, National Institute on Aging, in a session called “Dementia Diagnosis Roadmap: Pipeline, Trials & Research—What’s It All About?”

“There’s always a fear that’s associated with clinical trials,” Fuschillo said. “It’s a term that many people have heard, but they’re not fully aware of what exactly it means.”

Thambisetty explained the term and how to counter the fear.

“Clinical trials are research studies that help us understand whether a new treatment or a diagnostic test is effective and safe in people. Oftentimes they are the main methods through which scientists, doctors like myself, assess whether they are more effective than existing treatments and diagnostic tests.

“Education is the key to increasing awareness of clinical trials in general and specifically in regard to fear being a barrier to participation. It’s a legitimate concern, one that has also emerged out of historical mistakes that were made in the era when clinical trials were not regulated, and we didn’t have the guardrails to ensure participant safety.”

However, he said strict rules now govern how trials are conducted. All must be approved by a committee of the Institutional Review Board, which is made up of doctors, scientists and sometimes members of the public.



Tommy Song | Dreamstime

Should You Consider a Clinical Trial?

ARE YOU OR A LOVED ONE INTERESTED IN PARTICIPATING IN A CLINICAL TRIAL?

Please discuss this with your doctor and visit the website alzheimers.gov for ideas. AFA also offers links to clinical trials at alzfdn.org/clinical-research-trials.

“Today, every clinical investigator in the United States is monitored and follows a careful study plan, often called protocols, that lay out in extraordinary detail what researchers plan to do as part of the trial.”

Another safeguard is the informed consent, Thambisetty said.

“An informed consent has details about the study, what it’s goals are, how long it will last, what procedures the participants will undergo and whom to contact in case there are unexpected problems that develop.”

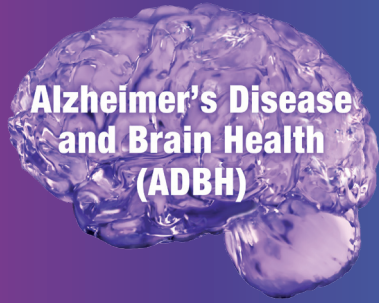
He recommended the following steps for those interested in participating in a clinical trial:

- Understand what the trial is aiming to do.
- Study the information about the procedures involved.
- Find out the time commitment required.

This information is available in the informed consent brochure, he said.

“The one thing I encourage my patients to do is ask questions. Get a good idea of what the potential side effects might be and understand what you might get out of the trial.”

The **AFA Fireside Chat** is an educational and informational web series open to family caregivers, professionals, clinicians and anyone else who wants to learn about Alzheimer’s and related dementias. Each episode features a topical discussion with experts from the fields of medicine, research and dementia care. Go to alzfdn.org/firesidechat to view the 2024 schedule and past episodes.



Alzheimer's Disease
and Brain Health
(ADBH)

FOUR DECADES OF ALZHEIMER'S RESEARCH NEVER GIVING UP



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At Eisai, everything we do is guided by a simple principle: patients and their families come first. We call this *human health care* or *hhc*: Giving first thoughts to patients and their families and helping increase the benefits health care provides.

A new federal program has been created to improve the quality of life for people living with dementia, to help them remain in their homes and to reduce strain on unpaid caregivers. This will be carried out through a package of care coordination and management, caregiver education and support, and respite services administered by the Centers for Medicare & Medicaid Services (CMS).

The Guiding and Improved Dementia Experience (GUIDE) model will allow CMS to test an alternative payment for participants who deliver key supportive services to people with dementia, including comprehensive, person-centered assessments, care plans and care coordination. Under the model, people with dementia and their caregivers will have access to a care navigator who will help them obtain clinical and non-clinical services and supports, including meals and transportation, through community-based organizations. The program, which is scheduled to go live in July 2024, will also provide a 24/7 support line.

The model is also designed to enhance access to the assistance and resources caregivers need. Evidence-based models of support for caregivers of people with dementia and dementia-capable community-based providers have been expanded over the last decade through investments in research and services by the U.S. Department of Health and Human Services (HHS), and others. The model will provide a link between the clinical health care system and community-based providers to help people with dementia and their caregivers access education and support, such as training programs on best practices for caring for a loved one living with dementia. Model participants will also help caregivers access respite services, which enable them to take temporary breaks from their caregiving responsibilities. Respite has been

found to help caregivers continue to care for their loved ones at home, preventing or delaying the need for facility care.

