

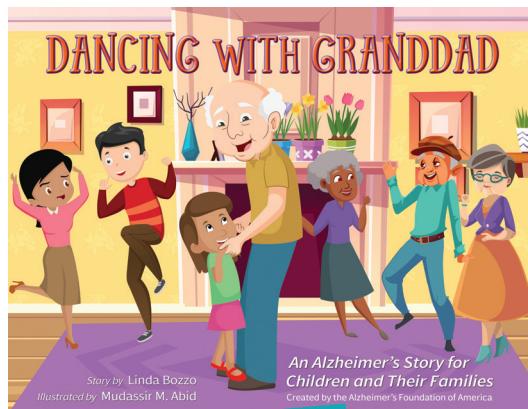
Alzheimer's TODAY®

The Official Magazine of the Alzheimer's Foundation of America

Dementia & Driving: When It's No Longer Safe



VOLUME 19, NO. 2



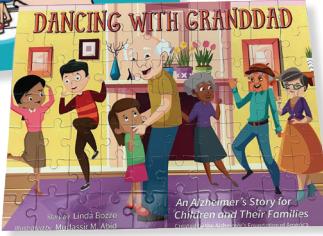
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— Dale V. Atkins, Psychologist



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

I'm proud to share that AFA held its inaugural Alzheimer's Advocacy Day in Washington, D.C. on May 23, and it was a tremendous success. Joining our staff were members of our Medical, Scientific, and Memory Screening Advisory Board, volunteers, and alliance partners.

Throughout the day, our teams interacted with all 535 U.S. senators and representatives, which included brief chats with their offices, meetings with their legislative staff, or speaking with members individually. We met with the co-chair of the Bipartisan Congressional Task Force on Alzheimer's Disease, Senator Mark Warner (D-VA), as well as Senator Jerry Moran (R-KS), Representative John Garamendi (D-CA), Representative Kat Cammack (R-FL), and Representative Jan Schakowsky (D-IL).

We held meetings with the offices of Senator Marco Rubio (R-FL), Senator Martin Heinrich (D-NM), Senator Tim Kaine (D-VA), Senator Tina Smith (D-NM), Representative Grace Meng (D-NY), Representative Tom Cole (R-OK), Representative Chris Pappas (D-NH), Representative Katherine Clarke (D-MA), Representative Anna Eshoo (D-CA), and Representative Nanette Barragán (D-CA).

We concluded the day with a meeting from a representative of the Special Committee on Aging, which is chaired by Senator Bob Casey (D-PA). These meetings allowed us to both establish and reestablish working relationships with members of Congress who are at the forefront of Alzheimer's specific legislation and public policy.

Our agenda included advocating for an increase in appropriations for FY'25 for Alzheimer's disease, in addition to advocating for legislation that AFA supports:

- ***The Change Act*** (H.R. 3354), which authorizes physicians to use a cognitive assessment test identified by the National Institute on Aging to detect cognitive impairment during the Medicare Annual Wellness Visit (AWV) and Initial Preventive Exam (the "Welcome to Medicare" visit).
- ***The Alleviating Barriers for Caregivers Act*** (S. 3109), which would eliminate red tape with Medicare, Medicaid, the Social Security Administration and the Children's Health Insurance Program to lessen the administrative burdens on families.
- ***The Connecting Caregivers to Medicare Act*** (S. 3766/H.R. 7274), which would inform Medicare beneficiaries about the option they have to fill out a form to give Medicare permission to share their personal health information with a family caregiver.
- ***The Credit for Caring Act*** (S. 3702/HR. 7165), which would provide up to \$5,000 in a non-refundable federal tax credit for eligible working family caregivers to help offset a portion of their out-of-pocket caregiving expenses.

Our day also featured a briefing by Senator Ed Markey (D-MA) who spoke to our staff, volunteers and esteemed guests on caregiver legislation and his own personal experiences with Alzheimer's disease. We were also honored to have our founder, Bert Brodsky, join us to discuss his story on how the foundation was created and his vision moving forward.

Overall, it was an incredibly inspiring day that fulfilled many of our goals. We were able to advocate for you, persons living with Alzheimer's and caregivers, while also providing information about AFA and the work we do every day. We look forward to making this an annual event, and we look forward to continuing the work AFA does throughout the country.





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THE GIFT OF A GOOD AIDE

By Ira G. Asherman

For the past 12 years, I have been the primary caregiver for my wife who is living with Alzheimer's. The years have been filled with both heartache and joy. I have learned a great deal about myself and the issues involved in caring for a loved one who is steadily fading away. I learned both from what I did and what I was unable to do.

One of most surprising things I've learned is the pricelessness of a good aide. If you have the financial resources to hire an aide, I recommend that you do so. Some lessons I've learned:

- **Allow the aide and your care partner to build their own relationship.** Your goal is twofold: to have them get so comfortable with each other that they can go on their own and you are comfortable allowing them to do so. Except for certain doctor's appointments, my wife's aide takes her everywhere.
- **Provide your aides the freedom and responsibility to do their job.** In the beginning, I spent more time with my wife and her aide; but as time went on and my trust increased, I spent less time with them.
- **Learn from your aides.** Your aides bring much experience to the job. Watch them and learn from them. Do not be afraid to ask questions as to why they are doing certain things. All the aides we have known have been more than willing to share their knowledge.
- **Embrace the cultural differences.** As our aides represent countries from every corner of the globe — Georgia, Mexico, Nigeria, Sierra Leone, Mali, Haiti, and Guyana — we've been privileged to embrace many aspects of these varied cultures. As food is a universal language, we've taken advantage of learning about and enjoying foods we'd never have otherwise experienced. These varied cultures now occupy an integral part of our lives, and what fun it's been. Our aides have attended



Caregiver Michele Baksh with the author's wife

bar mitzvahs, graduation parties, Passover dinners, birthdays, bridal showers and family barbeques. They have become a part of our family.

