Alzheimer's TODAY®

The Official Magazine of the Alzheimer's Foundation of America

The Power of Song:

Memory Choirs

Solving Dementia Difficulties

A Hidden Risk: Loneliness

VOLUME 20, NUMBER 3

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A Message from Our President & CEO

CHARLES J. FUSCHILLO, JR.

When I am facing a challenge in life and am looking for advice, I turn to my family, friends or colleagues whom I trust. They may offer a fresh perspective to a solution and provide encouragement.

I hope you feel that way about *Alzheimer's TODAY*, a trusted resource with caregiver friends and experts providing tips and inspiration that add to your own journey.

In this new issue:

We have a beautiful story about the growing number of memory choirs around the country. Eyleen Braaten, executive director of Giving Voice in the Twin Cities of Minnesota, says, "The act of making music together taps into abilities that remain strong even as dementia progresses, fostering a sense of purpose, belonging and emotional well-being." **(p. 9-10)**

Actress Natalie Toro, who cared for her mom for nine years at home, recommends that caregivers "keep a planner for every year, with written doctor appointments, the trips you took, your clocked hours, and the hours for aides. Save your receipts for everything, organized, even for a cup of coffee or a candy bar." Medicaid asked her to prove every hour of her mother's care for the years she lived with her, with receipts to back it up. **(p. 13-14)**

Alzheimer's and other forms of dementia-related illnesses often bring behavioral and quality-of-life difficulties that you can anticipate. We examine three of them more closely, along with some ways to manage: sleep disruptions, agitation or aggression, and UTIs. **(pp. 15-19)**

Our Brain Health section takes on the hidden risk factors of loneliness. Good news, though, we know that loneliness doesn't have to be a permanent state. It's a signal (like hunger or thirst) telling us to seek connection. **(p. 21-22)**

I am inviting you to take a look at our redesigned website at alzfdn.org. The new AFA website is now easier to use and an invaluable trusted resource to guide you on the journey of caregiving. Our Helpline (866-232-8484) has also been expanded 24/7 with our virtual assistant "Allison." Website users can ask questions by typing text into a chat box or through voice interactions. If you need to speak with one of our social workers, you can submit a ticket, and your call will be returned as soon as possible.

We remain committed to helping you. I hope that you can find gratitude in all your days.

Warmly,

CAREGIVER WELLNESS

Finding Gratitude

"There is emotional pain that all of us feel. It is difficult watching someone we love decline in front of our eyes," admits Ann Favreau of Venice, FL, who is a care partner to her husband, Ray, living with vascular dementia."Sadness is part of the caregiver's journey."

Favreau has begun writing poetry.

"Substituting gratitude for sadness became a way for me to reframe the situation. I needed to find joy in this journey. As I write, I find it cathartic. I examine my day to determine if I am experiencing any joy."


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The In Between

By Ann Favreau

Can I find joy in the in-between
The time each day that's seen
As being aware of the world?

Does the sunrise stir my soul
As I pour milk into the bowl
Of day's inauguration?

Before I realize, it's afternoon.
Tasks undone abound and soon
I've run out of ambition.

Sunset heralds in the night.
Has joy become an oversight
Slipping into oblivion?

No, it's been present all along
In floral scent and bird's sweet song
Despite his lack of conversation.

A quiet prayer and lively tune
Intercepted afternoon
Without my realization.

The in betweens been filled with joy.
Happiness' uplifting buoy
Has brought me satisfaction.

Just Breathe

The 4-7-8 breathing technique, developed by integrative medicine guru Dr. Andrew Weil, is a simple and powerful breathing technique designed to promote relaxation and reduce stress.

- **Exhale completely through your mouth with a "whoosh" sound.**
- **Inhale quietly for 4 seconds.**
- **Hold the breath for 7 seconds.**
- **Exhale for 8 seconds.**
- **Repeat up to 4 times.**


© Aaron Amat | Dreamstime

This method helps regulate the nervous system and can lead to improved mental and physical well-being. It's an accessible practice suitable for anyone seeking a quick way to alleviate stress and enhance calmness. The 4-7-8 breath is so effective, it's included in the core curriculum at the Andrew Weil Center for Integrative Medicine and used in practice to alleviate anxiety symptoms and support management of stress. —*AWCI Magazine*

What I'd Wish I'd Done

"I should have started earlier to search out an adult daycare so that I could reclaim part of the day for myself, including time for exercise."

—Martin J. Schreiber, author of *My Two Elaines*

A 10-Second Habit That Boosts Focus

Boredom, fatigue and anxiety can all get in the way of focusing. Not being able to pay close attention to something can turn a relatively short task into something that takes three times as long to complete. It can also be dangerous, such as if you are trying to focus on the road while driving.

According to a neurologist, however, there's an easy way to get your brain to concentrate on the task at hand that only takes 10 seconds.

If you want to zero in on things better, neuroscientist Dr. Hayley Nelson, Ph.D., tells *Parade*, "Splashing cold water on your face can offer a quick reset for focus."

Nelson explains that this simple action activates the mammalian dive reflex, which is an evolutionary response designed to help humans survive when they emerge in cold water. She says that when cold water hits the face, especially around the eyes and forehead, it sends signals through a major cranial nerve called the trigeminal nerve to the brainstem. When this happens, it triggers a rapid shift in the autonomic nervous system, which is a part of the nervous system that controls involuntary functions in the body, such as heart rate, digestion and breathing.

—*Parade*


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Take Care of You

Mental Fitness Tips to Improve Well-Being

Dr. Shannon M. Bennett, associate director of the Center for Youth Mental Health at NewYork-Presbyterian, recommends:

1. Plan regular check-ins.
At least a few times a day, pause and check in with yourself. Scan your body to notice how you feel mentally and physically. Take a few slow deep breaths to release any tension.

2. Practice single-tasking.
When we are single-tasking and a challenge arises, we are more able to remain calm, think through and manage the situation.

3. Let your mind rest.
For many of us, our first instinct during a free moment is to pick up our phone or check what's next on the to-do list. Taking as little as five to 10 minutes to sit alone with your thoughts can help us recharge and prevent burnout.

4. Practice your reactions.
When we're in a state of shock or heightened emotions, it can be difficult to think and act rationally. Try writing down a list of coping thoughts or phrases, such as "I am going to be OK" or "This is just temporary."

5. Make time for social connection.
Socializing in person is known to improve mental and physical health, resilience and even the length of your life, while reducing loneliness, anxiety and depression.

6. Remember to get physical exercise.
Working in some form of physical movement into your day can help you feel more relaxed and in touch with your body. Choose an activity you enjoy; that way, you'll be more likely to make a habit out of it.

