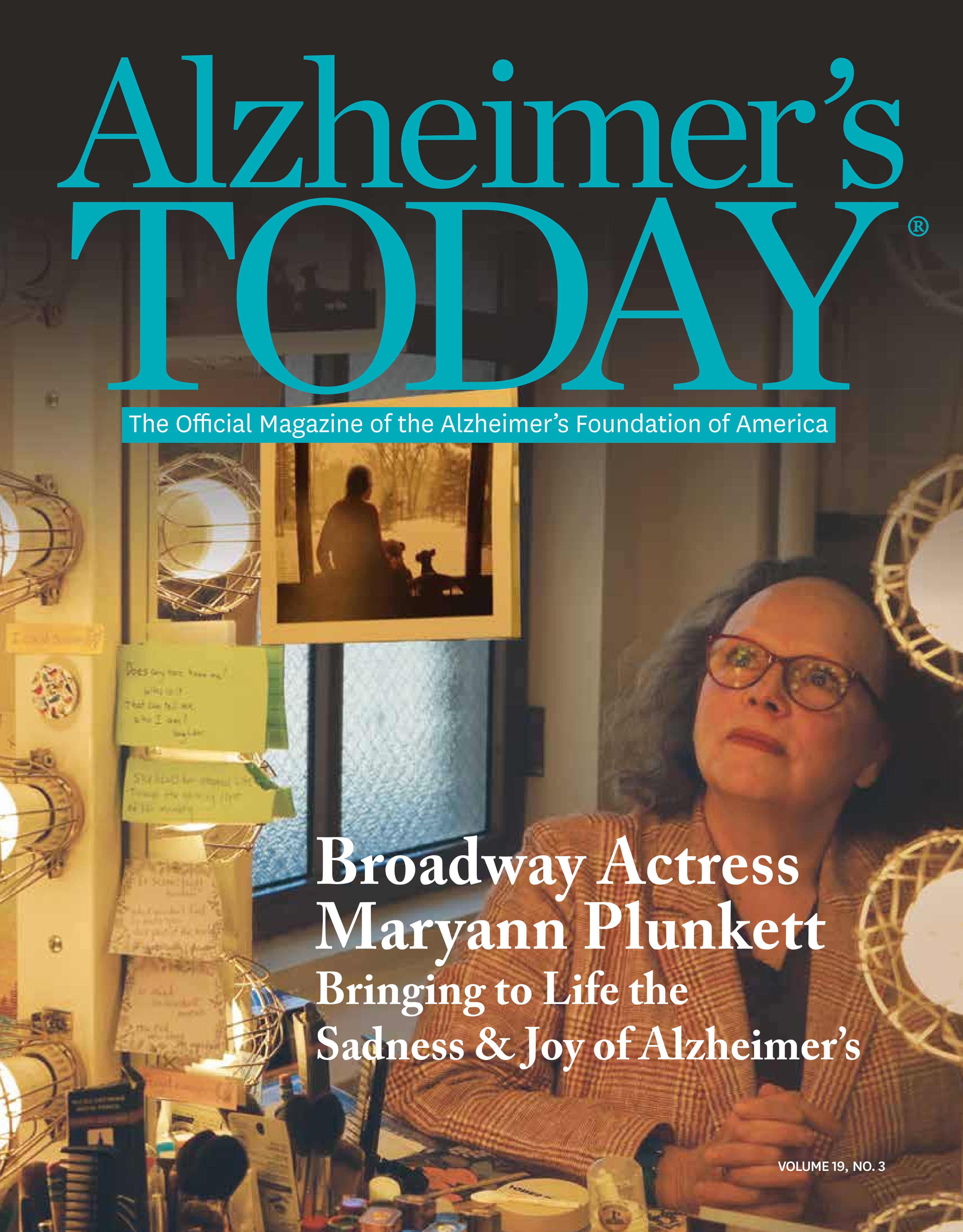
Alzheimer's TODAY®

The Official Magazine of the Alzheimer's Foundation of America



Broadway Actress Maryann Plunkett

Bringing to Life the Sadness & Joy of Alzheimer's

VOLUME 19, NO. 3

Help Available 24/7

AFA now provides 24/7 support with a newly created virtual helpline assistant to answer questions and assist caregivers and families affected by Alzheimer's disease and other dementia-related illnesses.

You are currently chatting with Allison, our virtual helpline assistant.

Hello. My name is Allison. I am your virtual helpline assistant. How should I refer to you?

Robin

Hello, Robin! How can I help you today?

What is sundowning?

Sundowning is a common type of sleep disturbance among individuals living with

Type your message here...

"Allison" is a friendly, professional avatar designed to supplement the live support provided by AFA's licensed social workers and make it easier for individuals to access helpful information whenever they need it. She is programmed to answer hundreds of dementia-related questions, ranging from basic ones such as "What is Alzheimer's disease?" to more advanced issues such as "What do I do if my loved one keeps asking to go home when they are already home?"

This free, fully interactive resource on AFA's website (www.alzfdn.org) answers questions about dementia, caregiving, brain health, memory issues and more when the social workers are unavailable.

When users ask questions by typing text into a chat box or through voice interaction using their device's microphone, Allison will provide instant feedback and information. At any time during a session, users can also ask Allison to create a ticket to have a Helpline social worker contact them to discuss more detailed, complex, or personalized issues.

The system is completely confidential and free to use 24 hours a day. Users do not have to input any personal information to use the system unless they are asking to speak with a licensed social worker, in which case they only need to provide contact information so the social worker can follow up with them.

Allison can serve individuals in all major languages.

Connect with Allison through AFA's website at alzfdn.org.

AFA is here for you.
alzfdn.org

CALL US

AFA Helpline, 7 days a week:
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Text us: 646-586-5283
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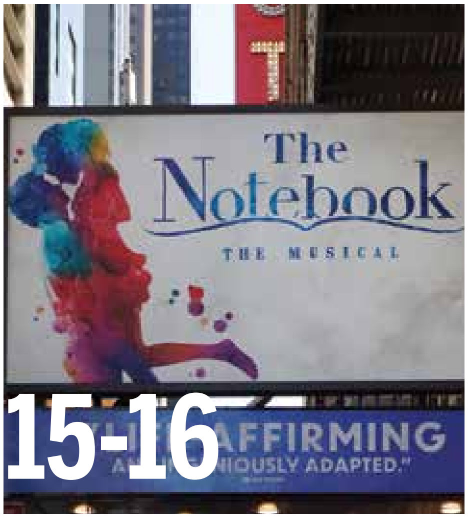


A MESSAGE FROM OUR PRESIDENT & CEO
CHARLES J. FUSCHILLO, JR.

Support and education are major missions of AFA, accomplished through our Helpline, our new virtual Helpline assistant, our Educating America Tours, professional trainings and Care Connections webinars. *Alzheimer's TODAY* is one of our most popular resources, reaching more than 250,000 individuals. You'll find human interest stories, caregiver tips and inspiration. Readers have told us the magazine helps them feel less alone, something that they can draw on again and again and pass on to others.

Some highlights of this new issue:

- Safety, with tips on creating a dementia-friendly home (pp. 17-18), securing firearms (pp. 19-20), and eating and drinking in later-stage dementia (pp. 21-22).

- In my Fireside Chat with Dr. Jennifer Carson, we look at the stigma still surrounding memory loss conditions for some, and how *we* can help change that story: "It is possible to live well with dementia, a belief that opens up a world of hope and possibilities," she says. (pp. 10-11)

- Do you have serious conflicts within your own family regarding the care of your loved one? You can get support from a court-ordered process designed to help you resolve these issues. (p. 29)

- We'll take you into the world of a backstage dressing room for an interview with Tony Award-winning actress Maryann Plunkett who is playing a character with Alzheimer's in the Broadway musical production of *The Notebook*. (pp. 15-16)

- We will also update you on legislation passed in the House and Senate this year affecting Alzheimer's and related conditions in our Capitol Report. (p. 27)

- And take good care of your own health. Sleep problems affect millions of us, especially as we age. We turned to our experts for a conversation on what causes sleep disruptions and how they might be better addressed. (pp. 32-34)

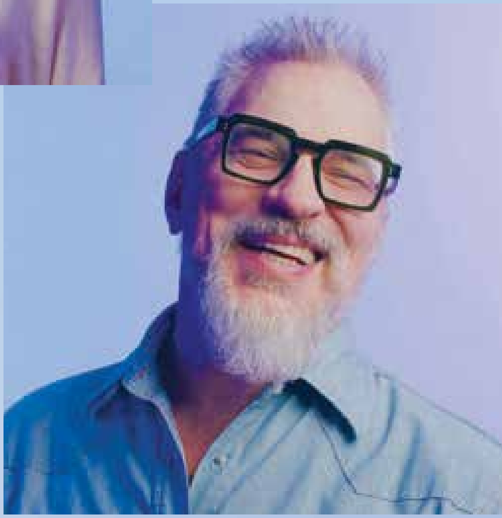
We enjoy hearing from you. Do you have a story idea for our editors for an upcoming issue? Please suggest it at info@alzfdn.org.

Wishing you all the best for the holiday season and the new year.

Warmly,

Chuck

Chuck



At Otsuka, we hold a deep respect for the value of every mind.

We will not rest until mental illnesses and brain diseases are approached with the same priority and urgency as our physical health and recognized as chronic diseases that warrant early, equitable, and accessible intervention.

Through products, programs, policies, and advocacy, Otsuka-people will defy any limitation that stands in their way until every mind is valued.

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Discover our commitment to health for every mind

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THE CAREGIVER'S DILEMMA: Balancing Responsibility and Boundaries

One Sunday evening, my grandmother called to inform me that her 24-hour shift home health aide had walked out on her.

My grandmother had always been unabashedly vocal about this particular home health aide, openly referring to her as an "incompetent country bumpkin." This time, she'd taken it one step further and slapped the aide. The aide had tolerated the verbal abuse, but she refused to tolerate the physical abuse.

I understand that it was my grandmother's Alzheimer's that had caused her to act out. The home health aide didn't. In Cantonese-speaking Chinese communities, some mistakenly refer to Alzheimer's as "old people crazy senile disease," and they attribute its physical manifestations to an individual's personality traits. Rather than attempting to assuage my grandmother, the home health aide left.

I called the home health care agency to find a replacement for the night, which proved futile because my grandmother had a track record of aides quitting on her. Also, it was a Sunday evening, and no one was available to pick up a night shift on demand.

When I relayed this to my grandmother, she insisted that I stay over. The idea had already crossed my mind — I lived across the street and could have easily stayed over before heading out for work early the next morning. But I was tired.

I was tired of being my grandmother's scapegoat.

Weeks earlier, my grandmother had told another home health aide that she didn't have to come in for her weekend shift because I would spend the weekend with her. The aide was skeptical and said that my presence shouldn't preclude her from doing her job. Upon hearing this, my grandmother tugged at her heartstrings instead. "Wouldn't you rather spend the weekend with your children than an old woman?" My grandmother had a pattern of either verbally abusing her home health aides to a point of no return or feeling like she didn't need aides because I lived across the street, which may have ignited her verbal diatribes against them.

