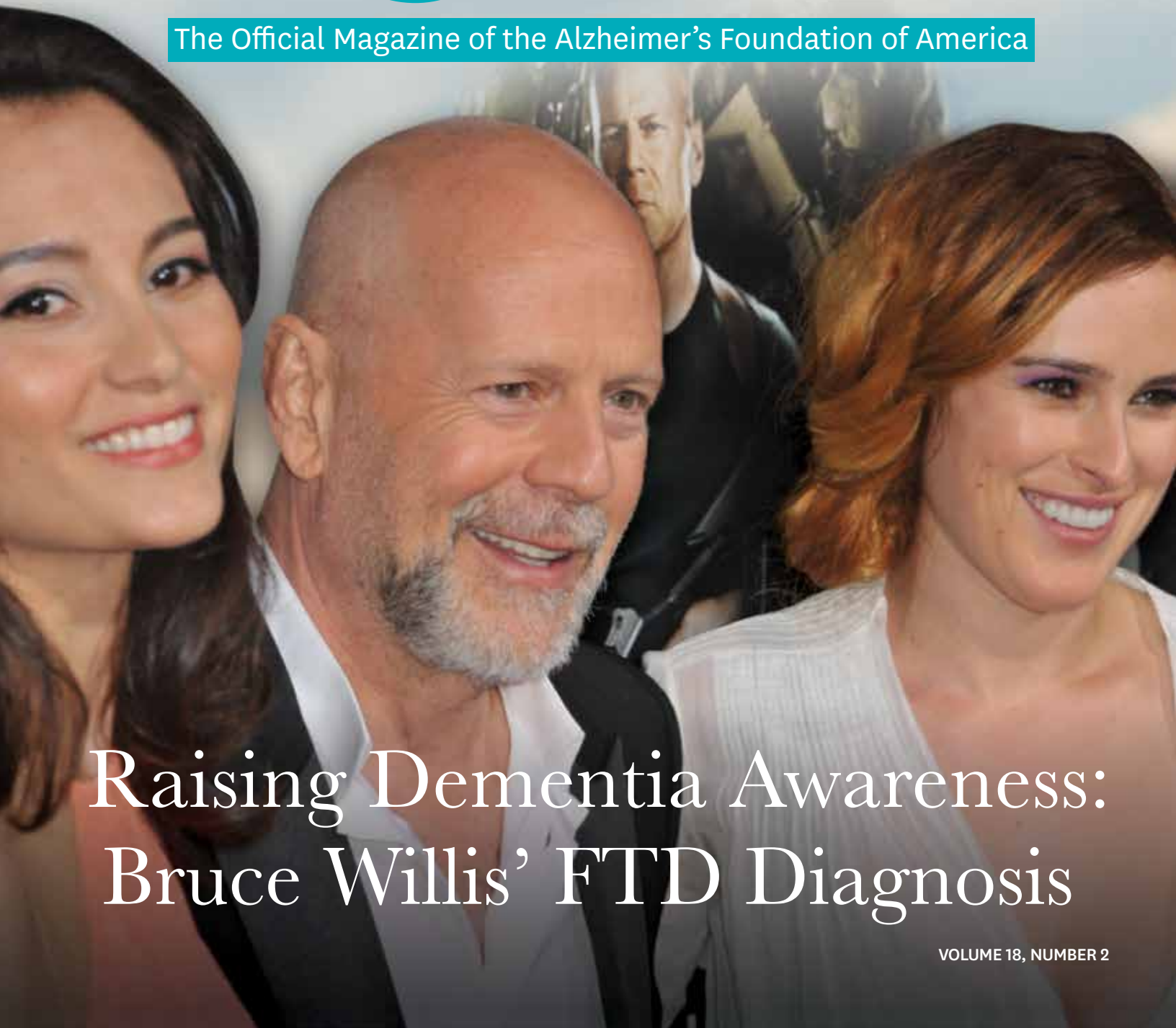


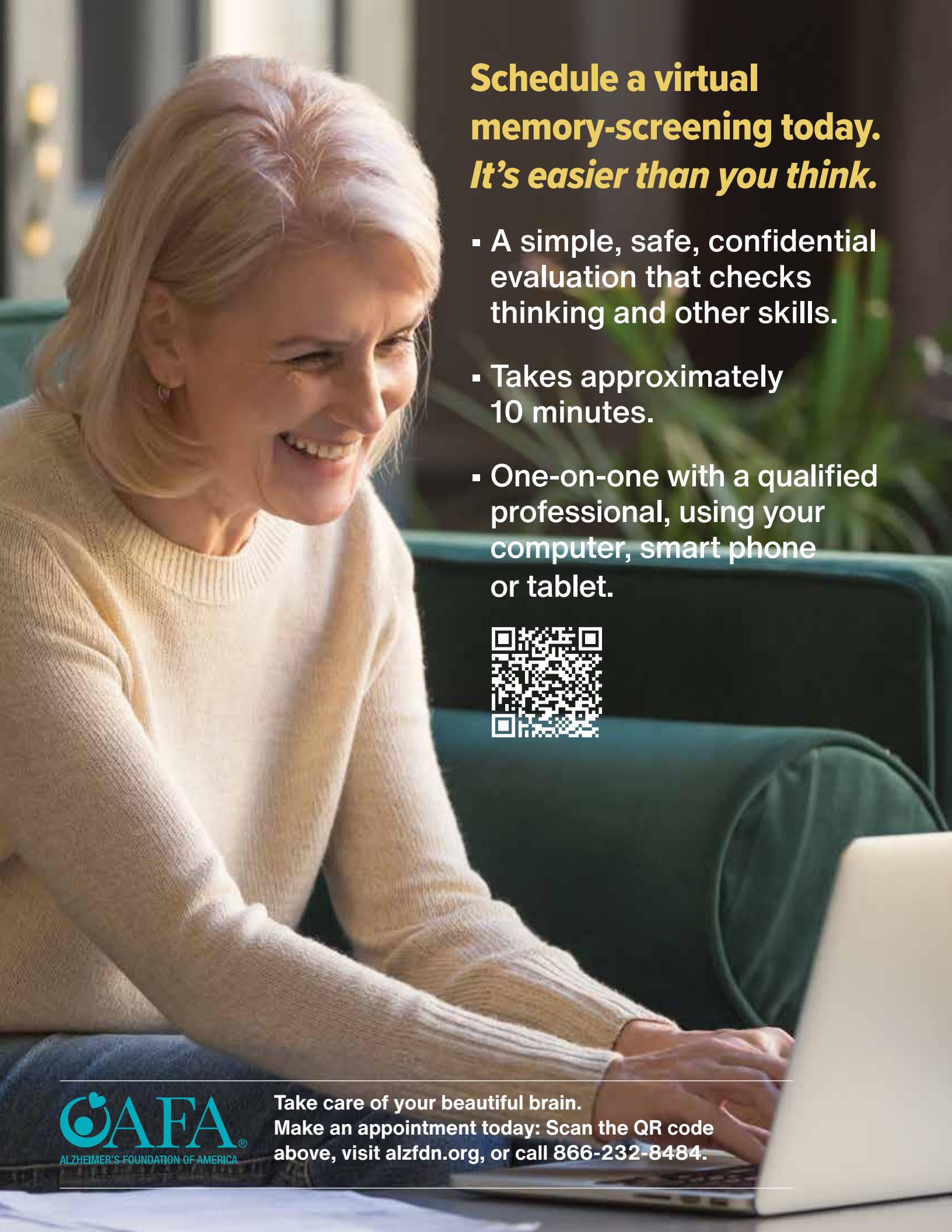
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The Official Magazine of the Alzheimer's Foundation of America



Raising Dementia Awareness:  
Bruce Willis' FTD Diagnosis

VOLUME 18, NUMBER 2



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

A few months ago, we received a 45-page submission for *Alzheimer's TODAY*.

