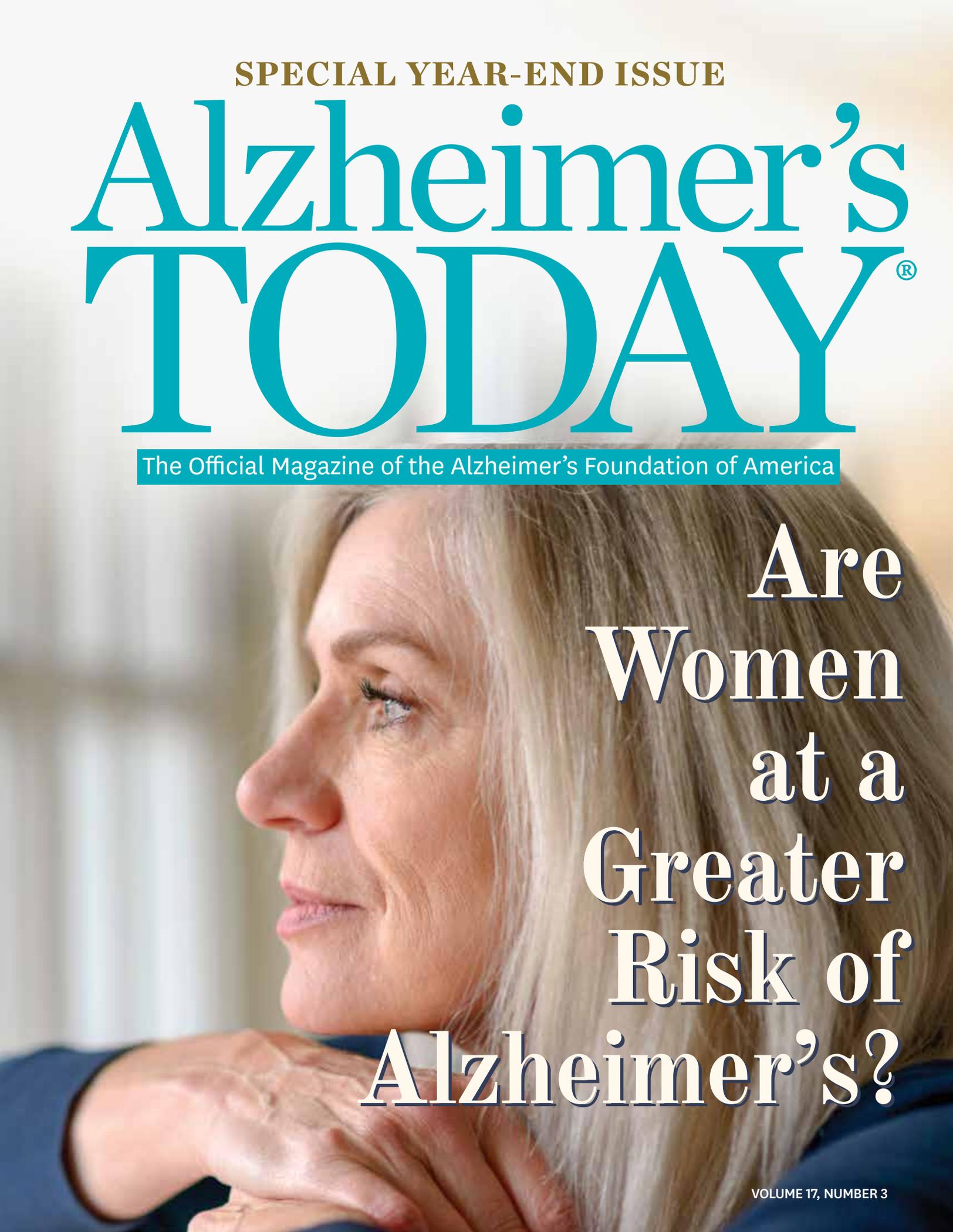


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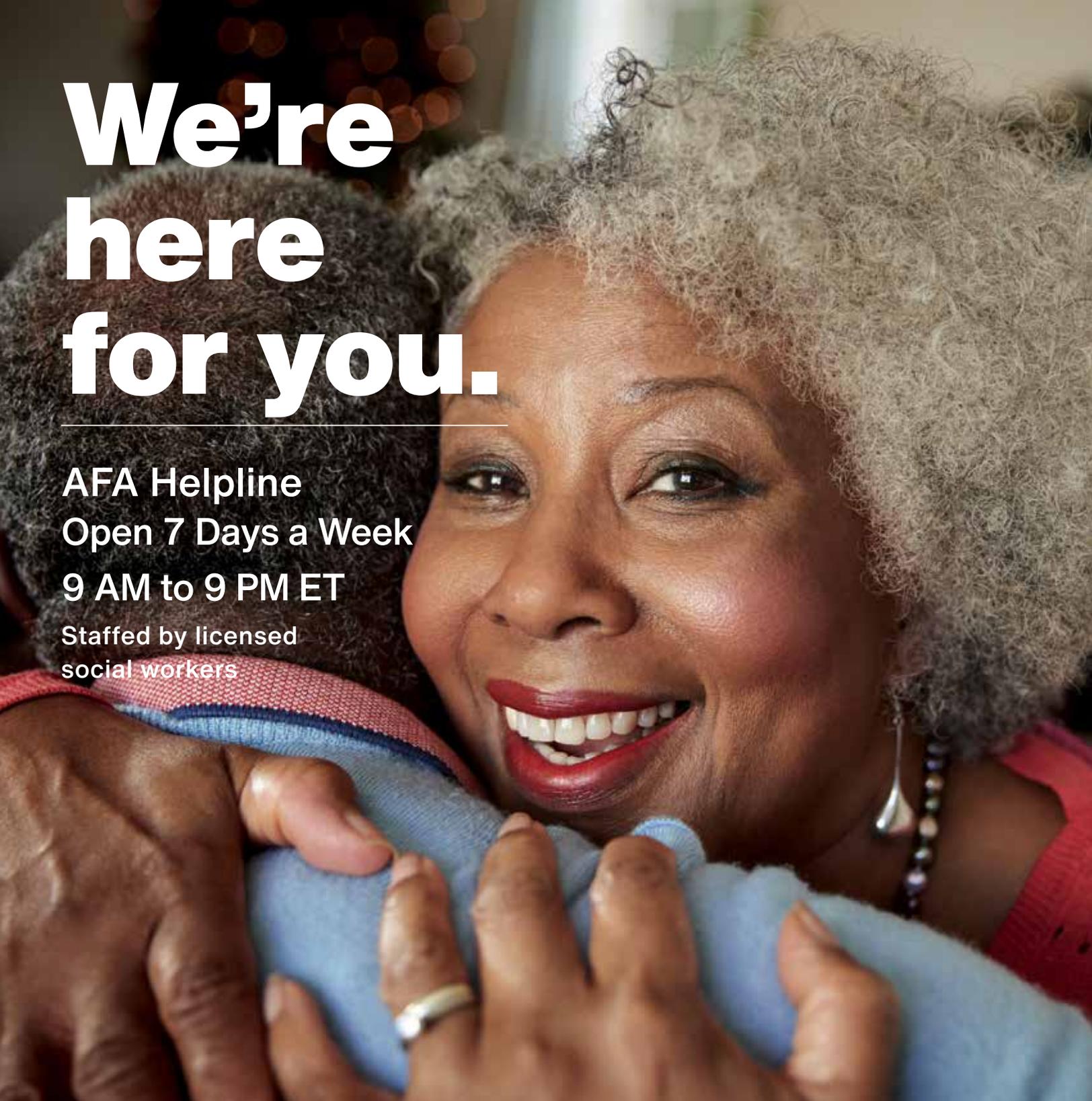
Alzheimer's TODAY[®]

The Official Magazine of the Alzheimer's Foundation of America



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TODAY[®]**

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Alzheimer's TODAY[®] is published quarterly by AFA.

VOLUME 17, NUMBER 3

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322 Eighth Avenue, 16th Floor, New York, NY 10001

www.alzfdn.org | 866-232-8484

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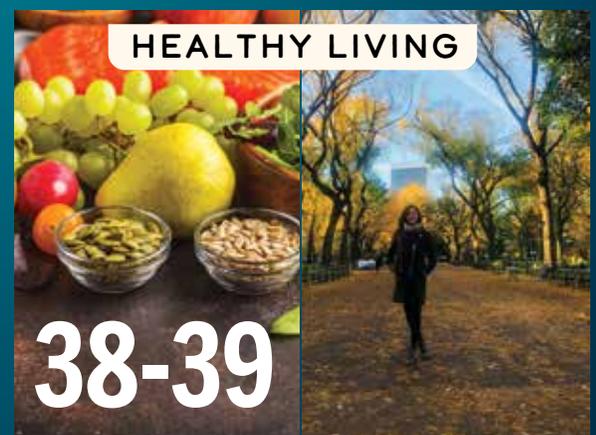
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**A MESSAGE FROM
OUR PRESIDENT & CEO
CHARLES J. FUSCHILLO, JR.**



Year's end is a time for both looking back and looking forward, reflecting on the accomplishments of the past while shaping the course for the future.

I'm enormously proud of AFA's impact in 2022, our 20th anniversary year. As I write this, we have already:

- **Delivered more than 36,000 minutes of support** by phone, webchat, and text message through our AFA Helpline, answering questions ranging from “What are warning signs of Alzheimer’s disease?” to “How can I deal with my loved one’s difficult behaviors?”
- **Grown our professional training offerings** to 12 different continuing education courses to help dementia care professionals enhance their skills.
- **Hosted a total of over 40 different Care Connection webinars and live interactive webinar trainings** that provided useful, practical information to help thousands of family and professional caregivers elevate the level of care they provide.
- **Launched a new “AFA Fireside Chat” educational and informational web series** designed to raise awareness about Alzheimer’s and related dementias, the symptoms associated with these diseases, health care disparities, and resources available to help.
- **Provided information on topics such as Alzheimer’s disease, brain health and wellness, caregiving, and advance planning to people across the country** through 10 different Educating America Tour conferences, (visit www.alzfdn.org/tour to learn more about the Educating America Tour).

- **Doubled the number of landmarks** that participated in our Light the World in Teal program, with a record 850 sites in all 50 states and 13 foreign countries “going teal” on November 3 to raise Alzheimer’s awareness (read more on p. 25).
- **Awarded over 1.55 million in grants** for Alzheimer’s research, community-based services provided by AFA member organizations, and college scholarships for high school seniors whose lives have been affected by Alzheimer’s disease.

And more!

In 2023, we look forward to growing our impact even further and launching initiatives such as:

- Our new **“Alzheimer’s & Dementia Online Academy,”** which will make our training offerings more convenient and accessible for dementia care professionals.
- A **new children’s book, *Gardening With Grandma***, the follow up to our *Dancing With Granddad: An Alzheimer’s Story for Children and Their Families*, to provide families with another resource to help explain Alzheimer’s disease to a child in an age-appropriate way.
- Additional **Respite Care Relief Parks**, which are free, dementia-friendly places where families affected by Alzheimer’s disease can go to get out of the house, relax, and enjoy the outdoors while also receiving educational information that can help them.

We’re grateful that you’ve been part of this amazing impact and look forward to having you with us as we do even more in the new year. Wishing you and your families the very best in 2023 and beyond!

Warm regards,

Chuck

ACCEPTING THE NOW



Many of us know or are related to loved ones living with brain change. We must adapt how we live, communicate and share with them.

I have found the following hints helpful in responding to my husband, Bob, who was diagnosed with Alzheimer's two years ago. They are the "Ten Absolutes" by Jo Huey to simplify daily tasks and create positive interactions:

- Never Argue | Instead *Agree*
- Never Reason | Instead *Divert*
- Never Shame | Instead *Distract*
- Never Lecture | Instead *Reassure*
- Never Say, "Remember" | Instead *Reminisce*
- Never Say, "I Told You So" | Instead *Repeat/Regroup*
- Never Say, "You Can't" | Instead Say, "Do What You Can."
- Never Command/Demand | Instead *Ask/Model*
- Never Condescend | Instead *Encourage/Praise*
- Never Force | Instead *Reinforce*

Just as it takes a village to raise one child, it takes a village to support our loved one who is living with brain change.

Mainly, I want others to know that Bob is the same person he has always been but that his brain functions differently now. Please, don't be uncomfortable, don't hesitate to engage someone living with brain change in a conversation (it might be interesting); offer to take a walk with them, go out for a nice lunch or even watch a movie together.

Bob is the same person, but he's experiencing the world differently. Accept him for who he is now and continue to love and respect him, and value him as a fellow human being.

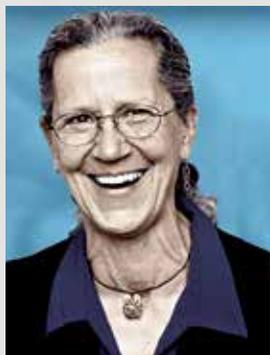
It's tough. It's a journey one day at a time. I want people to know we can live through this. That's my purpose.

ABOUT THE AUTHOR

Ann Berlam, 74, has lived in Naples, FL, with her husband, Bob, since 2000. This article is adapted from a longer version that ran in the *Naples Daily News*.

Photo courtesy of Ann Berlam

Why Do They Do That?