7. Prioritize sleep.
Getting quality sleep each night is crucial for mental health and for regulating our emotions.

—*NewYork-Presbyterian Health Matters*


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CAREGIVER RESOURCES

Top-Rated Support Programs

best programs for caregiving | guiding you to proven support for dementia care

A partnership between Benjamin Rose Institute on Aging and Family Caregiver Alliance

Best Programs for Caregiving (BPC) has been expanded to include a new website for family caregivers to learn about and enroll in proven support programs. BPC (bpc.caregiver.org) is a free online directory of nearly 50 top-rated programs that support caregivers of people living with dementia. The website allows individuals to enter their ZIP code to discover programs available in-person from local organizations, or nationally by telephone and online, which can be especially valuable for people living in remote or rural areas. Detailed information on the website includes the program description, the mode of delivery, any fees and how to enroll. Best Programs for Caregiving was developed by Benjamin Rose Institute on Aging in collaboration with Family Caregiver Alliance.

Here for You: AFA Helpline

Do you struggle to bathe your loved one? Is your family arguing about your dad's care? Do you have memory concerns of your own? The Alzheimer's Foundation of America Helpline is here for you. Reach out to the AFA Helpline to connect with licensed social workers who can provide compassionate guidance, emotional support and practical solutions tailored to your situation. Last year, AFA support expanded 24/7 with a virtual Helpline assistant, "Allison." Website users can ask questions by typing text into a chat box or through voice interactions on alzfdn.org. Remember, support is always within reach.

ConnectShareCare Offers Lifeline

Coping with illness, caregiving or loss can be deeply isolating. Dartmouth Health's ConnectShareCare (connectsharecare.org) platform offers a supportive online community to help people navigate these challenges. The platform has grown to more than 400 members and continues to expand, with plans for additional groups focused on long-term illness management. Created by a collaborative team of patients, caregivers, health care professionals and researchers from The Dartmouth Institute, ConnectShareCare provides a safe space for sharing personal stories, accessing crisis resources and finding in-person events — all aimed at fostering connection and compassion.

"ConnectShareCare is not about providing medical advice and treatment recommendations," said Sandra L. Knowlton-Soho, R.N., program manager of ConnectShareCare in the Dartmouth Health Office of Care Experience. "It is about people with lived experience talking to each other about their own frustrations or what has — or has not — worked for them. It's about people being able to say, 'I'm so glad to have found a group of people that make me feel like I'm not so alone.'"

Care That Opens Doors

By Everett Waters, Ph.D.

When we think of caring for someone with Alzheimer's disease, our first instinct is often to protect. We imagine soothing voices, watchful oversight and efforts to reduce confusion and risk. These responses are deeply human and essential. But in focusing solely on safety and comfort, we may be missing another vital dimension of care.

John Bowlby, the British psychiatrist whose attachment theory spans infancy to old age, reminds us that caregiving relationships are not just about protection — they're also what gives us the security to explore, to engage and to live as fully as possible. He called this dynamic the "secure base": a foundation of emotional safety from which people of all ages can reach out, try new things and stay connected to the world around them.

This idea — that security enables exploration — can seem counterintuitive in the context of Alzheimer's disease. Exploration here doesn't mean wandering into danger. It means emotional, social and creative engagement: reminiscing with family, participating in a familiar ritual or finding joy in small discoveries. Even as abilities change, the capacity for meaningful experience often remains.

For those living with Alzheimer's, the world narrows on its own. If caregivers focus only on guarding and soothing, they may unintentionally reinforce that shrinking. But when caregiving is also about creating a secure base, it opens space for spontaneity, curiosity, and joy — for both the person with dementia and those who care for them.

This may take the form of supporting familiar passions in new ways — like listening to music with a former musician, cooking a simple dish with a lifelong food lover or helping someone choose clothes that reflect their personal style. It might also involve small acts of exploration: coloring with a grandchild, participating in a chair yoga session, watching short, engaging videos or simply enjoying a walk outdoors. These are not just pastimes — they are ways of affirming agency, connection and life.

Serving as a secure base takes creativity, patience and flexibility. But the rewards can be profound. It allows us to support not just safety, but dignity, vitality and continued possibility.

As Bowlby taught us, security is not the opposite of freedom. It's what makes freedom possible. For those living with Alzheimer's — and for those who love and care for them — holding on to that truth can make all the difference.

ABOUT THE AUTHOR

Everett Waters, Ph.D., emeritus professor of psychology at Stony Brook University, is an internationally known researcher on infant-parent and adult attachment relationships. Additional contributors included Cory Chen, Ph.D. and Elizabeth Schumaker, Ph.D., ABPP.

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Book Corner

Still Me

A neuroscientist's guide to caring for someone with dementia

BY DR. SABINA BRENNAN

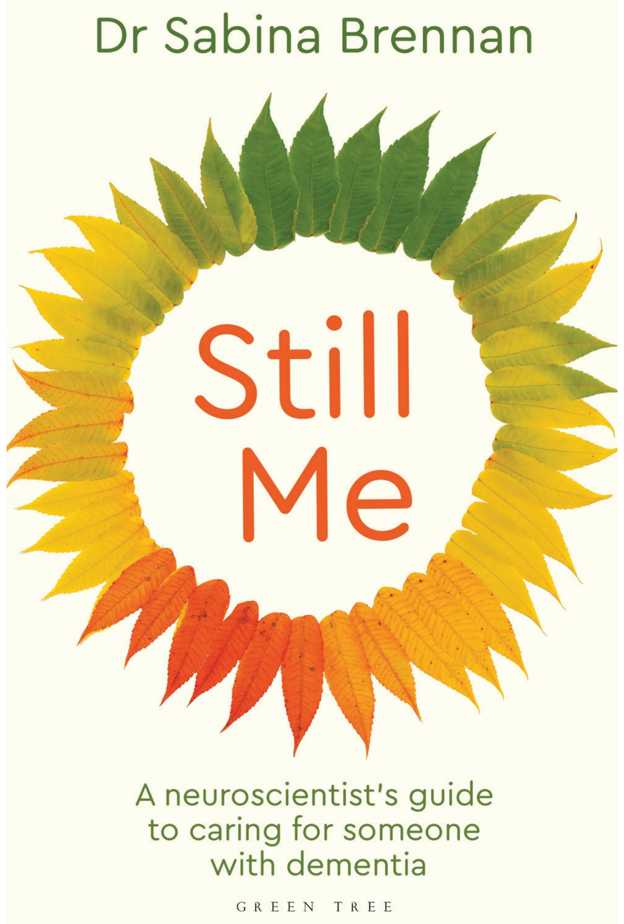
In her new book, *Still Me,* neuroscientist and psychologist Sabina Brennan has put together the equivalent of an at-home college course for care partners of someone with a memory loss condition. Meticulously researched and presented, it will equip the care partner to understand what is ahead and how they can prepare their person and protect themselves. The book is better suited if a partner's loved one has just been diagnosed or is in the early stages of dementia. Investing the time to read the book and work on the assessments at the end of each chapter will educate and prepare them for the journey of caring they face.