“The Story of Pepi and Sal” is a love story written by 70-year-old Salvatore Romano, who is living with dystonia, a progressive movement disorder, and his partner Pepi Ann Kahn (81), who is living with Alzheimer's. They met and fell in love at The Forum, an independent living center in Houston, TX.

Sal dedicated his inspirational story to all of you: the courageous people living with Alzheimer's who find themselves in the daily struggle and their heroic caregivers and families. He wanted to remind us that our loved ones living with Alzheimer's and dementia “can still have a fulfilling life.”

We were uplifted by the poems Sal wrote about their daily encounters and heartbroken when he revealed that after years together, he needed to move from The Forum to a new location. Today, he still makes arrangements to visit Pepi once or twice weekly, creating meaningful ways to engage with her. Here are just a few of them:

- **“Find the Ace”** card game: Using a simple deck of cards, Sal removes all the aces but one. Each player takes turns flipping over a card, attempting to find the ace. Sal and Pepi's caregiver always root for her.
- **Dancing while sitting on the couch:** Pepi and Sal simulate dancing on the couch. It becomes a safe and gentle way for Pepi to get a little exercise.
- **YouTube karaoke:** Pepi's care partner searches for her favorite songs, and they sing them together.
- **An occasional back rub:** A short, satisfying rub is a perfect way to keep a connection special.

Thank you Sal for being such an inspiration.



Sal Romano and Pepi Ann Kahn enjoying good times together.  
Courtesy of Salvatore Romano

***Sal shares his enduring respect and admiration for the caregivers — and we, in turn, share our enduring respect and admiration for Sal. For finding and nurturing friendship and love during a challenging time in his own life, and reminding us to make the most of our days, we dedicate this issue to Sal and Pepi.***



# Setting a Spark *with* Music



Jackie Vanderbeck, Sing For Your Seniors founder and producing artistic director, performing for a group.

**M**usic has proven to be one of the most effective ways to relate to people with Alzheimer’s or other memory loss diseases. Fortunately, many of them can still sing a familiar song even if they don’t recognize the person in front of them.

“You can see there’s a real connection,” says Dr. Concetta Tomaino, DA, LCAT, MT-BC. “There was a spark that set off a series of responses that showed me that there was a level of functionality, a level of personal awareness, a way of really connecting deeply to the personhood of that person and that set me on this quest.”

Tomaino is the executive director and co-founder (in the 1980s with Dr. Oliver Sacks) of the Institute for Music and Neurologic Function. They began studying how music integrated the neurological function to enable people to regain as much access to this function as possible.

“In the past 15 years or so, the world of neuroscience has really expanded with the capacity to look at how certain aspects of music, like rhythm and pitch, and emotional responses to music, are organized in the brain and how these different networks stimulate and inform each other, allowing people with dementia to stimulate areas that are still functioning,” Tomaino says. “These areas all work in consort, so when somebody hears a piece of music that is personally important to them, there’s an emotional connection to areas of the brain, like the hippocampus and amygdala, that light up immediately. The excitement of those areas of the brain start to stimulate these other brain networks into action.”

Typically when we think of memory loss, Tomaino says, we are thinking of damage to declarative memory, which includes recalling facts like the date, where were you born, who is the President, factual things one needs to know in the moment.

“These are the types of memory skills that tend to decline in the early stages of dementia and neurocognitive issues. However, there are many implicit skills that are well-ingrained in our brain that people can still have access to.”



Jerome Quek | Dreamstime



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*“I’ve been a music therapist for 44 years now and it has been my experience early on that there was this dramatic way we could connect with people who seemed to have lost a lot of cognitive function, who couldn’t recognize faces anymore, who didn’t know where they were, who weren’t able to verbally communicate that well but yet would come to life and seem to be present in that moment with a piece of music that they had a connection to when they heard it.”*

–Dr. Concetta Tomaino

Adapted from the AFA Care Connection webinar “Improving Quality of Life with Music-based Interventions for People with Alzheimer’s and Other Neurocognitive Disorders.” Dr. Concetta Tomaino is the past president of the American Association for Music Therapy, a founding board member of Music & Memory, an adjunct professor at Lehman College, CUNY, and author of *Music Has Power in Senior Wellness and Healthcare: Best Practices from Music Therapy*.

## HOW USING MUSIC CAN HELP

“A person may have trouble thinking about how to walk. They may have poor coordination yet you put on a piece of music with a good, strong, steady beat and it seems like that person is dancing to the music,” says Dr. Concetta Tomaino. “Their habituated, implicit knowledge for how to move to music is easier for them to access than thinking about what foot goes in front of the other. Many times we see people who are able to dance when they’re not able to walk. We can use strong, rhythm-based music at a steady walking pace to enable somebody to walk with more ease and flexibility.”

**Caregivers can benefit as well.** Tomaino knew a husband whose wife with Alzheimer’s fought taking a shower. In younger days, they had loved to dance, so he put on Duke Ellington “and he would dance her into the bathroom.”

**Singing can help people with word-retrieval skills.** “We’ve done research where after you have engaged somebody in singing a familiar song, that person is more apt to be able to identify an object on the table that they couldn’t prior to the singing,” Tomaino says. “This works because singing familiar lyrics primes or stimulates areas of the brain involved with verbal processing. It bypasses the whole thinking-about-how-to-do-something skill that’s often damaged. When you ask someone with dementia to do something, they first have to think about what you mean.”

**Engaging someone in music or song can carry over to other skills, such as feeding themselves and being aware of their surroundings.** It can reduce agitation and frustration and improve the skills they are working on with a physical therapist. Because listening to pleasurable music increases the release of brain opioids, it can reduce the perception of pain. “Sometimes when a person with dementia is aggressive or feels restless it is because they are in pain and they can’t verbalize that. The music makes them feel comfortable.”

Tomaino suggests people create a playlist of music their person had loved and put it on an Mp3 player or choose an online streaming service. She said YouTube has karaoke-type videos that that can be used to help improve speech volume and articulation when the person sings along.

Many organizations offer music programs for seniors. She also recommends online resources like Vera and Point Motion/Sound Health (links can be found on [imnf.org](http://imnf.org)). AFA also has free in-person and online music offerings that can be found at our website at [alzfdn.org/afatealroom](http://alzfdn.org/afatealroom).