The GUIDE Model will also advance health equity for underserved communities of Black, Hispanic, Asian Americans, Native

Hawaiian and Pacific Islander populations, which have a higher prevalence of dementia, are less likely to receive a diagnosis and have more unmet needs. These populations are also more likely to experience high

caregiving demands and spend more of their family assets on dementia care. By providing financial and technical assistance for developing new dementia care programs targeted to underserved areas, this model aims to improve the health outcomes and caregiving experience to individuals and their families through increased access to specialty dementia care.

Did You Know? **U.S. Government Announces Trial Payment Program for Care Providers**

For additional information, visit [CMS.gov](https://www.cms.gov); search for "GUIDE."



Another Dementia: Vascular Disease

When people develop memory loss the first thing that often pops into their head is *Am I developing Alzheimer's disease?* Dr. Charles Bernick, a staff neurologist at the Cleveland Clinic, says vascular disease is another common cause of dementia and it is treatable.

"It's something we can actually intervene with and hopefully stop or slow any noticeable decline."

Bernick defined vascular disease as damage that occurs to blood vessels. One type is stroke in which blood flow to the brain is disrupted because of blockage or from the rupture of an artery.

He said cognitive function can be affected in three ways by a stroke: You can have a big stroke, a strategically placed stroke in an area of the brain that causes memory loss or you can have

multiple strokes that "pick off different areas of the brain so it starts to accumulate."

People at risk are those who have already had a stroke or a transient ischemic attack (TIA), persons with atrial fibrillation, which is an irregular heart rate, and those with uncontrolled hypertension.

It's important to differentiate between Alzheimer's and vascular disease through testing, Bernick said, and then manage your risk factors.

"If you have vascular dementia and you can prevent further vascular disease, you can theoretically prevent or slow its worsening over time."

Adapted from the AFA Care Connection webinar "What If It is Not Alzheimer's Disease?" To view this recording, go to alzfdn.org; search for "Care Connection webinar archive."



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Ask the AFA HELPLINE SOCIAL WORKER

Support • Advice • Resources

My father, who is living with us, has dementia. He was recently hospitalized for something unrelated and is about to finish up a few weeks in a rehab facility. He is begging us not to place him in a facility again. We would like to accommodate his request for as long as we can. But my husband and I can no longer care for him by ourselves. Help! What do we do next?

Coordinating care for a loved one can be overwhelming. The best place to start is where you are: When leaving a hospital or rehabilitation setting, a discharge or transition planner will be assigned to your case and assist with next steps. These may be recommendations for in-home care as well as services that your doctor may have requested for your father in his home, such as physical therapy or nurse visits. Remember, many settings have their own in-home providers and will likely recommend them to you. For continuity of care, it may be helpful to use their recommendations, but remember you are not required to do so.

It's important to understand what your insurance will cover coming out of a hospital or rehab setting, for how long, and when those services will cease. Some closer investigation into your policies (Medicare, Medicaid, and personal insurance) will be needed at this time to properly plan. In-home care is generally not covered by insurance unless prescribed by a doctor.

You can pay for in-home care in different ways:

- **Private pay:** As long as you can pay for in-home care out of pocket, you can have as many hours as you want or need for as long as you want.
- **If your father is over 65 and on Medicare or Medicare and private insurance,** you may be able to access short-term care following a rehab stay, but only under a doctor's orders. "Short term" will be determined by your policies. Be sure to look closely into your father's insurance now. Some older policies (such as a former employer), as well as Veteran and union benefits do pay for in-home care.
- **Medicaid** (government health insurance for low-income individuals) is state administered (i.e., Specific offerings will be determined by your state.) In New York state, for instance, Community Medicaid covers some at-home care, such as a personal care aid. Chronic Medicaid covers nursing home care.