The one abiding truth is that everyone's story is different. You will be on an emotional roller coaster from early in the day to the time you turn out the lights — and often after that. Caregiving is filled with heartache and sadness. However, it does have moments of joy. It also provides real opportunities to learn and grow.

ABOUT THE AUTHOR

Ira G. Asherman lives in New York City with his wife, Sandy. They are the founders of the Alzheimer's Dementia Resource Center of NYC (adrcnyc.org).

Photos courtesy of Ira G. Asherman



Hands that used to hold you

are now hands that
HIT.

Agitation that may happen with dementia due to Alzheimer's disease

is a treatable condition, separate from dementia due to Alzheimer's.

Some symptoms include:

RESTLESSNESS, HITTING, & SCREAMING

For a complete list of symptoms, visit AgitationInAlz.com

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September 2023 11US23EUC0072

Actor portrayal



Yuri Arcurs | Dreamstime

Summer Travel

If you will be traveling this summer with someone who has a neurocognitive disorder, Lauren Vlachos, executive director/CEO of the Alzheimer's Disease Resource Center (ADRC) on New York's Long Island, has advice to help you manage your person's safety and possible agitation. Vlachos says traveling well with someone with dementia requires that caregivers understand all the benefits and challenges before making plans.

"There are many tools to help caregivers — medication reminder apps, technology tracking tags, Project Lifesaver bracelets, coolers to bring familiar food and drinks, and items that bring comfort and provide a sense of routine and familiarity, such as a favorite pillow, plate or cup and even towels."

When considering the various forms of transportation, Vlachos says each could present different challenges. Car trips allow one to stop and rest but often take longer. Air travel is fast but can be unpredictable, overwhelming and airports are often

crowded. Another risk to air travel is that the person might become agitated on the plane and end up having to be restrained in-flight. Buses and trains are often limited with handicap accessible options.

Vlachos shared the story of a caregiver who takes his wife with middle-stage Alzheimer's to visit their children in South Carolina two or three times a year. "They often drive because they can make frequent stops to rest and stretch their legs. Being in the familiar car helps keep the woman from becoming agitated, and there are no crowds to manage at the airport or terminals to navigate. It also makes it much easier to control wandering."

"Before planning a trip, it is best to consult with your health care professional about your individual's ability to handle travel. You'll need to prepare some things in advance, secure travel insurance, if needed, and have a plan for unexpected emergencies," Vlachos says.

CHALLENGES TO KEEP IN MIND

- Safety:** Individuals with neurocognitive disorders may have difficulty understanding safety instructions or recognizing dangerous situations. Understanding the safety of your accommodations and modes of transportation is crucial to having a good experience.
- Agitation and anxiety:** Changes in routine and unfamiliar environments can be triggers. Plan activities and accommodations that minimize your person's stress and keep them as close to their routine as possible.
- Medication management:** Create reminders on your phone to take medications at the right time.

Mobility and accessibility: Consider the physical limitations of your individual, including mobility and the need for wheelchair accessibility. Check websites for handicap accessibility.

Wandering: Take precautions to prevent wandering and ensure your person's safety when you arrive at your accommodations. Consider location and tracking tags.

Alzheimer's Disease Resource Center (ADRC) offers free care consultations, referrals and references, support groups, life-enrichment activities and a resource center. To learn more, visit adrcinc.org.

BOOK CORNER

The Future of Alzheimer's: Finding Inspiration & Hope Through Expert Insight

By Sharon Ricardi

As the president of Northbridge Advisory Services, Sharon Ricardi travels to clients nationwide to advise them on operational issues, especially focusing on memory care. When people find out what she does, whether they are sitting beside her on a plane or meet her at a professional event, she is frequently asked questions about Alzheimer's, so much so that she decided to address them in a book.

Drawing on her more than 30 years of experience in health care, and with her vast number of connections in the field, she chose the two most asked questions and put them to 20 leaders in research and treatment of the condition. *The Future of Alzheimer's: Finding Inspiration & Hope Through Expert Insight* offers an introduction that is factual but also conversational. Her sections are informative and concise, between four and 10 pages, an approach that is refreshing in the world of scientific writing.

"I wanted to start with practical advice," she says about her approach. "I wanted to work in a way that feels comfortable and not have a book that is overwhelming."

The questions each expert answers are: What advice would you give to the loved ones of someone newly diagnosed? Do you believe there will be a cure? And if so, when? Their answers are given chapter titles like "Carpe Diem," "Do Not Define the Person by the Disease" and "Education, Education, Education." Insight comes from academic and practical fields, as well as journalism and include Peter Reed, Ph.D., director of the Sanford Center for Aging and a professor of community health services at the University of Nevada, Reno; Lauren Aguirre, award-winning science journalist; Teepa Snow, one of the world's leading educators on dementia and the care that accompanies it; and Nancy B. Emerson Lombardo, Ph.D., president and founder of the

"... a trove of valuable insights from experts to a question that stumps every family when a loved one is handed a diagnosis: What's next?"

—MERYL COMER, author of *Slow Dancing with a Stranger*, co-founder of UsAgainstAlzheimer's

the future of alzheimer's



finding inspiration & hope
through expert insight

sharon ricardi

Brain Health and Wellness Center and adjunct assistant research neurology professor at the Boston University School of Medicine.

Ricardi chose her subtitle carefully. "I wanted the readers to have something positive and life-affirming. People need to have comfort."

Her carefully chosen experts offer helpful advice, but Ricardi says that ultimately "the best teachers" are those who have memory loss conditions.

"It goes back to the saying that if you know one person with Alzheimer's, you know one person with Alzheimer's. Observe people with Alzheimer's to see what works, what makes them comfortable and alleviates their fears."