Music therapy session with Alzheimer’s Alliance of Smith County, TX





## AFA MEMBER CLOSE UP: Rx Ballroom Dancing Ladera Ranch, CA

Norm and Leora Kredit taking each other's hands for a cha cha.  
Photo courtesy of Rx Ballroom Dancing

As Allan's memory loss worsened, he began isolating at home. When speaking became a problem, he stopped answering the phone. Erin Drake Angelo didn't let this stop her. She had plans for this 86-year-old gentleman.

She knew from his daughter that he had loved ballroom dancing before illness restricted his activities. Since she couldn't reach him by phone she drove to his home and, despite much resistance, convinced him to come to her dance class.

After being unable to remember his address in filling out the form, he sat by himself, determined to ignore what he thought was in his past. But Angelo once again persisted.

"When I turned on the waltz, Allan literally took off and waltzed around the room. He graced the floor and all the ladies wanted to dance with him."

As Angelo continued to pick him up, she found him waiting outside for her. He was also talking in sentences and responding to others. A professional ballroom dancer herself, Angelo wasn't surprised. She had read studies that proved this form of dancing helped improve balance and memory because of the "dual tasking" of maintaining posture and concentrating on steps, which is why she founded Rx Ballroom Dancing in 2018 for people with neurodegenerative illnesses. Since then, AFA has awarded this organization, based in Ladera Ranch, CA, grants three years in a row.

"It's like walking and chewing gum. You create multiple neuropathways all at the same time."

Rx Ballroom Dancing has grown from one location to nine within a 100-mile radius. It offers 16 classes a week, two of which are online, and has about 250 participants. Most come from local support groups or care organizations. Because ballroom dancing

classes cost more than \$100 a lesson, which makes them too costly for people on fixed incomes who are already dealing with the expenses of their illness, classes are free for all, including caregivers. If a caregiver doesn't want to participate, a volunteer partner will be provided.

The curriculum is based on that of the syllabus established by the National Dance Council of America in which all teachers are certified. Angelo enhanced her curriculum with her knowledge from her UCLA master's degree in education and through consulting with physical therapists, movement disorder specialists, a psychologist, a psychiatrist and a neurologist.

Through conversations with loved ones and their answers on questionnaires, Angelo has learned that participants are able to speak better and need less depression and anxiety medication because of the dopamine boost to the brain. Through the fast pace of the dancing, their endorphin levels rise and they enjoy socializing once again. She is sharing her results with researchers at the University of California, Irvine, who are studying the effectiveness of ballroom dancing on people living with neurodegenerative illnesses.

The healing benefits also extend to the caregivers who often experience depression and burnout.

"They get to engage with their loved one without the responsibility. The encouragement they bring is beautiful. They're not just sitting on the wayside at the doctor's office. They are totally participating."

**Interested in learning about the benefits of AFA's Member Network? Email [membership@alzfdn.org](mailto:membership@alzfdn.org) or call 866-232-8484 and ask to speak to a membership coordinator.**





# What is FTD?

**Q&A with Allison B. Reiss, MD**  
*AFA Medical, Scientific and Memory Screening  
Advisory Board Member*

The announcement of actor Bruce Willis' dementia diagnosis earlier in the year—frontotemporal dementia (FTD)—brought to the surface additional questions about what makes this type of dementia different from Alzheimer's. We went to our AFA Medical, Scientific and Memory Screening Advisory Board for the answers.

## What is frontotemporal dementia?

FTD is actually a group of brain disorders that cause progressive degeneration of nerve cells in the front and on each side (temporal lobes) of the brain. It has a relatively young age of onset, most diagnosed between ages 45 and 64 years.

## What are the symptoms?

There are a spectrum of symptoms spanning three categories:

- 1) **Behavioral variant FTD**, the most common, is marked by changes in behavior and deterioration of personality. The patient may exhibit apathy, reduced sympathy and empathy, poor judgment, altered food preferences, and repetitive behavior. Memory problems are relatively less prominent. There may be emotional outbursts, poor manners, and excessive familiarity with strangers.
- 2) **Semantic variant primary progressive aphasia**, most obvious in the early stages, is difficulty in naming objects. Over time, the patient loses the meaning of words and the ability to remember what a familiar object is or how to use it. There may be substitution of related words or replacement of a word they have lost with "that thing" or "the you know." Some behavioral problems may be noticed. Speech therapy may help for a time. Use of numbers, colors and shapes can be preserved longer than words. Motor abilities are retained.
- 3) **Non-fluent aphasic** variant is halting speech with sound errors. The person is using a lot of effort to speak and their grammar is poor, with impaired comprehension of complex sentences.



Bruce Willis with wife Emma Heming (left) and daughter Rumer Willis at a *G.I. Joe: Retaliation* movie premiere in Hollywood.

## What causes FTD?

This is unknown except in some rare inherited cases related to specific gene mutations. More research is needed.

## Can it be treated?

There is no cure for FTD, and we cannot slow its progress. Behavior modification techniques, SSRIs and, if necessary, antipsychotic medications can help.

## How is it different from aphasia?

Aphasia means difficulty speaking, usually because of damage to specific areas of the brain. It has numerous causes and is not associated only with FTD. Aphasia can be due to a stroke, head trauma or infection. Aphasia does not necessarily lead to inevitable loss of functioning and ability to care for oneself.

## How is it different from Alzheimer's?

Unlike Alzheimer's disease, FTD usually does not include formation of amyloid plaques. There is an association with abnormal tau protein. FTD tends to occur in younger persons. FTD and Alzheimer's all end similarly with language and behavior profoundly affected and memory dramatically reduced as well. Twenty-four hour care may be necessary, and, unfortunately, death may occur as a result of infections, such as pneumonia.

*Allison B. Reiss, MD, is an associate professor of medicine at NYU Long Island School of Medicine and head of Inflammatory Laboratory, Biomedical Research Institute, NYU Langone Hospital-Long Island.*

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BOOK CORNER:

# Everything Left to Remember

By Steph Jagger



Photo courtesy of Steph Jagger.

