

Alzheimer's TODAY

The Official Magazine of the Alzheimer's Foundation of America

Singing the Praises of Music

Using Music Therapy to Open Minds & Hearts



VOLUME 14, NUMBER 2

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A MESSAGE FROM OUR PRESIDENT & CEO

Dear Reader:

New things can be uncomfortable. Shoes, clothes and chairs are just a few things that can feel awkward or constrictive at first. Adaptation over time makes them become more familiar and normal.

Material possessions aren't the only things to which this applies. New experiences (or ones we haven't had in a long time) can be uncomfortable, too. But it's important to be open to change, try new things and embrace challenges. Look at things from a different perspective. That's where growth comes from.

Highlighting new ways that certain things we've been around most of our lives can be used differently for a great purpose is a focus for this issue.

"A Bridge to a Memory," our cover story, shows how music can be used as a therapeutic tool. Whether your loved one is in a professional care setting or living at home, there are ways to utilize the power of music to help improve mood, memory and quality of life for individuals living with Alzheimer's disease.

We'll show you how America's pastime, baseball, which has been a part of our culture since the 1800s, can be both a form of cognitive stimulation as well as recreation.

Additionally, this issue helps to provide a road map to deal with some things that can be unsettling.

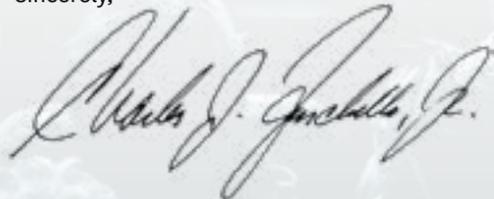
Guest author Matt Gurwell gives practical advice on how to handle an often difficult and uncomfortable conversation: telling your loved one that it's time to stop driving.

"Clinical trials" is a term we often hear but may not really understand. AFA Medical, Scientific and Memory Screening Advisory Board member Dr. Peter Davies answers some frequently asked questions about clinical trials to help familiarize you with their potential benefits, how they can be helpful and where to find one near you.

Finally, *Alzheimer's TODAY* reader Ginny Lawson candidly discusses her life with her "two husbands": Dean, who she married 16 years ago, and "Al" (short for Alzheimer's), who has been part of their marriage for the past decade.

As always, we hope you enjoy the articles included here and find them beneficial. If you're ever interested in submitting a story for possible publication, feel free to email it to us at info@alzfdn.org.

Sincerely,



Charles J. Fuschillo, Jr.
President & CEO
Alzheimer's Foundation of America

PS: Your feedback is important to us. Visit www.alzfdn.org/afamagazinesurvey to give us your input about stories and content you'd like to see in future issues.



TEAL TAKE - EDITORIAL



World Health Organization flag © Chelovek | Dreamstime.com

"I'm getting old, Alzheimer's must be setting in."

How often have you heard someone jokingly say something like that when they forget where they put their keys or parked their car?

They may be kidding, but as the old saying goes, there's a little bit of truth in every joke. And the truth is, a common misconception exists that dementia-related illnesses like Alzheimer's are a regular and inevitable part of aging, when, in fact, they are anything but that.

Changing the false narrative about dementia is something we're passionate about and continually working toward. That's why we're so pleased by the recent actions of the World Health Organization (WHO).

The WHO identified dementia as a public health priority in 2012 and has been working on a Global Action Plan. Most recently, the WHO released its first guidelines for reducing risk of developing dementia-related illnesses, as detailed in a May 14 article by the *Wall Street Journal*.

Recommendations such as regular physical activity, avoiding

WHO Cares

smoking and/or other tobacco products, and managing hypertension and diabetes are all aimed at getting people to change their behaviors to lower their risk of cognitive decline. Each of these recommendations, along with others such as a healthy diet, limiting alcohol consumption, managing weight and

cholesterol and stimulating the mind, carry additional health benefits for the body as well.

As the report noted, dementia affects approximately 50 million people worldwide, a number that is expected to triple by 2050. An aging population and increasing prevalence of risk factors such as physical inactivity, alcohol and drug use, and obesity highlight the challenges we face.

Empowering individuals to be proactive about their health and potentially reduce their risk of cognitive impairment is critically important to combat the growing health crisis of dementia (and is a long-standing AFA initiative). The WHO's recommendations reinforce that dementia is not a normal part of aging and that there are lifestyle changes people can and should take to potentially lower their risk and be proactive about keeping their brain and body healthy. And that's no joke.



Photo credit: © Toa555 | Dreamstime.com

How to Have the Difficult Driving Conversation

By Matt Gurwell

Having the difficult driving conversation with a loved one can be reminiscent of the last time you had a tooth pulled. Asking your mother or father to consider retiring from what has probably been a long and successful driving career has the potential to be a very emotional and uncomfortable conversation.

For some families, having discussions with the older driver about driving restrictions or driving cessation will come almost naturally and with minimal challenges. With other families, having these discussions will immediately be met with opposition, bitterness, animosity, and sometimes even anger. Sadly, the driving issue has, in extreme cases, driven a divisive and permanent spike between family members.

Develop the Right Mindset

The purpose of this article is to offer you a couple of simple tips and reminders that will help you in this very sensitive process. Not having this conversation with the older driver

in your family could be disastrous. The avoidance of these conversations could place people's lives in danger.

Marching forward with a very specific plan, rooted in empathy, tact and compassion, can help ensure a smooth transition from the driver's seat to the passenger seat, with minimal deterioration to independence. Have confidence in your approach. Remember, amateurs built the Ark; experts built the Titanic!

When to Start the Conversations

An ancient Chinese proverb reminds us that the best time to plant a tree was 20 years ago; the second-best time is now. Start these driving conversations with your loved one today, regardless of where they are on the safe-driving continuum. Don't wait until mom is involved in an accident, gets lost or receives a talking to from the police.