RECIPE FOR YOUR HEALTH



GREEK LEMON CHICKEN WITH SPINACH AND RICE

INGREDIENTS

1 ½ cups fat-free, low-sodium chicken broth
1 cup uncooked, instant brown or white rice
2 cups of packed baby spinach leaves
2 large tomatoes (chopped)
3 Tbsp. fresh lemon juice
1 clove garlic, minced
1 tsp. dried oregano
½ tsp. dried thyme
½ tsp. ground cinnamon
¼ tsp. pepper
4 boneless chicken breast halves
(about 4 ounces each); remove skin to reduce fat
2 Tbsp. fresh parsley, chopped for garnish
4 lemon slices, for garnish

For yogurt sauce:

8 oz. plain, fat-free Greek yogurt
2 tsp. fresh lemon juice

NUTRITION FACTS

Serving: 357 calories
7.3 grams fat
41 grams protein
32 grams carbohydrate
284 mg sodium

DIRECTIONS

1. Pre-heat oven to 375F.
2. In an 8-inch baking dish, mix the broth, rice, spinach, tomatoes, 3 Tbsp. lemon juice, garlic, oregano, thyme, cinnamon, and pepper. Place the mixture on the side of the baking dish.
3. Add the chicken breasts. Spoon some of the rice mixture over the chicken. Cover with aluminum foil.
4. Bake for 50-60 minutes, or until the chicken is cooked thoroughly and the rice is tender.
5. In a separate bowl, stir together the yogurt and 2 tsp. lemon juice.
6. When ready to serve, spoon the yogurt mixture over the chicken dish.
7. Garnish with lemon slices and parsley.



Recipe by Layne Lieberman, M.S., R.D., CDN, 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.

Lieberman, cooking with local lemons, on Poros Island in Greece.



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Linda Larsen NYC: A New Alzheimer's Functional Clothing Line



David German knows the heartache and challenges of caring for a loved one with Alzheimer's. His wife, Linda Larsen German, was diagnosed with young-onset Alzheimer's in 2013; she was 62 years old. They faced it together for eight long years before Linda passed away in November 2021.

Their daughter, Emmy, who was 20 years old when her mother was diagnosed, suggested the idea first: create "functional, accessible clothing" that her mom would have been proud to wear, rather than the limited options of "sweatpants and pajamas." She knew her parents' impressive careers in the fashion industry. Linda had been a top executive with the Liz

Claiborne company. David had owned a garment trim and apparel business.

German thought it was a "phenomenal idea."

"While there is some adaptive clothing in the marketplace, it's simply not adaptive enough for a person living with Alzheimer's or another form of dementia," German said. "Linda despised having something pulled over her head. Dressing her, sometimes three to five times a day, was often a struggle and a fight."

A new, innovative clothing line of dementia-friendly clothes is now born: Linda Larsen NYC (lindalarsennyc.com) will soft launch this month.

Continued on following page

LINDA LARSEN NYC: A NEW ALZHEIMER'S FUNCTIONAL CLOTHING LINE *cont'd from p. 11*

"From a design perspective, this challenge required out-of-the-box thinking. We pulled solutions from other areas to make this work. We wanted to create easy, comfortable, styled yet familiar clothing," German said.

Here's what distinguishes it from other lines:

- **Ease of use:** Garments are designed to reduce the time and stress of changing. This benefits the person with Alzheimer's and the caregiver.
- **Comfort and dignity:** All tops are made to be easily put on and taken off from either side, with snaps. Nothing goes over the head.
- **Functional design:** Pants slip on and close with two zippers.
- **Health monitoring:** Fabric is treated with a moisture-activated "invisible ink," revealing a pattern when wet. This function allows the caregiver to be alerted to a wet brief or bathroom emergency, which reduces the chance of UTIs and other infections.
- **Safety features:** Every garment comes with an inside pocket to hold a removable tracking device that alerts the caregiver if the person starts wandering (device sold separately).
- **Personal touch:** Most garments have a pocket to hold a comforting memento, such as a photograph or a cherished keepsake, for redirection of the person's attention.

Initial Linda Larsen NYC offerings include pants, long- and short-sleeved shirts and a short-sleeved, simple dress. Each piece of clothing is designed not only with Alzheimer's in mind but with Linda herself in mind.

"We hope these innovative changes in apparel make your day-to-day a bit easier," German said. A positive affirmation is on every garment that reads: "We are here for your journey."

Linda Larsen NYC welcomes caregiver feedback on the designs and your individual needs as the team works to continue to improve the line.

"You live and you learn. This is a dream come true for me, to be able to do something positive in Linda's memory," German said.

Check out LindaLarsenNYC.com to order.



Ask the Helpline 

Dementia & Driving: When It's No Longer Safe

My mother's cognitive decline has progressed to the point where I don't want her to drive anymore. Her doctor said she is in the early stages of dementia. She's never been one to stay home. Even if she has no specific engagement, she'll go to a coffee shop and strike up conversations with anyone who will talk to her. She lives in the suburbs with no way of getting around on her own without her car. How do I take away her car keys to ensure she's safe without having her angry with me?

We receive many calls like yours. It can be hard for families because it's the first time you've had to tell a parent they can't do something. It's a role reversal. Even when you know someone shouldn't be driving, it's normal to have a lot of ambivalence.

Driving is symbolic of autonomy and independence. Not being able to drive limits our ability to go out and shrinks our sense of self. You're taking away something vital, especially in areas with no other transportation options.

Some families have taken out the car battery and left the car in the garage, but this isn't the best solution. The person sees the car and they want to drive. It's a reminder. It's better to remove the car.

One option that has been successful is to take the car for a fabricated repair and arrange with the mechanic to call in a few days to say the car can't be fixed. Another is to ask the person's doctor to tell them they can't drive anymore. A third party giving the news keeps the person from blaming the family. You must be creative to come up with something they will accept.

If you experience resistance, know that your person may be using a coping mechanism, focusing on one thing because they are so overwhelmed with the confusion of their condition. They invest in that and get stuck. The coping skills they had before are not necessarily still there.