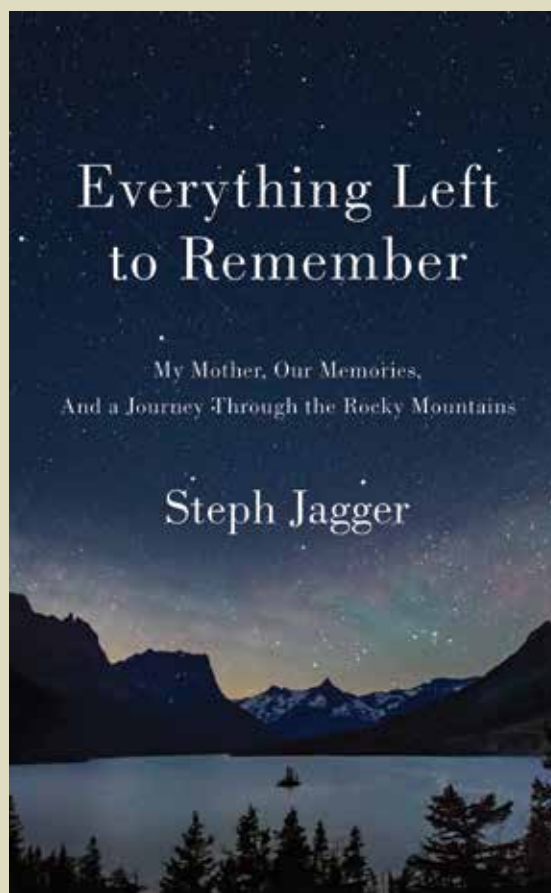
It took her mother's diagnosis with Alzheimer's in June 2015 for Steph Jagger to realize she didn't know much about this woman who had raised her and been a part of her life for three decades. She made a plan to change that and ended up learning even more about herself.

"The idea of Alzheimer's taking pieces of her away before I had the whole picture was unbearable to me," she writes in her memoir *Everything Left to Remember*. "The ache to know more of my mother had existed for a long time, but something about it changed when she was diagnosed — a dull and muted pain was replaced with something more searing."

To ease this consuming desire, Jagger set out alone with her mother on a road trip through the Rocky Mountains. She wanted to learn, and write, her mother's story before it was lost forever. And with it, her own.

"At the time, I had very little understanding of how deeply my mother and I had been woven together, of how intricately her seams had been stitched into mine, or how the pulling on one would lead to the unraveling of another."

As one can imagine this would take tremendous patience. But the physical and emotional journey brought gifts, starting in Yellowstone National Park. As Jagger drove a rental car through the vastness of the country's first national park she watched her mother cry, and then cry harder. When she stopped the car to see if she was in pain her mother replied, "It's so beautiful."



"I felt suddenly calm," Jagger writes. "I didn't know a lifetime of thirst could be slaked with three words."

But a short time later she had to wrestle with her conscious after telling her mother another "little white lie." In a convenience store in Gardiner, a small town just outside of Yellowstone's entrance, her mother persistently asked for Glayva, a drink popular in Canada where she lived. Knowing she wouldn't find it in Gardiner, Jagger searched for something that resembled the bottle and found Baileys and insisted to her mother that it was Glayva.

"She didn't have the words for it, but she knew I wasn't telling the truth," Jagger writes, wondering

when these little fibs had "become a regular thing . . . my hands grabbing for small pieces of wool to pull over my mother's eyes, all so I could move a little quicker, all to make it just a little easier."

Jagger's journey of discovery — of her mother, herself and the natural beauty around them — unfolds in anecdotes that will be familiar in theme to those living through the mental decline of a loved one, even if the locations are grander. "Some things may be forgotten. But in the process, we shall be remembered."



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# AT THE UNIVERSITY OF TEXAS: Building Empathy

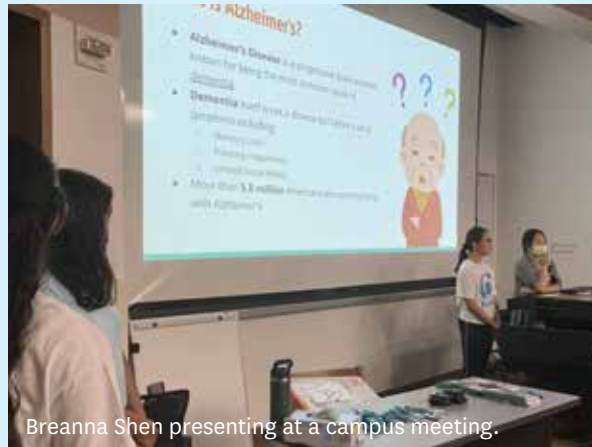
Avani Sharma arrived at the assisted living residence with paper and a desire to brighten the day for people living with memory loss. As she helped a senior resident who was withdrawn and nonverbal to make a paper snowflake, the University of Texas at Dallas student was touched by the initiative and interest that was sparked in the resident.

“This story is so inspiring, as are many others from the volunteers in our AFA on Campus chapter,” Breanna Shen said. Every visit that the volunteers make is full of meaning. The neuroscience major started the UTD chapter, which now has about 100 members, in March 2021.

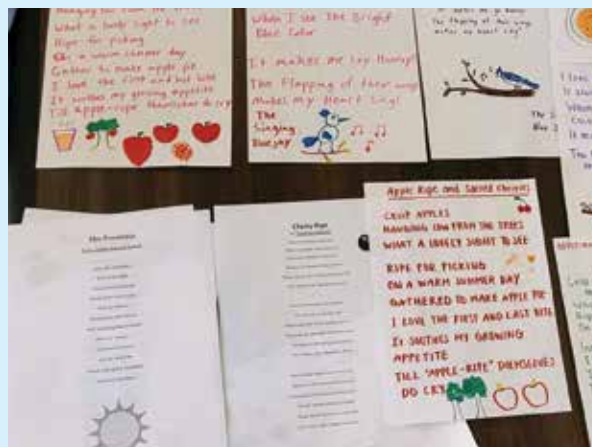
“My grandfather passed away with Alzheimer’s so I really wanted to do something to have an impact and better support patients and caregivers and as many people as we can.”

About 20 of the members are active in the visiting program, volunteering with Alzheimer’s residents and caregivers at five assisted living facilities in the Dallas area (two Manchester Care Homes facilities, two New Horizon Homes facilities, and the Teresa’s House assisted living). The visits are biweekly or monthly, with students leading small-group lessons in poetry and art.

“It’s been really rewarding and exciting to expand our volunteering program from our start in spring 2022 when we were awarded a \$1,000 Worsfold grant by the UTD Honors College. This enabled us to fund the supplies for a series of art and music classes and create Alzheimer’s disease patient-caregiver engagement groups at nursing homes



Breanna Shen presenting at a campus meeting.



in Dallas and virtually with the Mayo Clinic Senior Living Center in Rochester, MN.”

The chapter also recently hosted a talk by Sandi Greenberg, the director of nursing for Manchester Care Homes. She spoke to the members about working with Alzheimer’s residents and gave them tips for volunteering. They were coordinating another talk with a postdoctoral researcher who studies Alzheimer’s disease in a research lab at UTD. Shen credits chapter advisor Dr. Sheryl Skaggs for their success.

“We couldn’t have accomplished our endeavors without her.”

Shen said volunteers are committed to visiting, even if their presence isn’t acknowledged.

“Maybe they’re not able to talk, but I still think it’s a good experience for them. We share a poem and something about ourselves. Even if we’re not getting responses, they still feel we’re trying to connect.”

And the students are enriched as well.

“It helps younger people try to understand what seniors and people with Alzheimer’s are going through. It helps build empathy.”