"When dementia arrives in your life, it doesn't come with extra hours, extra energy or the extra headspace you need to come to terms with the diagnosis, make decisions AND meet the everyday and ever-increasing demands of providing care," Brennan writes in her introduction. "Dementia arrived in my life at a time when an ongoing stressful situation at work was impacting significantly on my health and a difficult boss was placing unreasonable demands on my time. I totally understand how the idea of self-care might feel like just another task on an already overloaded to-do list."

Many books on caring for a person with a memory loss and self-care have come across my desk, but I have never seen anything like the depth of *Still Me.* A first reaction could be, *Oh, this is so much work*, but Brennan has creatively put it together so that each chapter could be seen as a class. In class after class, week after week, we build on our knowledge and finish the semester with a sense of accomplishment. We do the work and then the knowledge cannot be taken from us. That's how I feel about this book: invest the time upfront while you still have time, and the knowledge will carry you through the challenges and rewards ahead.

In terms of the content, Brennan's book offers the basics — an explanation of the condition, managing feelings and what symptoms to look for that indicate you are overburdened. In this sense, it will be a helpful resource to refer to as your journey becomes more difficult.

"Once you have a good understanding of the disease, the aim really is to help you to focus on the person rather than their disease," she writes. "Developing dementia won't stop your relative from wanting the same things we all want — happiness, enjoyment and love. All of these are still possible once you shift focus from the disease to the person."



Dr Sabina Brennan

Still
Me

A neuroscientist's guide
to caring for someone
with dementia

GREEN TREE

Brennan directed a dementia research program at Trinity College Dublin, where her research included examining the impact caregiving has on spouses. Her work has involved advising both the Irish government and the All-Party Parliamentary Group on Longevity in the United Kingdom, bringing attention to the urgent needs surrounding dementia care and dementia risk reduction.

Reviewed by Retta Blaney, Writer/Editor
Alzheimer's Foundation of America

Precious Memories Choir
© Hedi Rudd Photography

The Power of Song

A growing number of memory choirs provide joy and hope to individuals with dementia and their caregivers.

Creating the Precious Memories Choir was far from the minds of Edith Lawrence-Hilliard and Keretha Cash when they attended an Alzheimer's conference in Madison, WI, in 2019.

"The conference brought in a choir from Milwaukee, and we were a bit perturbed because we have good choirs here in Madison, and we wondered why they were bringing in one from Milwaukee," Lawrence-Hilliard says. "When the choir was introduced, it was announced that the majority suffered from dementia and Alzheimer's and included their caregivers. We looked at each other and said, 'Ah-ha, Madison doesn't have a choir like that.'"

So along with Dr. Fabu Carter, senior program manager for retention, event programming and sponsorships at the Wisconsin University-Madison Alzheimer's Disease Research Center, they decided to create one, meeting at CocoVaa Chocolatier to eat chocolates and brainstorm, ultimately choosing to focus on gospel music.

"Spirituals and gospel are African Americans' great gifts to this country and the world," says Carter, who is also the senior program manager for recruitment and retention with African Americans Fighting Alzheimer's in Midlife at the research center.

Starting with five African American members, then stopping during the pandemic, they now have 13 members, Black and white, who perform at nursing homes and in malls. Cash and Carter are choir co-chairs; Dr. Sheryl Henderson is director. Singing experience is not required.

"We work with you where you are," Carter says. "No one will turn you away."

Choir members and audiences are touched by the messages of the lyrics. One song in particular, "I Need to Survive," stood out for Cash at a performance.

"I felt the atmosphere and spirit of the place change.

Continued on following page

We need people to survive and people with Alzheimer's need to know their families want them to survive. That's indicative of our mission."

Gleeful Choir

Caregivers overwhelmingly describe the Utah-based Gleeful Choir as a source of joy, emotional relief and meaningful connection with both their loved ones and with a wider community of caregiving peers. Choir director Emily Christensen formed Gleeful Choir in 2018. As a music therapist working in memory cafes and hospice care, she had heard about memory loss choirs. She worked for Jewish Family Services, which had a music and memory program, so she collaborated with those involved to form the choir. It meets weekly at the local library for a one-hour rehearsal and 45 minutes of refreshments and socialization.

Gleeful Choir about to perform.

She's experienced surprise at her choir members' ability to sing in rounds, with each side taking its part for songs like "Downtown." The choir gives five or six concerts a year at Alzheimer's walks, senior centers and conferences on matters dealing with aging.

"They do an amazing job. I did some research and found that people with dementia are able to learn new material week to week."

The choir is fun for the memory loss participants and for their caregivers who form friendships that extend past the time when their person has died. Christensen, who has a private music therapy practice, sees music as one of the most powerful ways to connect.

"They can do so much more in a choir than in other areas of life. I'm always amazed at what people can do."

Giving Voice

In the Twin Cities of Minnesota, Giving Voice formed in 2016. It was such a success that two more memory loss choirs were created, then two more. Eyleen Braaten, executive director since 2021, said the decision was made to help others form their own.

Giving Voice choir rehearsal.

"We realized we could teach people to fish rather than give them the fish. We really see us now as being an organization focused on inspiring and equipping communities to do the work. More singing is better."

Since 2017, Giving Voice has helped launch more than 70 choirs in the United States, Canada, Australia and the United Kingdom. This fall, they expect 15 more in rural Minnesota and Wisconsin. They accomplished this by developing a tool kit as a guide, promoting it in senior centers, memory cafes, conferences and with the Rotary Club, "the doers."

"The act of making music together taps into abilities that remain strong even as dementia progresses, fostering a sense of purpose, belonging and emotional well-being," Braaten says. "Our choirs not only uplift spirits but also break down the isolation that often accompanies dementia, creating a space where every voice is valued."

Choirs like these are part of a rapidly growing field known as neuroarts, she said.

"We are calling it a movement. We have choirs that are starting with our tools every semester."

Giving Voice network choirs across the country and tool kits for forming your own choir can be found at givingvoicechorus.org.