Artanika | Dreamstime

"I want to drive" is an assertion of independence. Many people have been driving since they were 16. Having that right taken away can trigger anger and paranoia.

If you have the resources, you could hire a companion with similar interests, or have them use a car service. More simply, you can suggest that your person ask to ride to church or the store with a neighbor or friend, or you can arrange this but know that your person might resist, saying they don't want to put someone out and would rather stay home. That's their last bit of control.

If your person won't budge, take yourself off the hook, especially if you are at a long distance. Remind yourself that it is necessary to "take away the keys." Then try reapproaching it every so often to see if they are more open to making adjustments for getting out.

We highly recommend joining a caregiver support group.

ABOUT THE AUTHORS

AFA Helpline social workers Linda Mockler, LMSW, M.Ed., and Melpo Voulieris, LMSW, contributed to this answer.

HELPLINE SUPPORT

If you need assistance in caring for someone with a neurocognitive disorder, please reach out to our free **Helpline**, seven days a week, at **866-232-8484**, via **text at 646-586-5283**, or **webchat at alzfdn.org** (available in 90+ languages).

AFA Teen Chapter: Minds Matter Initiative

When Josh Asada's mother began working in assisted living facilities in North Carolina, she enjoyed sharing stories about the residents. It seemed to Josh that with each uplifting story came one of dismay, such as staff losing their patience with the residents, or the residents feeling lonely from a lack of visitors.

"I come from an East Asian culture where the elderly are treated with the utmost respect, so hearing these stories was both a cultural shock and heartbreak at the same time," said Josh, a rising senior at Triangle Math and Science High School in Cary, NC. "I gradually became increasingly interested in working with these assisted living facilities and making sure the residents are cared for."

Josh found a way to do this through AFA Teens. His classmate, Arjun Bhonsle, founded the chapter at their school and serves as president of the group, known as Minds Matter Initiative (MMI).

"When I started this nonprofit, Kevin [Gencel], Josh and I wanted to emphasize providing care and developing relationships for those with Alzheimer's; we simply went by AFA Teens," he says. "After a trip to our first assisted living facility, assessing how we felt and receiving an email from the volunteer coordinator expressing gratitude on behalf of the residents, a name came to us almost instantly. By choosing Minds Matter Initiative (MMI), we hope to emphasize the message that people with Alzheimer's are cared for and deserve more than what is often given to them."

MMI students volunteer at senior care facilities, interacting with memory care patients by playing Bingo or Scrabble and

Teens with seniors at Glenaire, a life plan community in Cary, NC.



Arjun's chapter includes, in addition to Josh and Kevin, Sina Dehghani, Meryem Sena Golbasi and Vijaya Varadarajan.

Meryem shared a story about one of her visits with Dana, whom she met in a memory care unit. Dana had dementia and didn't talk much, but they enjoyed each other's presence.

"The first day we met, she picked out a deep-sea puzzle that had dolphins, fish and sea turtles, and we solved it together," she says. "Although she wasn't too keen on helping me, she did clap when I figured out the parts of the puzzle with fish. Through Dana, I found a new way to become friends with someone with minimal verbal communication. She made me aware of paying attention to details and taking our time together a little slower."

For information on forming an AFA Teens chapter, reach out to info@alzfdn.org or visit the AFA website at alzfdn.org and go to the "Young Leaders of AFA" tab.

participating in other fun activities.

They are engaged in community events like youth seminars in libraries and local walks. Since forming in December 2022, they have expanded to 16 schools in the country and are in the process of expanding to California, Virginia, Florida and New Jersey. They have more than 100 members and plan to increase that number this year.

"Eventually, people started to reach out to us to learn how they could become involved, which was a huge accomplishment for us," Arjun says.

Are You Experiencing Memory Changes?

Take a Thoughtful & Systematic Approach

By Nathaniel Chin, M.D.

As a geriatrician specializing in memory care, I have many patients who report noticing changes years before they see me. While it is never too late to get help, the earlier symptoms are addressed, the more that can be done. Evaluating cognitive symptoms requires a thoughtful and systematic approach. Here are suggested steps to take early in the process.

1. Talk to others about your experience.

Our brain changes as we age, and cognitive symptoms will develop. While these symptoms are normal, they can still cause worry. Age-related changes include slower processing of information, needing more repetition or cues to remember and word finding. Unfortunately, these same symptoms could be the earliest indicators of an abnormal process, too. It's helpful to talk with others about what you're experiencing. If they are also observing persistent changes in you, it would be beneficial to talk with your health care provider.

2. Collect your history. It's the most important information in the evaluation.

Cognition is our ability to think, acquire knowledge and understand what's happening in life. While memory is a part of cognition, other key functions include paying attention, using language, learning new information and problem-solving. Not all symptoms are related to memory. Your provider needs to understand exactly what you're experiencing in the context of your life, and the timing and changes of those symptoms. Additionally, it's critical to know your chronic health conditions and medications, family history, substance use and lifestyle habits.

Many reversible conditions can cause thinking changes such as depression, medications, poor sleep, sleep apnea or thyroid issues. A cognitive evaluation includes investigating these potential factors.

3. Cognitive screening tests do not provide a diagnosis.

There are many different types of cognitive screening tests. They vary in length and what parts of the brain they're testing. None provide a reliable diagnosis on their own. Cognitive screening tests won't tell you if you have dementia, but a low score may suggest your thinking difficulties are caused by more than getting older.

While a screening test can be done in a medical clinic, it can also be done over the phone or virtually by community organizations like the Alzheimer's Foundation of America (go to alzfdn.org and click on the Memory Screening program tab for more info). If your provider is administering the test, make sure they know your symptoms, are looking for reversible causes and explain to you the test. Afterward, you'll want to know how you did overall, the areas of the brain that didn't perform as expected, and what this may mean in the context of your symptoms. Make sure you have enough time to discuss this fully.