**For information about starting an AFA on Campus chapter, contact [membership@alzfdn.org](mailto:membership@alzfdn.org) or call 866-232-8484 and ask to speak to a membership coordinator.**

# Investing in Hope

AFA provides funding for research projects aimed at improving diagnosis and treatment, finding a cure, and improving quality of life for millions of people living with Alzheimer's disease. You can help us do more. Donate at [alzfdn.org/donate](https://alzfdn.org/donate).



## At-Risk Individuals

Researchers at NYU Langone Hospital-Long Island are conducting an innovative study called “Platelet-Rich Plasma in the Study of Alzheimer’s Pathophysiology.” The study focuses on amyloid, an abnormal protein in the brains of people with Alzheimer’s, which some scientists believe to be part of what kills healthy brain cells. The research has potential in both biomarker development — diagnosing who is at risk early on — and drug therapies to treat Alzheimer’s disease.

## Exploring the Role of Neuroimmune Interactions and Alzheimer’s Disease

A study by The Broad Institute of Harvard & MIT and One Mind is examining the role of the brain’s immune cells in the onset and progression of Alzheimer’s disease. This could lead to new biological insight and inform the identification of biomarkers used for early detection and monitoring of progression and therapies.

## Treating Hallucination and Aggressive Behavior

Conducted by the Litwin-Zucker Research Center for the Study of Alzheimer’s Disease at Feinstein

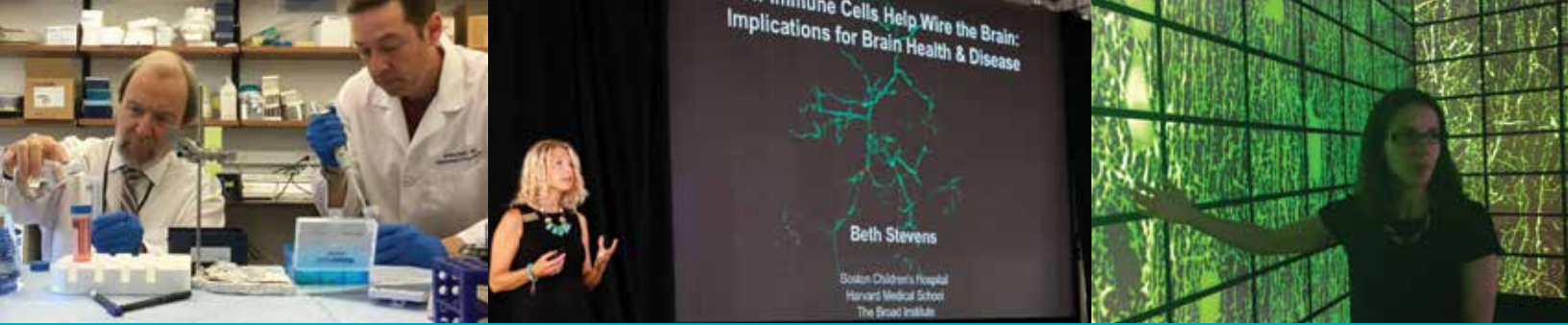
Institutes for Medical Research in New York, this study is exploring the causes of hallucination, agitation and aggression in relation to Alzheimer’s disease and how they can be treated. These are among the most troubling behaviors associated with Alzheimer’s and are often one of the main reasons families move their loved one into a residential healthcare setting.

## Improving Minority Outreach

Emory University’s Goizueta Alzheimer’s Disease Research Center (GADRC) is undertaking a comprehensive, grassroots outreach program to help Black families in the Atlanta-metropolitan area. According to GADRC, Black seniors are two to three times more likely to develop Alzheimer’s disease as compared to Caucasians; part of the reason







# SCIENCE IS IMPORTANT

“The discovery and development of new treatments for Alzheimer’s disease will only come from dedicated, focused research. There is no other way we will ever beat this awful disease. New developments in neuroscience and molecular biology have greatly increased the pace of research, and we will arrive at the answer. It is not a question of if we will succeed, but of when. We simply won’t quit until we do.”

— Peter Davies, Ph.D.

AFA Medical, Scientific and Memory Screening Advisory Board Member  
*posthumous emeritus*

stems from a higher reluctance among them to see a physician about memory loss and other symptoms of Alzheimer’s, often stemming from experienced and perceived discrimination by medical providers. Emory’s grassroots outreach program is successfully working with leaders in the community to connect people with free memory screenings and information about warning signs, ways to reduce their risk of Alzheimer’s and how to participate in research.

## Improving Early Detection & Treatment

The Hadassah Medical Organization in Israel is creating ways to detect Alzheimer’s disease earlier so that it can be treated more quickly and effectively. The research team is focusing on the brain’s orientation system to design new types of Alzheimer’s testing and a diagnostic app.

AFA also awarded grant funding for Hadassah to purchase a semi-automated system to screen the aging population to identify at-risk patients and assemble a clinical cohort with the goal of improving early detection at the pre-symptomatic phase and developing personal treatment plans.

## Uncovering APP’s Role in Alzheimer’s

The amyloid precursor protein (APP) gene family is essential for viability in mammals, but its function is unclear. Researchers at the City College of New York (CCNY) are aiming to identify the role that APP plays in brain health and Alzheimer’s disease. This research can then be translated into discoveries in mammals that could potentially lead to the development of new medications to treat Alzheimer’s that do not interfere with APP function.

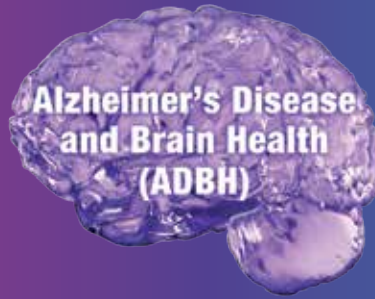
## Developing More Effective Treatments for Memory Loss

Researchers at Stony Brook University

are undertaking an innovative research project that uses Positron Emission Technology (PET) imaging to further drug development. Stony Brook’s research team hopes to improve therapeutic strategies that can more effectively target and treat damage and return neurons to a normal state to help improve memory.

## Measuring Blood Biomarkers

Hadassah Hebrew University Medical Center/Division of Clinical Neurosciences has purchased the Quanterix system for measuring blood biomarkers to identify pre-clinical Alzheimer’s patients and analyze their systemic immune system as well as how their body’s molecules are breaking down food and drugs and managing proteins. The ability to screen the aging population for patients who are at the pre-clinical stages of the disease, using a simple blood test based on this new technology, enables the Center to study this for the first time.



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# 10 WAYS TO SUPPORT YOUR CAREGIVER FRIENDS

By Marion Yoder

**Are you the friend of any of the 11 million Americans caring for someone undergoing brain change? At 71, with friends of all ages, I certainly am.**

My experience with a good friend's brain change began in earnest when we were both in our 60s. Another old friend, now in his late 70s, began the brain change journey more recently. We go back some 40 years; he still knows who I am. She doesn't, but she knows we're friends.

I've watched many other people in their 60s decline and die as a result of Lewy Body and other forms of dementia. My heart has ached for everyone, but I've learned caregivers need more than a friend's aching heart. It's possible, and even simple, to transform empathy into concrete action. The main thing is to be there when needed for them.