- Keep in mind that **PACE (Program of All-Inclusive Care for the Elderly)** is also available in some states. It combines Medicare and Medicaid benefits and may pay for some or all of the long-term care needs of the person living with dementia. PACE permits most people who qualify to continue living at home. To learn more, call **877-267-2323** or go to medicare.gov and search for "PACE."
- **In some states, there are programs that will pay you,** a family member, to provide care to those receiving Medicaid — this program may go by a different name in your state. In a very few states, programs are even available to those who do not qualify for Medicaid. But be warned, these programs vary widely, often with complicated criteria for eligibility.

To help you find a provider, a good place to start is **Community Resource Finder (communityresourcefinder.org)**, a database of dementia- and age-related resources by a specific location. You can also hire a geriatric care manager or aging life specialist to help you sort through it all. There is much more to this topic than we have been able to cover here. Go to the **Aging Life Care Association (aginglifecare.org)** to get started.

AFA Helpline social workers Linda Mockler, LMSW, M.Ed., and Melpo Voulteris, LMSW, contributed to this answer. If you need more assistance with this topic or others related to caring for someone with dementia, please reach out to the **AFA Helpline**, seven days a week, at **866-232-8484**, via text at **646-586-5283** or webchat at alzfdn.org (available in 90+ languages). The service is free.



**NUTRITION
FACTS
PER CODFISH
CAKE**

75 calories
4 grams fat
3.1 grams carbohydrate
5.7 grams protein
108 mg sodium

FISH CAKES

The benefits of Omega-3 fatty acids found in seafood are important for brain health and may reduce the risk of developing neurocognitive disorders. These helpful fats can reduce triglycerides, the risk of developing an irregular heartbeat, slow the buildup of plaque and can help with cellular signaling, which is important for all aspects of health.

The American Heart Association and other leading health organizations recommend eating at least two servings of seafood a week. Fatty fish, such as salmon, trout and sardines, or shellfish like oysters and mussels, are highest in Omega-3s. This recipe for fish cakes is versatile and can be served on a bun with lettuce, tomato and your favorite condiments. Makes 12 fish cakes.

INGREDIENTS:

- | | |
|---|------------------------------------|
| 12 oz. fresh skinless and boneless cod or wild salmon | 1/2 tsp. ground nutmeg |
| 1 1/4 cup low fat milk or oat milk | 1/2 tsp. ground black pepper |
| 1/2 tsp. sea salt | 2 tsp. potato starch or cornstarch |
| | 3 tbs. extra-virgin olive oil |

DIRECTIONS

1. Pat the fish dry to remove excess moisture.
2. Add the fish to the bowl of a food processor or blender.
3. With the processor or motor running, slowly stream in the milk, followed by the salt, nutmeg, black pepper and starch. (Omit or reduce salt if you are following a sodium-restricted diet.)
4. Process 2 to 3 minutes to achieve a smooth and thick mixture.
5. Dip a large spoon in warm water and scoop large spoonfuls of the fish mixture into 12 equal discs and flatten slightly.
6. Heat a large non-stick fry pan over medium to high heat.
7. In three batches, add 1 tablespoon of olive oil at a time to cook 4 fish cakes.
8. Sauté for 4 minutes on each side until golden brown.
9. When fully cooked, the fish cakes should be firm to the touch in the center. Serve with lemon wedges.

PREVENTING Neurocognitive Decline

When new patients come to his memory disorder center in Miami, Marc E. Agronin, M.D., says his first thought is not of a disease such as Alzheimer's. As an expert in neurocognitive disorders, Agronin plays detective. He begins by exploring three possible causes for a person's memory loss.

"I want to know what is going on in their day-to-day life that might be affecting their condition," he says. "Someone who has hearing loss is not going to hear and thus not remember things. Hearing loss is a big issue and big risk factor for cognitive loss."

Someone who is distracted, nervous or depressed is not going to be paying attention or concentrating as much. "This is going to affect memory and other cognitive skills."

Similarly, individuals who are not processing experiences and putting them into memory because of fatigue, sleep deprivation, illness or medication effects may also experience cognitive changes.