I didn't want to set a stronger precedent and have her believe that it was okay for her to physically assault her home health aides. I was worried that if I spent the night, she would solidify the idea that "It's okay if I treat my home health aides horribly. Regardless of what happens, Angela will come and save the day."

I reached out to my support group leader for caregivers of Alzheimer's patients and described my predicament. I didn't want to spend the night because I didn't want to set a precedent that would dissolve any semblance of boundary that existed between my grandmother and me. Simultaneously, I didn't want to leave her by herself — she was at risk of falling and had already once unknowingly left the stove on. I felt responsible for her well-being and safety.

But I also knew that I was responsible for mine. After chatting with my support group leader, I made the difficult decision to put myself first. To do so, I had to lie to my grandmother. She would've gone ballistics had she known that I was across the street. She would've considered it a selfish move, with zero understanding of the toll that it would take on me. My support group leader and I devised a white lie: I told my grandmother I couldn't come because I was attending a wedding in New Jersey and it would be very late by the time I returned.

Continued on following page

THE CAREGIVER'S DILEMMA: BALANCING RESPONSIBILITY AND BOUNDARIES

cont'd from p. 5

It broke my heart to lie to her. She was the person I loved most and I wanted nothing more for her than her safety and longevity. On top of that, I hate lying. But I did it. I lied to my grandmother. I told her to get some rest and that the next home health aide would be there tomorrow morning.

Then I wondered, *did I do the right thing?*

I called my support group leader again. My anxiety had skyrocketed. I wondered if I should maintain my lie. Maybe I should just go and spend the night. This way, I wouldn't have to feel worried about potential accidents. Maybe I should just tell her I've decided to leave the wedding early.

But then I realized that in exchange for my short-term mental well-being, in lying, I was working towards maintaining my long-term mental well-being. I was signaling to my grandmother that I have a life, that I can't be there at every beck and call. If I could stand my ground, the subsequent times would come more easily.

I spent the entire night tossing and turning, wondering if my grandmother was okay. I prayed that my phone, which I had near me at all times in case she needed to reach me, would not ring. I prayed for her to get through the next 12 hours. And she did.

I, too, made it through the night. It was in going through this experience that I was able to start setting boundaries with my grandmother. We must ensure that our cups are as full as possible before we start pouring into someone else's cup. We can't pour from empty cups.

ABOUT THE AUTHOR

Angela Choi (www.angelachoi.co) is a purpose coach, author, and writer who believes deeply in the power of mindfulness and self-love. After veering off the conventional path and making her way around the world, she documented her journey in her book *10 Life Lessons in 10 Years: The Things I Didn't Learn at Yale but Wish I Had*.

Photos courtesy of Angela Choi

DAY BY DAY PROJECT:
Transforming Dementia Care Through Music

AFA Member Close Up

Bruce sat alone in a corner, withdrawn. Once a conductor and composer, he now, at 90, lives in a memory care facility, cut off from others and himself in the late stages of dementia. That was how he spent his days until Kaylie Glenn came to visit.

Glenn knew a proven way to reach him. She put headphones playing Frank Sinatra songs on his head and the transformation was nearly immediate. He stood, raised both hands high and began conducting. He started crying and his face radiated joy.

"I feel we have a close relationship although we've never spoken," she says. "We've only connected through music."

Glenn's first experience of taking live music to memory care residences was as a 10-year-old visiting the facility where her mother worked. She went to play her violin to conquer her stage fright and was surprised when a woman who hadn't spoken in a long time stood and sang. The staff told her the woman had been an opera singer until dementia silenced her. Kaylie returned to play.

That experience propelled Glenn to start a nonprofit, The Dementia Project.

Now, at 22, she has refined and expanded the program into the Day by Day Project, which in part was inspired by the after-prom Silent Disco held at her high school, Cincinnati Hills Christian Academy. A silent disco is a dance party where people listen to music through wireless headphones instead of speakers. The music is broadcast by a transmitter and picked up by the headphones, so people without headphones can't hear the music.

While this method might sound as if it would isolate people in their auditory world, Glenn says it unites a group as they look out and see other people relating to the same music they are hearing.

"I remembered back to my high school after-prom and the group headphone experience of the 'Silent Disco.' And even though this technology had not yet been repurposed for the dementia community, I decided to give it a shot. This technology with our musical engagement program was incredible and became known as the Memory Disco™ Program."

Continued on following page

Photos courtesy of the Day by Day Project

Day by Day on a Mission

Glenn started Day by Day in 2015 and now works full-time as its president. She developed the program with the help of Dr. Rhonna Shatz, who oversees the memory care department at the University of Cincinnati. Glenn is assisted by Anish Ganesh as vice president. For him, dementia is personal. When he was in fifth grade his grandmother developed a memory loss condition. It was only through songs that he could connect to her.

"That's what drives me to do this." He will be attending graduate school at the University of Texas/Austin to become a neurologist. Both Glenn and Ganesh graduated from Ohio State University in 2023 with degrees in neurology.

Music has this power, Glenn has learned, because it's connected to emotional memory, which is stored in a different part of the brain.

"These are the core memories of life, like nursery rhymes and music from your wedding. Emotional memory is preserved throughout dementia."

Glenn chose the name for her program because she thought caregivers needed to focus on ways to cope one day at a time. She was unaware that "Day by Day" was the name of an immensely popular song from the 1970s — it reached #13 on the *Billboard* pop singles chart in 1972 — as the breakout hit from the Stephen Schwartz musical *Godspell*, which undoubtedly was seen by a great many of people in memory care now.

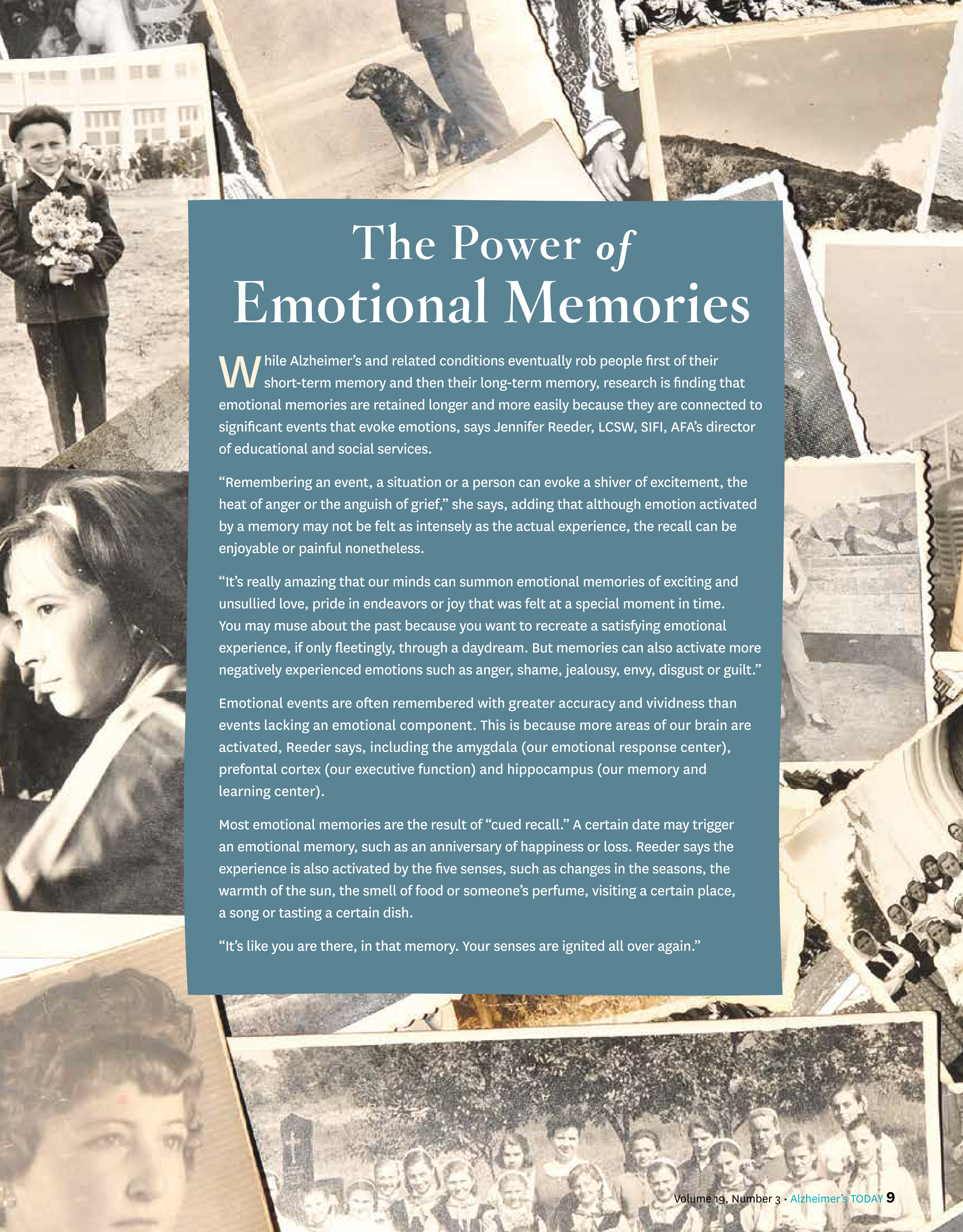
"Music is the bridge that you can walk across and be with them again. They are still in there."

Kaylie Glenn, Founder, Memory Disco™

Most of the program's music comes from the 50s, 60s and 70s. Glenn describes the Memory Disco™ Program as "a multisensory musical program designed to meet the needs of those living with and affected by dementia. After witnessing the power of the Memory Disco™ and its potential to increase accessibility to group music engagement, we worked for three years to develop our package, which includes everything a care partner needs to bring music into their daily care routine." This includes the group headphone technology (equipment), access to the Memory Disco Portal and support from the Day by Day Project team.

The package features 35 playlists. Sinatra is a big hit, as are the disco songs "Dancing Queen" and "YMCA." It also includes 15 activity guides that are step-by-step programming suggestions with a playlist for every activity. The package is available from the Day by Day Project website at daybydayproject.org.

Glenn said care partners feel more in control when they can connect to their person through music. From the outside it can seem the person is shut off, she says, like a castle surrounded by a moat and sharks. "Music is the bridge that you can walk across and be with them again. They are still there."



The Power *of* Emotional Memories

While Alzheimer's and related conditions eventually rob people first of their short-term memory and then their long-term memory, research is finding that emotional memories are retained longer and more easily because they are connected to significant events that evoke emotions, says Jennifer Reeder, LCSW, SIFI, AFA's director of educational and social services.

"Remembering an event, a situation or a person can evoke a shiver of excitement, the heat of anger or the anguish of grief," she says, adding that although emotion activated by a memory may not be felt as intensely as the actual experience, the recall can be enjoyable or painful nonetheless.