"Alzheimer's doesn't wait. We have to get out in the community and make it happen. The magical part of singing is that it's accessible. Music meets you where you are. Our No. 1 goal is to change the narrative of living with Alzheimer's."

And it connects people in surprising ways. Braaten remembers Emily, a daughter who used to bring her mother, who had been nonverbal for years due to her condition, to the weekly rehearsals and her mother sang every song. One day, after singing Elvis Presley's "Can't Help Falling in Love with You," which had been Emily's wedding song, her mother looked right at her and said, "Emily, I love this song and I love you." It was the first time her mother had known her and called her by name in years.

Photos courtesy of Precious Memories, Gleeful and Giving Voice choirs.

AFA Member Close-Up

Amazing Place, TX

Cooking That Stimulates Brain Health

Mike leaves the planning of his doctor visits up to his caregivers, with one exception. If it's meatloaf day at Amazing Place, he makes sure any appointment on that day is rescheduled. The three-course lunch at the Houston day facility for people with mild to moderate memory loss conditions and their caregivers is an anticipated part of the day for others as well.

Culinary director and chef Michael Lieb attributes this to Amazing Place, an AFA member, being the only day program in the country to follow guidelines set by the evidence-based Memory Preservation Nutrition Program™ developed by Nancy Emerson Lombardo, Ph.D. It pulls together hundreds of studies to improve cognitive and emotional health.

Founded in 1996, Amazing Place is a faith-based nonprofit governed by 16 churches and five at-large individuals. The intention with all meals is to stimulate the brain.

Continued on following page

Amazing Place chef Danny Yaburo at work.

"We cook food that maybe a lot of older people didn't get growing up. Brussel sprouts and artichokes are new to them, and they're surprised that they like them," Lieb says, adding that the nutrients from artichokes "go straight to the liver and help the body feel better."

"There are no refined grains or white flour, rice or sugar in the kitchen. There are lots of fresh fruits and vegetables, especially colorful ones that are flavonoids. We try to give variety to keep everyone happy."

Flavonoids are plant compounds in fruits and vegetables that have antioxidants and anti-inflammatory properties and are linked to improved cognitive function.

Foods are flavored with spices rather than salt. Lieb said his recipes contain less than a third of the daily recommendation for salt usage.

"We make all the salad dressings from scratch using yogurt and lots of herbs and spices to keep sodium levels down and give flavor."

Entrees are mostly fish or chicken, except for once a month when red meat, from grass-fed animals, is served. No sauces or gravies are served. For dessert, he bakes with coconut sugar or brown sugar.

Each table has a staff member to encourage socialization, and people are seated with those with whom they are most likely to have a connection, such as the Texans at one table, the Midwesterners at another, and people who worked in a common field, such as education, at their own table.

"Lunch is my favorite part of the day," says day program participant Bette. "Not only is the food good but it's so nice to sit with others at the table and share stories about our lives."

When the menus for the month are posted, participants pay careful attention. If a change is made later, they let the staff know they were expecting the original meal. The lunch menu is also announced in the morning. Lieb says participants are quick to notice changes.

"I'm amazed that three hours later they pick up on that. It's something they remember and think about. They might not know what activity they did 30 minutes ago, but they remember exactly the menu we gave them three hours ago."

Photos courtesy of Amazing Place

Caregiver Voice

My Journey with Mom

BY NATALIE TORO

Born in Puerto Rico, my mother, Luz, aka Lucy, arrived in New York City at 13, embodying the resilience and ambition of stories much like the musical *West Side Story*. Her beauty often stopped people in their tracks, mistaking her for Natalie Wood, which is why she named me Natalie. Much of my success as a Broadway actor with a career spanning more than three decades is due to my mother's relentless drive to see me succeed.

Despite being a young single mother raising my brother, Steven, and me, her work ethic was unparalleled. Later, she welcomed our baby brother, Kris James Diaz, into our family.

Working 12- to 16-hour days as an X-ray technician and later as a CAT scan and MRI supervisor, she proudly retired to Port Saint Lucie, Florida, humorously choosing it because her name was in the name.

Mom was my best friend. She traveled to see my shows, even flying to Tokyo for *In the Heights*. She loved music, dancing, and was the life of any party. Her Alzheimer's diagnosis was a shock, especially since she had already battled non-Hodgkin's lymphoma while living with me in the Bronx in a small one-bedroom apartment.

In 2020, during the pandemic, she moved in with me and my spouse in upstate New York. Her illness progressed. Navigating Alzheimer's was the hardest role I have ever played. I sought solace in resources like *The 36-Hour Day*, a book that changed my life. I joined caregiver support groups, spoke to Alzheimer's advocacy groups, and a therapist, yet I often felt alone.

With all the advice on "aging in place," I decided to add an extension to my little 872 sq. ft. house. She needed space for the aides. I wanted her to stay at home. But construction issues became challenging, and we could not move her in. Once again, a major decision was looming. My therapist asked me, "What is your plan B"? Plan B? I didn't have a plan B.

I reached out to all my resources once again, and they helped me find an assisted living memory care home for mom. This was supposed to be temporary.

Lucy Diaz enjoying a Florida beach

The Struggle is Real

Changing my mom's living situation marked a turning point in her journey. The relocation seemed to trigger a rapid decline, as if her brain used it as a reason to deteriorate with each passing day. Despite recreating her room with familiar furniture from our home and being there daily, she became increasingly angry, fearful and began experiencing hallucinations. Without medication to manage these symptoms, I faced the daunting task of rallying her neurologist to take action.


Mom and daughter on a cruise.

The facility struggled to care for her, and I often found medication discarded under her bed or on the floor. Her behavior eventually led to eviction, and an arrest, unbelievably so, after slapping another resident, leaving us in a desperate search for a new solution.

The word "advocate" became central to my life as I tirelessly sought ways to help her, to keep her calm, and to ensure her safety.

I couldn't go back to work even if I wanted to.

The summer of 2023 was particularly challenging, as I lost my sense of self amid isolation and stress. "Aging in place" advice, construction issues and Medicaid battles added to my anxiety. The financial burden of nursing home care loomed large, yet her dignity and legacy remained my focus.


Actress Natalie Toro as Eva Perón in *Evita* on its 20th anniversary tour.

When my mom needed to transition into a nursing home after her hospital stay, the uncertainty of Medicaid approval added an unbearable weight to my already heavy heart. Even with her approval for Community Medicaid, the question of why she wasn't eligible for Chronic Care Medicaid haunted me. I hired an attorney to help me pilot this unknown path. The nursing home provided excellent care, but the staggering $180,000 bill is a constant source of worry.