Teepa Snow, one of the country's leading educators on dementia, knows the answers to a question caregivers of individuals living with memory loss ask themselves regularly, "Why do they do that?" She shared her understanding of symptoms and situations of dementia in an AFA webinar in November.

Snow takes a hands-on approach to educating—literally. In explaining how Alzheimer's and other dementias affect a person's abilities, she held up her hands and explained that the thumb, index finger and middle finger are wired to the part of the brain that allows us to perform a skill, such as button a shirt or unscrew a lid. The ring finger and pinkie are for tasks that require strength, such as gripping a hammer.

"In every form of dementia that we know about, the dementia will rob you of skill before it takes away your strength, so instead of three skillful fingers and two strong, you end up with five strong and no skill."

Without this awareness, it's common for caregivers to see their person as the problem and think they're being uncooperative.

"One of the reasons people do what they do is because they're losing their skills in a variety of areas of function. If they're losing skill, who needs to develop skill so that things can still be done in a reasonable and accurate way? The answer is, we do."

In attempting to understand why individuals with memory loss do what they do, Snow says we need to turn the tables on ourselves.

"We need to understand our role and possible ways of making a change to respond to symptoms and situations so we can get a different outcome. We don't like what is happening, but we're the ones who can most effectively change because they're already changing."

HOW THE BRAIN IS CHANGING.

To illustrate why individuals with memory loss do what they do, Snow showed a slide comparing the brains of two men. They had been the same age and physical size, but one had died in a car accident and the other after living with Alzheimer's for a

decade. The Alzheimer's brain looked shrunken and withered in comparison to the healthy brain.

"If you can't see something, you say, 'Why are they doing this?' One of the reasons they're doing this is because their brain is deteriorating. By the end of the disease, you will only have one third of your brain tissue left."

Dementia brains have lost their connectivity, she says, explaining that the top part of the brain contains white matter, "the wiring." It is the part of the brain that allows you to get data from one part of the brain to another. "Without that wiring you can't send messages."

The outside edges of the brain contain "the dark-colored stuff called gray matter. That part is where you store things." Over the course of the disease, she says, "I'm losing my wiring. There's still a fair amount of storage capacity. I just can't get things in and out, and the prefrontal cortex is the part of the brain that can't do anything on its own."

Continued on following page



Snow said that in a healthy brain, the hippocampus performs three functions: It helps us learn and remember what we've learned. It acts as a way-finder, and it helps us understand the passage of time. She picked up a water bottle to demonstrate.

"I learn that water quenches my thirst. The second thing it [the hippocampus] helps me do is find my way to things that help me, that I need. The third piece of this that the hippocampus takes charge of is 'how long has it been since I've had something to drink?'"

But when someone in the late stages of dementia, who we think is probably thirsty, is given that water bottle they might turn it upside down or shake it. They don't recognize what it's for or, "even more frustrating," they manage to unscrew the top and then pour the water on the floor, prompting the caregiver to respond in a raised voice.

"Here's the challenge," Snow said. The person didn't know he was thirsty, but the caregiver assumed he was and handed him a water bottle thinking "it would click into place."

"You're going to want to do something like," she said, smiling and pointing to the water bottle in their hand while making a gesture of putting an imaginary one to her mouth. "You can hold the container until they take the first drink and then

understand. *You're* substituting for their prefrontal cortex that isn't able to do the job it used to be able to do."

In late stages of the disease, people also lose much of their vocabulary, the ability to say what they want, and comprehension of speech, the ability to understand what people are saying. Your person may become agitated and start yelling in crowded places because they are unable to separate background noise from conversations, and they are overwhelmed. The wiring in the sensory motor area of their brain is fraying.

"What we want to get really good at is using our big brain with so much wiring to try to figure it out, instead of saying, 'They don't get it.' Let's rethink this because we need to make decisions that are more consistent with what we can figure out."

"Dementia is not an easy journey. It's not an easy way to live life, but it sure gets a whole lot better when we decide to come together and work together to make a difference in a positive direction." ■

Adapted from the AFA webinar "Why Do They Do That? Understanding Symptoms and Situations of Dementia," which launched AFA's November Alzheimer's Awareness Month. View Teepa Snow's presentation at: www.alzfdn.org/teepa-snow-webinar



Michigan resident Barry Kaufman, 82, has been living with Lewy body dementia (LBD) for 12 years. He spoke with *Alzheimer's TODAY* about the life he has made for himself since his diagnosis.

You were diagnosed with LBD 12 years ago, well past the average timespan of five to eight years.

How have you beaten that timespan?

I beat the timespan because my daughter, Jacqueline, and wife, Annette, noticed my erratic behavior. I wasn't driving properly. I might miss an exit. My daughter, who is an associate professor of neuropsychology at the University of Michigan, arranged for me to get in touch with a neurologist there. Initially the diagnosis was Parkinsonism. They tested me for six months. I was diagnosed early. I got into testing programs to see my progress and into treatment programs that provided appropriate medication and lifestyle counseling.

How old were you? Were you still working at Blue Cross/Blue Shield?

70. I was happily retired from the best job I ever had. I was an administrative support person.

How did your life change?

It was progressive. There's the bike I used to ride, the golf game I used to play. I made changes. I had no ill feelings about it. I take a realistic approach about what I experience now and for the future.

What lifestyle modifications have you made?

Two times a week I go to the Y to exercise. I use a walker. I listen to classical music and modern jazz. It has a relaxing effect.

What are your biggest challenges?

The biggest challenge is with people when they learn I have Lewy body dementia. What do they think dementia is? That I can't do anything?

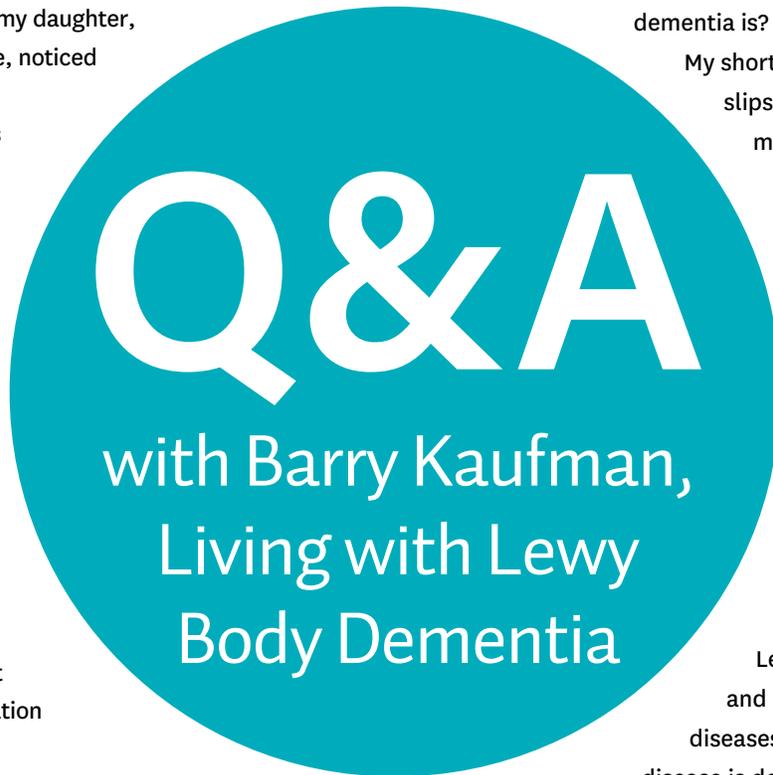
My short-term memory kind of slips on me, but my long-term memory is OK. I want them to understand that not all people with dementia are lost souls. What is my dementia? I walk with a walker. I have a brace on my leg. I can't even read my own writing. My balance is a problem. I have hallucinations. That's my dementia. People don't realize Lewy body, Alzheimer's and Parkinson's are called diseases and the effect of the disease is dementia.

I read a lot. Now I'm reading *Name Change* by Kirsten Fermaglich. (Full name: *A Rosenberg by Any Other Name: A History of Jewish Name Changing in America*.)

I've heard you describe your executive functions as being like a roller coaster, up and down. Would you please elaborate?

Right now, I'm pretty much at the top of the roller coaster. I'm cognitive. My activity level can be high and the next day I can't tie my shoe. When I'm down, I have levels of confusion. Did I take my pills? Feeling down for me is not that often, thank God.

Continued on following page



What have you learned from living with a dementia-related illness?

I learned I have a disease and it is fatal. I've accepted that fact. It doesn't bother me at all. I have a life. I'm going to live my life. I learned to be positive, active, and proactive. I learned to socialize with people.

What advice can you give to anyone living with LBD or another form of dementia?

I belong to a couple of support groups. One is the Brotherhood of Dementia Minds. (This is one of the groups available through the National Council of Dementia Minds, dementiaminds.org.)

When people come in with cognitive issues, I tell them, "You've got a life to live."

Are there any rewards?

There are a lot of rewards, like now I've been invited to sit on the steering committee of the National Council of Dementia Minds. There's all those Ph.D.s and then there's me.

What do you wish people knew about how to interact with a person with Lewy body dementia or similar illnesses?

Treat me like a person. If people are diagnosed with a disease having dementia attached to it, don't look at these things. Look at the individual.

You are participating in a research study. Why? Many people are unwilling.

They're afraid it might hurt or

What is Lewy Body Dementia?

Lewy body dementia (LBD) is one of the most common types of dementia in older adults, causing problems with thinking ability that seem similar to Alzheimer's disease.

Later, it has other symptoms, such as movement symptoms, visual hallucinations, and certain sleep disorders. It causes more trouble with mental activities than memory.

they're afraid of what might be found out. I'll do anything I can to possibly find a cause or cure for cognitive issues. I've had a CT scan, an MRI, three spinal punctures and blood drawn. I've gone through a lot of studies and been tested to see my cognitive levels. An important part of dealing with what I have is getting to contribute to research.

What advice would you give to caregivers?

One of the biggest things we talk about in Dementia Minds is our caregivers. I make sure my wife gets out of the house. My companion comes once a week for four hours. We usually go to lunch, play Scrabble and have discussions. Annette gets lost for four hours. The caregiver needs a life, too.

What are your hopes for the future?

My hopes for the future are simple. I enjoy my reading, my exercising. I have my friends and we go out to dinner. I feel I have a positive attitude and hopefully will continue to. I know I'll have some down days, but I'll come out of them.

People with these issues shouldn't hide them. Other people will be suspicious. Let it out. I'm very fortunate with my whole family. They can poke fun at me, and they do. A lot of it is attitude and a lot of it is support from friends and family. ■

Innovative WISH Sprouts Memories

Ruth approached her gardening with relish. Normally she used a walker and couldn't stand for long, but given a plot of land to plant, and she was transformed into her former self.

"I grew up on a farm. I grew up on a farm," she excitedly repeated as she planted winter vegetables in the accessible waist-high plot, no longer a woman with memory loss in her 90s but a child at her long-ago home.

Gardening, cook-outs, and fresh air exercise classes are lighting up people with Alzheimer's and related dementias now that Peachtree Christian Health (PCH) has expanded its successful therapeutic horticultural program to provide more culturally sensitive and dementia-safe spaces for participants and their families. The WISH (Wandering, International, Sensory, Habitat) Garden that opened in the spring at its adult day health center in Duluth, Georgia, includes African, Asian, Central American, Middle Eastern, and North and South American gardens with herbs, vegetables and art that are familiar to its ethnically diverse community and participants.



"Peachtree Christian Health is in one of the United States' most beautifully diverse counties where 38% of our neighbors do not speak English in their homes and 27% of our residents were born in another country," says Christi Heidt, Peachtree's program director. "We have found that gardening is a great cross-cultural and inclusive way for our friends to connect with one another. They love being outdoors."

One common element program directors have found across cultures and populations is their participants' pride and joy in sharing customs and memories of their countries of origin, particularly through gardening as the herbs, vegetables and flowers provide them a multi-sensory experience of home.