4. Consider factors that may affect the testing and if the result aligns with your symptoms.

Determine if other factors may have contributed to your score. Were you prepared to take the test or was it "sprung on you"? Did you sleep well the night before? Did you take your regular medications or any sedatives before testing?

If your score is low, determine if the results align with your symptoms. If you feel it is hard to multitask, did you score lower in the part of the brain where this function occurs? A lower score means more evaluation is needed. This will likely include blood tests, head imaging and possibly referrals to specialists. If you believe the test does not align with how you feel, then it is reasonable to repeat a cognitive screening test in 2-3 months. While waiting for that test, you can address reversible factors that may improve your symptoms.

Continued on following page



Aaron Amat | Dreamstime

5. Reflect on your symptoms and ask others for input.

Have you noticed changes and simply shrugged them off or attributed them to stress? Try to determine when your symptoms first started and how they have changed over time. It may be helpful to read a list of common thinking changes from questionnaires to see if they relate to your experience. Two available forms are the AD8 Dementia Screening and the Short IQCode. You may also want to keep a journal of your symptoms.

If you find yourself struggling to complete daily tasks, such as managing your finances or medications, this may be indicative of more serious brain changes. A change in performing daily activities should be reported to your provider immediately.

6. Follow up with your provider on the next steps in the evaluation.

Your provider may request a repeat cognitive screening test. It's beneficial to take the exact same test to compare scores and determine any changes. Ensure you're comfortable and prepared for this next test, but avoid practicing. You want your result to be accurate.

Your provider may refer you to a memory specialist who usually has training in neurology, geriatrics or psychiatry. Not all these specialists are experts in memory evaluations, so work with your provider to ensure you see the right person.

7. A diagnosis takes time. Address your brain health in the interim.

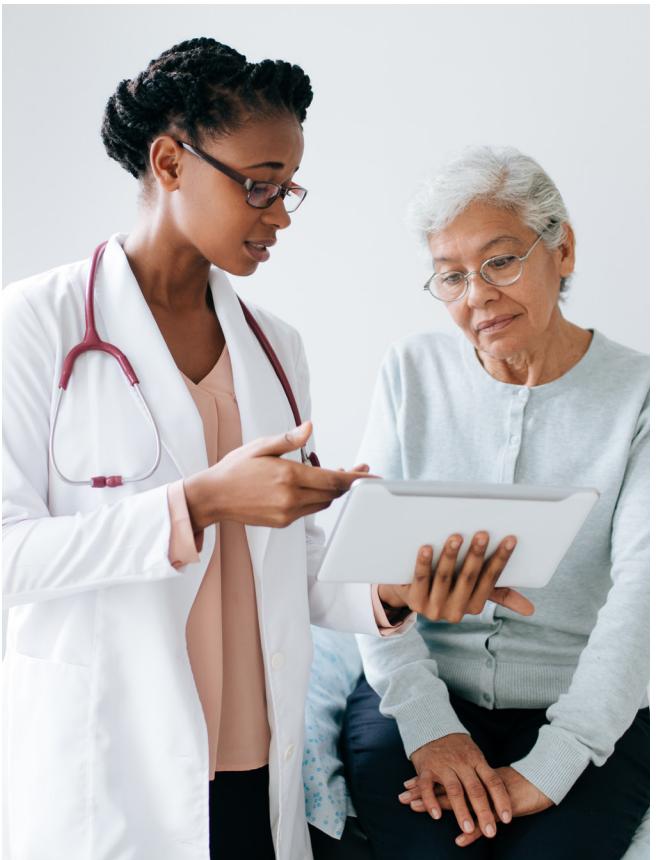
A comprehensive memory evaluation rarely is completed in one visit. While the evaluation is occurring, you can address reversible factors. Managing your lifestyle, medications and health conditions can significantly impact how you feel. Address hearing loss, high blood pressure, diabetes, depression and tobacco use. Engage in brain-healthy habits such as exercise, restorative sleep, mental and social engagement, healthy eating and stress reduction.

Being evaluated for memory and thinking symptoms can be scary. It's important to remember you are not alone and medical professionals are available to help you. There are ways to help your brain, and many of them do not require medication. This help starts with a conversation.

For additional support, AFA offers a brochure, "Understanding Your Cognitive Screening Results." To request a copy, contact the AFA Helpline at 866-232-8484 (phone), 646-586-5283 (text) or webchat at alzfdn.org.

ABOUT THE AUTHOR

Nathaniel Chin, M.D., is the medical director of the Wisconsin Alzheimer's Disease Research Center and a member of the Medical, Scientific and Memory Screening Advisory Board of the Alzheimer's Foundation of America.



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1. Elecsys® Method Sheet: ms_08821941190, ms_08846693160, ms_08846685190

2. Cummings, J., Apostolova, L., Rabinovici, G.D. et al. Lecanemab: Appropriate Use Recommendations. *J Prev Alzheimers Dis* (2023).

3. World Health Organization. Risk reduction of cognitive decline and dementia: WHO guidelines. Published January 1, 2019.

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WHY YOU NEED TO KNOW ABOUT LEWY BODY DEMENTIA

More than 1.4 million Americans have Lewy body dementia (LBD) and more than 11 million worldwide, numbers that are probably low, according to Norma Loeb, founder and executive director of the Lewy Body Resource Center.

"More people have LBD than ALS, muscular dystrophy and cerebral palsy combined, yet LBD is not commonly known. One reason LBD research has lagged that of Alzheimer's and Parkinson's for decades is due to an earlier notion that it was a rare disease. It is not rare," she says.

Lewy body is a degenerative neurological dementia, the second most common form after Alzheimer's. It's difficult to diagnose because a variety of symptoms present over time. Symptoms overlap with Parkinson's disease as well as Alzheimer's. One person with Lewy body dementia is not the same as another person with LBD.

In the brain tissue of people with this condition, there is an aggregation of misshapen protein particles, called alpha-synuclein deposits. These are known as Lewy bodies.