A tactical error some families make is waiting to talk to their loved one about a driving retirement when there has been

some sort of triggering event. Using dad's recent accident or triggering event as an opportunity to begin the driving conversation can be problematic for two reasons: 1) it may be too late, as the older driver may have caused a serious accident, and 2) this single, isolated event may actually serve to further convince the older driver that he/she is not a candidate for a retirement from driving.

Older drivers are often better historians than visionaries. How many times have we heard the argument, "I've been driving for 65 years, and this is my first accident ever! What's the big deal?" This potential response from your loved one offers yet another reason to start the conversation before a triggering event.

Who Should Do the Talking?

For these conversations to be successful, they must be a collaborative effort among you, other family members, and the older driver. No single family member should have to bear the burden of having the driving conversation with mom or dad. Instead, consider a more holistic approach. In addition to involving other family members, consider involving the family doctor, a favorite nurse, a respected member of mom's place of worship or even the family attorney. Remember, too, the value that an existing social worker or geriatric counselor or that of a close friend or neighbor of your mom or dad can bring to these discussions.

Remember the old adage, strength in numbers. Just be careful not to overdo the involvement from others; we don't want to shoot a mosquito with a bazooka!

Be a Good Listener and Use Facts, Not Opinions

Listening (not just hearing) to your loved one's counter arguments is critically important. Remember, the transition into driving retirement is one of the most difficult transitions any of us will ever have to endure.

One of the most sincere forms of respect is listening to what another person has to say. We're talking about actually listening to exactly what is being said and understanding what message your loved one is trying to send. Your listening skills are possibly the most important skills you have in bringing a peaceful resolution to this very sensitive issue.

Your conversations need to be based on a loved one's driving skills, not on age. It is critically important that family members remove their emotions, opinions and speculation from the driving conversation. Provide your loved one with specific examples of driving concerns. Replace your opinionated "Mom, you've become a very poor driver" with the more factual "Mom, I became particularly concerned when you turned left in front of those oncoming cars." As you are providing your loved one with your reasons for suggesting a driving retirement, keep top-of-mind the wise words of Sgt. Joe Friday: Just the facts, ma'am!

Maintaining Dignity, Pride and Independence

The key to a successful retirement from driving is directly equivalent to the family's ability to find and implement practical and realistic transportation alternatives. In other words, have your transportation "Plan B" in place before you ever start talking to mom or dad about this.

Remember that your goal is to keep mom or dad and the community safe while simultaneously helping to maintain pride, dignity and independence. A retirement from a long and successful driving career should not mean that your loved one is now under house arrest. At most, a retirement from driving might mean a loss of convenience, but it should never mean a loss of independence!

The consequences of not speaking up can be far worse than the talk itself. A family's way of handling (or not handling) this matter could ultimately mean the difference between life and death, for your loved one, as well as unsuspecting motorists. If not handled properly, forcing an older driver to give up driving under duress can trigger depression and isolation which, in turn, can cause deterioration in your loved one's physical health. No one wants this outcome, so take the necessary time to plan your work, and then work your plan.

The final take away: Be humble and respectful. Remember this is the same person who changed your diaper in the middle of the night and may have even taught you how to drive!

Matt Gurwell is the Founder and CEO of Keeping Us Safe, an organization that provides practical, real-life solutions to older drivers and their families, and a retired police officer who served 24 years with the Ohio State Highway Patrol.

Breaking the Ice

Starting these complex conversations should not be done with a stick of dynamite. Ease your way into a driving discussion by mentioning a current news event: "Dad, did you see on the news where the 81-year-old gentleman got lost? The reporter said he left home to run to the corner grocery store and ended up out of gas and disabled along the edge of the highway in the next state. The police officers that found him said he became confused and got lost. That could have ended a lot worse than it did."

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Proceeds support AFA's programs, services and research efforts.

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CAPITOL REPORT

Investing in a Cure

AFA Urges \$350 Million Increase in Federal Alzheimer's Research Funding

Congress and President Trump are working to develop the federal budget for Fiscal Year (FY) 2020, and AFA is working hard to ensure that federal policymakers continue to prioritize additional funding for the fight against Alzheimer's disease. Of utmost importance is greater investment in Alzheimer's disease research.

Washington delivered \$2.34 billion in Alzheimer's research funding in the FY 2019 budget. The figure marked a significant milestone: It was the first time federal investment for Alzheimer's disease research surpassed \$2 billion a year. Leading Alzheimer's scientists have said that number is the minimum amount needed to meet the National Plan to Address Alzheimer's Disease goal of finding a cure or disease modifying treatment by 2025.

Six years after the plan's unveiling, that benchmark was finally met. Further growth is critically important in order to make up for years of chronic underfunding and put the country on a more viable track to achieve the national plan goal. AFA has called for an increase of \$350 million for FY 2020.

Along with working toward a cure in the future, AFA also called for prioritizing programs that provide essential services to families affected by Alzheimer's now, including:

- \$50 million in enhanced investments for Alzheimer's disease programs to provide critical and necessary resources and support services for caregivers. These services help caregivers cope with the daily challenges of the disease, while helping to improve quality of life for individuals with Alzheimer's and delay the need for costly nursing home placement, which will save government resources.
- \$20 million to fund BOLD ACT initiatives to strengthen our health care infrastructure as it relates to Alzheimer's.
- Another \$5 million to fund the Missing Americans Alert Program, which provides training and technology to help first responders quickly locate individuals with Alzheimer's or autism who wander, a common and potentially dangerous behavior associated with these conditions.

"Washington has made tremendous strides in the battle against Alzheimer's, but the fight is not over. Congress and President Trump must continue building on the investments and progress made thus far and provide scientists with additional resources to find the cure for which millions of families are desperately hoping."

— Charles J. Fuschillo, Jr., AFA's President and CEO

Here's how you can help!

Contact your federal representatives and urge them to support these initiatives.

To find your Congressperson

Visit www.house.gov or call the Capitol switchboard at 202-224-3121 to connect with your Congressperson.