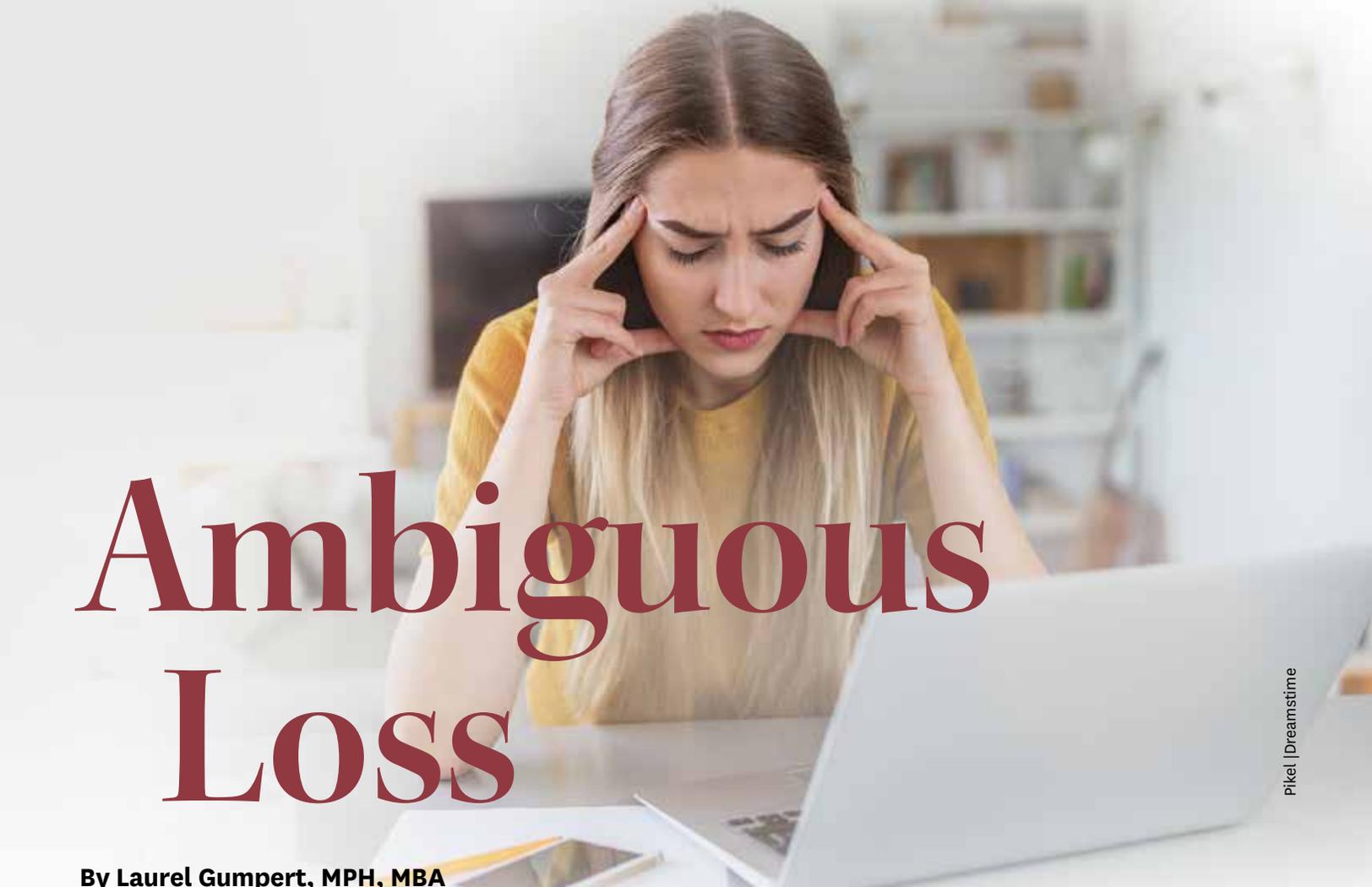
Activities in the garden are accessible to those experiencing cognitive, physical, and emotional decline. This allows them to communicate with each other, increase sensory engagement by stimulating the five senses and engage in activities. The garden also includes special seating to expand music and exercise therapy programs to outdoor spaces, along with a concrete loop walking path around the garden. "It gets boring walking inside. Out there they want to get moving and grooving,"

Heidt said. ■

AFA awarded a \$25,000 Anne and Irving Brodsky Innovation Grant for the WISH Garden project.

Ruth, 91, demonstrates her planting technique to Peachtree master gardeners. Photo courtesy of Peachtree Christian Health





Ambiguous Loss

Pikel | Dreamstime

By Laurel Gumpert, MPH, MBA

When you're on a plane, before take-off, the flight attendants will go through typical safety protocols, including, "If oxygen masks are needed, put your mask on first before helping others with theirs." There's a practical reason for this—if you can't breathe, it's impossible for you to help someone else.

The oxygen mask analogy relates closely to caregivers. Many times, they'll try to help their loved ones without regard to themselves, but that is not safe or sustainable. Making yourself a priority is imperative, especially with ambiguous loss.

Family therapist Dr. Pauline Boss created the term in the 1970s while speaking to families of soldiers who went missing in action. According to Dr. Boss, ambiguous loss is a loss that occurs without closure or a clear understanding—part of a person is with us and part of them is not.

Examples of ambiguous loss that can leave family members searching for answers include infertility, disappearance of a family member, death of an estranged family member, even what we have all experienced over the past two-plus years with the COVID-19 pandemic. But a common form of ambiguous loss is when a family member is physically alive, but cognitively changed due to Alzheimer's disease or another related dementia.

This phenomenon is incredibly common, even though it is not widely spoken about. If you think about the last couple of years, we've all experienced some form of ambiguous loss—loss of a job, time, or sense of safety and security. You may experience ambiguous loss from a breakup or a move across the country. Maybe you've lost trust in people, or lost hope in a future. And if you are caring for someone with Alzheimer's disease, you may be experiencing ambiguous loss.

Ambiguous loss is a difficult feeling, as it relates quite closely to anticipatory grief. Anticipatory grief occurs before physical death, but upon realizing that your loved one may die soon. We see anticipatory grief among families of those with a fatal illness or when a loved one is living with Alzheimer's disease or another related dementia. The family members know their loved one will decline and then pass away. It is anticipatory for this reason due to the knowledge that their loved one's mental state will continue to change. They begin to grieve early.

Understandably, these situations are difficult and potentially damaging for family members and caregivers. Stress, exhaustion, confusion, depression, anxiety, substance misuse, and PTSD are some of the physical and mental affects that ambiguous loss can cause. Finding ways to cope with ambiguous loss is vital.



Mark Adams | Dreamstime

Here are some ideas:

Call it what it is. Speaking about problems out loud and naming them can actually help make them a little less scary. Understanding that this is ambiguous loss and is different from traditional loss can give a person permission to grieve in their own individual way.

Practice “both/and” thinking. Society often thinks or acts in absolutes. Someone can either feel happy or sad, not both. Human beings do not operate in absolutes, so becoming used to “both/and” thinking is incredibly valuable. This gives permission to the person with ambiguous loss to settle with their current reality and not search for some perfect solution. Someone could feel both sad that their loved one is sick, and happy that they have a new grandchild. Or someone may both wish that the illness their loved one is going through is over and wish they could keep on living. Learn to accept “both/and” thinking and understand that it’s okay to feel all the emotions.

Do not seek closure. Dr. Pauline Boss states that we should not seek closure in ambiguous loss. In losses such as these, closure does not exist. Rather than seeking closure, we should find new ways to cope. Instead of striving for closure, we should look for individualized ways to continue to move forward in the face of ambiguous loss.

Find something new to hope for. Hope is a powerful thing. Despite what someone may be going through with a difficult ambiguous loss, find something that’s hopeful and uplifting. Whether that is a nice vacation or just a trip to your local coffee shop every Saturday, having something to look forward to can really make a difference.

Take care yourself. Make sure you are taking care of yourself in every way—mentally, physically, emotionally, and spiritually. And remember what the flight attendants always say: Put the oxygen mask on yourself first. ■

Have additional questions about ambiguous loss or need to speak with someone? Contact AFA’s Helpline social workers seven days a week by phone (866-232-8484), webchat (www.alzfdn.org), or text message (646-586-5283).



GlowOnConcept | Dreamstime

Will challenges in
neuroscience research
~~discourage~~ us?

motivate



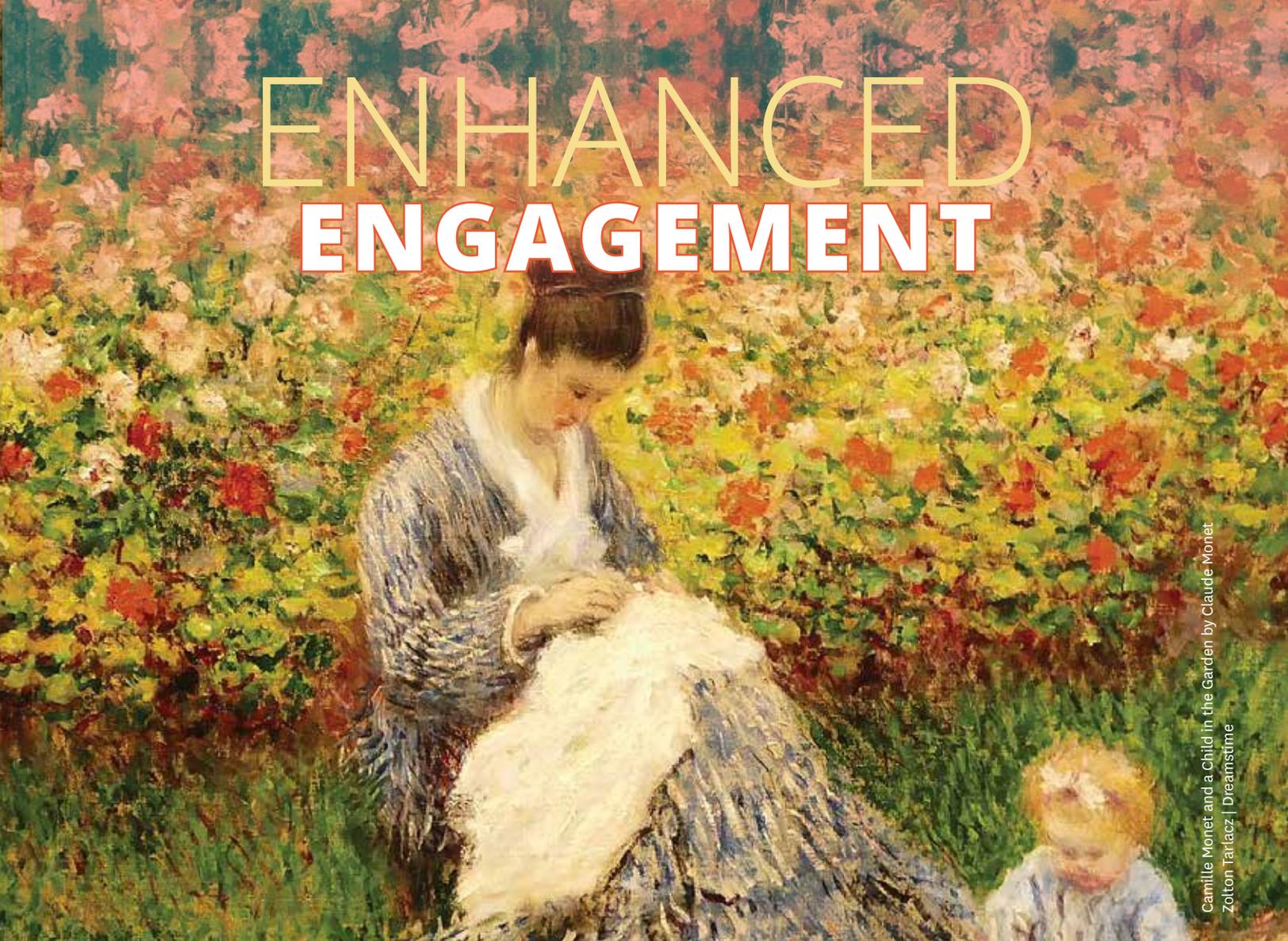
Ask bigger questions.

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ENHANCED ENGAGEMENT



Camille Monet and a Child in the Garden by Claude Monet
Zoltan Tarlacz | Dreamstime

The human spirit awaits within. It is our job and profound privilege to awaken it, says Laurette Klier about the challenges and rewards of connecting to a loved one with a dementia illness.

“The paradox with dementia is that while recent memories are added, early memories are illuminated as the core self remains. When we visit, we embrace the person who remains.”

Klier, a certified dementia practitioner, has discovered numerous ways to turn visits into “enhanced engagement.” They include pairing nostalgic fine art and literature that persons with dementia and their caregivers can enjoy together.

The current means of engagement is like a two-legged stool, she says.

“It’s made up of cognition and recreational activities. A vital addition to the mix is heart-centered activity that provides spiritual and emotional support and a better balance, reducing the need for behavioral and pharmacological intervention.”

While the time-tested activities are worthwhile, they “do not create many activities for people to connect on a deeper level. Heart-centered visits are life-altering and lifesaving.”

Klier developed her enhanced engagement approach while visiting her mother-in-law, Nana Mary, an avid reader until dementia turned this activity into a source of frustration. Klier searched for modified books to meet Nana Mary’s changing needs, but the picture and children’s books “were neither dignified nor stimulating.” So, she set out to create art- and literature-based books that are beautiful, engaging and that evoke nostalgia. She has now published a series of these *Nana’s Books*.

“Nostalgia significantly enhances psychological resources and research shows that reminiscence therapy facilitates adjustment to a diagnosis of dementia. Simply put, nostalgic, loving social engagement helps people to cope.”

Before visiting, set an intention to clear your mind of the day’s worries and focus totally on your person with dementia. Think about their life, past and present, and tell them what you like/love about them. Consider how you can impact their comfort and leave them with a deeper sense of joy and peace. “The caregiver needs that as much as the person living with dementia because, after all, it’s a relationship.”

Continued on following page

Here are some pointers on active and deep listening for care partners:

- Find a quiet, well-lit place.
- Pick up on your person's body language and facial expressions.
- Make simple, declarative statements.
- Keep questions open-ended and to a minimum.
- Allow them time to process.
- Seek to understand.
- Name emotions: "I think you are trying to tell me"
- Listen with an open heart and without judgment.
- Take a genuine interest.
- Validate what they are saying, their lived experience and life story.
- Honor their vulnerability. So much is out of their control. This is a wonderful time to make them feel safe.
- Pay a sincere compliment.