"It's really amazing that our minds can summon emotional memories of exciting and unsullied love, pride in endeavors or joy that was felt at a special moment in time. You may muse about the past because you want to recreate a satisfying emotional experience, if only fleetingly, through a daydream. But memories can also activate more negatively experienced emotions such as anger, shame, jealousy, envy, disgust or guilt."

Emotional events are often remembered with greater accuracy and vividness than events lacking an emotional component. This is because more areas of our brain are activated, Reeder says, including the amygdala (our emotional response center), prefontal cortex (our executive function) and hippocampus (our memory and learning center).

Most emotional memories are the result of "cued recall." A certain date may trigger an emotional memory, such as an anniversary of happiness or loss. Reeder says the experience is also activated by the five senses, such as changes in the seasons, the warmth of the sun, the smell of food or someone's perfume, visiting a certain place, a song or tasting a certain dish.

"It's like you are there, in that memory. Your senses are ignited all over again."

LET'S ELIMINATE THE STIGMA BY CHANGING THE STORY

Stigmas involving dementia originate in misconceptions about what it is and what it means to live with it, says Jennifer Carson, Ph.D., a clinical associate professor and founding director of the Dementia Engagement, Education and Research (DEER) Program in the School of Public Health at the University of Nevada, in Reno. If we want to change our culture's perception of dementia, we have to change our stories about it.

"My dad had the benefit of having had a dementia advocate in his life for 40 years — me. I was constantly teaching my own family about dementia, but even my own dad was afraid to seek a diagnosis because the negative narrative is so strong."

Carson has learned from him and others like him.

"People living with dementia have helped me to unlearn a lot of unhelpful things I learned through my formal education. A lot of that is about the tragedy narrative,

Jennifer Carson's family: Left to right, sister Michelle Berthon, Jennifer, dad Ray Arand, sister Lisa Nygren and brother Dave Arand

Photo courtesy of Jennifer Carson

which really doesn’t serve people living with dementia well, nor is it necessarily an actual portrayal of most people’s experiences,” says Carson.

Carson calls this the bio-medical-*only* paradigm.

“I kind of think of it as two eyeballs. The bio-medical view of dementia that I gained in my formal education is one of the lenses that I use to support people living with dementia. The other eyeball that I use is the social-relational view and that has primarily been informed by people living with dementia in my life.”

Carson understands that people living with dementia can make “incredible contributions in their own care, in their lives and their families’ lives and their communities.”

“I’m not demonizing the bio-medical view. It’s one of my eyeballs. I just know I see much better when I have both of my eyes open.”

How to Be a Better Care Partner

Rather than using stigmatized terms like “dementia sufferer” or “Alzheimer’s patient” that focus on the tragedy of dementia, Carson says we can honor each person’s humanity and change the narrative by using person-first language, such as “a person *living* with dementia.” Instead of being “caregivers,” we can support personhood and empowerment by seeing ourselves as “care partners.”

“While cringing inside, I kindly offer a reframe when I hear people say such damning things like ‘she’s a shell of her former self,’ or ‘he’s slowing fading away into nothingness.’”

“Our beliefs, and the words we use to describe them, merge with the beliefs and words of others and construct the lived reality of dementia to a great extent. Many people who are diagnosed with a dementia-related condition live with it for 10, 15 or more years, more like a chronic condition than a fatal disease. My dad was diagnosed with Lewy body and vascular dementia in 2016. Yes, I know his dementia is ultimately fatal. But I can’t imagine thinking of (or calling) him a ‘dementia sufferer’ for all those years. That would cause him to suffer more than the dementia itself. Instead, my dad and I believe it is possible to live well with dementia, a belief that opens a world of hope and possibilities.”

Adapted from the AFA Fireside Chat *Rethinking the Stigma*.

One Patient's Story Navigating Alzheimer's Disease from Diagnosis to Treatment

Sponsored by Eisai Inc. and Biogen Inc.

For patients like Jerome, a diagnosis of Alzheimer's disease (AD) can be a devastating and life-changing experience.

Jerome, who lives in Florida with his wife of 27 years, Joanne, was diagnosed with AD in 2019 at age 82. "When I received the news that I had Alzheimer's disease, I pretty much shut down," Jerome said. "My whole life I've been known for being outgoing, but after my diagnosis, I changed. I barely spoke to my family and friends, and I stopped doing the things that I love like reading and listening to jazz music."

AD is a brain condition that gets worse over time. It may happen when a protein called amyloid continuously builds up in your brain, forming harmful amyloid beta plaques. Though there are different types of amyloid proteins, all of them can damage brain cells.

Like many patients, Jerome was frightened by his diagnosis. When his doctor suggested he take part in a clinical trial for AD, he was reluctant. "I would purposefully forget to go to my appointments because I felt so hopeless," he said. "I credit my wife Joanne, my mother-in-law and my children for pushing past my stubbornness and making sure I attended my appointments and got the care I needed."

Slowing AD's Progression

Jerome participated in Eisai's Clarity AD 18-month clinical trial which studied the efficacy and safety of LEQEMBI® (lecanemab-irmb) to treat early AD. The study included 1,795 men and women, ages 50 to 90, from different ethnic and racial backgrounds.[3] The study was divided into two groups. One group took LEQEMBI (898 people), and the other group were on a placebo and not taking LEQEMBI (897 people). LEQEMBI (injection for intravenous use) is a prescription medication that received traditional approval from the U.S. Food and Drug Administration (FDA) in July 2023 for the treatment of AD. LEQEMBI was proven to slow the progression of mild cognitive impairment (MCI) and mild dementia due to AD, which together are called early AD. Even though you cannot stop AD from getting worse, with LEQEMBI, you can take steps to slow how fast it progresses. MCI is when symptoms, like forgetting names and confusion, are very mild and may not get in the way of daily life. Mild dementia due to AD is when symptoms, like trouble keeping track of your bills and difficulty with familiar tasks, start to get in the way of daily life.[1]

LEQEMBI can cause serious side effects including amyloid related abnormalities (ARIA), serious allergic reactions and infusion-related reactions. ARIA is most commonly seen as temporary swelling in areas of the brain that usually resolves over time. Some people may have small spots of bleeding in or on the surface of the brain, and infrequently, larger areas of bleeding in the brain can occur. Your healthcare provider will do magnetic resonance imaging (MRI) scans before and during your treatment with LEQEMBI to check you for ARIA. Tell your healthcare provider about all of the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements. Especially tell your healthcare provider if you take medicines to reduce blood clots from forming (antithrombotic medicines, including aspirin). Some medicines can increase the risk for larger areas of bleeding in the brain in patients taking LEQEMBI. Some people may have symptoms such as headache, confusion and dizziness. These are not all the possible side effects of LEQEMBI. **Please see additional important safety information and Medication Guide on the next page.**

Since starting LEQEMBI, Jerome and Joanne report that they've noticed what may be a slowing in the progression of his early AD. "Alzheimer's is a terrible, crippling disease for patients and their care partners, but the fact that we have an approved treatment that can slow the process is a great step in combating the disease. We went from feeling hopeless to having hope for our future," said Joanne.

How LEQEMBI Works

LEQEMBI works on fighting AD in two ways. LEQEMBI targets the different types of harmful amyloid proteins and LEQEMBI helps to remove existing amyloid brain plaque.[3] People taking LEQEMBI were shown to have less amyloid brain plaque starting at three months.[3] LEQEMBI keeps working through treatment to remove harmful amyloid brain plaque.[3] It's important to know if brain plaque is behind your symptoms.

The impact of AD on the brain begins long before a patient starts to have symptoms.[1] Early treatment with LEQEMBI can help you keep playing the roles you have for longer.[4] Once AD progresses to middle and late stage, LEQEMBI may no longer be right for you.[3] That is why discussing treatment with your doctor early on is so important.

"Memory loss, problems with thinking and other symptoms of Alzheimer's disease may be difficult to talk about, but it's important to have these conversations with your doctor as soon as you start to notice a pattern," said Dr. Julie Schwartzbard, a neurologist at Aventura Neurologic Associates in Florida who has been treating people living with neurological conditions, including AD and dementia, for 25 years. "For the first time ever, we're seeing significant advancements for AD treatment. For patients to maximize benefits, it's important for them to work with their doctor to diagnose AD and begin treatment as early as possible."

Please see additional important safety information and Medication Guide on the the next page.

If you or someone you love may be living with AD, it's important to speak with your doctor. To learn more about LEQEMBI, visit www.LEQEMBI.com.

LEQEMBI®
(lecanemab-irmb) 100 mg/mL
INJECTION FOR INTRAVENOUS USE

MEDICATION GUIDE

LEQEMBI® (leh-kem'-bee)
(lecanemab-irmb) injection, for intravenous use

What is the most important information I should know about LEQEMBI?
LEQEMBI can cause serious side effects, including:

- **Amyloid Related Imaging Abnormalities or "ARIA". ARIA is a side effect that does not usually cause any symptoms but serious symptoms can occur.** ARIA is most commonly seen as temporary swelling in areas of the brain that usually resolves over time. Some people may also have small spots of bleeding in or on the surface of the brain, and infrequently, larger areas of bleeding in the brain can occur. Most people with this type of swelling in the brain do not get symptoms, however some people may have symptoms, such as:
  - – headache
  - – confusion that gets worse
  - – dizziness
  - – vision problems
  - – nausea
  - – problems walking
  - – seizures

Some people have a genetic risk factor (homozygous apolipoprotein E gene carriers) that may cause an increased risk for ARIA. Talk to your healthcare provider about testing to see if you have this risk factor.

Some medicines can increase the risk for larger areas of bleeding in the brain in patients taking LEQEMBI. Talk to your healthcare provider to see if you are on any medicines that increase this risk.

Your healthcare provider will do magnetic resonance imaging (MRI) scans before and during your treatment with LEQEMBI to check you for ARIA.

Call your healthcare provider or go to the nearest hospital emergency room right away if you have any of the symptoms listed above.

What is LEQEMBI?

LEQEMBI is a prescription medicine used to treat people with Alzheimer's disease. It is not known if LEQEMBI is safe and effective in children.

Do not receive LEQEMBI if you:

- have serious allergic reactions to lecanemab-irmb or to any of the ingredients in LEQEMBI. See the end of this Medication Guide for a complete list of ingredients in LEQEMBI.

Before receiving LEQEMBI, tell your healthcare provider about all of your medical conditions, including if you:

- are pregnant or plan to become pregnant. It is not known if LEQEMBI will harm your unborn baby. Tell your healthcare provider if you become pregnant during your treatment with LEQEMBI.
- are breastfeeding or plan to breastfeed. It is not known if lecanemab-irmb (the active ingredient in LEQEMBI) passes into your breast milk. Talk to your healthcare provider about the best way to feed your baby while receiving LEQEMBI.

Tell your healthcare provider about all of the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements.

Especially tell your healthcare provider if you take medicines to reduce blood clots from forming (antithrombotic medicines, including aspirin). Ask your healthcare provider for a list of these medicines if you are not sure.

Know the medicines you take. Keep a list of them to show your healthcare provider and pharmacist when you get a new medicine.