Here's what I've found helps to support a caregiver:

1. Don't require them to talk about their loved one's condition. Let them talk about it if, and when, they choose.
2. When the conversation does turn in that direction, don't pity or patronize.
3. Do NOT misidentify the condition. Some caregivers become indignant at this, specifying that their loved one "does *not* have Alzheimer's." Refrain from using any descriptive name.
4. When with the couple socially, do NOT direct your attention exclusively to the caregiver or talk around the person whose

brain is changing. That's belittling to both. I know several caregivers to whom this has happened, in some instances years ago. It's still painfully remembered.

5. Let the caregiver know you're there, whether in person, by phone, card, email or text.
6. Don't *insist* on giving help but offer it kindly and regularly.
7. If you find information about something that may interest the caregiver, such as respite care, give it to them but don't follow up. If they want to use it, they will.
8. Sincerely offer the caregiver a real change of pace. Let *them* tell you what they'd like and do your best to make it happen.
9. Be there when you say you will.
10. Repeat the above.

***Feel free to share this article with friends to help them understand what you may need as a caregiver.***

#### ABOUT THE AUTHOR

Marion Yoder spent 40 years practicing law but now devotes her time to volunteer work and writing. She's lived many places but was born in Wyoming, where she lives now with her husband, Terry Roker.

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# Creating a Caregiving Family

Sheila Warnock's father was a teacher and her mother a nurse, but she had "no desire to be either." Her creativity led her into a career as an advertising and creative director where she learned to work with different teams of people. Little did she know her familiarity with these three professions would prove to be grist for the mill for her current role as a pioneer in reinventing caregiving for the 21st Century.

The caregivers Warnock is targeting now are those caring for someone with Alzheimer's or other memory loss diseases. She's preparing a third edition of her highly respected book, *Share the Care: How to Organize a Group to Care for Someone Who Is Seriously Ill*, which will be released next year. The second edition was judged by *The Library Journal* to be "one of the best consumer healthcare books of 2004."

"I always knew Alzheimer's was one of the more difficult challenges for caregivers," she said. "I felt the need for a Share the Care group to be able to function in that environment."

The caregiving model Warnock created with her friend Cappy Capossela seems so obvious it's a wonder no one thought of it before. Her evidence-informed system of bringing together a large caregiving team is an intentional practice of what people have been doing for years in less charted, smaller ways. This leads to a large-scale caregiving family pooling their resources with no one burning out or being isolated.

Her journey began when her close friend, Susan Farrow, needed assistance as she lived with advancing cancer. Because Farrow had no family nearby, her therapist, Sukie Miller, suggested she schedule a meeting and invite as many friends, neighbors, colleagues and others that Farrow could name. Miller presided, helping Farrow to identify her needs and the members of the group how they could meet those needs — together. Over the three and a half years before Farrow's death, they developed a system that engaged the caregivers without any one person feeling burned out. That system is outlined step-by-step in *Share the Care*, which includes a workbook filled with well-tested materials.



"Bob's Brigade" caregiving family



"Morning Glories"



The first "share the care" caregiving group: Susan Farrow's "Funny Family"



## Share The Care SEVEN PRINCIPLES<sup>®</sup> FOR TEAM BUILDING

- 1 Sharing responsibility is key to not burning out.
- 2 Know your limits and stick to them.
- 3 It won't work unless everyone gains something personally.
- 4 There's no one right way to do it.
- 5 Anyone who wants to help should be encouraged.
- 6 Trust the group; support each other.
- 7 Keep your own life in good working order.

©copyright—Sheila Warnock and Cappy Capossela Share The Care, How to Organize a Group to Care for Someone Who Is Seriously Ill, 1995 and 2004, Simon & Schuster

**Continued on following page**

**CREATING A CAREGIVING FAMILY** *cont'd from p. 17*

“The first meeting is the heart of everything,” Warnock says. Participants fill out sheets rating their strengths and availability. An extensive list of tasks that are likely to arise are assigned accordingly. Tips are given for how to approach someone who might be reluctant to accept care and how to anticipate and avoid the most common caregiver problems.

“She developed it by doing it,” says Gregory Johnson, president and CEO of Greg Johnson Partnerships, Int’l, Inc. and chief advisor for Family Caregiving, Office of the CEO, EmblemHealth. “Her mission came from her journey. She found something missing and created it. That is the story of people devoted to caregiving.”

Warnock sees a need to add a section on forming a caregiving family for someone living with Alzheimer’s because the way this disease manifests “is all over the map,” turning talkative people quiet or causing gentle people to fight or run away. “It’s much more intricate than how cancer manifests.”

Share the Care’s system will allow people who live by themselves to remain independent longer. Doctors in the field agree that many people in the early stages of Alzheimer’s can live alone if they have routine and ongoing care.

Someone who lives alone has a greater need for a support group, Warnock says, and the members must be “very, very connected.” Church volunteers or others helping out don’t provide this kind of intensity of care.

“A Share the Care group knows the person,” Warnock says. “That’s what makes this group unique. We don’t just tell a volunteer what to do. We teach teamwork.”

Many of the relationships continue long past when the care has ended.

“Everything starts with a group. You can’t change the world by yourself. Nobody has all the answers. If each person brings special abilities, together that will make it bloom.”



Members of the “Care Crew”

Photos courtesy of Sheila Warnock



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



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Yuri Arcurs | Dreamstime

# BE PREPARED: CRUCIAL LEGAL DOCUMENTS ENSURE WISHES ARE MET

Loss of control is one of the more frightening elements of Alzheimer's, but you can mitigate that risk. With proper legal planning, we can have some control, says Matthew S. Raphan, Esq., a partner at Raphan Law Partners, LLP, who specializes in Alzheimer's planning.

"The Durable Power of Attorney is probably the most critical document we have in our toolbox to plan for our incapacity," he says. "The Power of Attorney (POA) is where we, as principal, the creator of the document, appoint an agent to handle our financial affairs for us in the event we lose capacity to handle them on our own. It is the premiere way for us to hedge against our own incapacity."

The most important criteria in appointing an agent is whether they are trustworthy. It's also smart to pick someone younger, Raphan says.

"This person is going to have access to our financial accounts, our investments, our retirement accounts, our checking and savings accounts, life insurance policies, anything financial is the purview of the Power of Attorney so, of course, we want to appoint someone who is honest, who's going to be a doer, who's going to run around to our various banks and record the document with the banks, who's not going to sit on their hands and let our finances unravel."

Giving this level of control to a third party can be frightening, Raphan says.

"Theoretically an agent under a Power of Attorney has the power to clean us out, so to speak."

One way to alleviate these concerns is to limit the agent's ability to handle one's affairs by making the document "springing," meaning the powers spring into effect upon the occurrence of an event, typically in the context of incapacity.

"That is one way we can make people feel a little more comfortable about giving this level of power to others."

Raphan says if someone wishes to draft their own POA without the help of an attorney, they should be sure they are using the most current form. A document that is executed appropriately will never expire even if the form changes.