To find your Senators

Visit www.senate.gov or call the Capitol switchboard at 202-224-3121 to connect with the two Senators from your state.

COVER STORY

Alzheimer's Community Care music therapist Bree Gordon, MT-BC, performing in their West Palm Beach, FL, care setting.



A Bridge to a Memory

How to Use Music to Make
Every Day Better



Sing For Your Seniors volunteers performing at a care setting.

Hear Chubby Checker’s *The Twist* in the car while at a traffic light and you’re propelled back to your first sock hop. Frank Sinatra’s *Stardust* makes you shed a tear. Favorite songs mark time in our lives and can serve as a bridge to a memory. They stir emotions, help us relax, make us cheerful, playful and sentimental.

But did you know that music is an evidence-based therapy that can be used in both clinical and home settings to improve the physical, emotional, cognitive and social needs of an individual?

A credentialed musical therapist can provide a treatment plan to help strengthen abilities or provide avenues for communication. For people with a dementia-related illness such as Alzheimer’s disease, research and current real-life experiences prove that music can be much more than joyful recall. Studies show that a person’s ability to enjoy music may be preserved into the late and severe stages of dementia. Music can help manage stress, alleviate pain, and decrease anxiety as well as stimulate memories, improve communication and create an outlet for the expression of feelings.

Music Therapy in the Community

While the exact brain changes of these wonderful effects are still being studied by scientists, lots of real-life experience across the country bears it out.

“For most patients, music therapy is transformative,” says Mary M. Barnes, President and CEO of Alzheimer’s Community Care (ACC), which serves the West Palm Beach area of Florida. ACC was recently able to expand its music therapy offerings in three of its centers with an AFA grant.

“Alzheimer’s patients thoroughly enjoy the sessions,” said Mary. “They sing and dance—even those who are unable to walk will move their feet and ‘dance’ in their chairs.” According to ACC, the vast majority of seniors (95%) participate in their mid-afternoon program, and all show elevated mood and increased socialization through 5:00 p.m.

AFA’s Education & Resource Center in New York City regularly has a number of free and very popular musical therapy offerings as well. The “‘I Got Rhythm’ Drum Circle” is facilitated by a board-certified music therapist from Berko Music Therapy. Participants actively engage by playing a percussion instrument: congas, djembes, shakers, and tambourines.

“Playing or experiencing music decreases the sense of isolation, powerlessness, and disorientation that often comes with aging. Whether it is through singing, playing piano or tapping a beat on a drum, individuals living with Alzheimer’s learn to be more present in the music and experience it at a deeper level. It changes the overall atmosphere in the living environment and improves the interactions of those living with

dementia and their caregivers,” said Berko Music Therapy owner and primary therapist Ariel Weissberger, MA, MT-BC, LCAT.

Another AFA member organization, Sing For Your Seniors, features Broadway and Broadway-bound volunteer performers who travel to care settings to sing and interact with seniors, including those living with Alzheimer’s and other dementia-related illnesses. Sing For Your Seniors was created from the personal experiences of its founder, Jackie Vanderbeck, who used to sing at her great-grandmother’s care setting as a way to bring live performances to people who might not have the opportunity to experience them.

“Sing For Your Seniors was inspired by my love and admiration for my great-grandmother, Frances Hughes, who we called Grandma Dee Dee,” said Jackie. “She always loved hearing my friends and me sing when we visited her senior care home. I felt a unique connection to my grandma when I sang to her. That connection and her emotional response made me realize music has enormous therapeutic value for seniors, especially those who are showing signs of withdrawal.”

Bringing Aspects of Music Therapy Home

AFA’s Recreational Therapist Jackie Gatto, MS, R-DMT, believes care partners can use aspects of music therapy in home settings, too. “Really get to know and understand what your person likes to listen to and how often. That’s key. I have worked with clients under and over the age of 85 whose music tastes ranged from swing to disco to Katy Perry. The best type of music is music that is familiar to the individual and something they enjoy.” So make sure to ask, test it out and see what sparks their interest.



Participants having fun at an Alzheimer’s Community Care program.

Where can you find a music therapy program?

Call AFA’s Helpline at 866-232-8484 to speak with our licensed social workers who can make referrals in your area. A number of AFA member organizations, including adult day programs, assisted living facilities and direct providers of services, offer this type of therapeutic programming.



Berko Music Therapy's Ariel Weissberger leads a session at AFA's Education and Resource Center.



Caregiver Tips for Using Music

Music can and should be incorporated throughout

the day for individuals living with dementia, according to Jackie Gatto, MS, R-DMT, AFA's Recreational Therapist. If you are using CDs or a handheld device, use a speaker or stereo/audio system to improve sound. Jackie likes using her iPhone with a Bluetooth speaker because they travel well. Smart phones give you the opportunity to search a variety of music (e.g., YouTube, Spotify, Apple Music, Pandora). You don't have to learn a musical instrument, but having small instruments such as hand shakers, bells, and hand drums are fun and useful for engagement and sensory stimulation, too.

"Learning from the individual's cultural background is a valuable tool, too," says Jackie. "Music from their specific culture or listening to music from all over the world can allow individuals to be creative, explore something new and help with memory recall." She has also found that instrumental music with a steady beat (i.e., Latin, jazz, big band, reggae, folk) can be useful when lyrics become distracting.

Find music that suits your activity. When Jackie is creating programming, she'll create a playlist or gather a series of albums with a variety of genres from the 1920s to today to meet everyone's needs. When she facilitates cognitive word games, she plays smooth jazz or classical music in the background to help with focus. For meditative practices or relaxation, soft instrumental music and classical or ambient music will help with calm and releasing tension.

How do we know if music therapy is helping?

"Sometimes we cannot actually see engagement. Engagement varies from person to person. It is best to understand and respect each individual's unique way of engaging in music," says Jackie. Examples of engagement could include playing a musical instrument, singing or humming along to songs, creating or writing music, sitting quietly while watching and listening to musicians play, closing eyes, lying down and allowing music to drift one to sleep, dancing or moving to music, and using your body to create it. Foot tapping, finger snapping, hip swaying, that's what we're talking about. The right happy tune can more than turn a frown upside down.