The fear is still palpable, as my attorneys and I engage in a battle with Medicaid and the county, awaiting a fair hearing for over a year. It was a bitter pill to swallow, knowing that my mom, who dedicated her career as a civil servant to the State of New York, faced such bureaucratic obstacles in her time of need.

This experience taught me the harsh reality that navigating Medicaid requires not just persistence but also legal support. Medicaid had me prove every hour of her care for the years she lived with me, with receipts to back that up. I spent over 160 hours doing this for them only to be shut down and told I was wrong. I am not.

On May 10, 2025, the day before Mother's Day, my beautiful mom, Luz N. Diaz, released her soul to the heavens after a nine-year battle. Her legacy as a civil servant in New York and a loving mother will never be forgotten. I feel so blessed to have shared this journey with her, filled with laughter, tears and love.

As I slowly return to my career, I plan to write a book to help other caregivers at the start of their Alzheimer's journey. If I can change one life through my performances, and change one life with my book, then I've done my job.

NATALIE TORO'S 5 CARE TIPS FOR CAREGIVERS

- **Keep a planner for every year** with written doctor appointments, the trips you took, your clocked hours, the hours for aides. Save your receipts for everything, organized, even if it's for a coffee or a candy bar. Medicaid asked me to prove every hour of my mother's care for the years she lived with me, with receipts to back that up.
- **Maintain a journal of behavioral changes** about your loved one and even yourself. Remember that you are also a part of this journey, and this will certainly change you.
- **Try not to "fluff off" the advice of others** when they tell you to take care of yourself. You will not feel like you're the important one, and you'll say that you're fine. The bottom line is that you are not fine, and you need respite and breaks. This will break you.
- **Advocate and ask questions** even if you think they are absurd. My favorite poet, Rainer Maria Rilke says, "Live the question."
- **Tell your loved one that you love them** a million times, kiss them a million times, smell their hair, their clothes, hold their hands, look into their eyes. It will never be enough.

ABOUT THE AUTHOR

Natalie Toro is an accomplished actress and singer, Broadway and beyond, known for roles in Les Misérables, Cats, Evita, A Tale of Two Cities *and* In the Heights. *Visit her website at www.natalietoro.com to learn about her lifetime of achievements.*

Photos courtesy of Natalie Toro

Dementia Difficulties

Understanding Sleep Disruptions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> *"People with dementia cannot go to sleep at 10 p.m. and wake up at 8 a.m."*
>
> –Mehrdad Ayati, M.D.

Many people experience changes in sleep patterns as they age but none as acutely as those living with memory loss conditions. Mehrdad Ayati, M.D., a physician, author, and educator, explains how the brain's circadian rhythm impacts our sleep-wake cycles, and why there's a link between sleep and memory.

Getting quality sleep is essential for restoring and rebuilding the brain. It plays a key role in memory consolidation, clearing out waste and keeping cognitive functions sharp. During sleep, short-term memories stored in the hippocampus are processed and transferred to the cerebral cortex, where they are turned into long-term memories. This overnight "filing system" helps the brain organize information and make room for new learning the next day.

"Sleep is like the office janitor," Ayati says, cleaning the office up at night. Without sleep, we can't form or maintain the pathways in our brain that allow us to learn and create new memories."

Continued on following page

Circadian Rhythm

The brain’s internal biological clock, or circadian rhythm, regulates our sleep-wake cycles. Our bodies keep track of day and night through the natural rhythm of light and darkness captured by the lens of our eyes. When light enters the eye, it signals the pineal gland to regulate melatonin production — a hormone that promotes sleep, synchronizes our internal clock and influences many other essential body functions.

But this mechanism is ineffective for people living with dementia.

People living with Alzheimer’s don’t have circadian rhythms. “The roads are getting blocked by amyloid plague and tau tangles,” Ayati says.

Because of this, people with memory loss conditions have a very sporadic sleep cycle, often sleeping for two hours and then awake for several hours and then sleeping again. This cycle can happen during the day or night.

In many cases, your person will sleep more as the condition progresses, sometimes as much as 20 hours a day, Ayati says. That is to be expected.

Ensure that your person can be turned in bed to prevent pressure ulcers. When they are awake, make sure they are hydrated and getting some nutrition. “If you see they wake up for three or four hours a day and they’re not really functioning, then you should discuss with your doctor,” Ayer says.

“The brain is in a dementia situation. It’s very simple. I know it’s a term we don’t like to hear, but it is a ‘dying’ brain’. It’s downsizing its business. Imagine a shopping mall that is closing its stores. The brain is under inflammation and struggling. That’s why it tries to hibernate.The reason the brain sleeps more is because it’s trying to save its living neurons to still be active for the vital organs. It selectively chooses to be in sleeping mode to survive. Don’t discourage this excessive sleep.”

Adapted from AFA’s Care Connection webinar “Sleep and Dementia.” Mehrdad Ayati, M.D., is a physician, author and educator. An adjunct associate professor of medicine at Stanford University School of Medicine, he is a medical advisor to the United States Senate’s Special Committee on Aging and co-author of *Paths to Healthy Aging.*

Handling Sleep Disruptions

“People with dementia cannot go to sleep at 10 p.m. and wake at 8 a.m.,” Mehrdad Ayati M.D., says. “It’s a ridiculous expectation that we have for them. This is our problem that we want them to sleep.”

Ayati shares the following advice for managing sleep disruptions:

Ask yourself: What is the total sleep time in 24 hours that my person is getting? “It could be 10 hours when you put it all together. Even if it’s sporadic sleep, it’s still 10 hours, and that means it’s OK.”

Look for signs of physical disruptions that can affect sleep: restless leg syndrome or sleep apnea. Speak to a doctor about them.

Try to make sure that they are getting enough exercise during the day. Taking one to two walks could be helpful.

“Give calmly reassuring cues to orient the person, especially in the evening and closer to bedtime. If they are active during the day, these calming activities can make them tired and better able to sleep.” Avoid action movies. Give them a backrub. “Keep it as quiet as a library.”

Ensure the room is well lit to avoid shadows, but not so bright that it causes glare.

If your person refuses to go to bed, don’t push them. Offer an alternative, such as sleeping on the couch or in a reclining chair.

At night, they may want to be awake, come out of their bedroom and even have a snack. “Let them. Don’t push them to get in bed because you’re going to make them more agitated, and they will act up more.” If needed for safety, get a caregiver for nighttime.

Regarding the use of medication to induce sleep, Ayati says there is “lack of evidence” to support its use with dementia patients. In fact, sleep medications can worsen sleep disturbances: create confusion, daytime sleepiness and rebound insomnia, and even worsen cognition. If medication must be used, use it on a short-term basis and discuss with your doctor.