Dr. Fritz Jacob Heinrich Lewy discovered these clumps of abnormal proteins in the nerve cells of brains in 1912. However, the first case of LBD wasn't described until 1961, with the first set of clinical criteria put forth in 1996.

Famous people who have had LBD include Robin Williams, Tom Seaver, Estelle Getty and Casey Kasem. Ted Turner is currently living with it. Health journalist Max Lugavere chronicles the difficult search for answers with his mother, Kathy Lugavere, in his new film *Little Empty Boxes* (see pp. 19-20 for our Q&A).

"Too many people are misdiagnosed and many people who are diagnosed with Alzheimer's also have Lewy body," says Loeb, who has been leading LBD support groups for 15 years. "More than 40 percent, for sure, have both, we believe."



Kateryna Kon | Dreamstime

Loeb says key identifiers of LBD can include:

- **Cognition issues:** trouble with multi-tasking and problem-solving more than memory issues, which come later. Many people have a slower time retrieving words in conversation and need more time to respond.
- **Fluctuations** in cognition and awareness.
- **Parkinsonism:** slowness of movement, shuffling walk, rigidity, balance issues. About 80 percent of people with LBD have Parkinson's. Many people don't have tremors, but rather slowness of movement, trouble getting out of a chair and balance problems resulting in falls.
- **Hallucinations and delusions:** seeing and hearing things that aren't there in nearly 80 percent of people living with LBD. They occur early in the condition and typically are realistic and detailed, often involving small animals and children. Delusions involve making up stories that aren't true, such as a spouse having an affair.
- **REM Sleep Behavior Disorder:** physically acting out dreams, flailing, hitting bed partners. "When we're sleeping, our bodies are generally frozen. If we're dreaming of throwing a ball or running, we're not moving our arms or legs. With someone who has REM Sleep Behavior Disorder, they physically act out their dreams. They can hit the person they're sleeping with, knock over a lamp and fall out of bed. This can be a very early sign. It can have started 10 years before the other symptoms."
- **Visuospatial and depth perception problems:** reaching out for a glass and missing or walking into the wall next to the door. "People often say they need to go to an eye doctor, but the problem isn't in their vision."
- **Sensitivity to medications** such as those that treat psychosis or are used for anesthesia. "The wrong medications can make symptoms much worse."

Continued on following page

"If you don't remember most of these, please remember fluctuations. Somebody with Lewy body can be having a regular conversation and then later that day or the next can barely answer a simple question. That can go on for a few hours or a couple of days."

Other symptoms:

Depression. "If someone has had depression or anxiety in their lives then it will be worse if they have Lewy body," Loeb says, adding that even if they've never had depression most people with LBD develop it.

Anxiety. This is triggered if they are trying to think of something to do, and they are unable and can't figure out why.

Apathy. "They cannot get up the oomph to get up and do anything."

Incontinence and constipation. "In conjunction with everything else, these can be an early sign."

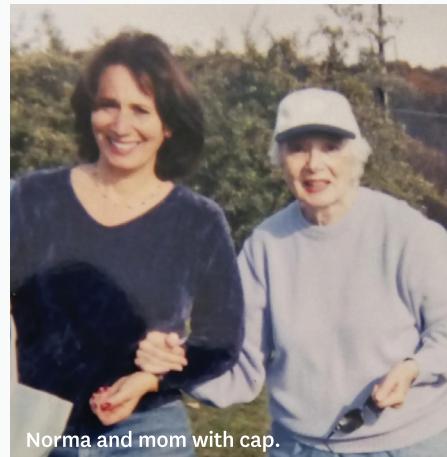
Orthostatic hypotension (when blood pressure drops suddenly). This often happens when someone gets up too quickly and can result in falls.

Why is it important to diagnose LBD correctly?

Like Alzheimer's and Parkinson's, LBD has no cure, but it is different because of the sensitivity to medications it brings.

"It's extremely important that someone is diagnosed correctly because of this. Many people have told me a physician told them because there aren't any cures for these conditions, it's not important to describe them. That is not so," Loeb says.

She suggests a care partner keep a list of all symptoms their loved one has and take it as a history for the doctor.



Norma and mom with cap.

Loeb's involvement with LBD began after her mother, Lillian, at 75, started having trouble with her checkbook. She took her to an internist who said that was a normal part of aging.

She was referred to a gerontologist who diagnosed her mother with Alzheimer's,

although he couldn't understand why her cognition was so sharp. After two years with that misdiagnosis, the doctor said he wanted to watch her mother walk because he thought she might have Parkinson's.

"I said she's been walking like that for the two years I've been bringing her here. I was then told to take her to a neurologist. That continued for three-and-a-half years."

Eventually, Loeb took her mother to a doctor at Mount Sinai Hospital in New York who mentioned Lewy body.

"When I went home, I looked online, and she had almost every symptom there was."

After her mother passed away eight years ago, Loeb founded the Lewy Body Resource Center with the mission to raise crucially needed awareness and support.

The Lewy Body Dementia Resource Center (lbdny.org) provides support groups and help in seven languages. It also offers a national helpline at **516-218-2026** or **833-LBD-Line** from 8 a.m. to 8 p.m. Norma Loeb invites questions at norma@lbdny.org.

This article is adapted from AFA's Care Connection webinar "Lewy What? What is Lewy Body Dementia and How Do You, Healthcare Professionals and Caregivers, Deal with It?"