When possible, capitalize on proximity. "A touch, a hug, a squeeze of the hand, sitting side-by-side are all so important to people with dementia. Touch is healing and we all need it to thrive."

ANOTHER WAY OF GETTING CLOSE IS TO SHARE A BOOK OR PICTURES.

"Caregivers and people with dementia alike lean into faith, heritage, and cultural traditions to sustain them. Books that include representation matter to everyone, especially to people who long to again feel relevant, revered and included."

Bring books with consistent layouts, such as oversized pictures on the left and large (at least 16-point) type on the right. The pictures should have depth of field rather than just a flat image. Books with short passages of wit or wisdom are good conversation starters. A picture book of little girls playing with their dolls or of holiday scenes could prompt childhood memories.

"Nostalgic texts take the pressure off all parties and provide a ramp into a shared discussion. Unlike personal photo albums, they do not place any expectations on a person living with dementia to remember a loved one or family member when they cannot."

PICTURES OF ART AND NATURE ALSO PROMPT CONVERSATION.

"Bring a beautiful natural vista and masterpieces of fine art to someone who may not be out in a forest or able to walk the halls of a museum again."

And embrace their time slips.

"When we go with them where they are in their mind's eye, we can get to know them in a way we never have before. I knew my mother-in-law for 30 years on a very superficial level, and only got to know her deeply, and to deeply love her, through the prism of dementia. There's lots of joy to be found and memories to be made." ■

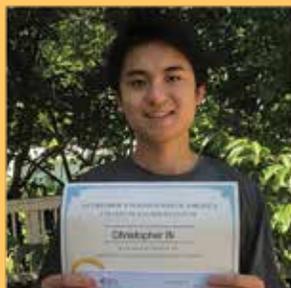


"A touch, a hug, a squeeze of the hand, sitting side-by-side are all so important to people with dementia. Touch is healing and we all need it to thrive,"
says Laurette Klier.

Adapted from the AFA Care Connection webinar, "Enhanced Engagement of Every In-Person and Virtual Visit." In addition to being a certified dementia practitioner, **Laurette Klier** is a certified senior advisor and certified in cognitive stimulation therapy. She holds a master's and undergraduate degree from Boston College in communications.

Do you know a high school senior who has been impacted by Alzheimer's?

NOW Accepting Entries!



AFA's Teen Alzheimer's Awareness Scholarship 2023



AFA's Teen Alzheimer's Awareness Scholarship provides educational funding to college-bound high school seniors who have been impacted by Alzheimer's disease.

Applicants are asked to write an essay (1,500 word maximum) or submit a video no more than 4 minutes long, describing the impact of Alzheimer's disease or another dementia-related illness on themselves, their families or their communities, and what they have learned from it.

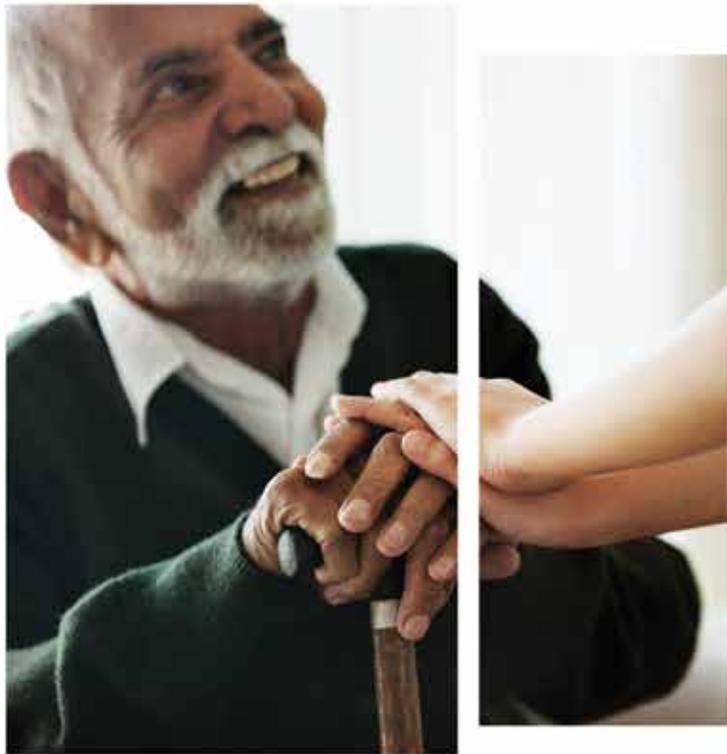
The grand prize winner receives \$5,000, with additional prizes awarded for runners-up. More than \$350,000 in college scholarships have been awarded since the program's inception.

Deadline for submission: March 1, 2023

Learn more at alzfdn.org/scholarship.



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We are approaching the treatment of Alzheimer's
and other neurodegenerative diseases
in an entirely new way.

By restoring the function of the brain's innate immune system, we are developing new therapies intended to maintain neurological function with the hope of one day halting, or possibly even reversing, the course of disease.

Alector is proud to partner with the
Alzheimer's Foundation of America.



Is It Hoarding?

Loretta took pride in her home. She collected antiques and had a flair for decorating. A friend joked that her apartment always looked “open for inspection.” Even after Loretta began developing dementia, her home continued to look neat to her daughter, Heather, when she visited from out of town.

But after Loretta moved to a nursing home and her daughter was clearing out her apartment, Heather was shocked when she opened the door of the den closet. The floor and shelves were filled with large brown grocery bags with what looked like a huge collection of the trinkets her mother received for her charitable donations.

Heather reached for one to begin taking them downstairs to recycle when she noticed some pretty greeting cards. Heather loved sending snail mail cards, so she sat down to sort through them. She found that among the cards her mother had stashed were bank statements, tax forms and other highly sensitive personal information, in every bag. She later found more of these bags under beds and in kitchen cabinets.

Luckily, Loretta’s hoarding was not dangerous, but that may not be the case for others with memory loss. Hoarding is most apt to begin in the early stages of Alzheimer’s and related diseases.

A symptom of anxiety, hoarding involves accumulating items most people consider worthless. When they pile up around the home, they present multiple tripping hazards. Stocking up on food, another common practice, can lead to infestation of pests and food that’s unsafe to eat.

“As people lose the ability to recognize family and friends and can’t remember where they placed things, hoarding gives them a sense of control,” explains Jennifer Reeder, LCSW, SIFI, director of educational and social services at AFA.

HERE ARE TIPS FOR HANDLING THIS POTENTIALLY DANGEROUS HABIT:



- Be sensitive. If possible, try to involve the person in the removal of items and don’t rush them—reduce a little at a time. Suggest they donate to family or a charity. Take photos of items that your person can keep.
- Remove items near radiators, stoves or electrical appliances; sharp objects like knives, forks or glass; and spoiling food or garbage.
- Try to stay on top of hoarding by removing excess items immediately.
- Check wastebaskets before emptying. There is always a chance something is hidden there.
- Consider securing unused closets and cabinets to reduce potential areas to store and frequently check under beds, couches and empty spaces.
- If your person becomes upset *and* the hoarding is not a safety issue, you can always accept it for the time being. Sometimes, as they say, we want to “pick our battles.” ■



~1 in 9

Americans age 65 and older are affected by Alzheimer's Disease

In 2022, the total national cost for caring for people with Alzheimer's or other dementias was estimated at **\$321 billion.**

59% of family caregivers of people with Alzheimer's or other dementias rated the emotional stress of caregiving as high or very high.

Alzheimer's disease remains the **fifth-leading cause of death** among individuals age 65 and older.

Currently, clinical trials are researching new therapies for those battling Alzheimer's. By enrolling you have the opportunity to play a more active role in your own healthcare while also helping others get a chance for new therapeutics.

How Can I Participate?

To find a clinical trial right for you, visit **ClinicalTrials.gov** and/or talk to your health care provider.



You can learn more about clinical trials and current trials being conducted by Otsuka by visiting <https://otsuka-us.com/clinical-trials> or scanning the QR code.

For Immediate Support

Alzheimer's Foundation of America Helpline: **866-232-8484**
(9 a.m. - 9 p.m. ET, 7 Days a Week)

Otsuka is a healthcare company with an unwavering belief of doing more. We are not bound by what others have done before and strive to defy limitation, so that others can too. We do everything in our power to reach our mission in three different categories: Neurosciences, Nephrology, and Digital Innovation.



EXPLORING Women's Alzheimer's Risk

About two-thirds of the more than six million Americans living with Alzheimer's are women, who are two times more likely to develop the disease than men, according to information from the Centers for Disease Control and Prevention. Why Alzheimer's affects women disproportionately is unknown, but clues exist that can help women safeguard their risks.

"Women definitely have a higher risk of developing Alzheimer's," said Allison Reiss, M.D., an associate professor of medicine at New York University Long Island School of Medicine. "They have more severe clinical symptoms, and they may progress more quickly."

CONTRIBUTING FACTORS

One factor that increases women's susceptibility is hormonal, having to do with menopause. Women who experience early menopause are more likely to develop Alzheimer's as well, Reiss said.

Another factor is the way women metabolize cholesterol.

"There are some clues of where we need to go to figure this out because we really do need to explore it and find out why there's such a difference."

Social determinants such as income levels play a part, and women are more likely to be on the lower economic level than men.

"In general, with lower socio-economic status comes less access to many things that are good for one's health and Alzheimer's, like a constellation of diseases, is exacerbated and made worse when you don't have good health care," Reiss said. This is more apt to affect women both here and around the world.

WOMEN CAREGIVERS AT RISK, TOO

While women are disproportionately impacted by Alzheimer's in comparison to men, they are disproportionately affected in another way. Two-thirds of family caregivers are women who often suffer from burnout and its related medical problems.

"The way that it's approached is that women tend to give the personal physical care and men are more likely to make arrangements. They will ask for help and bring in other people to do it," Reiss says.

Reiss said that assuming the day-to-day responsibilities can dramatically impact the caregiver, leading to stress, depression, anxiety, and the tendency to neglect one's own health.

"People tend to gain weight and to stop exercising and it may be relentless. They put off their own doctor visits. They need to have backup."

Continued on following page



PREVENTION TIPS

Caregivers need to safeguard their own health as well as that of the person they are caring for because a poor diet is another factor that can lead to Alzheimer's disease.

"When people don't have a lot of money to spend for food, they tend to eat a poorer diet and that also impacts one's risk for Alzheimer's," she said, adding that failing to exercise is another element that can contribute to the disease.

Stress, which is high in lower socio-economic groups and women, also can strongly affect cognitive health.

"If I could put into a pill what it will do for your health to eat right, to exercise, to not smoke, to be moderate about alcohol, that's a multi-billion-dollar pill; yet it's so hard for all of us to do those things. I guess they're counter to some of the things that give us pleasure."

Finally, Reiss said monitoring blood pressure is crucial.

"I always say, 'heart health and brain health really go together.' You want to have good blood flow to the brain." We can't prevent Alzheimer's but maybe we can stave off the debilitating effects, she said.

We can do this by making small changes in our lives, starting with greatly reducing consumption of sugar, which damages the brain.

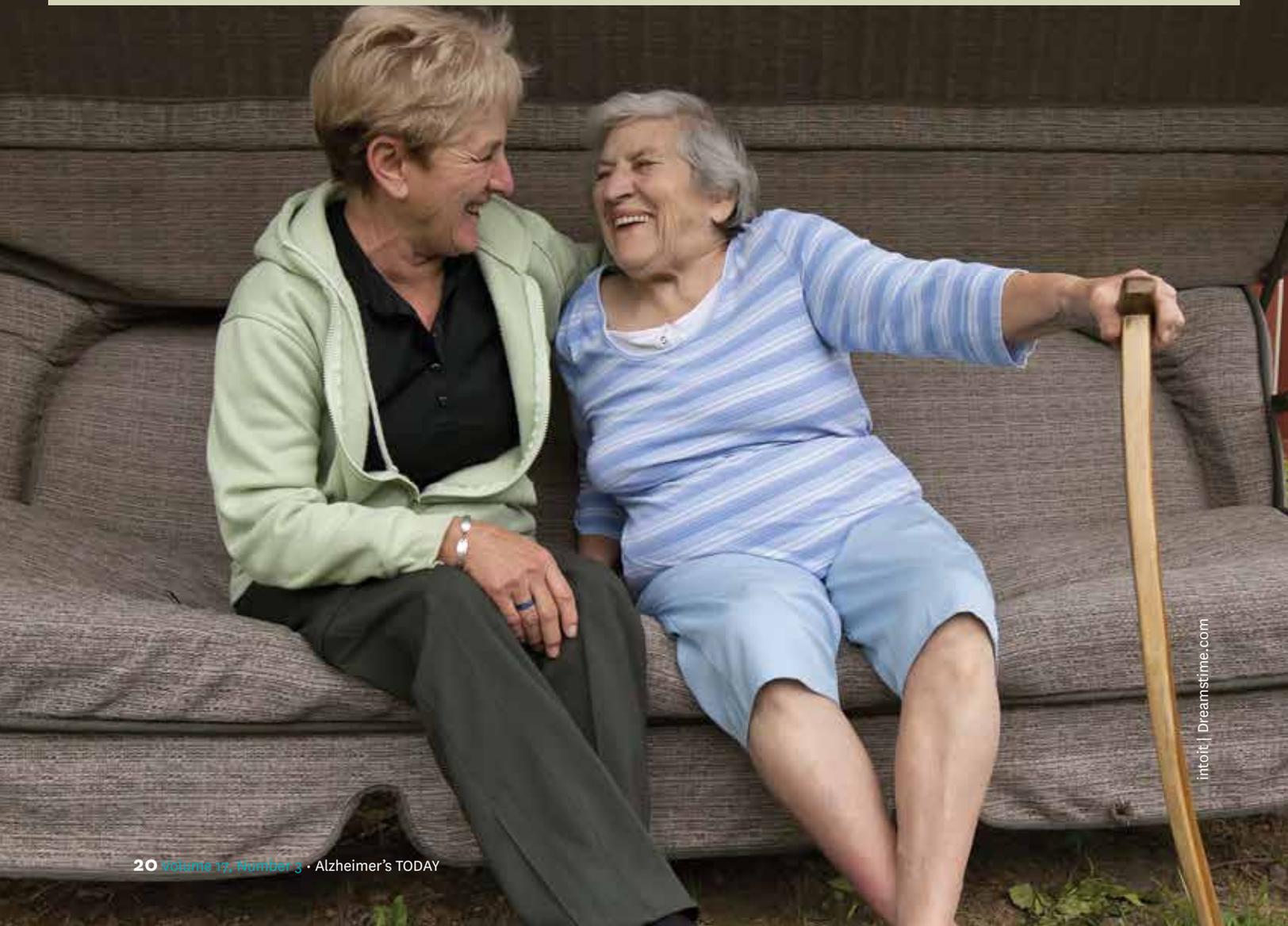
"Try to think of where you could cut sugar," she said, advising people to read labels because sugar "is hidden" in many foods, such as ketchup and tomato sauce. "See if you can make substitutions."