## How does one use the Durable POA?

Typically, the agent will bring the original document to the principal's bank and record it. The bank makes a copy and returns the original to the agent. The bank then adds the agent as a signatory on the account.

For other assets, such as insurance policies or brokerage accounts, the rules may vary, Raphan says, but generally it's a matter of sending the institution a copy of the document, having them accept it and add the agent as a signatory.

**Continued on following page**



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### BEING PREPARED: CRUCIAL LEGAL DOCUMENTS ENSURE WISHES ARE MET *cont'd from p. 19*

Only a Durable POA stays in effect after the principal has become mentally incapacitated. A nondurable POA should be used in limited situations, such as appointing an agent to buy property for you in another state, Raphan says.

#### POA Limitations

The POA does not cover medical decisions, says Raphan, adding that this is the case in New York State where his firm is based. Medical wishes are spelled out in New York in a Health Care Proxy document. In some states this document is called a Power of Attorney for Medical Decisions.

Married couples should each have their own Durable POA because “there’s nothing that gives a spouse an inherent right to act on your behalf in a financial way.”

#### Health Care Proxy

“This is a similar document in which the principal appoints an agent to make decisions for them, only this is medical based,” Raphan said. “Who’s going to make decisions about our surgery, medications, anything health-related if we cannot speak freely on our own behalf.”

#### Living Will

“Advanced dementia is something that is irreversible. Most people would not want to be kept alive artificially. For those who feel this way there’s the Living Will, which used to be called a DNR

for Do Not Resuscitate and it may still be called that in some places.”

It “serves as a roadmap” for the health care agent. “It keys out in very clear terms what our wishes are with respect to life support. Not only is it a statement of our intent, which is obviously helpful, but it can limit the health care proxy’s sense of guilt.”

#### What If You Don’t Have These Documents?

Your need for care or settling of your affairs will be decided by a court-appointed guardian. “You’ve lost the ability to make these decisions and now a third party who you’ve never met is making these decisions for you.”

Getting to that point takes time and a great deal of money. “The person who is alleged to be incapacitated is paying for all of this. It could be tens of thousands of dollars, and it could be more than that depending on the nature of the proceeding, if it’s complicated and litigated. We’re talking about an enormous amount of money here. When you compare that to the cost of doing a Power of Attorney and Health Care Proxy the contrast is staggering.”

**Adapted from the AFA Care Connection webinar “Which Legal Documents Are Needed When Alzheimer’s Touches Your Family?” featuring Matthew S. Raphan, Esq., a partner at Raphan Law Partners, LLP.**





# Cognitive Impairment as We Age

Katie Nesling | Dreamstime

**T**he thought of developing dementia frightens most people, often to the point that any forgetfulness worries them. Dr. Gregory A. Hinrichsen, Ph.D., clinical professor, Geriatrics and Palliative Medicine, Icahn School of Medicine at Mount Sinai, offers a reassuring perspective on how our minds change as we grow older.

“There are normal, age-related changes in thinking that are not usually regarded as cognitive impairment,” he says. “As we age, it takes longer to learn and process new information.” This starts early.

“By the time you are in your late 20s, you don’t think as quickly as you did in your early 20s, and learning new information is slower than when you were younger. Basically, the brain, which I think of as the hardware, like the rest of your body, is slowly wearing out as you age, and those circuits don’t work as fast.”

He says people worry when, for example, they can’t remember the restaurant they went to the night before or the movie they saw, which often is part of normal aging.

“It’s not as if it’s not in there; it’s just walking out a little more slowly. Sometimes as a clinical psychologist I hear people say, ‘I have Alzheimer’s disease’ and they don’t. They have normal age-related changes and there are many studies over 50 years that document this.

“I hasten to add that people continue to learn in their later years and often gain life perspectives and experience that usually you don’t have when you’re younger. That’s the upside of getting older.”

## **More than normal aging. Is it dementia?**

A step beyond these normal age-related brain changes is **mild cognitive impairment** (also known as mild neurocognitive

disorder), which manifests as more than usual changes in mental ability that don’t really interfere with your ability to do things. “You’ll see the person isn’t really doing as well in one or more areas in mental functioning, but it doesn’t mean it’s going to get worse. It doesn’t mean it’s going to get better. It just may remain the same, but it’s a little bit of a flag that something is not what we expect it to be.”

**Dementia** (also known as major neurocognitive disorder) is the progressive decline in mental abilities. This can be diagnosed by trained health care providers, often by a neurologist and in conjunction with neuropsychological testing.

Hinrichsen says dementia is a general term, “like there is the general term ‘heart problems’ but within it there are different kinds of heart problems. People often use Alzheimer’s as a general category, but it’s a specific type of dementia. That’s important to understand. There are different types of dementia, and sometimes people can have several of them at the same time.” Neurological testing can be helpful to diagnose what form of dementia a person is developing.

## **Depression and dementia**

Depression is fairly common among people with dementia, but before taking your loved one to the doctor for treatment, consider carefully what the person seems to be experiencing.

“There’s a difference between everyday mood fluctuations, clinically elevated symptoms of depression and clinical depression,” Hinrichsen says. “The everyday meaning of ‘I feel depressed today’ is in the normal range of mood/feeling states. There’s just a range of mood states that we all experience and are considered normal, reflecting the ups and downs of life.”

*Continued on following page*

## COGNITIVE IMPAIRMENT AS WE AGE *cont'd from p. 21*

Hinrichsen says between 30 to 50 percent of people with dementia will at some point develop clinical depression. "People say, 'Wouldn't you be depressed if you had dementia?' And, indeed, some people with dementia develop depression in reaction to it. Counseling can be helpful to deal with stresses of the onset of dementia. But there are also brain changes associated with dementia that may increase risk for depression."

Health and mental health professionals can diagnose depression. "A first step is often to administer a 'depression screen,' which is a brief series of questions. One depression screen is the Geriatric Depression Ratings Scale.

"Clinically elevated symptoms of depression are intense and persistent, often with changes in feelings, thoughts and/or behavior. Clinically elevated symptoms affect about 15 percent of adults and older adults." Rates almost doubled during the pandemic, he said.

"We are sensitive barometers of what's going on in the world and in our lives. It just shows you to what degree your emotional states are not just a function of who you are but a function of what is going on in the world. That's important to keep in mind."

Symptoms of clinical depression (also known as major depression) last longer and often include a variety of problems, some of which

are difficulty with daily functioning, changes in sleep and appetite and sometimes thoughts that life is not worth living.

"Clinical depression not only affects the way you feel, it often reduces your interest in things. It also affects your thinking. Generally, it's more negative. You have to push yourself to get things done or you don't get things done. It affects your outlook toward life, which is generally more pessimistic.

"Clinical depression is a powerful thing. It is more severe and debilitating and encompassing than everyday mood fluctuations or even clinically elevated symptoms of depression.