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Q&A with Max Lugavere

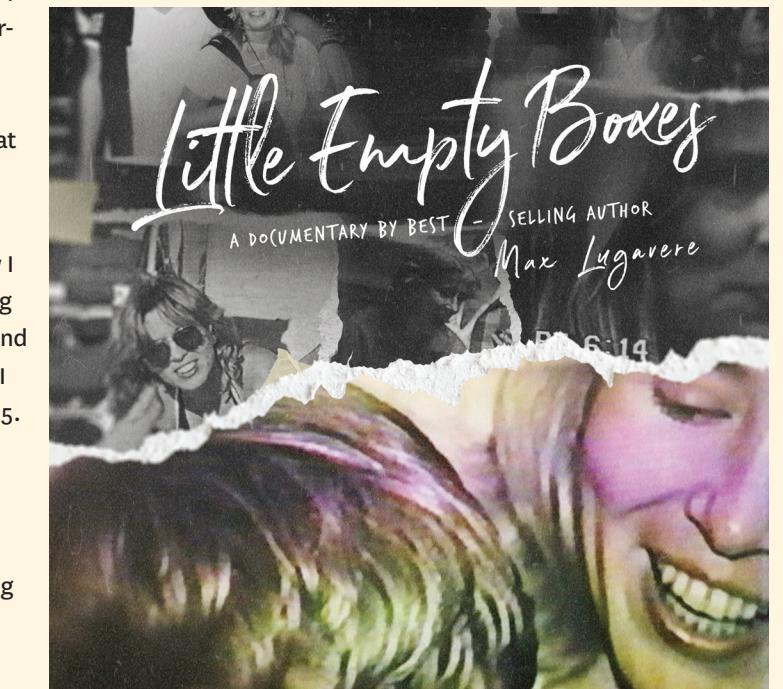
Executive Producer/ Co-Director: Little Empty Boxes
A Documentary That Chronicles a Young Adult Son's Quest to Find Answers to His Mother's Dementia

Genius Foods, The Genius Life, and Genius Kitchen as well as starting a now top-ranking podcast, *The Genius Life*.]

The film chronicles the fuzziness around your mom's diagnosis. You decide to move back to New York City to help.

At first, she had nonspecific cognitive decline and some movement symptoms. It took a weeklong trip to the

Continued on following page



Little Empty Boxes opened in April 2024 in New York City and Los Angeles. Go to littleemptyboxes.com to learn where you can see it near you.

Cleveland Clinic to receive her first diagnosis of some sort of neurodegenerative complex. The diagnosis was a Parkinsonian condition (Parkinson's "Plus"). But she also had striking cognitive decline at that point, and was ultimately diagnosed with Lewy body dementia. The Alzheimer's connection came about because we weren't really sure what it was at first, and I've learned that many neurodegenerative conditions, while not the same, do share some commonalities — certain risk factors, for example. Alzheimer's is also the most common form of dementia and the type most studied regarding lifestyle risks. There's a lot less data on Parkinson's disease and even less on Lewy body dementia.

A good part of the film also focuses on your conversations with doctors and other medical experts as you try to investigate the possible causes.

My mom was still very young. We didn't have dementia in our family lineage and my two brothers and I were in utter disbelief. What the film attempts to do in broad strokes is examine the dietary and lifestyle factors that may predispose one to developing dementia. The film doesn't present a silver-bullet solution. It doesn't offer a magical "prevention diet." It basically brings to light important and actionable ideas about nutrition and lifestyle, such as exercise and yoga, which can potentially play a protective role and possibly even slow progression.



"My world stopped in 2011 when, on what was supposed to be a relaxing summer vacation, my mother couldn't recall what year it was. Pressing her, in disbelief, she struggled to find the answer and began to cry. That was the moment I knew our lives would never be the same. *Little Empty Boxes* wasn't a film I planned to make. It crept in, claws out. Watching dementia cripple her life was excruciating, but within that pain bloomed a purpose. I had to do my best to understand this condition, not just for her, but for everyone facing the abyss of cognitive decline. My film isn't about medical pronouncements or miracle cures. It's raw, messy, and deeply personal. It's a plea for empathy, a tribute to my mom, and a love letter to the science of dementia prevention. It is my hope that by sharing my mom's story, we can illuminate the path not just to delaying, slowing, or even, possibly, preventing this condition, but to cherishing every fragile memory, every laugh, every 'I love you' before the boxes become truly empty. This film isn't about endings; it's about making the most of what remains, together."

~Max Lugavere

Make sure the people in your life know that you love them, and make sure they know that you know that you are loved.

Kathy Lugavere, 66, passed away December 6, 2018 of pancreatic cancer after living with Lewy body dementia for 8 years.

IN THE NEWS

Memory, Music, Bone Health, Olive Oil



A MEMORY JOGGER

Recent experiments by psychologists shed new light on how we remember our real-world experiences. In two experiments, researchers asked participants to repeatedly study pairs of items and scenes that were either identical on each repetition or in which the item stayed the same, but the scene changed each time. Researchers found that memory was better for the items that had been paired with different scenes compared with those shown with the same scene each time. For example, if you want to remember a new person's name, repeating the name but associating it with different information about the person can actually be helpful.

Science News, University of Pittsburgh



BONE HEALTH AND BRAIN HEALTH

People who have low bone density may have an increased risk of developing dementia compared to people who have higher bone density. The study does not prove that low bone density causes dementia. It only shows an association.

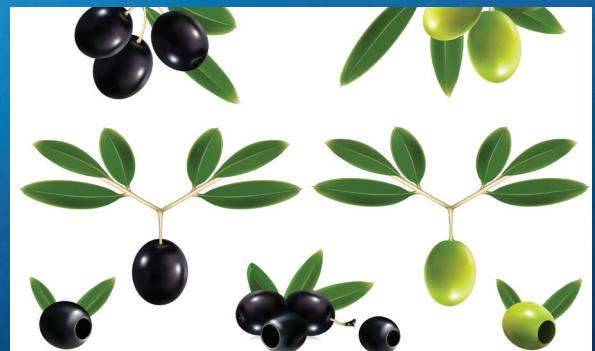
Science News, American Academy of Neurology



MUSIC HAS LONG-TERM EFFECTS

Engaging in music throughout your life is associated with better brain health in older age, according to a new study. Scientists working on PROTECT, an online study open to people aged 40 and over, reviewed data from more than a thousand adults over the age of 40 to see the effect of playing a musical instrument — or singing in a choir — on brain health.