Include exercise in your lifestyle change as well. People who are working can squeeze in exercise by using the stairs or taking a walk with a friend during lunch break, she said.

It's especially important for caregivers to look out for themselves in this way, Reiss says.

"What a caregiver goes through is a lot of grief. They go through a lot of pain; but if you speak to them, they'll also say what a beautiful and loving and special experience it is to care for someone you love. There's so much that is hard about it, but it also comes with some beauty of the capacity for love that we have." ■

Allison Reiss, MD, is a member of AFA's Medical, Scientific, and Memory Screening Advisory Board. Her comments are adapted from the AFA Fireside Chat series, Episode 7. View Fireside Chat episodes at www.alzfdn.org/firesidechat.



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Amy Lutz | Dreamstime

How Chronic Illness Affects Partners

Research suggests that middle-aged and older couples influence each other’s mental and physical health and, over time, that chronic illness has a long-term impact on both the individuals and their spouses or cohabiting partners.

Studying mutual health-related influences is important because more than two-thirds of adults in middle or later life are married. Courtney A. Polenick, Ph.D., an assistant professor of psychiatry at the University of Michigan Medical School, found that when husbands have higher pain intensity, their wives report increased depressive symptoms, and that, in turn, affects their husbands. “We’ve also found when wives have higher depressive symptoms their husbands develop a higher number of chronic conditions over time.” This could be because husbands often rely on their wives to manage their health problems. If their wives experience poor mental health, they are less likely to provide that support.

Dr. Polenick is among the researchers who have studied how conditions such as depression and high blood pressure in one partner can influence the other partner, including people living with dementia. She says research has traditionally focused on one partner in the couple, either the person living with dementia or the caregiver. Her research focuses on mutual health-related influences among middle-aged and older couples who are married or cohabiting, considering how the mental and physical health of each affects the other. Looking at the factors together could enhance clinical care and interventions to support people living with dementia and other chronic conditions.

Recent findings suggest that couples who recognize this mutual influence and work to help each other manage their conditions often feel that their relationship has become closer. Many couples say that talking and expressing their feelings is key, along with staying positive and keeping things in perspective.

Recent findings suggest couples who recognize this mutual influence and work to help each other manage their conditions often feel their relationship has become closer.

“Although chronic illness can be stressful for both partners, these findings suggest that couples who support one another in managing their conditions may also experience benefits and growth in their relationships,” Dr. Polenick said.

Jennifer Reeder, LCSW, SIFI, director of educational and social services, said in situations like this, where the relationship is personal, the spouse providing care can consider themselves a “care partner” in the beginning stages

of the disease, because at this point it is helpful to partner with their loved one when planning for the future, as opposed to making decisions for them. Maintaining independence and an active lifestyle is important, especially when someone is experiencing cognitive decline.

“The task of the caregiver is going to change as the disease progresses,” she said. “Thinking of their relationship as a partnership allows the couple to make plans together. In this way the person with the illness can express what they want for their finances, their medical care and legal decisions. What do they want their future to look like?” ■

FIND JOY.

No Regrets

Lisa Marshall's husband, Peter, was diagnosed with young onset Alzheimer's at 53 in April 2018. He died in December 2021 at the age of 56. For most of that time Lisa was his sole caregiver. She has written extensively about her experience on Facebook, Instagram and in a new book, *Oh, Hello Alzheimer's!*

Your Facebook posts about your caregiving journey have attracted close to 30,000 followers. Why do you think you've gotten such a response?

Because the story I'm telling is very real and raw and I didn't sugarcoat anything on the way. There's little information about young onset, under 65. Peter was just 56 when he died.

Tell me about the signs of the disease you said you only recognized in hindsight.

In the beginning I didn't want to face what was happening. I chalked it up to natural aging. He would forget his phone when he went to work or his wallet. Just general forgetfulness.

The second thing that happened was his word bank started to become depleted. He couldn't remember the word so he would describe it, "You know the thing we get on to see the kids and we take our luggage." He meant the plane. That was the straw that broke the camel's back about what was going on. I took him to a doctor.

After he was diagnosed, you were Peter's only caregiver, eventually retiring from your career as an advertising saleswoman when he could no longer be left alone. When your burnout became overwhelming, you gave yourself a two-week respite by placing Peter in a long-term care facility.

My Plan A was to care for him at home. My Plan B was to care for him at home and My Plan C was to keep him at home. Plan D, if I couldn't do it alone anymore, was to hire help, which I did about three months before Peter died.

I toured eight different memory care facilities. I wanted to be prepared should I need it.



Looking back, would you do anything different in your years of caregiving?

I wish I had gotten a diagnosis sooner and wish I would have called hospice sooner to take advantage of their services. Once I had, it was a huge relief. At least begin the conversation. If you don't qualify, you will have a baseline to compare later.

What were some of your coping mechanisms?

Self-care is paramount. The problem with self-care is feeling guilty for taking time away from home. I'd feel uncomfortable for getting my toenails done. You really have to concentrate on being diligent about asking people for help.

I developed my Four A's:

ACCEPT help from people who are offering.

ASK for help.

ARTICULATE exactly what you need—time to take a shower, to take a walk for 20 minutes or if you're too exhausted to cook ask someone to bring you some of their dinner, if they make extra.

ACTUALLY: Saying "actually" gave me a second to pause. It gave me a chance to come up with something I needed. Saying the word forced me to ask for help.

How did you change? Were you always patient? If not, how did you develop patience?

I wasn't always so patient. I'm a much different person from before my journey. I focus on finding joy and vibrating positive energy to other people. I don't stress things that don't matter. I go through life enjoying things and not in a manic pace. That doesn't have to be.

Tell me about your inspirational tattoo, "Find Joy. No Regrets."

It was close to the end, a few months before Peter died. That had been my motto all along. I wanted to find joy, not just focus on this horrible thing that happened to us. Not that I wasn't depressed at times because I was, but I enjoyed holding hands with Peter, taking walks, finding joy where we can.

For "no regrets," if I was feeling impatient and may have been ready to snap at Peter, then I was doing things too fast; I had too much on my plate. Then I got rid of those things in my life that were making me too busy. I wanted to be the gentlest with Peter. He wasn't trying to give me a me a hard time; he was having a hard time.

It was touching that Peter asked you to marry him, not knowing you were already his wife. How did your feelings in your vow renewal compare to your first wedding?

Totally different. I expected it the first time around because it was a natural progression of our relationship. I was so flattered he fell in love with me again. It was also heartbreaking because he didn't remember our first wedding and our memories. It was terribly mixed emotionally, both good and bad.

What three pieces of advice do you hope readers will take away from your book?

I'm hoping people will get rid of guilty feelings and care for themselves. You can't care for your loved one if you are empty.

Second, make your mantra to have no regret. When you're not patient, get help as soon as you can afford it or ask family and friends so you can get a break.

Third, when you're dealing with medical experts you've got to be your own advocate. If something doesn't sit right with you in the doctor's office, be a fierce warrior. You have to advocate for your loved one's care. ■

Photos courtesy of Lisa Marshall

Can neuroscience
preserve a ~~mind~~?

sense of humor?



Ask bigger questions.

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Buildings Worldwide Light the World in Teal for Alzheimer's Awareness

Iconic structures across the country and around the world joined the fight against Alzheimer's by "lighting up" as part of AFA's Light the World in Teal annual public awareness campaign. This initiative, which takes place every November as part of Alzheimer's Awareness Month, inspires buildings here in the United States, and internationally as far away as Australia and New Zealand, to light up in teal on a single day to raise Alzheimer's awareness and show support for the millions of people affected by Alzheimer's disease. Skyscrapers, stadiums, tourist attractions, bridges, care settings, government buildings, and other sites all take part in this awe-inspiring campaign. Eight hundred fifty structures in all 50 states and 13 other countries, including New York City's Empire State Building and One World Trade Center, Chicago's Willis Tower, and Los Angeles' LAX Airport, participated by "lighting up" on November 3, 2022. A full list of participating sites can be found at www.lighttheworldinteal.com. ■



ADDRESSING DEPRESSION AND SLEEP PROBLEMS

Across neurological diseases depression has the greatest impact on quality of life in patients, said Jeffrey Cummings, MD, ScD, AFA Medical, Scientific, and Memory Screening Advisory Board member. “When your loved one is depressed, you feel sad, you feel guilty, you feel like you’re doing something wrong and that’s why they’re sad. Linking those changes to Alzheimer’s disease is often not the first intuitive step that a caregiver takes.”

However, an estimated 40 percent of people with Alzheimer’s and other dementias experience some level of depression. In fact, depression and sleep problems are two major behavioral and psychological symptoms of dementia.

Depression causes, symptoms

Cummings says the causes of depression in those living with dementia are unknown but are likely multifactorial. “We know many of the chemical transmitter systems that are implicated in depression are also implicated in Alzheimer’s disease, so there’s very likely a biological contribution—at the same time the patients are losing their memory, losing their function. They are variably aware of that and certainly those who are aware are likely to have reactive depression as part of their illness.

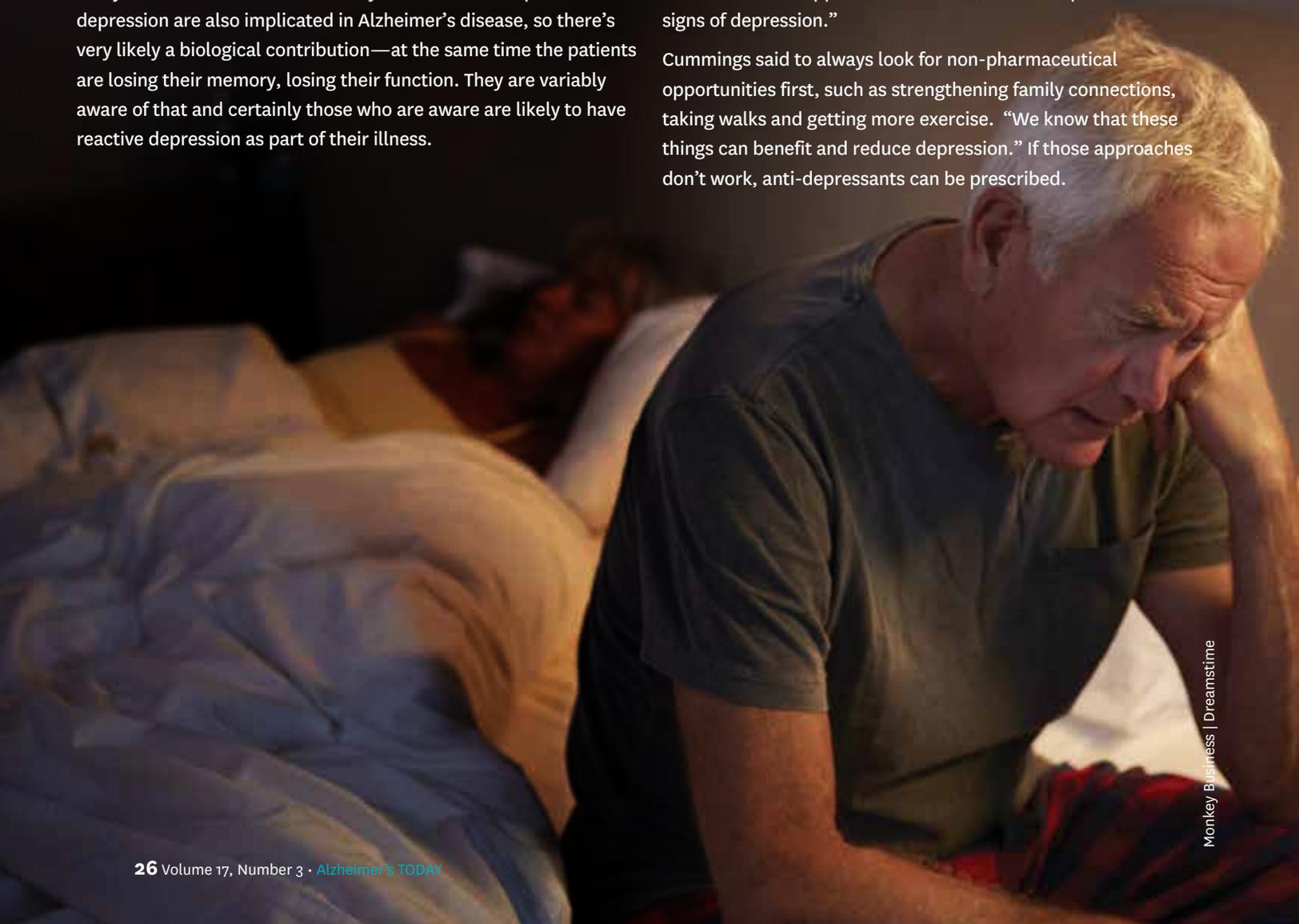
“I’d also like to make the point that the depression may not be crying. It might be sleep disturbances, appetite disturbances or irritability as a much more subtle presentation. A good doctor is going to ask these questions to try to understand more about the mood state because it may not be as obvious as we currently think of depression.”