How will I receive LEQEMBI?

- LEQEMBI is given by a healthcare provider through a needle placed in your vein (intravenous (IV) infusion) in your arm.
- LEQEMBI is given every 2 weeks. Each infusion will last about 1 hour.
- If you miss an infusion of LEQEMBI, you should receive your next dose as soon as possible.

What are the possible side effects of LEQEMBI?
LEQEMBI can cause serious side effects, including:

- **see "What is the most important information I should know about LEQEMBI?"**
- **Serious allergic reactions.** Swelling of the face, lips, mouth, or tongue, hives, or difficulty breathing have happened during a LEQEMBI infusion. Tell your healthcare provider if you have any symptoms of a serious allergic reaction during or after LEQEMBI infusion.
- **infusion-related reactions. Infusion-related reactions are a common side effect which can be serious. Tell your healthcare provider right away if you get these symptoms during an infusion of LEQEMBI:**
  - – fever
  - – flu-like symptoms (chills, body aches, feeling shaky and joint pain)
  - – nausea
  - – vomiting
  - – dizziness or lightheadedness
  - – changes in your heart rate or feel like your chest is pounding
  - – difficulty breathing or shortness of breath

If you have an infusion-related reaction, your healthcare provider may give you medicines before your LEQEMBI infusions to decrease your chance of having an infusion-related reaction. These medicines may include antihistamines, anti-inflammatory medicines, or steroids.

The most common side effects of LEQEMBI include:

- – infusion-related reactions
- – swelling in areas of the brain, with or without small spots of bleeding in or on the surface of the brain (ARIA)
- – headache

These are not all the possible side effects of LEQEMBI. For more information, ask your healthcare provider or pharmacist.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

General information about the safe and effective use of LEQEMBI. Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. You can ask your pharmacist or healthcare provider for information about LEQEMBI that is written for healthcare professionals.

There is a registry that collects information on treatments for Alzheimer's disease. The registry is named ALZ-NET (Alzheimer's Network for Treatment and Diagnostics). Your healthcare provider can help you become enrolled in this registry.

What are the ingredients in LEQEMBI?

Active ingredient: lecanemab-irmb.

Inactive ingredients: arginine hydrochloride, histidine, histidine hydrochloride monohydrate, polysorbate 80, and water for injection

Manufactured by:
Eisai Inc.
Nutley, NJ 07110
U.S. License No. 1862
LEQEMBI® is a registered trademark of Eisai R&D Management Co., Ltd.

For more information, go to www.LEQEMBI.com or call 1-888-274-2378.

This Medication Guide has been approved by the U.S. Food and Drug Administration.

Revised: 7/2023

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Eisai

Biogen

Caregiver Creativity

A Treat That's Refreshing in Every Way

Photos courtesy of Jelly Drops

In 2018 when Lewis Hornby was a 23-year-old student in a postgraduate course called Innovation Design Engineering, he was given six months to work on any project he chose. His thoughts went to his grandma Pat who had been living with dementia for about seven years. Her condition had dramatically declined, and she became completely unresponsive. She was rushed to the hospital and the family was told to expect the worst.

"When she arrived, they realized it wasn't her dementia that was the issue. She was severely dehydrated. After 24 hours on IV fluid, she was back to her normal happy self and went on to enjoy a good quality of life for years after," Hornby said. "I was shocked that something so simple as staying hydrated had such a huge effect on grandma's health. Looking into it further, I found the situation wasn't uncommon."

Hornby consulted with a dementia psychologist to understand why people living with dementia may struggle to stay hydrated and learned that many no longer feel thirst, may not recognize cups or have the dexterity to hold them. To understand this better, he stayed in his grandmother's care home for a month, observing residents and speaking with staff and families.

With drinking such a challenge, he started to focus on eating habits and found much more independence, especially with finger foods.

"It seemed much more intuitive, and the removal of cutlery helped reduce distractions. It was also more social. Grandma would often try to share her food.

"Still, it was often difficult to encourage people to eat. That was unless you offered them a treat. Most people in the care home ignored me until I gave them chocolates or sweets. Then everyone wanted to chat and take a handful.

"I thought if I could create a hydrating sugar-free treat, then people living with dementia could hydrate independently, and with dignity. I made a prototype. When I gave it to my grandma, she ate seven in the first 10 minutes."

Hornby posted a video of that interaction that spread around the world.

"I quickly had 50,000 people email me and many of them were in the United States. I teamed up with co-founder Claudia Arnold, and we set about working full-time to make the product a reality."

Backed by the UK Alzheimer's Society Innovation Accelerator, and acknowledged through numerous awards, they built a team. After 18 months of development, their London-based factory launched via website in the UK in 2020 and in the U.S. with www.jellydrops.us two years later. Canada followed in 2023.

"To date, we're proud to have supported over 80,000 people living with dementia to stay hydrated. It's been a privilege to see so many people enjoy Jelly Drops as much as grandma. Over one million Jelly Drops are eaten every month."

Hornby's class project has ballooned beyond his expectations.

"We are really lucky to have a hugely engaged community of caregivers and family members whose insightful feedback have informed lots of improvements to the original product. It's this daily feedback from families, showing they are helping that makes it all worthwhile for us."

Caregiver support groups can register to be a Jelly Drops Champion to receive a free box of 22 samples at www.jellydrops.us/pages/champions.

BACKSTAGE CONVERSATION WITH *The Notebook* Star Maryann Plunkett

The black-and-white photo on the dressing room mirror is of a woman, shot from behind, looking out a window at a snow-covered yard, with the backs of two little stuffed animals on the windowsill beside her. It evokes a sense of tranquility and timelessness. For the owner of this photo, Tony Award-winning actress Maryann Plunkett, it represents the presence of her mother in a tiny nook in a large Broadway theatre.

Plunkett's mother is present to her as well in the much grander space of the stage at the Gerald Schoenfeld Theatre where the 72-year-old actress is starring as Older Allie in *The Notebook*, the musical based on the best-selling novel by Nicholas Sparks, which became a movie starring Rachel McAdams and Ryan Gosling.

"I try to enter the world she lived." That world is dementia. Plunkett's mother died at 91 after living with the condition for many years. Allie is played by three different actresses, representing youth, early adult life and elderly with Alzheimer's. The story at all levels is about the love between Allie and Noah. It's captured in a notebook Allie wrote in those earlier stages, and it's what Noah reads to her after she no longer knows him, in the hopes that the times portrayed may break through to her.

For large parts of the show Allie and Older Noah, played by Dorian

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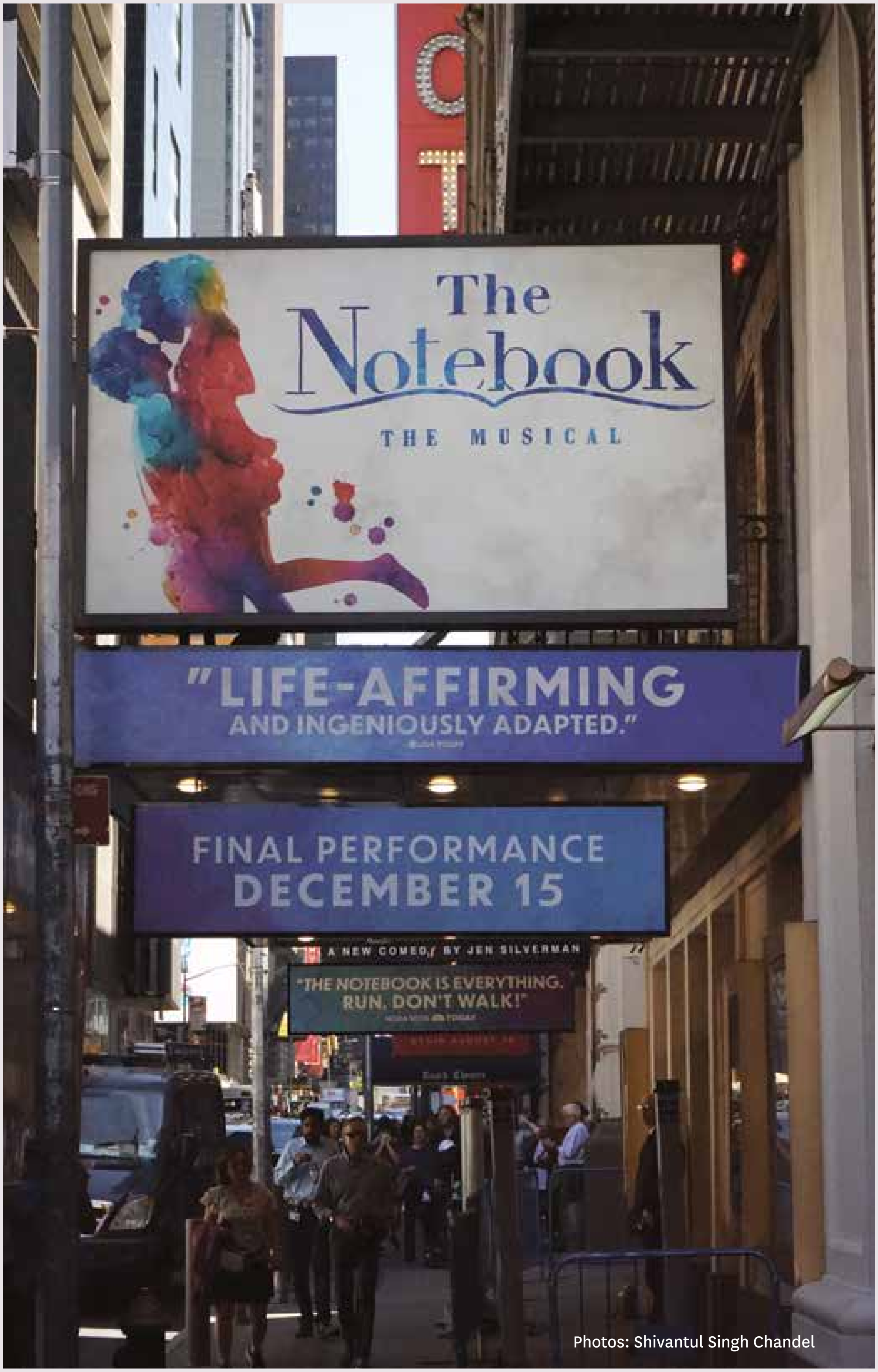


Photos: Shivantul Singh Chandel

Harewood, sit to the side of the stage while the young and early adulthood couples play out the memories Noah is sharing. Plunkett is intensely in character the entire time as Allie tries to understand this story that is her life.

Plunkett, who received a Tony nomination for her portrayal of Older Allie, was drawn to the show by Bekah Brunstetter's book and Ingrid Michaelson's music and lyrics, as well as the story, which she can relate to her mother's experience.

"I was clearly drawn to that. Allie's an artist and my mom was a musician and she liked to doodle," she says, pretending to draw on a book on her vanity table. "It's the creative force in a person. I think the script and music and lyrics are so spare and so deep. It makes me honest. I really feel it."