Here are some times during your day when it may be useful to put on a little music:

- **During transitions:** Play familiar music or sing together as you travel from home to an appointment.
- **Day-to-day tasks:** Use music during meals to help with focus or rhythm to help with chewing consistently and thoroughly.
- **Walking/balance:** Rhythm in familiar music, with a steady beat, can help individuals stay motivated and focused while walking, and provide ease in the body with balance.
- **Self-care:** Play soft or familiar music of choice when feeling stressed and/or anxious to help re-organize thoughts and find a sense of calm.

7 Tips to Help with Sleeping



The benefits of a good night's sleep are undeniable. Sleep not only rests and restores your body, but it can also help mobilize the body's defenses against illnesses. Sleep deprivation can cause mood shifts, agitation, forgetfulness and irritability.

Getting a good night's sleep can be challenging for anyone; however, it can be especially challenging for someone with Alzheimer's disease or other dementia-related illnesses. Dementia may impact an individual's internal clock, causing a disruption in sleep-wake cycles.

Here are some suggestions for family caregivers to help ensure their loved one gets the best possible sleep:

Establish a routine sleep schedule, with a set bedtime each night. This can help the body's internal clock "set" itself for when it should feel tired or want to wake up. Seven to eight hours of quality sleep each night is ideal.

Help your loved one stay active. Physical activity is beneficial for many reasons, including helping with sleep quality and duration. Being physically active requires the body to burn energy, helping it feel tired and ready to rest.

Schedule activities for earlier in the day. This will help the body "wind down" as bedtime approaches.

Limit or avoid giving the individual beverages or foods containing caffeine. Caffeine is a stimulant that "wakes" the body up. Ingesting caffeine closer to bedtime can make it harder for the body to feel like it's time to rest.

Be aware of different stimuli as you prepare for bedtime, including television, electronic devices, bright lights, and/or loud music. Each of these things can stimulate the brain and the body and may make it harder to fall asleep.

Be mindful of the impact naps can have on evening sleep. Taking long or frequent naps during the day, or napping later in the day, can disrupt the body's normal sleep routine.

Take precautions to help safeguard your loved one from wandering at night. Individuals with a dementia-related illness are prone to wandering, including in the middle of the night when their caregiver may be sleeping. Consider installing electronic chimes or doorbells on doors to alert the caregiver if the individual tries to exit, but be mindful of how this alert can impact the individual. Also ensure that the person's basic needs (such as utilizing the restroom) are met before going to bed.

If sleep problems become persistent, consult the individual's physician for additional information.



LIVING WITH

By Ginny Lawson

Dean is a rare jewel, a man of integrity, quality and a tenderness of heart. Marrying him and receiving his life and love was truly a blessing.

At this point Al needs to be introduced. Al joined our family about 10 years ago. He intruded with little warning and has made himself quite at home. Al (short for Alzheimer's) desperately tries to imitate Dean. He, too, will talk to any and all. However, he can only use the same few greetings or silly comments every time.

Dean rarely notices Al and maintains his role as a gentleman. He opens doors for women, helps with their chair at the dinner table, and will rinse off dishes as soon as a meal is over. Al attempts to do the same while he is unmindful of his proximity to others either serving or sitting close by. I'm very grateful for the way Dean helps clean up the kitchen; but when it comes to putting clean dishes away, Al will insert himself later. Many times I will have to hunt for a missing utensil or bowl.

Al, too, loves to travel, but his knowledge of geography has almost disappeared. His directions and sense of time have become useless. I've given Dean a calendar each month, with the activities and appointments scheduled. He is thankful for this, but Al will still question each day's agenda. The need to repeat is ongoing. I'm reminded of my grandchildren. When they were young, their minds overloaded quickly. It is the same with Al. He cannot process more than one or two instructions or details before his mind clutters with misunderstanding or self-perceived ideas.

As with us all, age has become a hindrance for Dean. Bumping into counters or dressers, tripping over a blade of grass or simply not picking up his feet have proven that Dean needs to use a cane and/or walker. We live in an area that is quite flat and "old-age" proof, so, fortunately, Dean can go for walks in our area. We make sure he has one of his walking aids and cell phone with him. During the walks, Al robs Dean of his strength. He causes him to scuff his feet and not see obstacles in his path. I always give thanks when Dean returns home without new bumps or bruises. We have a drawer in

Dean is the man I married almost 16 years ago. We both shared many wonderful and difficult life experiences with our former spouses. Dean's wife spent 25 years battling chronic illnesses that required many surgeries and even the amputation of her leg. My husband lived with a neuromuscular disease for 40 years, spending the last six years of his life in a skilled nursing home.

Both mates died within three months of each other. Dean and I didn't know each other then, but after we met, our similar history and experiences drew us together into husband and wife.

Dean loves people (he talks to everyone) and is generous, kind and helpful whenever possible. At 87, he is still quick to help a friend lift his wheelchair into the back of his car or shuffle tables and chairs in the church fellowship hall prior to an event.

Travel is another delight for Dean. Before and during our marriage he traveled to many countries and experienced many wonderful sights. Today, he just wants to "go" someplace, even if it's to simply take a walk on the pier at the beach.

Reading the Bible is perhaps the most important thing in Dean's life right now. He spends hours going over the book used by his study group and works hard to find answers to questions posed.

TWO HUSBANDS

our home that is filled with various-sized band-aids. My handbag has a compartment dedicated to many of the same. Al robs Dean of his awareness... aware of uneven sidewalks, of people in his vicinity, of open cupboards. His arms are covered with dark splotches and cuts because of falls for just as many and various reasons.

Another thing stolen from Dean is his memories of the wonderful life he has lived. With two children, six grandchildren and 10 great-grandchildren (not to mention those in my family), numerous experiences and much love have abounded for many years. Al now looks at family pictures unable to recognize names or make associations. Every so often, Dean will speak of a memory, and we cherish the times this happens.