Signs of depression

Listen to what they are saying. “There’s often content if someone is aware of their depression,” Cummings says. They might say they wish they weren’t such a burden or that they want their end to come. “Those are the kind of things that just speak to that depressive content that the patient is experiencing.” Consider also if the person looks sad.

“The secondary signs of depression, which are sleep disturbance and appetite disturbance, can be important signs of depression.”

Cummings said to always look for non-pharmaceutical opportunities first, such as strengthening family connections, taking walks and getting more exercise. “We know that these things can benefit and reduce depression.” If those approaches don’t work, anti-depressants can be prescribed.



Sleep disturbances

A common manifestation of sleep disorder is what is known as **sundowning**, which occurs as evening approaches. The person is more likely at that time to have a period of agitation that might last for several hours. It's recurrent and can be extremely distressing. "Once it starts it's likely to be present for several months or even a year or two, so we often have to resort to drugs that would help control those agitated periods, particularly if there's any danger of harm for either the caregiver or the patient.

"The important thing about sundowning is that it speaks to the disruption of the circadian, or daily, rhythm. Our daily rhythm of sleep and wake cycles are governed by our brain, and as the brain is affected by Alzheimer's disease there is a breakdown of that rhythm."

Reducing noise, directing the person's attention to a pleasurable activity and closing curtains to minimize shadows can help reduce sundowning agitation.

Improving sleep

As for helping your person achieve improved sleep, Cummings recommends:

- Keeping them physically active during the day.
- Maintaining a steady daily rhythm in terms of times to get up, eating each meal and going to bed.
- Limiting their liquids before bedtime.
- Avoiding caffeine at night.
- Relieving their chronic pain with medication before they lie down.
- Not allowing them to use electronic devices before bedtime.

"It's well worth the payoff given the high cost of sleep disturbances to both the patient and the caregiver.

"When the patient is awake the caregiver is bound to be awake. So as the sleep disturbances get more and more common as the disease goes on, you're also eroding the sleep of the caregiver and making their daytime life much worse." ■

AFA Medical, Scientific, and Memory Screening Advisory Board member Jeffrey Cummings, MD, ScD, is the director of the Chambers-Grundy Center for Transformative Neuroscience at the University of Nevada, Las Vegas. This article is adapted from the AFA Fireside Chat series, Episode 3. View AFA Fireside Chat episodes at www.alzfdn.org/firesidechat.



Anna Griessell | Dreamstime

THE ART OF PERSUASION

BY PAM OSTROWSKI

If you're a family member interacting with your loved one with Alzheimer's, it's pretty safe to say you've gotten frustrated with how to get them to do tasks that seem pretty straightforward to you. Here are some examples that will show how to implement broader techniques that will help avoid frustration on both your parts.

Note that most of the struggle comes from using wording that the person with Alzheimer's doesn't recognize. So, get creative. Keep your sentences short and simple. When in doubt, act it out.

DRIVING

It is common for those with early-stage Alzheimer's to not recognize they have the disease, creating the potential for some difficult conversations. The medical term for this is anosognosia. With anosognosia, there is a limited ability to have insight into one's abilities, which can impact memory, general thinking skills, emotions and physical abilities.

If you believe your loved one with Alzheimer's should not be driving, then it's important for you to have the conversation from their perspective, both in your mindset and your words.

• Mindset

Many caregivers tell their loved one, "We have to take away the keys." This wording communicates a mindset of authority, superiority, control and a judgment that the loved is incompetent. Instead, adjust your mindset to "aging seniors can be victims of many threats while driving." Note that this is not saying, "Mom/Dad/Spouse, you're a danger to others while driving." Would you want someone to say that to you?

• Wording

Have a courteous conversation with your loved one. Point out the vulnerabilities that exist for them (e.g., flat tire, someone hits their



car, a person crossing the street between lights, etc.). Avoid talking about their driving skills and instead ask them how they would handle each of these threatening situations.

Express concern about them being harmed, not them harming others, which could cause resistance. Ask them what their biggest concern is with not having a car and then discuss options to address that concern. Ask if they'd be willing to try it for a month. Lastly, express how badly you would feel if something tragic happened to them. They'll feel loved and needed versus feeling scolded and treated like a child.



LEAVING THE HOUSE

Depending on your loved one's stage, you might meet with resistance when it comes to their leaving the house, especially for social situations. It's common for someone who is struggling cognitively to feel embarrassed about their condition and fear embarrassing family. It's safer to stay home and isolated. However, that's not good for their brain health.

• Keep it simple

It's best to keep leaving the house simple. So often, family will say, "Dad, we have to go to your doctor's appointment at 10 a.m. Get ready. We'll leave at 9:30 and stop at the bank." That's too much information, and some of it is vague. What does "get ready" mean? What time is 10 a.m.? Keep it simple. Less information can be better.

• When in doubt, act it out.

"Dad, let's put on our shoes so we can go out." Bring his shoes and set them down next to him and bring yours, too. Put on your shoes to show him what he needs to do. After everyone's shoes are on, do the next step, whatever that might be. There's no need to overshare where you're going ("out for a drive" is fine) and when. That information may cause resistance, so it's best to keep it to yourself.

EATING

As Alzheimer's progresses, activities of daily living, such as eating, can be challenging.

• Over and under can both be unhealthy

If a person with Alzheimer's is living alone, they may not eat because they think they already did. They may overeat because their satiety cues may be off, so they'll start to gain weight. Overmedicating or under-medicating may also happen, which can result in serious health issues.

• Likes and dislikes change

It's important that you not assume your loved one has the same tastes and likes they once had. They are becoming a new person with new likes and dislikes. Allow them to try things as if they are completely new.

Nutrition may also get compromised because sweet things taste so much better than veggies and protein. Plus, veggies and protein require remembering how to shop for and prepare a meal. A bag of candy bars is so much easier to buy and eat.

There is also the challenge in mid-to-late stages of your loved one not recognizing eating utensils. That's why communal eating is successful for those with Alzheimer's. They can mirror what others are doing at the table.



Sarayuth Punnasureyaporn | Dreamstime

Even recognizing toothpaste vs. another tube may become difficult. Understanding what a toothbrush does and why one should use it may be difficult. If your loved one is refusing to brush their teeth, join them. Make it an activity where you both brush your teeth, with you (or a caregiver) helping with setting up the toothbrush. ■

ABOUT THE AUTHOR

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



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



Consider participating in the study if:

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

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



To find out more about participating in the **evoke** and **evoke+** studies, please contact:

1 (844) 420-2857

<https://evokeadstudy.com/Alztoday>

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

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

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

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MAKING HOLIDAYS DEMENTIA FRIENDLY

For many, the holiday season is a joyful one spent with family and friends. Being adaptable and creating an inclusive environment are key to making the holidays dementia friendly.

Here are some things to keep in mind:

Adapt favorite traditions or create new ones.

Build on traditions where you can, such as making familiar and favorite pies. But don't hesitate to start new ones around things your person likes to do, such as touring neighborhood holiday lights. Whenever possible, involve your person by asking what traditions are important to them. This will help you prioritize and plan.

Prepare the person for guests.

Build familiarity by showing photos of expected guests or arranging a phone call or Facetime chat with visitors.

Be open with your guests.

Share information with your guests about your loved one before the visit, such as ways they can communicate better and what may upset your person. This is especially important for those your person doesn't see regularly.

Preserve normal routine.

Changes in routine can be challenging for someone living with dementia. If the person takes an afternoon walk, build in time for that. If they go to bed early, hold celebrations earlier.

Connect with loved ones through technology.

Videoconference technology can include others who can't attend in person.

Create a safe and calm space.

Avoid fragile decorations that can shatter and create sharp fragments and ones that could be mistaken for edible treats. Reduce clutter to avoid tripping hazards. Hook Christmas trees to the wall and use menorahs or kinaras with electric candles. Avoid overdecoration. Too many flickering lights or decorations can be overstimulating and disorienting for some.

Take a strengths-based and person-centered approach.

Focus on what the person can do rather than dwelling on what they used to do.

Need more support? Call the AFA Helpline at 866-232-8484, 7 days a week.

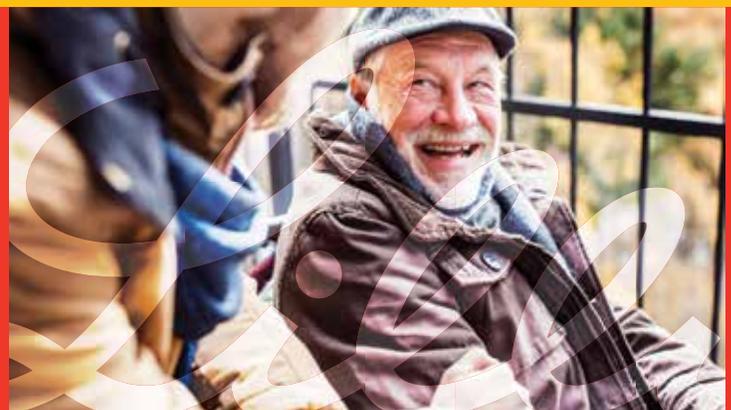
LILLY FOR BETTER

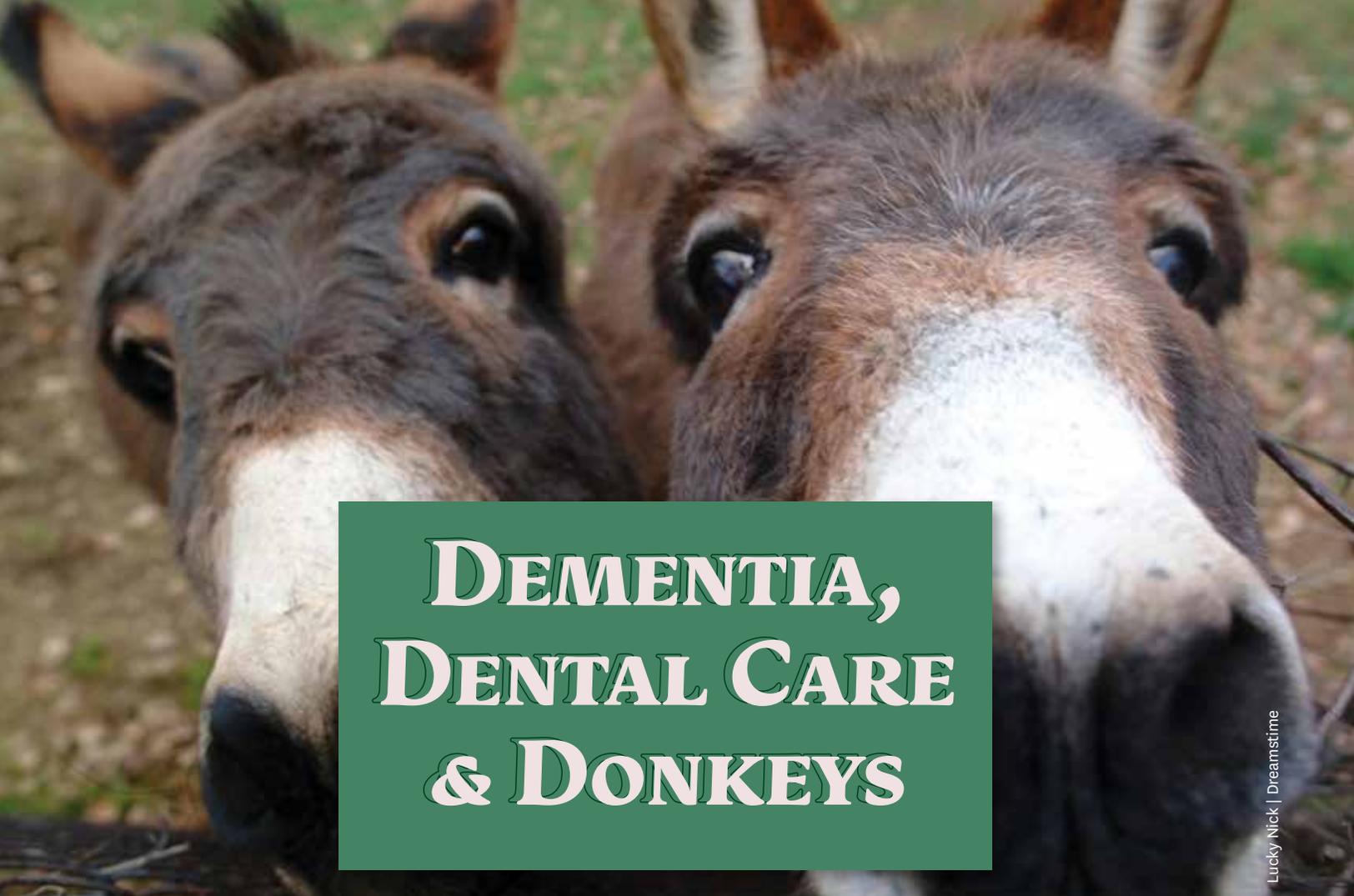
It begins with a purpose to create medicines that make life better. To find a way to come through, no matter the odds. To be stronger than we thought we could be and to share our strength with the world around us. Our purpose makes us who we are. And every day, we work to share our purpose with those we touch. And to help them fulfill theirs.