Dementia Difficulties

Detecting & Preventing UTIs

Urinary tract infections (UTIs) can be a problem as people age, so it’s important for caregivers to know that symptoms can manifest differently in someone with a memory loss condition, says Nathaniel A. Chin, M.D., associate professor at the University of Wisconsin Department of Medicine, Geriatric Division. Chin is a member of AFA’s Medical, Scientific and Memory Screening Advisory Board.

“People without memory loss usually experience traditional urinary complaints of fever, chills, dysuria (pain or discomfort while urinating), urgency, frequency and may notice changes in their urine,” he said. “In dementia, you may not experience the fever or chills, or even the urinary complaints. Instead, you could experience abdominal or pelvic discomfort, loss of appetite, fatigue, malaise, confusion and restlessness. Sometimes people with dementia have a hard time explaining what they’re feeling or sensing.”

Women traditionally have more UTIs than men because they have shorter urethras than men, Chin says. This makes it easier for bacteria to travel to the bladder. UTIs are also more common for women after sex.

According to Chin, caregivers should be aware of the following UTI symptoms in individuals living with a memory loss.

- Their temperature and heart rate can become elevated while their blood pressure may decrease due to whole-body inflammation.
- You may observe changes in behavior, fluid intake and food consumption. Eating and drinking less, confusion, restlessness and agitation are also common.
- An increase in urination frequency may occur. There is no exact number that indicates a UTI, but when a person urinates more often than their baseline, that could be a sign.
- A person may appear uncomfortable when urinating. Sometimes people with dementia deny painful urination but grimace when it happens. Try to talk about it using simple terms.
- Urine may be dark, cloudy and have a foul odor.

Here are some ways that UTIs can be prevented, according to Chin.

- Try to ensure that your person urinates completely.
- Keep them well hydrated.
- Help them to maintain proper hygiene by wiping from front to back and avoiding irritating cleaning or feminine products. UTIs are most often caused when bacteria from the anus infect the bladder.
- If they are wearing incontinence pads, make sure they are changed frequently.
- When a UTI is diagnosed, use an antibiotic, prescribed by a doctor, to treat the bacteria.

Chin said opinions on the effectiveness of drinking cranberry juice are mixed. “It’s not going to hurt. If infections are recurring, it’s worth a try. Later in life, some people are on chronic antibiotics, but that’s a serious conversation to have with a doctor. Being on chronic antibiotics can lead to resistant organisms that become hard to treat. Additionally, a person could develop kidney injury, side effects and even a dangerous colon infection caused by a separate organism called C. Diff.”

Chin doesn’t recommend routine screening for UTIs because bacteria are usually present in the bladder and do not necessarily indicate infection.

When Delirium Occurs

UTIs do not cause or worsen dementia. They cause delirium, which people with memory loss conditions are at greater risk of developing. Delirium is acute confusion, disorientation and fluctuation in attention due to another medical issue. It resolves with time or when its cause is treated effectively.

“It may look as if the dementia is worsening, but when you treat the cause of delirium, people get better — although some don’t recover to their prior baseline. That’s why it’s important to treat it right away. UTIs are one of the most common causes of delirium in people with memory loss. You can see delirium in a cognitively healthy person, but they’re less vulnerable.”

Dementia Difficulties

Agitation & Aggression

Agitation and aggression are common behaviors of people living with memory loss conditions. This is not a reflection of who they truly are, but a symptom of an inability to communicate, and it's often related to pain.

"We see this most of the time in medical and surgical settings and care facilities like nursing homes," says Jeremy Koppel, co-director of the Litwin-Zucker Center for the Study of Alzheimer's Disease, Feinstein Institutes for Medical Research, in Manhasset, NY. The relationship between pain and agitation is an active focus of his research. Koppel is also a member of AFA's medical advisory board.

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Recent surgery, a "cardiac event," urinary tract infection, even constipation, "all of these things are sources of pain." A cognitively healthy person in a hospital or care facility will complain when they are in pain.

"They're going to verbalize to navigate their environment, hoping to get relief. Someone who is cognitively impaired, who may not have the language skills to marshal a response from their environment, is far more likely to express the pain nonverbally," Koppel says.

That expression can be walking the floor in a hospital at night or calling for help. Upon examination, nothing appears to be wrong.

"Frequently, the clinician will think they're just agitated. It's their dementia, and they'll give them an anti-psychotic medication to quiet them when really that verbal agitation is a poorly articulated cry for exactly what they want. They don't say 'pain.' They just say 'help' because they don't have words for pain. The agitation is related to untreated pain."

It's important to realize this, Koppel says, because the typical response to anti-psychotic medication is not to manage the pain; it's to give sedation.

"These drugs create a spiral problem. Now the patient is on a whole new pathway and has a whole new set of problems."

These problems include stroke or sudden death and have acute long-term consequences.

"When doctors prescribe an antipsychotic, they're attempting to induce a shutting down of the motor system. If they want to reduce aggression, there's no more impactful intervention. It makes aggression impossible."

Koppel said that although many people with memory loss can no longer articulate that they are in pain, they have enough language comprehension to affirm pain through their behavior.

Finding solutions.

If hearing is an issue, rather than yelling, try writing a note that asks, "Are you in pain, yes or no?" Koppel says. "Look for a lot of motor activity that would indicate trying to get into a more comfortable position. Also, follow their daily routines. One of the most common sources of pain for people with dementia is constipation."

He said the person might be on many medications that could cause constipation.

"After a day or two, that hurts, and so the way they can express that is by screaming. It's not pain from the dementia; it's from chronic health conditions and surgeries. As language fails, and communication begins to be disrupted, the ability to seek help for pain deteriorates.

"If you look at infants, they cry to communicate distress and pain. It's not by saying, 'I'm in pain and you need to treat me.' It's by crying and screaming. That is the natural, primitive reaction to pain when nothing else is available. It makes sense that when language is not available, agitation will be an expression of pain."

When discussing aggression and agitation with a family member, Koppel says the first thing he wants to know, other than a patient's medical history, is how long the behavior has been happening.

"I want to see if there's something we can do environmentally to avoid giving medication. Usually by the time they come to my office, they've done these things. They've done music. They've done pets. They've done watching reminiscence videos, videos of family. They haven't worked.

"Then they get to me with a moderate-to-severe agitation and we need to have a conversation about the risks and benefits of starting treatment. The reality is that once you're giving antipsychotic medication, this is palliative care. You're doing something that's going to make the underlying condition worse. Antipsychotics promote cognitive impairment. They accelerate the rate of decline and increase mortality.