"All of these things can affect both short- and long-term memory. If we can identify some of these changes, these are easy to treat and reverse right away. We always should be keeping in mind how we can optimize our brain function."

If it is determined that a person has a neurocognitive disorder, which Agronin says is now the preferred term for a memory loss illness, it's important to separate that from the occasional confusion many people experience and explore the cause.



"Think about it like the term infection. If you have an infection, it means you could have many different types of infections — pneumonia, skin infections, things like that. Similarly, if you have a dementia or major neurocognitive disorder, meaning your brain function is declining, there are many different causes. It's important to keep that in mind.

WHAT ARE THE RISK FACTORS?

"There are risk factors for both developing Alzheimer's disease and perhaps other forms of neurocognitive disorders, but there are also risk factors for making it worse. If you look at all the risk factors for Alzheimer's in particular, about 35 percent of them are potentially modifiable, meaning you can change them if you reduce them." Agronin broke down the risk factors according to life stages. In early life, they are genetics and education. In midlife, they are hearing loss, hypertension and obesity; and in late life, after 65, they are smoking, depression, physical inactivity, social isolation and diabetes.

Continued on following page

PREVENTING NEUROCOGNITIVE DECLINE *cont'd from p. 23*

“One of the most well-recognized risk factors for late-onset Alzheimer’s is having one or two copies of the Apolipoprotein E4 or APOE-4 gene, which is found on chromosome 19 and produces a protein involved in cholesterol transport in the body. We don’t routinely test for this gene, however, because there isn’t anything specific to do if you have it other than to adopt a brain-healthy lifestyle, which everyone should do regardless of their genetic make-up.”

“Knowing what you have is really not going to do that much for you. That’s why we don’t routinely test for it. I don’t like people to find out and then fret about it. What I tell people is everyone should be on a risk-reduction, brain-healthy lifestyle regardless of their genetic risk.”

As for the role of education, “Theoretically, lack of education limits your cognitive reserves. The more you build up earlier in life, especially through higher education, seems to make a difference. Once you get into late 20s and middle age, it’s not clear whether education is really going to be the same risk reduction in terms of Alzheimer’s disease. Without question though, it’s going to build up your cognitive reserve, and so it’s important.”

OTHER POTENTIAL RISK FACTORS

“Traumatic brain injury, especially early in life with loss of consciousness, increases the risk of Alzheimer’s disease. Little bumps or minor concussions, not as much. Repetitive head injuries, such as in sports, is associated with chronic traumatic encephalopathy and Alzheimer’s disease.”

Researchers have found another contributing factor — oral hygiene.

“Studies have shown that poor oral hygiene increases bad bacteria and is associated with increased risk for amyloid protein, which is one of the toxic proteins that cause Alzheimer’s disease in a really stunning way. Think about how close the mouth is to the brain. People can get oral infections that can seep to the brain, so brushing your teeth and seeing your dentist are ways to reduce your risk of Alzheimer’s disease.”

Sleep disorders, such as apnea, deprive the brain of oxygen, creating the risk of brain damage, as do elevated levels of cholesterol. In menopausal women, the decrease of estrogen is a risk factor. “This is why many women are of much higher risk after menopause than men.”

WHAT CAN YOU DO TO MAKE THINGS BETTER?

Agronin says to skip all the “magic formulas” promised in over-the-counter brain formulas. “I will tell you none of which do anything. The only people benefitting from all these products are the people who are making and selling them.”

Agronin says to stick to “the old standbys” for cognitive enhancement. “You don’t have to spend a lot of money to address these.”

- **Exercise** – moderate exercise most days of the week, between 30 and 60 minutes, improves blood flow to the brain so your brain cells can make more connections.
- **Diet** – the 10 brain-healthy food groups are: vegetables (especially green leafy ones), nuts, berries, beans, whole grains, fish, poultry, olive oil and wine, but no more than one glass a day. To be avoided are sugar and processed foods.
- **Keep your brain stimulated** with games, puzzles, volunteer work, adult education and learning new skills and languages.
- **Get enough sleep and hydration.**
- **Reduce stress and create mindfulness** with meditation, yoga and prayer to help you center your brain.
- **See your doctor regularly** to discuss known risk factors.