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Lucky Nick | Dreamstime

DEMENTIA, DENTAL CARE & DONKEYS

Providing good oral care for people with Alzheimer’s and other memory illnesses is challenging, but dental hygienist Anita Siddall discovered a way to relax her patients and even bring joy to an effort that is often resisted. Before she reaches for her floss and a toothbrush, she brings out a donkey. Not a stuffed one—a real, live furry one. And her memory loss clients are transformed.

“We learned it was extremely important that we enter the heart of our clients before we’re allowed to enter their personal space. When people come to my dental office, they know what they’re there for.”

But caring for patients in long-term care centers presents major obstacles, even for a dental hygienist with 37 years of experience.

“This was a different situation and we had to figure out new ways to do things. Anyone who is in need of personal care is in need of toothbrushing assistance.”

Introducing Jack

Her family had an unusual pet, a formerly abused donkey named Jack that had become a loving, gentle animal. Siddall was inspired to take Jack to the care facilities where she had clients who fought toothbrushing assistance or oral screenings. When she led them outside to meet Jack, her clients bonded so deeply some cried when it was time for him to leave.

Once Siddall was able to break through in this way, her clients were more willing to trust her through the tooth-cleaning process. With results like that she founded Toothbrushers & Balaam’s Donkey, in Cedar Rapids, Iowa, with a partner and expanded by adding additional help. She calls this her “toothbrush ministry.”

“We now have intentional emotional therapy as part of our daily provision of care. We have to remember this is personal space. Their mouth is probably tender and it’s likely infected. When you have a place that’s uncomfortable you don’t want someone in it.”

People with memory loss often have multiple contributing factors that affect the health of their mouth. Partially chewed food packs inside their cheek and can build up, leading to tissue irritation and tooth decay. They will commonly forget to brush or may not be capable of completing the task adequately, yet they resist opening their mouth for a caregiver. Siddall says that “100 percent” of people with moderate to advanced Alzheimer’s have oral disease, which can lead to larger health problems.

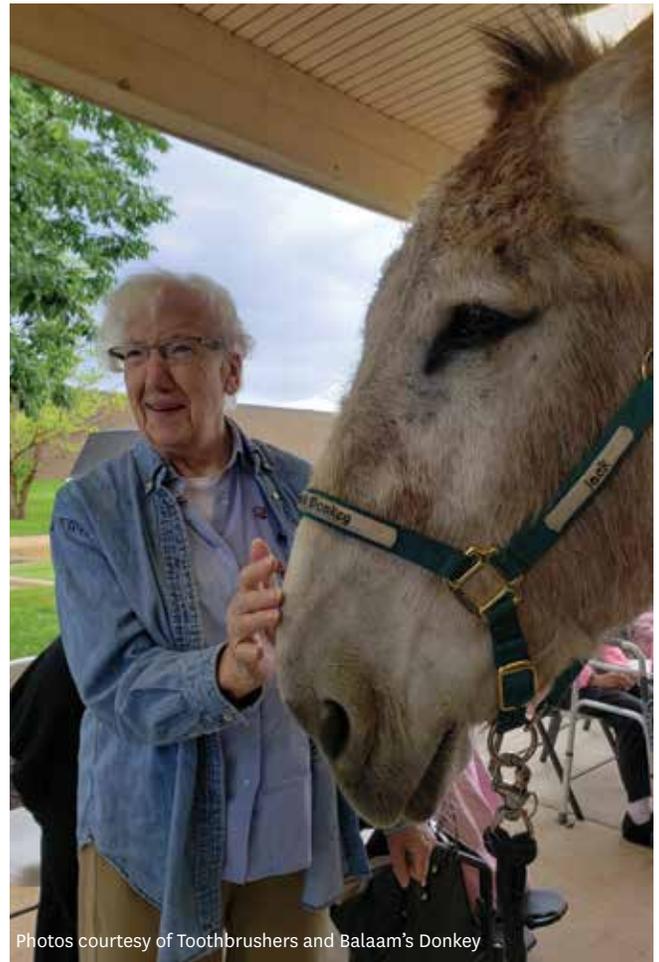
“Overall wellness can only occur when every area of the body is healthy. Our mouth is an important part, and it can only be

Continued on following page

DEMENTIA, DENTAL CARE, AND DONKEYS *cont'd from p. 31*

healthy if the ever-accumulating bacterial plaque is thoroughly removed. There are no chemicals or toothpaste that remove the plaque that grows in our mouths. This plaque must be removed by mechanical means, like toothbrushing and floss.”

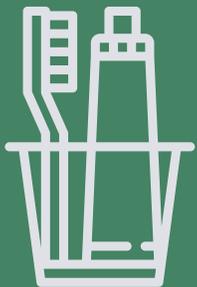
Professional and family caregivers need to remember a person’s mouth is extremely personal space. “Donkey time has to come first,” reminds Siddall. “Adopt the mind of a servant; you’ve got to change your approach from leader to follower. Take your time and be super gentle. Remember, if thorough plaque removal has not been routinely completed, these people’s teeth and gums will be very tender.”



Photos courtesy of Toothbrushers and Balaam's Donkey

How to Brush Teeth

For the actual toothbrushing, Siddall recommends setting up a tray with all the tools of daily cleaning: an antimicrobial solution with fluoride (but no alcohol), gauze or washcloth, soft pic, power toothbrush, floss, mirror, and flashlight. Then take the following steps:



- Wash your hands or wear gloves.
- Soak the gauze or washcloth in the solution, then gently wipe out all the food between the teeth and lips.
- With the soft pic, start in the upper right of the mouth and trace each tooth and rub under the gum line. Be sure to go around and in between each tooth. Keep

the pic moist by dipping it in the solution frequently. The solution helps to kill germs and adds fluoride.

- Dip the toothbrush into the solution and apply it to each tooth for three seconds, longer if teeth haven't been cleaned in a while. If it's been some length of time since the last cleaning, don't turn on the power. Just brush gently.
- If the care receiver will allow it, brush the tongue to reduce bacteria. They may be less resistant if you use the washcloth or gauze initially.
- Floss. Wrap it around your middle fingers and use your first fingers as the drivers. “Plaque is like ice. It needs to be scrapped. Rub the surface of each tooth like an ice scrapper rubs the windshield.”

- Do a final wipe with the solution to kill residual germs and apply fluoride.
- Use the flashlight and mirror to screen entire mouth including lips, palate, cheeks, gums, throat and teeth. If you have concerns, consult a dentist.

Do these steps in the same order. Care receivers are more comfortable with predictability. Don't worry if you don't finish the whole process at first. With patience and consistency, tenderness will end.

With dentures, soak them, then rub surfaces to remove slippery film until they feel squeaky-clean. Gently wipe the person's mouth before replacing the denture. If skin where the denture rests is very red, consult a dental professional before placing denture into mouth.

Through all of this, don't forget the donkey. A donkey is a humble servant.

“What our clients have taught us is to think like them and be like them. Touching people's heart has to be part of our intention. We try to take an approach that is all about them.”

For more information and to watch oral care videos, visit toothbrushersandbalaamsdonkey.org. ■

A photograph of two elderly women, likely of Asian descent, looking down at something together. The woman on the left is wearing a colorful floral patterned shirt, and the woman on the right is wearing a light-colored, possibly white, shirt with a decorative element. The background is softly blurred, suggesting an outdoor setting with natural light.

Navigating Difficult Behaviors

By Lynn Wood

Szepei | Dreamstime

When our loved ones begin their journey with dementia, they transition into visual learners. They watch us, as their caregivers, for visual cues on how to feel, react, or respond to their environment. When we talk about behaviors, we really need to start with ourselves. We reflect our state of mind, be it angry or nervous, or patient and relaxed. Our loved one is using these emotions as a guide and will respond accordingly and often mirror our demeanor. Difficult behaviors may also be a response to our lack of visual signals when our loved one is communicating a need. We can ask ourselves, “Is my loved one hungry, thirsty, in need of the bathroom, in pain?” If we meet that need, then the behavior may cease. We may also need to ask ourselves what happened before the behavior. Can we identify any triggers? Understanding triggers and needs will help better manage these difficult behaviors.

Common behaviors of a person living with Alzheimer’s or dementia are rummaging, wandering, hallucinations, shadowing, repetitive questioning, and paranoia. Not everyone living with dementia will have these exact behaviors. Some families may experience other negative behaviors or even no difficult behaviors at all. Sometimes the best way to deal with a behavior is to not deal with it. Ask yourself whether the

behavior really matters or is hurting anyone. Try to find a way to use the behavior to your advantage. Here are some ideas:

- **Rummaging** through things may be due to boredom, fear or anxiety. Use the behavior of rummaging as an activity. Create a special place where the person can rummage freely or sort things. This is a great activity for hand/eye coordination.
- **Wandering** may be the person’s attempt to “go home” or communicate they are uncomfortable; possibly the environment is too warm or cold. It is possible that there are too many stimuli and the person needs to flee. If your loved one wants to “go home,” ask them why. Do they have something to “do” there, or do they just want to “be” there? Gaining as much information as possible will help you identify the appropriate response or activity to redirect their mind.
- **Hallucinations** are sensory experiences and occur in at least half of all cases. When a person is experiencing a hallucination, do not try to explain reality. Instead, state that you understand their distress and be present through it. Keeping their environment simple and increasing lighting may help eliminate distractions.

Continued on following page

NAVIGATING DIFFICULT BEHAVIORS *cont'd from p. 33*

- **Shadowing**, or following the caregiver physically, may represent insecurity. The person living with this behavior may be saying, “If I am out of your sight, will you forget that I need you?” I like to think that a person may follow me around for a feeling of safety. Of course, having someone follow you around can be nerve-wracking. Try asking your person to hold something for you or open a jar or container. Getting their mind on a specific task may give you a moment of solitude.
- **Repetitive questioning** is due to short-term memory loss. Asking questions multiple times is common and expected. Give the person the answer that they are looking for, even if you have given it several times. Try distracting the person with a favorite activity or redirect them to another room.
- **Paranoia** is linked to memory loss and can worsen as a person’s memory dissipates. Try not to react if you are being blamed for something. Do not argue; they have lost their ability to reason. Instead, validate the feeling that something is missing and ask if you could join the search for the missing item. If possible, have extras of frequently lost items. Keep original and important pieces in a safe place. If possible, make color copies if they want to carry these on their person.

Caregiving is challenging, even under the best circumstances. Dealing with difficult behaviors can be time consuming and



frustrating. Before trying to stop a behavior always ask yourself, “Does it matter?” If the behavior is not harmful, it may be better to adapt and redirect. ■

ABOUT THE AUTHOR

Lynn Wood is a Positive Approach to Care (PAC) certified Caregiver Support Coordinator at Mental Health America of the MidSouth, in Nashville, Tennessee, and a member of the National Council of Certified Dementia Practitioners.

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Managing Incontinence

Dementia-related illnesses cause functional abilities to decline. For toileting issues, they can inhibit someone from reacting quickly enough to the urge to use the bathroom or recognizing they need to go—particularly in later states. There may be difficulties remembering the toileting process, or remembering where the bathroom is located. Difficulties with communicating needs also complicate this activity of daily living. As a result, individuals with dementia are more likely to experience incontinence—difficulty controlling one’s bladder and/or bowels. Soiled underwear and bed sheets, leaking urine and problems going to the toilet are all signs of incontinence.

Is it treatable?

Although incontinence affects people with dementia, it may not always be due to the illness itself. Incontinence can also stem from a variety of treatable conditions, including:

- Urinary tract infections
- Diet (caffeinated/carbonated drinks, chocolate, citrus fruits, and sugary/spicy/acidic foods can all stimulate the bladder)
- Medications
- Dehydration (highly concentrated urine can irritate the bladder)

Speak to your loved one’s physician when they experience incontinence, as there may be treatments that can help.