Interesting is the fact that Dean has always loved music, and today he still can sing hymns and "barbershop" with the best of vocalists. This is one area that Al has not invaded and, thankfully, research has found that music will remain in both Dean and Al's mind. Singing in our church choir and community chorale are highlights of Dean's week.

As stated before, Dean loves God and studying the Bible. Al has interrupted this intimate time by putting up walls in Dean's mind. Walls of limited understanding and/or application. Fortunately, Dean is not totally aware of this distraction, so he continues his reading.

Recently, Al began invading my mind, too. Not in the same way as Dean's, but still very intrusively. Al is both a giver and a taker. What he gives me is more frustration, impatience, anger, and selfishness. The ongoing frustration of dealing with Al's apparent "stupidity" by asking questions that have been answered several times already. Being an impatient person at the get-go, Al's lack of comprehension creates even more impatience. Then the anger comes when shame and guilt surface. "Self" can raise its head in a caregiver's life more than anyone would want. But I guess that goes with being human, and the hardest part of being human is just that, being human.



Experience showed me a huge difference in caring for someone who is physically disabled and one who is cognitively impaired. Physical disabilities don't necessarily affect the mind, so communication can still take place. However, as mental awareness lessens, meaningful conversation becomes rare, then quickly forgotten even if a thought needed to be expounded on.

Dean and Al are both gifts in my life. Of course, I didn't know that I would be married to two husbands when I said "I do" 16 years ago. However, recognizing Al for whom he is and what he does has helped separate my "two husbands." Dean is precious to me. I'm learning to be more thankful for the soft and lucid times we share. As for Al, I can't ignore him or his presence. Sadly, Dean's neurologist has said that Al will continue to get more and more invasive. Yet remembering that he is not, nor ever will be, in control of Dean, is a great comfort. God is totally in control of both Dean and Al... in fact, all of us. For this, I am eternally grateful.

Ginny Lawson is a caregiver for her husband, Dean, who is living with Alzheimer's disease. Ginny and Dean reside in Seal Beach, California.

Managing Care Transitions

Throughout the course of Alzheimer's disease and other dementia-related illnesses, the person living with the illness might experience one or more care transitions. A care transition refers to the move of an individual from one care setting to another. Two types of care transitions exist: unexpected and planned.

Acute medical emergencies that require hospitalization are an example of an unexpected transition. Planned transitions include relocating someone from their home to a long-term care setting.

While care transitions of any type can be stressful, planning and preparing for such transitions can help things go smoother. Being ready helps reduce stress, alleviate anxiety and ensure the person's needs are met throughout the process.

Here's what caregivers can do to help facilitate a smooth transition:

Be ready to "go": Create a "go kit" that includes personal, medical, and daily-living items. In the event of an unexpected transition, you'll be ready and won't have to waste precious time and energy in a potentially stressful situation pulling these items together.

Familiarize yourself with the new environment: Whether it's a short-term hospitalization or a long-term care transition, nothing warms a new setting like the comforts of home. Photos, personal care products and other favorite items can make a new space feel more familiar and personal. Make every effort to ensure the person contributes to their new environment. Involve them in the

process of choosing items to bring with them whenever possible. What is most important and/or valuable to them may not be what we may initially think.

Talk to the team: Alert staff at the new setting of the person's medical history (e.g., current medications, allergies, physical limitations, hearing or eyesight problems) and preferences (e.g., food, leisure and daily schedule). Continually communicate with the team throughout the entire transition process.

Be an advocate: Express the person's known wishes on their behalf. Ensure that the facility has the individual's health and legal documents (e.g., power of attorney, advance directives) on file to ensure the staff adheres to those wishes. If their wishes are not known, try to make decisions that are in their best interests.

Take part in the process: Get to know each member of the person's medical team and understand their responsibilities in caregiving. Having everyone on the same page is important to ensure optimal care.

Be supportive: A transition can be overwhelming and affect a person's overall wellbeing, causing changes in mood and behavior. Soften the adjustment by bringing personal items to the new space. Be supportive by remaining calm and attentive. Showing the person love and care can help them adapt to change.

Have questions or need additional information? We're here to help! Speak with a licensed social worker by calling AFA's Helpline at 866-232-8484 or connect through our website, www.alzfdn.org.



★★★★★
CHARITY NAVIGATOR
Four-Star Charity



AFA Earns Top Rating 5 CONSECUTIVE YEARS!