PURPOSE IMPROVES HEALTH AND LONGEVITY

Maintaining strong relationships, doing volunteer work and keeping a positive attitude toward aging can reduce the risk of Alzheimer’s by nearly 40 percent and increase life by up to seven years, Agronin says.

“What I have found in my research on the strengths of aging is that people who have an increased sense of purpose have fewer heart attacks and strokes and lower rates of mortality, which reduce the risk of Alzheimer’s disease and other forms of dementia. It’s really stunning.”

This article is the second of a two-part feature adapted from AFA’s Care Connection webinar “Preventing Neurocognitive Decline: Before and After Diagnosis,” featuring Marc E. Agronin, M.D. Part One, “The Power of Healthy Brains,” was featured in the special year-end issue of *Alzheimer’s TODAY*.

Alzheimer’s Not the Same as Dementia

By Nathaniel Chin, M.D.

Fear and anxiety permeate the walls of the memory clinic where I work as a geriatrician. Patients and families dread the possibility of Alzheimer’s disease and a future they won’t recognize. But it is not the disease that drives this worry; it’s the symptoms of dementia.

Dementia describes the symptoms that affect people’s thinking and ability to do daily tasks. Alzheimer’s disease, an accumulation of proteins that eventually kill brain cells, is the biology that can cause dementia. To patients and families, the words dementia and Alzheimer’s are often used interchangeably. Both capture the fear and sorrow marked by living with a failing brain.

Emerging Alzheimer’s treatments raise the stakes for understanding the distinction between dementia and Alzheimer’s disease, in terms of knowing when new FDA-approved treatments may or may not be useful.

The Food and Drug Administration recently approved Leqembi, which removes from the brain one of the key proteins in Alzheimer’s disease. By targeting the biology, Leqembi can modify Alzheimer’s course and impact dementia symptoms. As a result, both biology and symptoms matter in providing care. Memory clinics are the epicenter for providing this care, bridging the symptoms with the disease. I’m seeing it already.

One of my patients, Molly, is a 74-year-old woman diagnosed with Alzheimer’s disease at another clinic. She wanted a “second opinion.” Nothing about her case was unusual. Her memory and thinking difficulties extended to some of her daily activities, including managing medications and dressing appropriately for the weather. After her workup, Molly and her daughter did not want to talk about the diagnosis — moderate stage dementia due to vascular disease — only about how Molly could get the new drug that would “reverse her Alzheimer’s.”

But the drug wouldn’t benefit Molly. Her dementia was too advanced and she didn’t have Alzheimer’s. When I told her this,



she was relieved it wasn’t Alzheimer’s, but sad her symptoms would not go away.

Leqembi and drugs like it are changing the landscape of memory care. Helping patients understand the terms and meaning of their diagnoses takes time — a luxury we don’t always have. Evaluations for memory care are already extensive. The addition of treatments adds further complexity. Now, evaluations will include a person’s symptoms, history, and Alzheimer’s biomarkers. Health care providers will need

to discuss, obtain, interpret and share a person’s biomarkers in the context of their symptoms and determine whether these new treatments are right for the patient.

However, not everyone with thinking changes has Alzheimer’s disease. Not everyone with Alzheimer’s will receive the newest therapies. Not everyone on therapy will benefit. These nuances exist at every stage and require discussion so patients can understand what is happening to them and their options for care. Doing this means taking time to talk with patients and families. Doing it well means using the right words.

Advancements in Alzheimer’s research and therapy are driving a revolution to distinguish the language of Alzheimer’s disease from the symptoms of dementia. Health care providers must diagnose syndromes like dementia based on symptoms first, and then diseases like Alzheimer’s based on biology second. Doing so will not only lead to better outcomes but may address the fear and anxiety that permeate those clinic walls.

This guest essay is based on an opinion/editorial that first appeared in *Newsday*. It reflects the views of Nathaniel Chin, M.D., medical director of the Wisconsin Alzheimer’s Disease Research Center and member of the Medical, Scientific and Memory Screening Advisory Board of the Alzheimer’s Foundation of America.



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Source: Centers for Disease Control and Prevention



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