"You need to know that there's a quality-of-life trade-off," Koppel says. If your person is physically aggressive to you and you want them to remain with you in your home, it may be important to provide antipsychotics. The trade-off is that they will be able to stay in their own home with family.

Koppel advises keeping a journal to help your clinician construct a timeline of behavior that could help determine non-pharmacological interventions and, if medications are needed, the caregiver can track the effects.

This article is based on an AFA Fireside Chat, hosted by AFA President and CEO Charles J. Fuschillo, Jr., with Jeremy Koppel, M.D., co-director, Litwin-Zucker Center for the Study of Alzheimer's Disease, Feinstein Institutes for Medical Research, Manhasset, NY. Koppel is a member of AFA's Medical, Scientific and Memory Screening Advisory Board. Go to alzfdn.org/firesidechat to learn more.

RECIPE FOR YOUR HEALTH

FALL HARVEST APPLE CRISP

This healthy fall harvest apple crisp recipe is vegan and high in prebiotic fiber. The walnuts provide protein and omega-3 fatty acids. Top with plain low-fat yogurt for additional protein, calcium and probiotics.

INGREDIENTS

Choose organic ingredients when available.

For Fruit Base:

4 medium apples (Honeycrisp or Pink Lady), washed, cored and thinly sliced (Leave the skin on if you want more fiber.)

¼ cup pure maple syrup

1 Tablespoon extra-virgin olive oil

½ teaspoon cinnamon

⅛ teaspoon ground ginger

¼ teaspoon vanilla extract

Pinch nutmeg

For Topping:

¾ cup rolled oats

⅓ cup walnuts, crushed

½ teaspoon cinnamon

⅛ teaspoon ground ginger

1 Tablespoon extra-virgin olive oil

1 Tablespoon maple syrup

DIRECTIONS

1. Preheat oven to 350°F and coat an 8-inch round or 8-by-8-inch square baking dish with cooking spray.
2. In a large bowl, combine the ingredients for the fruit base and mix well. Pour the apple mixture evenly into the bottom of the baking dish.
3. Then, in the large bowl, combine the ingredients for the topping. Layer the topping evenly over the fruit base.
4. Cover the baking dish with foil and bake for 25 minutes. Remove the foil and bake for another 15 minutes, or until apples are fork-tender and topping is golden.

This recipe serves 6-8.

NOTES

1. If the topping browns quickly, tent the baking dish with foil.
2. If you prefer softer apples, bake covered for an additional 5 minutes.
3. You can add sliced strawberries, other berries or dried cherries to the fruit base.
3. The apple crisp should be refrigerated and will stay fresh for four days.
4. To make this certified gluten-free, use certified gluten-free oats.

Nutrition Facts based on 6 servings:

Calories: 200 (15 grams)	Total Fat: 8 g	Dietary Fiber: 5 g
Carbohydrates: 36 g	Protein: 3 g	

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

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Brain Health

LONELINESS:

A HIDDEN RISK FOR MEMORY DECLINE

Research shows that chronic loneliness can increase the risk of developing memory loss conditions like Alzheimer's disease or other dementias, says Dr. Christina Chen, a geriatrician and internist at the Mayo Clinic, explaining that there are biological and behavioral mechanisms behind this.

"Loneliness can trigger a chronic stress response that increases stress hormones and impairs the growth of neurons and their connections that are critical for learning and memory. Over time, this can accelerate brain aging."

Chen says loneliness also leads to reduced cognitive stimulation, less social engagement, fewer novel conversations and reduces exposure to mentally stimulating environments. Without these "mental workouts," brain networks that challenge memory, language and problem solving are impacted.

"From a behavioral and lifestyle perspective, lonely individuals tend to be less physically active, experience sleep disturbances, have poorer lifestyle choices and may delay medical care. They may also have a higher risk of mental health conditions such as depression, which itself is an independent risk factor for dementia."

(Continued on following page)

Loneliness doesn't have to be a permanent state. It's like a signal (such as hunger or thirst) telling us to seek connection. Use this signal as a prompt to make some changes in your life that can help you thrive.

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THE STATS

In a 2024, a meta-analysis of 600,000 individuals from multiple NIA-funded population-based studies found that **those feeling lonely were associated with a 31 percent increased risk of developing dementia, including Alzheimer's disease, and a 15% increase in cognitive impairment (non-dementia memory/thinking decline).**

"While loneliness, depression and social isolation can overlap and cause things to worsen, loneliness by itself is a biologically and psychologically distinct state. It remains a stand-alone predictor due to the underlying impact on the stress pathway, cognitive load, and neurobiology," Chen says. "This is why interventions that specifically address the feeling of loneliness (not just increasing social contact) are important for brain health."

Social Isolation vs. Loneliness

"I have seen this in many patients and even in my own mother. After the COVID pandemic, many individuals who were socially isolated even for what seems to be a short period of time (months) have noticed cognitive changes. Social isolation measures how much contact you have with others. Loneliness measures how connected and emotionally satisfied you feel in your relationships. You can spend most of your day alone but may still feel fulfilled and not lonely. If you have meaningful relationships, feel content in your friendships, and understood by others, you can still have the autonomy you enjoy.

On the flip side, you can be surrounded by people and still feel lonely if you lack emotional closeness, feel misunderstood or don't feel comfortable sharing your authentic self. The brain responds to loneliness, not headcount. It's the quality of your relationships, not the quantity, that helps keep a deep, emotionally satisfying and reciprocal connection."

Assessing Loneliness

Concern for a friend

Simply asking, "Are you lonely?" doesn't often yield accurate insights because this can be subtle and hard to describe.

Chen says to look for symptoms of withdrawal from activities the person once enjoyed, decline in self-care, mood changes, irritability or restlessness. Focus more on functional and feeling-based questions, such as "Do you feel you have enough people to talk to?" "Do you feel there are people who understand you well?" "When was the last time you spent doing something you enjoy?"

Concern for yourself

The key to addressing your own loneliness is taking the time to discover what will work best for you. It often takes a bit of creativity to discover the right solutions. Some ideas:

1. **Optimize your connection circle.** Identify three to five friends who truly empower you and lift you up, whether these are friends, neighbors or co-workers who you can intentionally connect with a few times a week. Make a concerted effort to make this part of your weekly routine
2. **Keep your sense of purpose at the heart of your caregiving.** Remind yourself why your role matters. Pair caregiving with social moments. For example, invite a friend or another caregiver to join you in an activity you do with the person you care for.