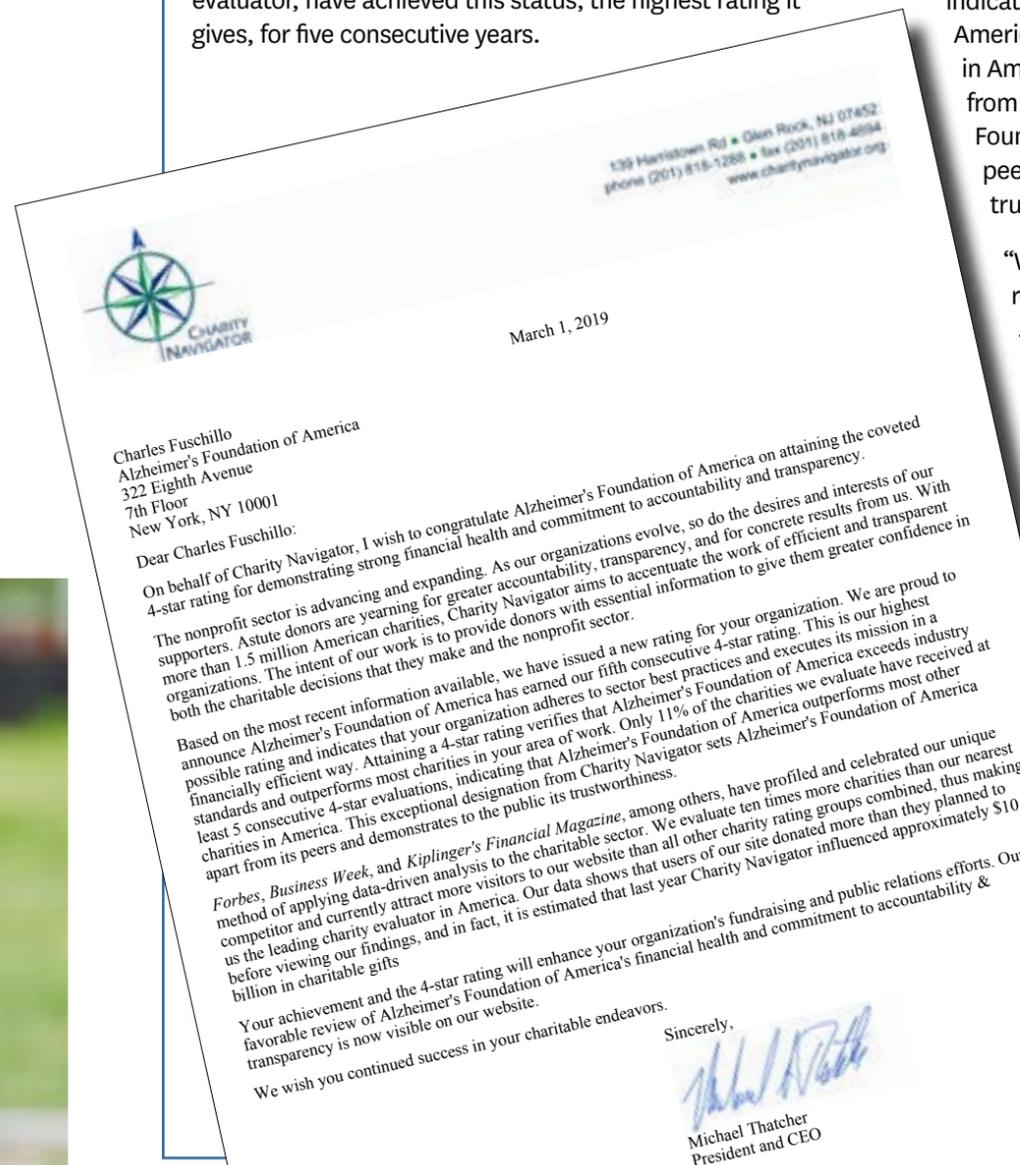
AFA has earned Charity Navigator's coveted four-star rating for a fifth consecutive year in recognition of its sound fiscal management and commitment to accountability and transparency. Only 11% of charities evaluated by Charity Navigator, the world's largest and most utilized independent charity evaluator, have achieved this status, the highest rating it gives, for five consecutive years.

According to Michael Thatcher, Charity Navigator President and CEO, "Attaining a 4-star rating verifies that Alzheimer's Foundation of America exceeds industry standards and outperforms most charities in [their] area of work. Only 11% of the charities we evaluate have received at least 5 consecutive 4-star evaluations,

indicating that Alzheimer's Foundation of America outperforms most other charities in America. This exceptional designation from Charity Navigator sets Alzheimer's Foundation of America apart from its peers and demonstrates to the public its trustworthiness."

"We are immensely proud to receive this recognition," said Charles J. Fuschillo, Jr., President and CEO of the Alzheimer's Foundation of America. "Alzheimer's disease is a public health epidemic affecting more than 5 million Americans, a number the Centers for Disease Control and Prevention (CDC) estimates could nearly triple by 2060. Our work has never been more important."

"I founded AFA in 2002 because I wanted to give families the tools and strategies for coping with their loved one's condition—something I felt sorely lacking in my own life when dealing with my own mother's condition," said Bert E. Brodsky, AFA Board Chair and Founder. "Today, I could not be prouder of how much we have been able to accomplish in these past 17 years. AFA has become a lifeline for so many families."



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Questions and Answers about Clinical Trials

“Clinical trial” is a term you may have heard before. But do you know what they are, how they can be beneficial and where to find out more about taking part in one?

AFA Medical, Scientific and Memory Screening Advisory Board member Dr. Peter Davies answers some frequently asked questions about clinical trials.

What is a clinical trial and how are they performed?

Clinical trials are tests of new ideas for the treatment of a particular disease, in our case, Alzheimer’s disease, dementia or memory loss. These ideas range from drugs, hormones, exercise, dance and many other possibilities.

What’s the potential benefit of pursuing a clinical trial?

The major benefit is to be involved in new programs that might directly improve the life of the patient. Consider this: At some time (hopefully soon!) an effective treatment for Alzheimer’s disease will be found. It will be proven effective in a clinical trial. Wouldn’t you want your loved one to be among the first to get the successful treatment? Even if a particular treatment doesn’t prove effective, this is also important, as we need to know what does *not* work.

When should I consider pursuing a clinical trial?

Our answer is the sooner the better. Trials have the best chance to show effectiveness in patients who are still early in their disease process, whether they are drug trials or trials of exercise or other physical and social activities.

Are clinical trials safe? Are they regulated?

I would strongly recommend participation in trials that are registered with the government, as they are tightly regulated and as safe as experimental treatments can be. All major clinical trials can be found on www.clinicaltrials.gov. Go to this website and type in the name of the disease for which you want to find a trial. On May 13, 2019, there were 2112 studies found for Alzheimer’s disease.

Can I pursue a clinical trial on behalf of someone else?

It is certainly possible for someone other than the patient to explore what trials there are and who might qualify. The patient always needs to be involved in the final decision to participate or not.

How do I find a clinical trial?

The best site to use to find a clinical trial for Alzheimer’s disease, dementia or memory loss is www.nia.nih.gov/alzheimers/clinical-trials. The site provides information on what is going on nationwide and allows people to choose trials in locations that are convenient to them.