While Harewood is only pretending to be speaking the notebook's words, Plunkett stays in character by watching the younger actors. She imagines Allie's reaction.

"I'm [Allie] hearing a story. What am I seeing? I'm seeing parts of me that I don't know."

She said her mother was often looking for something and was afraid she would run out of money, so the family kept a wallet in a drawer in the buffet with 20 one-dollar bills in it. The denomination didn't matter. Her mother felt secure counting all those bills.

"I brought a couple of moments like that. I try to enter the world she lived."

Plunkett's father, who died three and a half years before her mother, is also present at the Schoenfeld. Beside the photo of her mother, Plunkett has written on a small piece of paper the Latin expression *Ab initio*, meaning in beginning or from the beginning. This is how he signed all his cards to her mother.

Plunkett shared caregiving with her father and four siblings, going to Massachusetts from New York once a month for a week or four days twice a month. In the final years caregivers and nurses assisted.

"There was also joy in the years with my mother. She had a curiosity and a seeking. As sung in *The Notebook*, 'the sadness and the joy'."

Besides this personal element of the show, Plunkett appreciates that the older couple, which is the one making audiences cry the most, is portrayed seriously and not for laughs or sentimentality as is so often the case with older characters. Both she and Harewood have had long marriages. She and her husband, actor Jay O. Sanders, celebrated their 33rd anniversary Oct. 1.

Plunkett says she is frequently met at the stage door by people sharing their stories of a spouse or parent who had Alzheimer's. Twice someone has told her they've just been diagnosed with the condition. One of them said the show had given him hope that he might have a spark of memory as Allie does at the show's end.

The musical, which played Chicago before beginning performance in New York in February, is ending December 15. It will begin a national tour in Cleveland in September.

Asked what she would tell her mother now about her understanding of the experience of living with dementia, she pauses and her eyes fill with tears.

"I'm getting emotional. Simply, 'thank you.' It's been a joy being with her again."

Home Safety

CREATING A DEMENTIA-FRIENDLY HOME


The Kitchen

At first glance, visitors to AFA's studio apartment in Manhattan are impressed by how homey and comfy it looks. They don't recognize that this space was specifically designed as a model for people with memory loss because the safety features and modifications don't stand out. That was intentional.

"We created The Apartment to showcase ways that practical design and technology can greatly increase the quality of life for someone living with dementia and help family care partners protect their loved ones," said Leah Daly, MPH, CHES, AFA's education program manager. "Modification of the living space will grow and change as the person's condition progresses."

"We have to think about privacy and the influence we have as care partners. Consider intervening with minimal impact. You want to keep them safe but don't want to make them feel like you're spying on them or controlling everything."

How can you help?

"We encourage care partners to make a plan with their loved one. Some of the main things you'll want to consider when modifying your space are affordability, feasibility or how able you are to carry out modifications. Maybe you want to start slow. Each individual experiences dementia differently, so the needs of your space are going to be unique to your individual. Remember this change can be a gradual process as people progress into their condition," reminds Daly.

Overall, when considering materials in furniture, avoid busy patterns, which can be overstimulating and confusing and promote agitation. Choose simple patterns.

Consider the lighting system, adjusting it to an automatic setting that gets brighter and dimmer based on the weather or time of day.

The front door lock can be another helpful way to be part of the household safety without feeling too intrusive. Buy a lock for the front door with a code or a keypad that you can change from an app on your phone.

At the front door

"If a person with a memory loss condition sees a line of doors that look the same in an assisted living or apartment setting, it might be hard for them to tell which one is theirs. We encourage people to hang decorations that will stand out."

AFA's door features a red berry wreath on the dark-blue door.

Continued on following page

"In Alzheimer's and dementia, the ability to distinguish contrast between two colors decreases as the condition progresses. If you want someone to see something, you need to highlight color contrast."

People also lose their depth perception, so a wreath of a different color will stand out. Numbers and letters are not always helpful because as the memory loss condition progresses individuals have a hard time reading.

In the kitchen

This can be the most dangerous room in any household. AFA's kitchen counter holds those items for those with memory problems, such as an electric kettle with an automatic off switch that activates as soon as the water starts boiling. The stove has a removable cover over smart burners. These smart burners will get hot enough for cooking without starting an oil fire. The burners have a motion sensor and automatic off switch and can pop in and out of a standard range, saving you the cost of buying a new oven.

"If an item is on for too long or if the motion sensor notices that the person has walked away from the stove, it will automatically turn off."

Another helpful security addition is an automatic thermostat that can be programmed from afar. "This can be useful for care partners to monitor whether the home is at a comfortable temperature. Something to look for is extremes."

The right smoke and carbon monoxide alarm is also crucial. Look for one that has unique chimes. "High-pitched or shrill chimes can be disorienting for people with Alzheimer's or dementia. If they're disoriented, they might not know what to do next."

Daly said some include the option to record a message, such as: "Hi Mom. There's a fire. You should get out of the house as soon as possible."

In the dining room

It's helpful to make design adaptations to the table setting. Use different colors for the placemat and each plate. Make sure the food isn't the same color as the bowl it's being served in, such as corn in a yellow bowl. Consider adding a Meal Lifter™ to raise the plate a bit closer to the person's face, making it less likely they will spill their food.

In silverware, look for heavy, sturdy pieces. People with memory loss conditions often develop tremors that make it likely they will spill food. Purchase mugs with large, easy-to-hold handles that make it less likely the person's fingers will touch a hot surface.

The floor in AFA's apartment is purposely without rugs and features glare-resistant tiles in light gray and blue. "Things that are shiny or provide a glare can be disorienting and uncomfortable."

The bathroom

"One of the first things most people notice in AFA's Apartment is the bright yellow toilet seat. Color contrast is important. You're looking at the yellow against the white."

Nightlights at floor level add to safety but don't disrupt the person's circadian rhythm as an overhead light might, making it harder for them to get back to sleep.

Shower time can be problematic because persons with memory loss conditions can resist being under the water's spray. An inexpensive showerhead with a pause button allows the caregiver to control the flow and adjust the temperature. Safety bars may need to be inserted on the walls and a shower chair for comfort.

AFA Apartment in-person and virtual tours may be arranged by writing to Leah Daly at ldaly@alzfdn.org or education@alzfdn.org. More information is also available on AFA's website: alzfdn.org/theapartment, including a 20-page resource guide that can be requested.

Home Safety

FIREARM INJURY PREVENTION

Close to 40 percent of households in the United States with older adults have at least one firearm on the premises. Handling a gun safely requires good vision, eye-hand coordination, motor skills, strength and balance. Age or medical conditions can affect any of those, says Emmy Betz, M.D., MPH, the founding director of Firearms Injury Prevention Initiative and a professor of emergency medicine at the University of Colorado School of Medicine. If the medical condition involves memory loss, the dangers increase.

"Ideally, it's not about confiscation or restriction. Ideally, it's about helping people make these decisions ahead of time."

Betz's Firearm Injury Prevention Initiative surveyed caregivers of people with memory loss who had firearms in their homes. They asked if the person had any plans of what to do with their guns when it became unsafe for them to use them. Only slightly more than half said they did. She urged people to think about the gun *now*.

The sooner people can start this process the better. "This could be part of the tool kit of things that people are given to think through, like finances, housing and medication options, when a diagnosis is made. Home safety should be on the list."

"All this in many ways is easier said than done. Making these changes is difficult and I don't want to minimize that. For some people firearms are deeply tied to their identities and sentimental," says Betz.

Considerations

With someone in the early stages of memory loss, consider whether they are having judgment changes, insight changes or personality changes. "Are there any depressive symptoms or are they saying things about wanting to die or about not wanting to be around people? We know that among older adults firearms are the most common method of suicide."

Some people may have the motor skills, the mechanics of firing, but they may not have the judgment, the insight anymore. In fact, "This is the space where it might be reasonable to think about going to the range with dad to see how he's doing and determine if he still seems safe."

Continued on following page

Jacqueline Lee | Dreamstime

BE AWARE OF WARNING SIGNS

Have you or others noticed some of these changes?

PHYSICAL

- Challenges holding, carrying, loading/unloading, shooting, or cleaning your firearm?
- Vision or hearing loss? Challenges seeing, reading, or hearing instructions?

COGNITIVE

- Trouble remembering if the safety on your firearm has been engaged, or if a firearm is loaded or not?
- Times when you've forgotten where your firearms are kept or stored?

BEHAVIORAL

- Times when you were told that you weren't safely handling or storing a firearm?
- Times when a trusted friend, family member or shooting friend expressed fear or discomfort when you are shooting?

EMOTIONAL

- Mood changes, like being more short-tempered, anxious, agitated or angry?
- More depressed, helpless or down?
- Feelings, like being more disconnected from family, friends, or activities you typically enjoy or used to enjoy?

Source: Firearmlifeplan.org

Keep in mind, "The person with dementia may have been a lifelong hunter, firearms user, police officer, military service member, and perhaps even the protector of the family their whole life," said Betz. "Remember, it's not the person, it's the disease. It can be hard for family members to realize that the person has changed. It can be hard for someone to accept that your spouse of 40 years poses a risk to you now in the middle of the night if they still have a gun."

Taking away ammunition is not always enough either. Depending on the level of impairment, the person could go out and purchase more. Guns can be disabled in a way that the person with memory loss can't tell that they are no longer operational, but that isn't always the solution, Betz says. "The downside to that option is that to a visitor or a physical therapist coming over, the gun would still look like a regular gun, so it could lead to some issues."

She acknowledged this could turn dangerous if the person with the disabled gun was standing on the front porch with it and police officers arrived. The person might not be able to respond to police commands promptly.

Victoriass88 | Dreamstime

A Solution: Firearm Life Plan

Betz wanted to develop resources that could help caregivers deal with all these difficult issues.

The Firearm Life Plan, available at firearmlifeplan.org, helps people think about important questions related to their firearms and to protect their families from the burden of making difficult decisions without guidance.

It features worksheets and resources that can be downloaded. The inventory worksheet outlines what you want done with your firearm, where it is stored and access codes. The legacy map lets you share the importance of firearms in your life and preserve your memories. Another worksheet deals with broaching the conversation with a loved one who might need to give up their gun and how to assess when that time has come.

Messages about gun safety need to be spread through national and local dementia groups, health care professionals, national firearms organizations and retailers, Betz says.

"As a health care provider, absolutely, I believe that we in health care have a role to play here, but it can't just be us."

Adapted from AFA's Fireside Chat, *Dementia and Firearms: Navigating a Difficult Situation Safely*

CONVERSATION STARTERS FOR FRIENDS & FAMILY

"I know we've never talked about it, but what do you want to do with your firearms as you get older?"

"I've noticed [shaky hands, difficulty seeing] are giving you trouble lately. Next time you go to the shooting range, may I go with you? I'd like to see how you're shooting these days."

"I care about you, which is why I wanted to talk to you about your firearms. I've noticed some changes over the years that I was hoping to talk to you about."

"I know that a lot of things have changed over the years. I think it might be a good time for us to talk about how things are going with your firearms."