"I am currently caring for my cognitively impaired mother who has a bone marrow disorder and needs chemotherapy," Chen says. "I take her for treatments a few times a week, and I go with my husband. We spend time with her, have coffee with her, and reminisce about memories that she recalls from my childhood. It turns a stressful moment into a joyful one."

3. **Strengthen your own daily joy rituals.** Integrate small routines that elicit joy or happiness — morning coffee on the porch, play favorite music, meditate, walk your dog. These create predictable moments of comfort and satisfaction that build emotional resilience.
4. **Care for your body.** This is important, Chen says. Don't neglect yourself. Physical activity boosts mood and keeps you physically and functionally capable. Seek help without guilt. Make time for yourself to replenish your energy and maintain an uplifting mindset shift.

Loneliness doesn't have to be a permanent state. It's like a signal (such as hunger or thirst) telling us to seek connection. Use this signal as a prompt to make some changes in your life that can help you thrive.

Dr. Christina Chen is a geriatrician and internist at the Mayo Clinic in Rochester, MN, who cares for patients in the community and long-term care. Her passion and area of research is improving the quality of life for patients with dementia by transforming the living environment into a space of hope and joy.

Brain Health NEWS

Sign Up for Dance Lessons

Research studies in many countries and cultures have found that dance lessons improve memory in older adults. It doesn't have to be a particular kind of dance — ballroom, swing, salsa, tango or line dancing — and it can be solo or with a partner.

Does it help on day one? Probably not. Most published studies that find improvements in memory involve attending a dance class for six months or more.

Best of all, the neuroscience reveals that you won't just learn some dance moves that you can do at your granddaughter's wedding. You'll actually gain more brain. Researchers have found that dancing increases brain volume through a process called neurogenesis, in which you sprout new neurons.

It might seem odd that dancing would help, but study after study finds that, at least for older adults, it's more effective than taking up other exercise routines. Part of it is consistency — people are more likely to keep going to dance classes whereas they might give up on something equally effortful that they do independently — but another part is that it combines physical, mental and social skills. In a dance class, you have to get your heart pumping, you have to remember the steps and you have to joke with that person you keep bumping into.

– *Mayo Clinic Press*

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Sense of Purpose Linked to Less Cognitive Decline

A large, decade-long study of older adults has found that those with higher levels of well-being, especially a strong sense of purpose, also tended to show better cognitive functioning and less cognitive decline over time. The study, published in *Psychological Science*, suggests that well-being and cognitive health are closely linked in later life, with each influencing the other in a dynamic and reciprocal relationship.

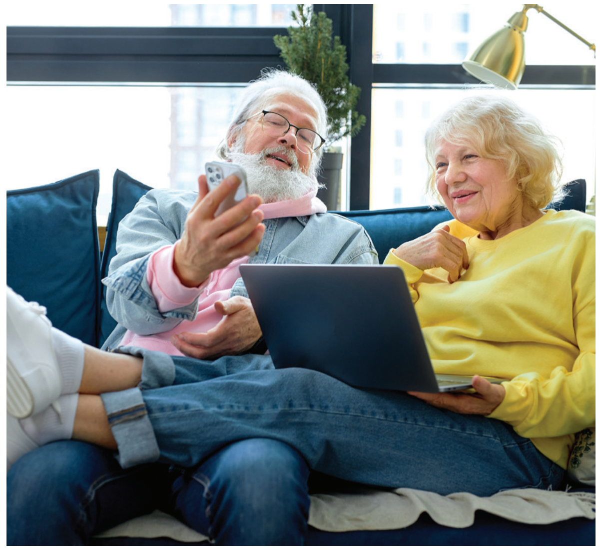
"I have been interested in the construct of sense of purpose since early in my graduate school experience," said research lead Gabrielle Pfund, Ph.D., an assistant professor of human development family science at Auburn University. "

As I continued throughout graduate school, I came across more and more research that highlighted the predictive power of purpose, particularly for healthy aging. Like many, I've personally experienced the pain of losing a loved one to dementia. With pharmacological interventions still nascent, establishing nonpharmacological opportunities to combat the development of dementia and slow cognitive decline is imperative."

–*PsyPost*

Maybe Tech Isn't So Bad

Is daily smartphone use rotting our brains and bringing on cognitive decline? Probably not, according to new research. An analysis of 136 studies covering 400,000 older adults reveals digital technology users have a 58 percent lower risk of cognitive impairment — a direct challenge to the notion that smartphones and computers harm our brains.



"The great fear was that using computers, the internet and smartphones could lead to worse rates of cognitive impairment," explained Dr. Michael Scullin, associate professor of psychology and neuroscience at Baylor University, Waco, TX. "Instead, 90 percent of the studies indicated that digital technology use was linked to [a] lower risk of cognitive impairment, even when controlling for factors like education, socioeconomic status and general health."

Brain scans reveal why this might be happening. Older adults who had experience with internet searching showed more neuronal activation than novices. After just one week of online search training, previously inexperienced users showed increased neural stimulation in regions controlling thinking and memory.

— *MedicalNewsToday*

If you're struggling, ask for help.

In decades past, mental health issues were shrouded in stigma, shame, and misconceptions. Even today, individuals may hesitate to seek help for their mental health issues because they don't want to be viewed as "defective" or "weak." However, stats show that if you have mental health symptoms — such as depression, anxiety disorders, memory loss, brain fog, or problems with focus — you're no longer in a small minority. A wide-scale survey reported in *The Lancet* of individuals in 29 countries published in 2023 found that by age 75 about half the population will develop 1 or more of the 13 mental disorders considered.

Remember that asking for help is a sign of strength, and spreading awareness will contribute to ending the shame around mental health conditions.

— *Amen Clinics*

An Unexpected Dementia Symptom

A lesser-known symptom of someone's dementia could appear on your birthday, according to an expert. This could actually be one of the "first signs" of Alzheimer's disease.

"Starting to have an issue with reading and writing, where the person hasn't previously had a problem, is often an indicator of dementia. This could be seen through a change in handwriting in birthday cards, for example," said care expert Michael Berkley-Blezard, from the Elmfield care group home Old Sarum Manor, in Salisbury, UK.

His warning is backed by a study published in *Intelligent Data Analysis* in 2020.

Study authors explained: "Neurodegenerative diseases like Alzheimer's and Parkinson's impair the cognitive and motor abilities of the patient, which brings memory loss and confusion. As handwriting involves the functioning of the brain and motor control, it is affected. The handwriting gets shaky due to loss of muscle control, confusion and forgetfulness. The symptoms get progressively worse. The handwriting becomes illegible and phonological spelling mistakes become inevitable."

— *Daily Express*

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