Science Daily, University of Exeter



OLIVE OIL MAY REDUCE DEMENTIA RISK

People who incorporate olive oil into their everyday diet may decrease their risk of dementia-related death, according to a new study by Harvard T.H. Chan School of Public Health. The study was published in JAMA Network Open. "Olive oil is rich in monounsaturated fats and contains compounds with antioxidant activity that may play a protective role for the brain," Anne-Julie Tessier, research associate, said in a UPI article about the study.

Harvard T.H. Chan School of Public Health

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BUILD GOOD HABITS

Many people regularly practice good habits to protect their physical health, but don't give much thought to developing practices to promote their brain health. Allison B. Reiss, M.D., is passionate about raising awareness of the ways people can prevent cognitive decline. Reiss, an associate professor of medicine at NYU Grossman Long Island School of Medicine, is an internal medicine physician, educator and a member of AFA's Medical, Scientific and Memory Screening Advisory Board who studies the causes and treatment of Alzheimer's disease and other forms of cognitive impairment.



Dr. Allison Reiss enjoying the Bronx Botanical Garden, Bronx, NY

Diet

The Mediterranean diet has long been recognized as increasing life expectancy. It also keeps our brains strong. Focus on eating plant-based foods (vegetables, fruits and olive oil), and lean meats such as chicken and fish. The most emphasis is placed on dark green leafy vegetables, berries, whole grains and healthy, unsaturated fats (such as salmon, avocados, olives and nuts). It also consists of a low intake of sugary foods and beverages, fried foods and red meat.

"In general, foods that are heart healthy are also brain healthy," she says, adding that there is growing recognition of the link between a healthy digestive system and a healthy brain.

"Diet plays a crucial role in determining the composition of the gut microbiome, which can affect the function of the brain through the microbiota-gut-brain axis. This means, at the most

basic level, what you eat and how you digest it affects many aspects of your health and most certainly your brain. Adequate fiber intake is beneficial to the gut microbiome. Consider adding fermented foods to your diet. They contribute to gut health and may offer protection to our brain cells."

She says the wide variety of fermented foods can suit every palate, mentioning kefir, tempeh, kimchi, sauerkraut and kombucha.

"Diet is not one type fits all. If you do not like it, you will not eat it long-term."

Exercise

A healthy diet needs to be supplemented with exercise, which is good for the brain and heart.

"Find activities you enjoy and try to do a mix of aerobic exercise, resistance training and stretching, balance, range-of-motion activities. Physical activity keeps the heart and vascular system in good shape so they can supply blood and nutrients to the brain. Exercise also lifts mood and relieves anxiety, and we know that stress and depression can negatively affect mental function. Physical activity also helps to maintain attention and vigilance."

Continued on following page

Growing evidence finds that meditation can alter brain activity patterns in beneficial ways, improving attention, reducing stress and enhancing feelings of well-being.



Sleep

Sleeping well and getting enough hours of sleep are important elements in brain health.

“During sleep, there is consolidation of learning and memory and strengthening of synaptic connections,” Reiss says. “Many physiological processes occur that are vital to maintaining brain health, restoring balance to the nervous system and ridding the brain of waste products. Getting a consistent sleep every night is key; at least seven to nine hours is ideal. Poor sleep quality can bring on or exacerbate depression and depression is associated with poor cognitive function.”



Social Life & Learning

Our cognitive health is also positively influenced by our social relationships and support systems. Loneliness has a negative impact on mood and quality of life. Reiss encourages people to interact in their community and

1. Get out of the house. Do not sit in front of the TV or computer all day. Get some fresh air and enjoy time surrounded by nature.

2. Vitamin D is important for the brain.

People whose levels are low are more likely to develop Alzheimer’s and other forms of dementia. Although sunlight is the most common source of vitamin D, many people avoid sun exposure. Even though milk is fortified with vitamin D, a lot of yogurt brands are not, so check labels. Did you know that just about the only plant that gives us vitamin D is the mushroom? Especially if you are vegan, consider adding mushrooms to your diet for natural vitamin D.

3. Avoid empty calories. So many of us, myself included, enjoy sugary foods. My approach when I crave

sweets is to make sure there is at least some nutritional value and some component that is filling and satiating. Good examples are strawberries or banana slices

participate in group activities. Realize that exercising our brain by continuing to learn is as important as exercising our body.

“Learning and challenging the brain to do new things builds up nerve pathways and helps to cushion you from loss of brain function by bolstering cognitive reserve. The mental stimulation that comes with learning helps to give the brain resilience and keep it sharp. Never stop trying new things outside your comfort zone. Exposure to music is especially powerful. Melodies can reach areas of the brain, even if they have been damaged, through separate circuits from other kinds of stimulation.”

For Reiss, spreading this information is central to her being.

“I am fundamentally a person of ideas and my purpose in life is to apply my creative skills to finding treatments and cures for diseases that afflict millions of people like Alzheimer’s and cardiovascular disease. As the leader of a research initiative that has the potential to affect millions of people with Alzheimer’s and their loved ones, I feel every day the responsibility not to let them down. If the benefits of doing all these things could be captured in a pill, that pill would be worth untold billions of dollars.”

dipped in chocolate (at least you get some fruit), a peanut butter and chocolate combo, a mix of nuts and chocolate, and a brownie recipe made with beans or zucchini.

4. Avoid head injury.

It’s something that doesn’t get enough attention and increases the risk of cognitive issues. Traumatic brain injury is a big problem that can be averted with care, helmets and other headgear, seatbelts and measures to prevent falls. If you do sustain a concussion, follow all protocols outlined by your health care provider and take every precaution to steer clear of another one.

5. Keep in touch with friends and family. Nurture relationships. These connections enrich your life and keep you thinking. Combat loneliness with a

support network.

Adapted from an interview by Maria Angelova in *Authority Magazine* (medium.com/authority-magazine).

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