"You always taught me about firearm safety. That's why I wanted to talk about some changes I've noticed lately."

"It's hard to think about anything ever happening to me or you, but making a plan just to be safe is always a good idea."

Source: Firearmlifeplan.org

EATING & DRINKING IN LATER-STAGE DEMENTIA

As a person living with Alzheimer's or another form of dementia progresses through the many phases, the loss of various skills, unfortunately, is predictable. Eating and drinking can become challenging and maintaining proper nutrition a major concern. "Feeding problems afflict 86% of people with an advanced dementia," says Nancy Weintraub, M.D., clinical professor of medicine, UCLA, and director, UCLA Geriatric Medicine Fellowship. "The ability to feed oneself is usually the last independent skill that a person with dementia loses."

Many people with late-stage dementia forget how to swallow properly, which can lead to weight loss, malnutrition and aspiration pneumonia (when a person inhales food, stomach acid or saliva into the lungs). Remember that the trachea, which leads to the lungs, is in front of the esophagus, which leads to the stomach. To swallow, the trachea needs to close properly. When we consider that just swallowing uses some 50 pairs of muscles, some voluntary and some involuntary, you can begin to understand how complicated it is. A speech pathologist can evaluate these problems, help initiate swallowing studies at bedside and using x-rays, and may find safer food and liquid solutions.

"When someone has a late-state dementia, it's important to allow them to eat what they are willing to eat," says Weintraub. A preference for sweets is often maintained. You may find yourself using a lot of pudding, but try any of their known favorite foods and new foods. Tastes will definitely change.

What about straws? "You'll notice straws are everywhere in hospital settings, but for a person with swallowing difficulty, straws are not your friend," says Weintraub. "Sucking from a straw shoots droplets all over your mouth that are hard to collect, making it easy to aspirate liquid."

Maintaining a person's independence and preferences for as long as possible is important to quality of life. So adjusting food textures and liquid consistencies and providing feeding gadgets are important steps for caregivers to take on this journey. Some changes that may be recommended by a speech therapist or doctor follow.

Continued on following page

Food & Liquid Consistencies to Consider

Puree

(smooth-pudding consistency)
pudding, yogurt, cottage cheese, cream soups fruits/vegetables, pureed and thickened

Ground

(use gravy or sauces to make moist)
canned tuna, soft ground meats and vegetables

Soft foods

(foods that "stay together")
macaroni and cheese, scrambled eggs, pancakes with jam or syrup, soft casseroles, meatloaf, egg/tuna/chicken salad with mayo

Complex textures

pasta, soft cheeses, cold cereal in milk, chopped or steamed vegetables (green beans, carrots)

Liquid

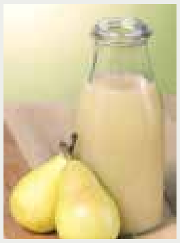
Over-the-counter products exist to thicken liquids to these consistencies to assist with swallowing.

Honey-thick

(i.e., the consistency of honey)

Nectar-thick

(i.e., the consistency of pear/apricot/peach nectar or tomato soup)



Feeding Gadgets

Weighted utensils

Good for a person with tremors; keeps food from falling as easily.

Bowls with lips & rubber bottoms

Keeps food/plate in place when pressed or leaned against.

Universals cuff

A wrist cuff, with an attached utensil, for someone who can no longer use their hand.

Baby spoon

Long-handled baby spoons Ideal for a person who needs to be fed a small amount of food at a time; discourages rushing.

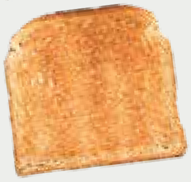
Careful: Food Textures Harder to Swallow Safely

Hard to Eat Foods

celery, fresh fruit, corn, crunchy peanut butter, brown/wild rice

Flaky foods

toast, crackers, popcorn, nuts



Foods that melt

ice cream, milkshakes, chocolate candy, sherbet, gelatin (Jell-O)

Sticky or bulky foods

white bread, mashed potatoes, potato salad, refried beans

BOOK CORNER

Dying at Home: A Family Guide for Caregiving

By Andrea Sankar with CM Cassady

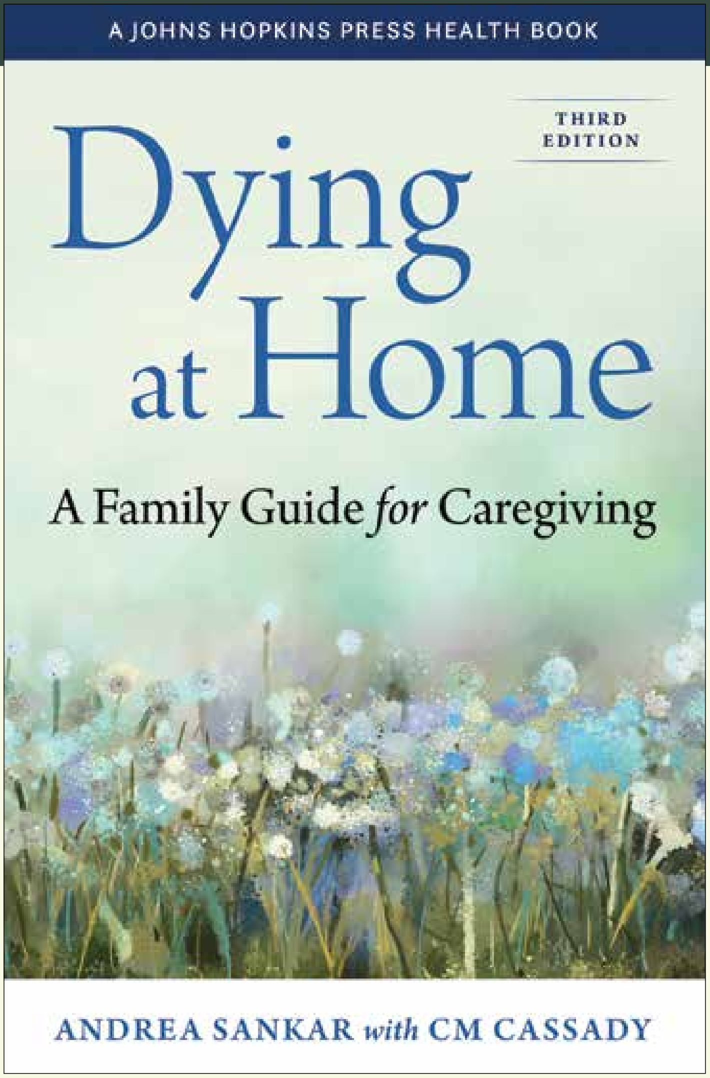
Everyone caring for a person with a neurocognitive disorder knows one thing: The person they are caring for is dying. Increasingly this involves a decision on where the death will take place. As of 2020 in the United States, deaths at home have exceeded those taking place in a hospital. With this in mind, Andrea Sankar and CM Cassady have just updated the 1991 edition of their book *Dying at Home: A Family Guide for Caregiving*.

The authors identify factors driving this shift—the growing awareness of hospice services coupled with the desire for a "nontechnological death" and managed care that "is forcing dying people out of the hospital into outpatient settings."

This third edition of their book, with more than 400 pages of information and intimate interviews, is a solid resource for those taking on the challenge of overseeing a home death, especially since "society does not adequately prepare or support them."

Sankar, a professor of medical anthropology and Cassady, a Ph.D. candidate in social work and anthropology, both at Wayne State University, did extensive interviews with people who cared for someone during a home death. All but one agreed that although the situation was challenging it was also one of the most rewarding experiences of their lives.

"The caregivers in this book were chosen to represent different types of relationships and different types of caregiving problems," they said. "Some caregivers spoke of a kind of peaceful simplicity and calm that descended on their lives as they abandoned other roles and responsibilities and focused exclusively on caring for the dying person. This calm often stood in contrast to the extreme stress they were under, the sacrifices that terminal care demanded of them and the overwhelming nature of the fatigue and strain."



Among the information provided are chapters dealing with:

- The decision to discharge the patient
- Strangers in the home: The use of formal support
- Challenging situations: Slowing or hastening death
- Demystifying death

Caregivers interviewed said the at-home death allowed their loved one the experience of "living while dying."

"This means treating the dying person as an intact individual no matter how debilitated and fragile they have become."

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Ask the AFA Helpline

with Linda Mockler, LMSW, M.Ed.

Support • Advice • Resources

I have recently been diagnosed with Alzheimer's. I'm trying to process this but I feel depressed and fearful. Where can I go to get emotional support? Where do I start?

Shock and distress are normal ways to react to this diagnosis. You may need a little time to process the news. Common emotions include anger, denial, isolation and grief.

Think about who you can reach out to share the news with and start creating a circle of care for yourself.

How can I manage all my feelings?

Share your feelings with your family and friends. If you are feeling overwhelmed, pick one or several people you feel most comfortable with. If you have a care partner, keep communication open and let them know what you are experiencing and the ways in which you need help and support.

Remember, this will be a process and these are just the first steps.

What are your goals?

Knowing what kind of support you are looking for is a great place to start.

- A counselor or social worker can provide emotional support and can be someone to whom you express your concerns.
- A support group provides an environment with people in a similar situation.
- Case managers can discuss potential resources.

Stay connected to yourself.

- Remain engaged by continuing to do the activities you've been involved with and enjoy.
- Stay physically active.
- Stay cognitively active with crossword puzzles, word and number games and puzzles.
- Stay socially active. See friends and family.

Stevanovicigor | Dreamstime

Take time to process the diagnosis and the accompanying feelings. Many people have found activities such as journaling, yoga and meditation helpful.

Find community: It takes a village

If you live alone, create a support system. These can be based around memory loss conditions or not. Look into support groups like AFA and community Memory Cafes, social gatherings where people living with memory loss, Alzheimer's and related dementias and their care partners can meet and enjoy time together. Cafés aim to decrease the social isolation that often accompanies dementia and caregiving.

Reach out to AFA

- AFA Helpline social workers are available seven days a week, 9 a.m. to 9 p.m. ET: 866-232-8484.
    - ◇ You can also text them at 646-586-5283 or webchat with them at alzfdn.org (see lower right-hand corner).
    - ◇ Text and webchat are available in 90+ languages.
- Reasons to call:
    - ◇ short-term supportive counseling
    - ◇ explore local and national resources
    - ◇ schedule a family meeting with a social worker
    - ◇ sign up for our educational webinars (alzfdn.org/caregiving-resources)
    - ◇ find therapeutic programs in your area

CAPITOL REPORT

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

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The BOLD (Building Our Largest Dementia) Act passed unanimously in the House of Representatives on September 18, 2024. This legislation was first signed into law in 2018 with a focus on the creation of an Alzheimer's public health infrastructure. The infrastructure sought to focus on interventions, early detection, diagnostics, risk management and reduction, and the reduction of hospitalizations. The bill allowed for the Centers for Disease Control and Prevention (CDC) to provide funding to state health departments that help to oversee interventions, such as supporting the needs of caregivers, with a focus on health equity.