Preventing accidents.

While it’s not always preventable, caregivers can take steps to reduce the chances of an accident:

- **Be proactive.** Remind the individual to use the toilet periodically—don’t wait for them to ask. If you’re going out in public, plan time for bathroom stops. Schedule regular trips to the bathroom.
- **Help them remember.** Take the person to the bathroom or show them where it is.
- **Look for warning signs.** Watch for any pulling on clothes or other behavior that may signal a need to use the toilet.
- **Keep things loose.** Loose, comfortable clothing that’s easily removed (i.e., pants with elastic waistbands rather than buttons and zippers) makes toileting easier.
- **Improve visibility and accessibility of the bathroom.** Make sure the door is open and there is a light on. You can also label the door or provide a pictorial cue.

- **Limit fluids in the evening.** This makes overnight accidents less likely.
- **If there are accidents during the night,** try putting a portable commode near your loved one’s bed.

Incontinence supplies, such as adult diapers (or incontinence briefs that resemble underpants) or bed protectors (a waterproof mattress cover protects the mattress and large bed pads can protect the bedding), can be helpful. They are available at drug stores and medical supply stores.

When accidents occur.

Maintain dignity. Incontinence can be embarrassing or depressing for the person experiencing it, so try to be understanding and avoid looking angry or upset. Staying calm and reassuring your person will help both you and them.

Additional caregiver resources.

Dealing with a loved one’s incontinence can be upsetting. Adult children may feel uncomfortable or anxious about the role reversal of helping their parent in the bathroom. Spouses and partners may feel a shift in their relationship. Talking about these natural feelings, in a support group or with a professional or trusted confidant, can be helpful. If it proves too difficult to comfortably help your loved one, look for a trained professional to meet both your loved one’s needs and those of your family. ■

AFA’s licensed social workers can provide you with additional information. Connect with them 7 days a week through the AFA Helpline by calling 866-232-8484, webchat at alzfdn.org, or sending a text message to 646-586-5283.

Intuitive Eating for Older Adults

BY STACEY SIMON, MS, RDN, CSG, CDN, NBHWC

Nina Firsova | Dreamstime

Intuitive eating is growing in popularity as a way to fuel our bodies. You may have heard about intuitive eating, but aren't sure what it involves or how you may be able to incorporate it into your lifestyle. Here, we will discuss the basics and how intuitive eating can support our wellbeing throughout the aging process.

What is intuitive eating?

Intuitive eating is a non-diet approach to eating developed by two registered dietitians in the 1990s. It consists of 10 principles that, instead of focusing on external markers of success like weight and clothing size, focus on internal markers such as honoring hunger and fullness levels, listening to our bodies, and feeling satisfied with the foods we consume. Rather than following a strict diet, intuitive eating allows for flexibility and gets rid of “black and white” thinking around foods. It allows all foods a place without judgment or guilt.

Becoming an intuitive eater.

Rather than following a restrictive diet, intuitive eating teaches us to listen to what our bodies need to get the right amount of nutrition. Identifying hunger and fullness signals, eating when hungry and stopping when comfortably satisfied, helps us to consume the right amount of nutrition. Checking in with satisfaction levels throughout the course of the eating process, granting ourselves full permission to eat at “odd” times, allowing all foods to be enjoyed without guilt, and stopping eating when comfortably satisfied can help us to eat the ideal amount for our bodies.

Intuitive eating also prioritizes satisfaction and enjoyment when eating and drinking. We oftentimes think of eating “healthy” foods as a chore and eating fun foods as a treat. Intuitive eating reframes this thought process; we can find joy in eating foods that make our bodies feel good, and we can enjoy every bite. Intuitive eating also allows us to enjoy fun foods without guilt; all foods truly have a place in a balanced diet.

Is intuitive eating healthy?

A common misconception about intuitive eating is that it leads to overconsumption of fun foods like cookies, cakes, and pizza. To the contrary, intuitive eaters are actually found to enjoy more balanced meals and snacks. When all foods are morally equal, our bodies often crave more fruits, vegetables, lean proteins, and healthy fats. Intuitive eaters also feel less compelled to overeat fun foods because they're always “allowed” on the menu, which can take away those feelings of lack of control around sweets.

Over 125 studies (and counting) have demonstrated the health benefits of intuitive eating. Intuitive eaters have lower triglyceride levels, blood sugar levels, body mass index (BMI), and more.

Intuitive eating throughout the aging process.

Intuitive eating is a practice that can be adopted at any age. Learning to incorporate foods and beverages that make our bodies feel good is a key piece of aging. Most older adults require more protein, calcium, and vitamin D than their younger counterparts; and most older adults don't consume enough fiber or drink enough water. Finding ways to make nutrition joyful and satisfying can help to get the right kinds of foods and beverages to support nutrition needs.

As we age, our taste preferences often change. Many older adults find that they have a stronger preference for sweet

foods. Finding ways to incorporate pleasurable flavors, textures, and temperatures can help older adults get the nutrition their bodies need without sacrificing enjoyment.

How to get started.

Despite the name, intuitive eating can feel anything but intuitive at the beginning of your journey. Learning to feel hunger and fullness levels, respecting our bodies, and allowing all foods without guilt can feel like hard work. Working with a certified intuitive eating counselor can help you learn to trust your body and give it the nutrition it needs to thrive. ■

10 Principles of Intuitive Eating

1. Reject the diet mentality
2. Honor your hunger
3. Make peace with food
4. Challenge the food police
5. Discover the satisfaction factor
6. Feel your fullness
7. Cope with your emotions with kindness
8. Respect your body
9. Move. Feel the difference
10. Honor your health with gentle nutrition

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HEALTHY LIVING

Somewhere That's Green

Jennifer Walsh brings a missionary zeal to her work of educating people about the simplest and least expensive way to improve their brain power and mental health. She points them out the door and tells them to head for someplace green.

“I’m a simple girl from the Bronx who fell in love with nature,” she told a gathering at AFA’s September Educating America Tour in Manhattan. “It’s innately in us to reconnect with nature.”

Walsh is a self-described serial entrepreneur and wellness expert focused on bridging the gap between brain health and nature. She is an advisor for the Brain Health Initiative, which is a living lab under Mass General and Harvard, and is an advisor for the Center for Neuroaesthetics at UPenn School of Medicine.

Among the study results she shared was one that found patients who had the same surgery recovered differently depending on their room post-op. Those who had a window needed less medication and were released earlier than those who saw only bare walls. An experiment in a Maryland school found children had higher test scores and fewer absences in a classroom that played bird songs.

“We need to go back to where we came from. The research keeps coming.”

Her book *Walk Your Way Calm*, which was published in February, features 101 different ways to walk. They include scent walks to notice all the different smells, leaf peeking and wheelchair walks, which benefit the person in the wheelchair as well as the caregiver.

“I didn’t plan on doing this. It just kind of evolved. I love research so I made sure I had the science behind what I talk about. It’s one thing to say it’s pretty and another to partner with scientists,” she said.

Studies before the pandemic found that most people spend 93 percent of their days indoors, a percentage that is higher now. While others are unable physically to get out, they can benefit from YouTube videos of nature.

Walsh practices what she preaches, taking a walk in New York’s Central Park every day. On the first day of autumn, she invited a writer for *Alzheimer’s TODAY* to join her.

“Green is fascinating,” she said, surrounded by it. “It’s the one color that has the most shades. It relaxes us.” People with memory loss can benefit just by touching a leaf or tree. “It sparks memories of childhood.”

Photo courtesy of Jennifer Walsh.



Pmartike | Dreamstime

Trees release aerosols known as phytoncides. Inhaling that air activates our natural killer cells (NKC) to ward off sickness and help build our immune systems. The practice of “forest bathing,” taking time in a park or forest, is beneficial during times of stress and depression. “Being in that tapestry of nature puts us in a place of awareness and gives us a sense of gratitude.”

Neighborhoods with lots of trees have less crime.

“The more nature we have, the more empathetic we become.”

As Walsh walks down a path on the east side of the park, she spots something on the ground that delights her.

“It’s a pinecone,” she says, stooping to pick it up. “Don’t forget to touch things.”

During the summer months Walsh gets her fill of a different kind of nature. She spends the weekends with her parents living in a 20’ by 20’ tent in Ocean Grove, NJ. A connected cabin houses a kitchen, bathroom and sitting area.

“After I walk in the morning I swim with the sunrise.”

Continuing her Central Park walk, Walsh comes to a tiny stream. In addition to its comforting sound, running water, whether from a stream, ocean or fountain, also gives off negative ions that help us relax and ease depression and anxiety.

Besides giving talks and writing about nature and the brain, Walsh is an adviser on biophilic design, which brings natural elements like plants, waterfalls and green walls indoors, “offering us a little bit more well-being.”

Walsh says lawmakers in Congress have recognized the importance of nature to our mental and physical health and are hoping to have access to nature designated as a human right.

“That’s why education is so important.” ■



20 Years of Making a Difference Therapeutic & Activity Programming

The songs of Stephen Sondheim were well represented on a recent afternoon at AFA as three performers from Sing For Your Seniors belted out Broadway hits and took requests. Other offerings such as dance/movement therapy, art classes, therapy dog visits and horticulture therapy fill the Education & Resource Center (ERC) every week at AFA's Manhattan headquarters. AFA launched these free programs for individuals living with cognitive impairment and their care partners in 2017 and expanded to a new, larger space in 2019, as demand for these services grew.

In 2019, Jackie Gatto, MS, R-DMT, LCAT-LP, CDP, was given the opportunity to oversee and facilitate in-person therapeutic program offerings as AFA's manager of therapeutic programming. In this role, Gatto brought the Louis J. and June E. Kay Foundation's grant-funded artist-in-residency program into fruition, developed AFA's first dance/movement therapy program, and created socials like the "Sock Hop," "Beach Blast" and "Snowflake Soiree."

"The ERC brings community members into our space and gives them the opportunity to socialize," Gatto says. "All of our facilitators and performers have a background in dementia care, so we can cater to everyone's needs."

AFA continued catering to those needs during the pandemic. Of the many challenges COVID-19 created for families affected by Alzheimer's, isolation was one of the greatest concerns. On March 16, 2020, AFA began livestreaming daily virtual therapeutic programs on Facebook. These programs were also extensively shared with care settings and healthcare professionals, nationally and internationally, serving individuals living in severe isolation. In a further effort to deliver cognitively stimulating programs, AFA provided weekly activity tips encouraging the community to stay active and engaged in the safety of their home. Together, these programs reached more than 725,000 people in 2020.

With the success of AFA's 2020 virtual presence, the AFA Teal Room was developed in 2021 and is currently available on the AFA website. ■

The AFA Teal Room (alzfdn.org/afatealroom) offers daily, virtual therapeutic programming as well as a "library" of more than 350 free dementia-friendly programs and activities organized by topic: creative arts therapies, music performances, fitness/movement-based sessions, and nature-based programs.



Advancing New Discoveries: Uncovering APP's Role in Alzheimer's

Researchers at The City College of New York (CCNY) are undertaking a new project aimed at learning more about the role that disrupting amyloid precursor protein (APP) plays in causing Alzheimer's disease. The research, supported by a \$250,000 AFA grant awarded in July, could potentially lead to the development of new medications to treat Alzheimer's disease.

The APP gene family is essential for viability in mammals, but its function is unclear. Mutations in the genes for APP and in the enzymes that interact with APP have been found in familial Alzheimer's disease (a form of Alzheimer's that is linked to genes and affects at least two generations of a family), suggesting that disruption of APP can lead to Alzheimer's disease.

"An estimated 6 million Americans are living with Alzheimer's disease and that number is estimated to almost double within the next few decades. This grant from the Alzheimer's Foundation of America will support the important research being led by Professor Christine Li and her research team," said Vice President for Institutional Advancement and Communications Dee Dee Mozeleski, who is also the executive director of The Foundation for City College, Inc.

The project aims to identify the role that APP plays in brain health and Alzheimer's disease using the *C. elegans* model system. This research can then be translated into discoveries in mammals that could potentially lead to the development of new medications to treat Alzheimer's that do not interfere with APP function.

"We are immensely grateful to the Alzheimer's Foundation of America and its donors for their support of our research. Alzheimer's disease is a

devastating disease not only to the individual, but to the family. All different avenues of research must be pursued to identify possible therapies to alleviate symptoms and, ultimately, to find a cure," said Christine Li, PhD, principal investigator and professor CCNY, Department of Biology. ■

AFA is able to award research grants such as this through the generosity of individuals and organizations. To make a donation to support AFA's research efforts, as well as programs and services for families affected by Alzheimer's disease, visit www.alzfdn.org/donate or use the enclosed envelope.



Left to right: AFA President & CEO Charles Fuschillo, Jr.; AFA Founder & Chairman Bert Brodsky; Dr. Christine Li, principal investigator and professor, CCNY Department of Biology; CCNY President Dr. Vincent Boudreau

Did You Know?

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

OVER HALF of all dementia family caregivers provide care for four years or more.

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

Source: Centers for Disease Control and Prevention



Make a donation. Make a difference.

As we near the end of our 20th anniversary year, you can help families get the support they need and fund research for better treatment and a cure.

alzfdn.org/donate