"I hasten to add that depression is a treatable condition in most people. And for people with dementia and depression, one strategy to improve the depression is to increase pleasant events in the person's life. People with dementia are not immune to the favorable emotional impact of doing things that are pleasant. Even if they may not at the end of the day exactly remember what they did, there's emotional carryover of good feeling that comes with that."

Adapted from the AFA webinar "Depression in Older Adults with Cognitive Impairment." Gregory A. Hinrichsen, Ph.D., is a geropsychologist who has been in the field of aging for 45 years. He is clinical professor, Dept. of Geriatrics & Palliative Medicine, Icahn School of Medicine at Mount Sinai.



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# Ask the AFA HELPLINE SOCIAL WORKER

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**My husband was diagnosed with Alzheimer's three years ago. He was handling his own finances at first but then began to bounce checks and forget to pay bills. I started to take over this task for him. Everything was fine at first, but in the last six months he has become convinced I'm stealing from him. He's also started to suspect me of having an affair when I leave the house to go grocery shopping. I'm increasingly frustrated and hurt. Any ideas for me?**

We receive a high volume of calls with this type of concern. Family members say their loved one has become delusional or paranoid and is accusing them of such things as stealing from them (typically money) or being unfaithful. This is especially poignant because it's hard for family members to understand that the situation isn't personal.

Being a caregiver is stressful under any circumstances, but when a loved one is accusing you of doing something you didn't do, the situation can be especially painful.

This is a time when you may find it hard to separate your relationship with your husband from the disease. It may seem as if the person living with dementia is no longer the person you had a relationship with, but your "core person" is still there. Neurological changes are impacting your person's ability both to carry out tasks they once could do and to perceive an objective reality. The illness creates a different reality. Your person may be struggling to identify what feels disorientating or "not right." It's normal for you to feel a sense of sadness and mourning, though, for the relationship you once had.

It's unclear why some people develop a sense of paranoia. It's probably a combination of cognitive impairment and a feeling of anxiety and lack of control. In situations like this, it might be helpful to share the bill paying with another family member or even hire an outside bill payment company to remove you from the situation. Another idea is to give your husband an old, invalid



Wave Break Media | Dreamstime

checkbook. Writing checks may help him feel he has some control over his finances again.

As for suspicions of infidelity, these situations are heartbreaking for you, we're sure, because you no longer have this relationship to fall back on. Your history feels like it is being erased by this illness.

Because this adds to the already challenging task of being a full-time caregiver, joining a spouses' support group can be helpful. People have different approaches to managing and you may find one that works for you. **AFA will be offering a spouse support group in late summer. Contact senior social worker Linda Mockler at [lmockler@alzfdn.org](mailto:lmockler@alzfdn.org) for details.** Personal therapy is also an option.

Other techniques to manage delusions include redirecting, changing the environment and asking a more neutral person to step in until the moment has passed.

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

**Have your own concerns and questions? Please reach out to the AFA Helpline, staffed by licensed social workers, seven days a week at 866-232-8484, text 646-586-5283 or via online chat at [alzfdn.org](http://alzfdn.org) (available in 90+ languages). The service is free.**



# Dramatizing a Dramatic Diagnosis:

A Conversation with  
Sam Simon



Trained as a lawyer, Samuel A. (Sam) Simon started his career as a member of Ralph Nader's first legal advocacy group in Washington, D.C. He went on to start his own consulting firm and became a regular commentator on national news programs. In 2018, he was diagnosed with MCI (Mild Cognitive Impairment). In 2021, he was diagnosed with early Alzheimer's disease. He has written and is performing a play, *Dementia Man: An Existential Journey*, about his experience with the disease.

Your background is in law and public affairs. How did you come to write your first play, *The Actual Dance*, about being the spouse of someone living with cancer? You went on to become a playwright and performer.

I was taking improv classes with a theatre group in New York in 2000 when my wife was diagnosed with advanced breast cancer.

We had been married for 34 years. I had to come to terms with it. She was not supposed to survive. One improv exercise was to stand up and talk for 20 minutes. In that 20 minutes, I began talking about something I had not realized was in me. It's what I call "spiritual trauma." I had an experience that I needed to talk about. Theatre enabled me to find an outlet for it.

Fortunately, Susan did come through her cancer. Now you have a different diagnosis to deal with and have again turned to dramatic expression.

Yes, my diagnosis of Alzheimer's. It never occurred to me that I could write and perform a play with Alzheimer's. A theatrical friend and colleague, Gail Schickele, who markets solo artists and who was a fan of my work, encouraged me. She had seen *The Actual Dance*. I can't tell you how energizing it is. I have a huge need to change the narrative around and reimagine the use of that dirty word "dementia" and the stereotypes. This feels like the most important work of my life. My mission is to make it available to everybody who needs it. I believe in the power of the arts.

Theatre discovered me through the role of being a caregiver of the wife I was expected to lose. It's a privilege to be there for that person. Now the shoes are on the other foot.

The preview portion of *Dementia Man* that you have finished was showcased in January at the highly selective Association of Performing Arts Professional Conference in New York. What was the reaction?

It had an extraordinary reception. I held the script because I didn't have it memorized. The playwright Jeffrey Sweet said, "Keep the script. It becomes part of the show. When you got on the stage and talked, we heard you. We didn't notice the script." It makes sense in the context of the play. I was humbled by the feedback and encouraged to get this out there.

Your character describes your shockingly insensitive treatment by your first neurologist. When you asked, "What's next?" he replied, "There's only one future for you, down. Things will get worse." What do you have to say about that now?

The neurological world is profoundly broken. I experienced Susan going through breast cancer. People were there to help. There were support groups. There was literature. With my diagnosis of dementia (I prefer "neuropsychological disease") it was, "Get your affairs in order." I wasn't told about any support groups. It was about as stark a contrast as you can get.

What's next for you and the play?

I'm delighted to report that *Dementia Man, An Existential Journey*, has been selected for premiere in the Washington, DC. Capitol Fringe Festival in July 2023. I've already had one reading at community center, and, in May, ANDTheater Company hosted a work-in-progress performance in New York. We received terrific feedback that we will use to keep getting better.

My goal is to show that even with a cognitive disorder it is possible to live with dignity and have a meaningful life. I am so animated. I'm in the early stages and every day I learn something new. There's no doubt I'm impaired but only mildly impaired now.

I'm not going to walk away from my disease and feel sorry for myself. I will embrace the life I'm given. Choose life. That's a bit of my faith. The cardinal rule of Judaism is to choose life. I've been made to use my disease to be useful to myself and others.

***"I am now at the five-year mark from the initial MCI diagnosis. We have since learned a lot more about Alzheimer's. And I can sense things getting worse. It raises the stakes on what to do next. What are my choices?"***

***. . . Maybe, I should stick around, and figure out how to live a meaningful life as a deeply forgetful and confused person. Maybe I can cause trouble, and advocate for the world to accommodate me as I will be. I have been a troublemaker most of my life."***

**Excerpt from *Dementia Man***



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## Did You Know?

**MORE THAN 6.5 MILLION**  
individuals are living with Alzheimer's.

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

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*Source: Centers for Disease Control and Prevention*

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