Since 2018, the CDC has allocated 66 awards to 45 state, local, and tribal health departments. The impact of the bill really made a difference in 2023 when the CDC announced 43 BOLD award recipients — the most in a single year.

The NAPA Reauthorization Act (S. 133 / H.R. 619) and the Alzheimer's Accountability and Investment Act received Congressional approval this fall and were signed into law by President Biden. Both new laws go a long way toward ensuring that Washington continues investing in Alzheimer's research toward a cure, while also focusing on improving early detection, enhancing caregiver support, risk reduction and raising awareness.

President Biden also signed the Alzheimer's Accountability and Investment Act (S. 134 / H.R. 620), which extends through 2035 a requirement that the director of the National Institutes of Health submit an annual budget directly to Congress (a Professional Judgement Budget aka Bypass Budget) estimating the funding necessary for NIH to implement fully NAPA's research goals.

Earlier this year, a new version of bill, H.R. 7218, S. 3775, *BOLD Infrastructure for Alzheimer's Reauthorization Act of 2024*, was introduced in both the House of Representatives and the Senate. The bill would expand key components of the original legislation to 2029 with an additional $33 million appropriation from 2024 to 2029. While it passed unanimously in the House of Representatives, we await its passage in the Senate. After that, the bill will head to the Oval Office for the President to sign. We are hopeful that this will occur before the end of the 2024 calendar year to ensure that the public health programs are well funded for the remainder of the decade.

The bipartisan group of four senators who authored the act include U.S. Senator Susan Collins (R-ME), Catherine Cortez Masto (D-NV), Shelley Moore Capito (R-WV), and Tim Kaine (D-VA).

"Alzheimer's disease is one of the greatest and most under-recognized public health threats of our time. Millions of Americans and thousands of Mainers are living with the disease, and that number is soaring as our overall population grows older and lives longer," said Senator Collins, a founder and Senate co-chair of the Congressional Task Force on Alzheimer's Disease, in a public statement. "Reauthorization of the B*OLD Infrastructure for Alzheimer's Act* will ensure communities across the country have access to resources to promote effective Alzheimer's interventions and better cognitive health that can lead to improved health outcomes."

Mirza, living with Alzheimer's

Dementia, Family, and Conflict: Eldercaring Coordination Can Help

Dementia may impact the lifespan of a person, but it doesn't have to split the family tree.

By Sue Bronson, Linda Fieldstone, Karen S. Willard


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The Dunwithit family hasn't spent holidays together for years. The adult children gave up obligatory occasions to avoid the resulting tensions. But since Dad passed, Mom's confusion has increased, forcing family members back to the table to discuss their views.

Allegations heat the discussion, erupting with blameful degradations, and a legal battle ensues while Mom's condition continues to deteriorate.

Ideally, the Dunwithit family could share information, listen to one another's concerns, priorities, and feelings, and then make informed decisions collaboratively. When families dealing with dementia already have difficulty communicating, they could contact a qualified elder mediator to facilitate a formal agreement to address areas of concern. But, sadly, for some families, elder mediation may be seen as yet another opportunity to blame and vent, further exacerbating their discord.

Conflict adds additional dimension to an already complex situation, especially as dementia progresses. What will cause the flurry of nasty emails this time? Who will get blamed? The deterioration of family functioning has a rippling effect and leads to loss of caregiving ability, which may compromise the safety of the older adult. Everyone suffers. Young and old are watching and learning.

There is a solution. Eldercaring coordination is a court-ordered process designed specifically for families in higher conflict regarding the care and safety of the older person. The highly qualified and trained dispute resolution specialist, called an eldercaring coordinator, works with a family for a period of up to two years to reduce conflict and develop small doable steps in action plans to address the concerns and highlight the voice of the person with dementia. Families learn new ways to communicate and problem solve while building upon their strengths to enhance the safety and well-being of the older adult.

Dementia may impact the lifespan of the person, but it doesn't have to split the family tree. The way a family copes and unites to help their loved one with dementia can build collaboration and reinforce compassion that brings a legacy of peace to future generations.

Eldercaring coordination was highlighted by the United Nations as an Awareness to Action Model for the Welfare of Ageing Persons in honor of World Elder Abuse Day in 2019. To learn more about eldercaring coordination, and to reach out to find an eldercaring coordinator, visit the website www.eldercaringcoordination.com.

ABOUT THE AUTHORS

Sue Bronson (Wisconsin) and Linda Fieldstone (Florida) are co-chairs of the ACR/FLAFCC Elder Justice Initiative on Eldercaring Coordination, along with Florida Judge Michelle Morley. Karen S. Willard, J.D. (Michigan), focuses on elder law and alternative dispute resolution and is a public policy advocate and Alzheimer's volunteer.

RECIPE FOR YOUR HEALTH

APPLE OLIVE-OIL CAKE

NUTRITION FACTS

Servings: 8

Calories: 319

Total Fat 17g

Saturated fat 2.6g

Cholesterol 47mg

Sodium 108mg

Total carbohydrate 36.9g

Dietary fiber 4.8g

Total sugars 19.1g

Protein 7.5g

Vitamin D 4mcg

Calcium 55mg

Iron 2mg

Potassium 392mg

This easy-to-make apple olive-oil cake is delicious and full of healthy ingredients. Be sure to use fresh cold-pressed, extra-virgin olive oil. The freshness of the oil impacts the antioxidant strength and taste. Chickpea flour is high in protein, fiber and minerals. You can use pears when apples are out of season. This recipe is easy to make, especially when using a food processor to mix the wet ingredients.

DRY INGREDIENTS

2 cups of semolina flour

1 cup chickpea flour

1 tsp. baking soda

½ tsp. ground cinnamon

¼ tsp. salt

WET INGREDIENTS

3 large apples, cored and quartered

2 large eggs

½ cup cold-pressed extra-virgin olive oil

⅓ cup maple syrup

DIRECTIONS

1. Preheat oven to 325°F.
2. In a large mixing bowl, evenly combine dry ingredients.
3. In the bowl of a food processor, pulse the wet ingredients until apples are finely chopped. Do not over-process into an applesauce (you want to retain the texture from the chopped apples).
4. Make a well in the dry ingredients and fold in the wet ingredients.
5. Mix until evenly combined, but do not overmix.
6. Coat an 8-inch round cake pan with olive oil.
7. Evenly spread batter into cake pan.
8. Bake for 45 minutes or until done. Serves 8.

NOTES:

1. To make this cake gluten-free, use gluten-free almond flour, though it does taste better with semolina flour.
2. This is a slightly sweet cake. If you like more sweetness, use ½ cup maple syrup.
3. Serve with plain low-fat yogurt and fresh berries or pomegranate seeds.
4. You can use pears instead of apples or a mix of both.

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

SLEEP
A Keystone Habit

From the time we are young we are told to get a good night's sleep, so we'll do well on a test or other important task. As we get older, falling asleep and staying asleep naturally becomes harder, and nearly impossible for the millions of people over 50 who suffer with insomnia. The advice to get a good night's sleep takes a different turn when it's given as one way, along with a Mediterranean diet and exercise, to avoid developing a memory loss condition. In the podcast "Dementia Matters," Dr. Nathaniel Chin and Dr. Allison Reiss, members of AFA's Medical, Scientific and Memory Screening Advisory Board, discussed the importance of sleep and brain health. This column is drawn from their discussion.

Dr. Reiss: Nate, why do you think sleep is so important?

Dr. Chin: I think about sleep from the brain health and lifestyle habit perspective. It is a keystone habit, one that has a big impact on other areas of your life, often triggering a domino effect so that other habits become easier or more manageable. If you aren't sleeping well, I can't imagine you're going to be willing to exercise, eat well, manage stress effectively, enjoy time with others, stimulate your brain beyond what is required and make healthy choices. So while I want my patients to do all those things, and more, I recognize that if their sleep is poor, they may struggle and not because they don't care or believe these things are important.

Dr. Reiss: Are scientists recognizing the importance of the link between sleep and brain function? Are they studying the issue?

Dr. Chin: Yes. I did a quick search on the website www.clinicaltrials.gov looking at sleep and cognition or dementia. There were over 100 studies listed, some completed, others recruiting and some currently happening. Studies like ours at WRAP* look at sleep as a variable when we follow people over time. Interestingly, our study did *not* see a relationship between poor sleep and the development of brain amyloid. Allison, can you share what we know about the glymphatic system?

Dr. Reiss: The glymphatic system is a network of channels or pathways within the brain that helps remove waste products.

It is similar to the body's lymphatic system. It was discovered that the glymphatic system was mostly inactive during wakefulness but becomes active during natural sleep, particularly during stage 3 sleep, which is our deepest stage. Studies have shown impaired glymphatic clearance being associated with neurodegenerative conditions like Alzheimer's but also in aging. It's an area of active investigation and I think a lot still needs to be understood.

We are gaining more and more awareness that amyloid is not the key factor. The study of the glymphatic system in relation to Alzheimer's may broaden to include other measures, such as looking at inflammation, mitochondrial function and bioenergetics.

Given what you've found in the WRAP study and your beliefs about the value of good quality sleep, what are your general recommendations to patients who ask about sleep?

Dr. Chin: I talk about quantity and quality, getting between seven and nine hours of sleep, trying to avoid less than six or more than 10. Good quality means minimal interruptions and feeling refreshed in the morning.

Consider what factors impact your sleep: needing to use the bathroom, pain, racing thoughts, the dog on your bed. Is the sleep environment cool and dark? Do you use a sound machine and blankets? Some medications and substances like coffee and alcohol can lead to poor sleep or impact sleep.

Dr. Reiss: For those with chronic insomnia who know the sleep hygiene factors, what else is available for them?

Dr. Chin: Sleep journaling daily so you can see what factors might be leading to sleep issues. A review of medications, supplements, and substances with your primary care physician. Seeing a sleep medicine physician. Supplements for sleep like melatonin, valerian root and chamomile tea. Avoid benzodiazepines for sleep.

I know it's important to establish and maintain a circadian rhythm, a regular sleep-wake cycle in your life. This is something I know that you are particularly interested in. What can you share about the importance or role of circadian rhythm? Sleep is foundational for our health, but not everyone has the natural gift for sleep, or needs as much sleep as others. Can people function well on less than six hours of sleep, and are they still at risk for developing Alzheimer's?

Dr. Reiss: There are people who may do well with less sleep. I envy them, and likely there's something about them genetically that allows for them to sustain their abilities with little sleep. With that said, I'm not sure how many of them truly exist, and I suspect they are likely the exception and not the rule.

We have clock genes that work together to create a 24-hour rhythm in the body's physiology and behavior. They help us to keep our sleep-wake cycle regular. Our brain and body resist sleeping during the day and staying awake at night, but frequent international travel, shift work and artificial lighting can lead to circadian rhythm disturbance.

There is a back-and-forth interconnection between sleep and neurodegenerative diseases, where on one side, neurodegeneration can lead to disrupted circadian rhythm and sleep disorders. On the other hand, sleep disruption can promote neurodegeneration by inciting neuroinflammation and interrupting the clearing of protein debris in the brain.