Peter Davies, PhD, is the Director of the Litwin-Zucker Center for Alzheimer’s Disease & Memory Disorders at the Feinstein Institute for Medical Research.



Dr. Peter Davies, photo by Northwell Health Studios.



GRILLED FISH TACOS

Seafood twice a week, including fatty fish such as salmon and sardines, is beneficial for heart and mind health. Choose mild, medium or hot salsa as a condiment to spice up the start of the BBQ season. Get creative with your own toppings and share this delicious, healthy and fun recipe with family and friends!

INGREDIENTS

- 2 tablespoons fresh lime juice
- 1 tablespoon Cajun seasoning
- ¾ pound firm white fish fillets (such as red snapper, halibut or striped bass)
- 4 fat-free flour tortillas

When fresh wild seafood is unavailable, freshly frozen or sustainably farm-raised varieties are economical options. Check with your market's fish department to find the best quality.

TOPPINGS SERVED FAMILY-STYLE

- 1 cup plain Greek yogurt mixed with ½ cup finely chopped scallion
- 1 cup avocado, mashed
- 1 cup red cabbage, finely shredded
- 1 cup diced tomatoes
- 1 cup baby arugula
- 1 cup jalapeño salsa
- Optional: ½ cup grated cheddar cheese, preferably reduced-fat

DIRECTIONS

1. Prepare and preheat grill.
2. Place yogurt mixed with scallion in the fridge so that flavors can meld.
3. Sprinkle fish with lime juice and seasoning. Grill fish on medium to high heat just until opaque in center—2 to 5 minutes per side depending on thickness of fillets. Transfer fish to bowl and flake into bite-size pieces with fork.
4. Place tortillas on grill and cook until lightly charred on both sides, about 15 to 20 seconds per side.
5. Divide fish among tortillas.
6. Serve with toppings to be divided evenly.

Serves four.

Optional: To prepare fish in the oven, place on a baking sheet coated with cooking spray and bake at 350°F for 10 to 12 minutes or until fish flakes with a fork.



Recipe and photo by Layne Lieberman, MS, RD, CDN, culinary nutritionist and award-winning author of *Beyond the Mediterranean Diet: European Secrets of the Super-Healthy*. For more information and recipes, visit www.WorldRD.com

Traveling America to Talk About Alzheimer's

AFA's Educating America Tour and Lecture Series are bringing Alzheimer's-related educational programs and resources to communities across the country.

Join us at one of our upcoming events!
All programs free and open to everyone!

August 6

Portland, ME
Educating America Tour

September 17

Long Island, NY
Lecture Series:
Wandering Prevention Program

September 19

St. Louis, MO
Educating America Tour

October 2

Oklahoma City, OK
Educating America Tour

October 3

Chicago, IL
Lecture Series:
Alzheimer's Disease from A to Z

October 17

Seattle, WA
Educating America Tour

October 22

Piscataway, NJ
Educating America Tour

Learn more or register for these free educational events by visiting www.alzfdn.org or calling 866-232-8484.



Heather Saposnick, LMSW,
answers your questions.

Question 1

My mother is in the later stages of Alzheimer's and lives in a nursing home. Her aides and I are having a difficult time getting her to open her mouth to brush her teeth (she does not wear dentures). This is a new behavior for her. Do you have any suggestions that may help?

Unfortunately, this is not a completely unexpected behavior from an individual in the later stages of Alzheimer's.

As Alzheimer's progresses, an individual may stop understanding that teeth need to be kept clean or not be able to physically brush them. Something else to consider, your mother may be experiencing some sort of physical pain in her mouth which is preventing her from wanting to open it for tooth brushing. It is important for a doctor or dentist to do a pain assessment on her mouth. Signs that your mother may be experiencing physical pain may include grimacing, yelling or even hitting when touched in the area or only chewing food on one side of her mouth.

It is also possible that this new behavior may be in response to something in her environment or the approach that you and her aide are taking. Here are strategies to consider to improve the situation:

Environmental Considerations

- Consider what's the best time of day to engage in oral care. Some individuals with Alzheimer's disease experience sundowning syndrome, which causes increased agitation in the late afternoon and evening. If this is the case, attempting oral care earlier in the day may create a better outcome.
- Play relaxing music to soothe and distract.

- Hang a picture of a serene landscape on the wall; encourage her to look at it and imagine herself in a peaceful place.
- Provide a stuffed animal to stroke during oral care, which can be soothing.
- Consider using lavender aromatherapy scents for their calming benefits.

Communication Strategies

- Provide simple, clear instructions. Always address her from the front. She may become agitated or alarmed if you speak to her out of her line of sight.
- Speak at eye level by crouching next to her. Speaking to a person when they are in the prone or seated position while you are standing over them may elicit feelings of vulnerability or fear and can bring out resistance or difficult behaviors.
- Provide verbal reassurance in a calm tone of voice and gentle touch. Encourage a few deep breaths and resume treatment once calm has been established or re-established.

I would also recommend that you consider calling a care plan meeting, which could include her doctor, head nurse, social worker and, if possible, a dental professional to

review what plan of oral care has been used for your mother. Find out what techniques and dental products along with approach have been used. Perhaps when all the professionals review her care, new ideas on how to manage her oral hygiene will emerge.

Poor oral health may be associated with pain, inflammation, infection, nutrition, weight loss and diminished quality of life. I commend you for paying attention to this change in your mother's behavior. Timely and daily mouth care is important for good oral health which is important to overall health and wellbeing.

Question 2

My mother, grandmother and great-grandmother all had Alzheimer's disease. I am worried that I will get the disease. What is my risk genetically? Can I prevent it?

Having an immediate relative with Alzheimer's disease does not necessarily mean that you will develop the disease. But it is another risk factor. There are two distinct categories or types of Alzheimer's disease. The first type is often called "late-onset" Alzheimer's. This type accounts for nearly 95% of all cases of Alzheimer's disease. It affects people in older adulthood, usually after age 65, and progresses gradually. Only about 20% of families with a history of sporadic Alzheimer's disease are at greater risk for developing the illness in future generations.