Patients with Alzheimer's have disturbances in the expression of clock genes. Light treatment during the early part of the day can improve sleep quality and cognition. Nighttime light exposure has also recently been found to be associated with Alzheimer's.

Dr. Chin: Allison, I'd like to end our conversation with a difficult question I get asked from my female patients. Why are women more likely than men to develop insomnia?

Dr. Reiss: Hormone changes that occur around perimenopause and menopause cause hot flushes, night sweats, restless legs, sleep apnea and mood changes, particularly depression and anxiety. Women are more likely to lose sleep as a result of stress, compared to men.

Women's circadian rhythms can also be affected by societal, work and family pressures, and women are more likely than men to develop pain syndromes like migraines, carpal tunnel, IBS [irritable bowel syndrome], RA [rheumatoid arthritis] and fibromyalgia that can impact sleep.

Dr. Chin: Allison, your answer reinforces a key message that we need to talk openly about sleep issues — address the factors within our control and talk to our health care providers about interventions and ideas to improve sleep. It's worth the effort to get better sleep, for our bodies and brains.

(*WRAP is the Wisconsin Registry for Alzheimer's Prevention, which started in 2001, one of the world's largest and longest running studies of people at-risk for Alzheimer's. For more information, go to www.wrap.edu.)

Continued on following page

Tips for a Snoozy Night's Sleep

Go to sleep and wake up at the same time every day, including weekends. It's important for your body to have a regular sleeping schedule.

Set a relaxing bedtime routine, such as listening to calming music, reading a book or taking a warm bath or hot shower.

Make sure your bedroom is cool. Your body temperature naturally decreases to initiate sleep. A bedroom temperature between 60 to 67°F helps promote sleep.

Make sure your bedroom is quiet. Turn off noisy distractions such as a TV. Silence unwanted noise with earplugs or use "white noise," such as from a fan, sound machine or an app.

Make sure your bedroom is dark. Use a blackout shade to block out unwanted light and dim the lights on your digital clock.

Sleep on a mattress and pillows that are comfortable and supportive.

Finish eating meals two to three hours before bedtime.

Exercise regularly. A low-impact fitness program, like walking, swimming or yoga, is helpful for managing pain and stiffness and improving sleep.

Try to limit how many caffeinated products you consume in the afternoon.

Alcohol and nicotine in your body can disrupt sleep and can cause nighttime waking. For optimal sleep, skip them close to bedtime or altogether.

Turn off electronics that emit blue light, such as your computer or phone, one to three hours before bedtime.

Limit napping to less than 60 minutes and not late in the afternoon (ideal is between 12 noon to 2:00 p.m.)

Manage stress by writing in a journal, using a weighted blanket, listening to calming music or mindfulness apps.

If you can't fall asleep within 20 minutes, get up and do something boring, using as little light as possible.

ABOUT THE EXPERTS

Nathaniel Chin, M.D., is the medical director of the Wisconsin Alzheimer's Disease Research Center. Allison Reiss, M.D., is an associate professor of medicine at NYU Grossman Long Island School of Medicine. Both are members of AFA's Medical, Scientific and Memory Screening Advisory Board.

The "Dementia Matters" podcast is available at adrc.wisc.edu/dementia-matters.

Brain Health
IN THE NEWS

Dementia Risk & Watching TV

Individuals who watch more than five hours of TV a day are nearly 50 percent more at risk of developing dementia compared to those who watch less television, according to researchers from Tianjin Medical University in China.

The participants who watched more than five hours often had less grey matter and smaller memory centers, the researchers said.

Experts believe that being inactive can trigger chronic inflammation and reduce blood flow to the brain.

According to the findings, excessive computer use was not associated with an increased risk of developing dementia.

Toronto Sun

Alcohol Consumption Raises Dementia Risk

In a recent study published in the journal *eClinicalMedicine*, researchers investigated whether raising the consumption of alcohol causes the risk of developing dementia to increase among individuals who currently drink. Their findings indicate that, as predicted, as alcohol consumption increases, so does dementia risk, challenging previous knowledge and suggesting that no amount of alcohol is safe when it comes to dementia prevention. Genetic analysis showed that people with genes linked to higher alcohol consumption were more likely to develop dementia, especially women. This suggests that alcohol may play a direct role in increasing dementia risk, particularly with heavier drinking.

News Medical

Excessive Light Pollution Risks

Eighty percent of the world's population are exposed to excessive or inappropriate use of artificial light outdoors, dubbed light pollution. Light exposure at night can lead to many health problems, including disrupted circadian rhythms and subsequent sleep problems — a known risk factor for neurodegenerative diseases. Researchers have now found that exposure to light at night could increase the prevalence of Alzheimer's disease, especially in a younger population.

In some places around the globe, the lights never go off. Street lights, roadway lighting and illuminated signs can deter crime, make roads safer, and enhance landscaping. Undisrupted light, however, comes with ecological, behavioral and health consequences.

In the United States, some states have legislation in place to reduce light pollution; however, levels of light at night remain high in many parts of the country. Now, researchers there have investigated correlations between outside nightly light pollution and Alzheimer's disease (AD).

"We show that in the U.S. there is a positive association between AD prevalence and exposure to light at night, particularly in those under the age of 65," said first author of the *Frontiers in Neuroscience* study, Dr. Robin Voigt-Zuwala, an associate professor at Rush University Medical Center. "Nightly light pollution — a modifiable environmental factor — may be an important risk factor for AD."

Science News

Variety is the Spice of Learning

When Ilber Manavbasi attempts a tricky piano riff, he rehearses more than the notes on the page.

"I practice in diverse conditions and contexts. I practice hungry, tired, angry and happy. I practice different songs at different speeds and sometimes with different pianos," said Manavbasi, a graduate student researcher at the Beckman Institute for Advanced Science and Technology. "It's the variety of practice that makes me a better performer." Variety may also make us better learners, according to recent research conducted by Manavbasi and his colleagues at the University of Illinois Urbana-Champaign. The researchers observed that varied practice, not repetition, primed older adults to learn a new working memory task. Their findings, which appear in the journal *Intelligence*, propose diverse cognitive training as a promising whetstone for maintaining mental sharpness as we age.

Continued on following page

"People often think that the best way to get better at something is to simply practice it over and over again, but robust skill learning is actually supported by variation in practice," said lead investigator Elizabeth A. L. Stine-Morrow, a Beckman researcher and professor emerita of educational psychology at Illinois.

"While the importance of diversity in practice has been well established in the area of motor learning, our study demonstrated that this principle applies to the development of mental skills as well," she said.

ScienceDaily

Falling for Financial Scams May Be a Sign

Findings from a new University of Southern California Dornsife study suggest that when older adults fall for financial scams, it could be an early warning sign of Alzheimer's disease. Researchers used MRI scans to find that older adults with thinner brain regions linked to memory and decision-making — areas often affected early in Alzheimer's — were more likely to be vulnerable to financial scams.

The findings offer hope that financial vulnerability could be used as a simple screening tool to help identify early signs of cognitive decline, especially in people over 70.

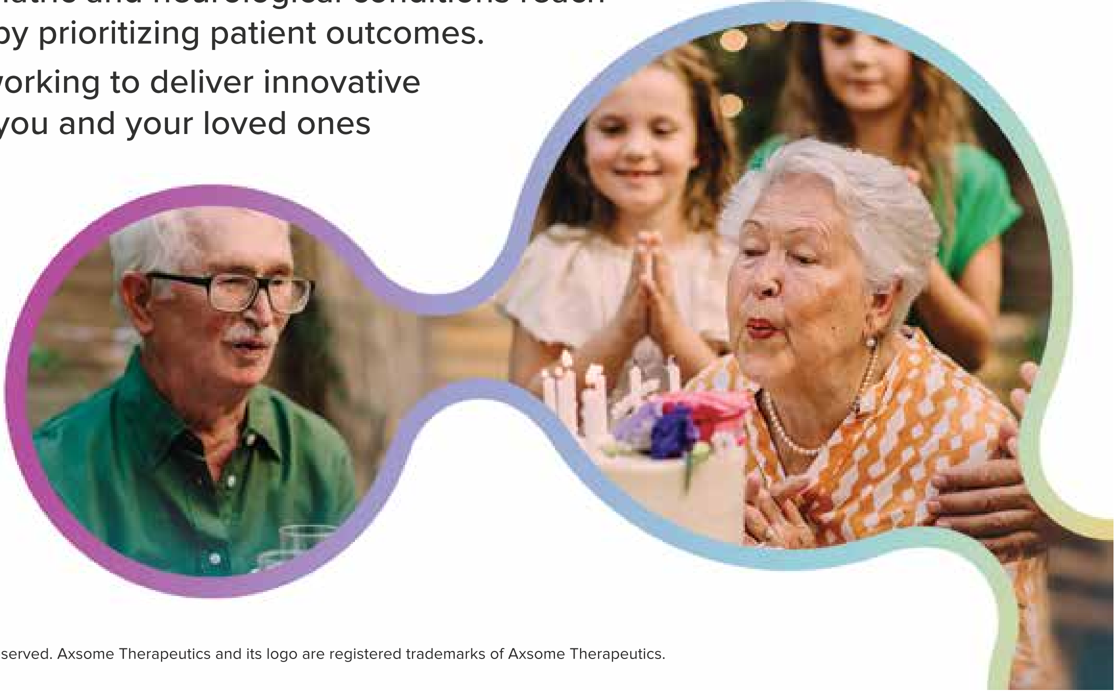
ScienceDaily

Hopeful Evidence About Prevention

The 2024 update of the *Lancet* Commission on dementia provides new evidence about dementia prevention, intervention and care. As people live longer, the number of people who live with dementia continues to rise, even as age-specific incidence decreases in high-income countries. This further emphasizes the need to identify and implement prevention approaches. Cognitive and physical reserve develop across the life course and a reduction of vascular damage by reduced smoking and treatment of high blood are likely to have contributed to a reduction in age-related dementia.

Evidence is increasing and is now stronger than before that tackling the many risk factors for dementia — less education, hearing loss, hypertension, smoking, obesity, depression, physical inactivity, diabetes, excessive alcohol consumption, air pollution and social isolation — reduce the risk of developing dementia. New compelling evidence finds that untreated vision loss and high LDL cholesterol are also risk factors.

The Lancet Group, 2024 Commission Report



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AFA provides funding for research aimed at improving diagnosis and treatment, finding a cure and improving the quality of life for millions of individuals living with Alzheimer's. Here is a sample of our ongoing research partners:

- NYU Langone Hospital-Long Island
- The Broad Institute of Harvard & MIT and One Mind
- Litwin-Zucker Research Center for the Study of Alzheimer's Disease at Feinstein Institutes for Medical Research
- Emory University's Goizueta Alzheimer's Disease Research Center (GADRC)
- Hadassah Hebrew University Medical Center
- Stony Brook University
- City College of New York

Through these collaborations, we drive innovation and discovery in Alzheimer's research.

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