The second type of Alzheimer's disease is often called "familial" Alzheimer's or "young-onset" Alzheimer's. This version affects people who are usually younger than 65 and accounts for only about 5% of the cases of Alzheimer's. This type has a strong history in families, and the odds of future generations developing the illness are higher than the odds for someone without such a family history. However, it is very important to know that a family history of young-onset Alzheimer's does not indicate that everyone else in the family will develop the illness.

Genetic testing for Alzheimer's disease is a very personal decision. It is possible to test for certain mutations of specific genes, but it is important to understand that people without the genetic markers can still develop Alzheimer's, and people

with the genetic markers may not. The test only has about a 50% predictability factor.

We recommend that you speak to your doctor about any concerns you may have regarding your risks. He/she can refer you to a geneticist for testing as well as genetic counseling so that you can understand the implications of any test results.

Unfortunately, at present, Alzheimer's disease cannot be prevented, reversed or cured. However, even if your family history puts you at greater risk for the illness, a healthy lifestyle may help, according to current research. Regular physical activity, a healthy diet, vitamin supplementation, social activity, and intellectual stimulation are all important. We recommend that you discuss any lifestyle adjustments with your primary health physician for additional planning and health management. Your physician can assist you with a smoking-cessation plan, reducing your consumption of alcohol, lowering high blood pressure and adjusting poor cholesterol levels as well as depression and anxiety. A rule of thumb: What's good for the heart is good for the brain.



Contact our social workers seven days a week through AFA's National Toll-Free Helpline at 866-232-8484 or through our website, www.alzfdn.org.



Play Ball!

Five Ways Baseball is a Home Run for Brain Health

Baseball is more than just the national pastime; it can also be a useful tool to exercise your brain. With baseball season in full swing, the Alzheimer's Foundation of America is encouraging everyone to play ball.

"Baseball stimulates cognitive functions, promotes social interaction and helps relieve stress, all of which are great for brain health," said Peter Davies, PhD, Medical, Scientific and Memory Screening Advisory Board Member for AFA and Director of the Litwin-Zucker Center for Alzheimer's Disease & Memory Disorders at the Feinstein Institute for Medical Research.

"Whether you're a veteran player or a rookie, getting involved in the game can be a home run for your brain," said Charles J. Fuschillo, Jr., AFA's President and Chief Executive Officer.

Here are five ways baseball supports brain health:

1. Increases critical thinking, concentration and focus.

Baseball is a game of situational strategy. Players are constantly thinking. Pitchers and catchers are selecting pitches. Batters are trying to figure out what pitch is next. Fielders must anticipate where a player is going to hit. Even just watching the game helps as your brain "plays along."

2. Helps relieve stress.

Stress negatively affects brain functions such as memory and mood. Playing a game,

throwing the ball around or going to the batting cage expands physical energy and gets your mind focused on something enjoyable.

3. Promotes social interaction.

When you're on a team, having a catch or watching a game and talking about it with friends, you're interacting with others. That social interaction positively impacts your brain by relieving stress and anxiety.

4. It can be a new skill.

If you've never played before, that's ok! Like all muscles, the mind needs exercise to keep strong. Learning new skills and getting your brain to think outside of its normal routine promotes cognitive stimulation and fosters good brain health.

5. Increases vitamin D levels.

Vitamin D is known as the "sunshine vitamin" because the body produces it naturally (and primarily) from being in sunlight. Some scientists have found that low levels of vitamin D are linked to cognitive decline, depression and dementia.

For additional information about brain health and wellness, visit the Alzheimer's Foundation of America website at www.alzfdn.org or call AFA's National Toll-Free Helpline at 866-232-8484 to speak with a licensed social worker.



Beautiful Works Preserve Memories While Fighting Alzheimer's

What do you do when your artist mom refuses your request to buy a favorite painting and then you watch her sell it to a work friend for \$300? One day, you lie. Watching pieces of art leave the house as her mom, Evelyn Niemeier Selim, was in the early stages of Alzheimer's, daughter Mona Selim felt she had little choice.

"I wanted to be happy for her as I watched the paintings leave, but I actually felt like a piece of us was gone. I believed no one could appreciate the work as much as I did," she wrote in *Evelyn Niemeier Selim, Artist*, the coffee-table book, passion project of art and reflections created by her brother Ali Selim, a filmmaker and writer, known for the award-winning *Sweet Land* and *Looming Tower*. Mom didn't want to give or sell them to family. So Mona would explain that so-and-so from work wanted this one or that one and ended up buying nearly 125 paintings and drawings from her own mother. "Expensive for sure," reflected Ali, "but what incredible vision."

So while Mona safeguarded the art in her home, about two years ago, the siblings hired an archivist, Daniel Dennehy from the Minneapolis Institute of Art, to digitize all the pieces.

"First and foremost, since each of my mom's paintings is a singular thing and there are five grandchildren, I wanted to find

a way that all of them could have access to all of my mom's great art," said Ali. The next project, a book, just made sense. "Many people could have access to everything. They could enjoy their favorite painting or track the trajectory of my mom's career. Also, the pinnacle for any artist is a museum show accompanied by a coffee-table book. I couldn't give my mom the museum exhibit, but I could approximate the book."

Ali more than "approximated" the book. It's a 10 3/4" x 12 1/4" hard cover showcasing all her pieces with personal reflections from family and friends. He sold many of them for \$200 each and donated all the funds to the Alzheimer's Foundation of America. The book raised over \$7,000—all this culminated in this 15th year that his beloved mother has been living with Alzheimer's disease in Edina, Minnesota.

"Many people told me they love the book," said Ali, "but everyone told us they love the idea and the effort and the purpose."

The book made his mother's "vision and contribution intact and impactful for generations to come." This uplifted them. In his reflections, Ali says, my mother "taught me a simple, guiding principle that refined the way I live and love my life: Everything is beautiful."



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