The Official Magazine of the Alzheimer’s Foundation of America

Seth & Lauren Rogen

Bringing Light to Alzheimer’s
WHO WILL YOU WALK FOR?
Walk in your community as part of AFA’s virtual fundraiser during NATIONAL ALZHEIMER’S AWARENESS MONTH.
Support care, education and research toward better treatment and a cure.

Registration and sponsorship information available at www.afawalk.com

Contact AFA’s Development Department at 866-232-8484 for additional information, help with registration or sponsorship opportunities.

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

“It’s not always easy loving someone with Alzheimer’s or other forms of dementia. But it’s important that you do. And it’s a lot easier when you love the new person they’ve become and join them on their journey.” — G. Dubose

That’s one special reminder from an Alzheimer’s TODAY reader who shared this quote with their survey response. A big thank you to all who took the time to fill out our reader survey in the last issue. We received heartwarming feedback on the role the magazine is playing in your lives and some wonderful ideas for future issues. We are pleased that the magazine is making a difference for so many of you.

With this new issue, we have more helpful content, including plenty of nuggets of hard-won advice and wisdom. Here are just a few:

- “Talk about it! Share your story. You are not alone. And if you are a caregiver, please don’t be afraid to ask for help,” advises Lauren Miller Rogen in our cover story Q&A with filmmakers Seth & Lauren Rogen. They share their personal story and how they’ve turned into advocates on pp. 12-14.
- “Be kind to yourself… if you won’t do it for yourself, do it for your loved one,” says Pam Ostrowski in “The Emotional Rollercoaster of Dementia.” The emotional highs and lows, and years, of dealing with a dementia diagnosis are difficult. Check out pp. 4-5 for some solid tips.
- “Many aspects of [Alzheimer’s] disease are quite unique and vary from person to person,” points out Dr. Allison Reiss in a brief roundup of those differences in “The Course of Alzheimer’s Disease,” on p. 19. Some individuals move through the various stages in a just a few short years, while others have a prolonged period that stretches over two decades.
- “Take note of what seems to bring joy,” says Lonna Whiting in a wonderful article about the importance of making the most of every moment with your loved one, “How to Have Meaningful Moments,” pp 9-10.
- “Take the time to share with your children the changes that are going on with a family member and help them be part of the caregiving process,” advises Perla Castro and Celita Castro, RN. The sisters share their family’s Alzheimer’s journey in “Bringing Information, Support, & Hope to Latino Families,” pp. 16-17.
- “Alzheimer’s disease does not erase a lifetime of love—it only amplifies it,” reminds Siyi Chen, one of our Teens for Alzheimer’s Awareness College Scholarship Essay Contest winners in “Live in the Moment,” pp 20-21.

We have so much to share with you and each other. Be in touch with your stories, ideas, and suggestions at info@alzfdn.org.

Sending my best to you and your families, always,

Charles J. Fuschillo, Jr.
AFA President & CEO

THE IMPORTANCE OF GETTING VACCINATED

“Getting vaccinated is one of the most important steps families affected by Alzheimer’s disease can take to protect themselves and their loved ones,” said J. Wesson Ashford, MD, PhD, Chair of AFA’s Medical, Scientific, and Memory Screening Advisory Board. “Individuals living with Alzheimer’s disease are often older and at higher risk of developing serious complications from COVID-19, and family caregivers cannot provide proper care to their loved one if their own health is compromised. COVID-19 has added enormous new hardships for families affected by Alzheimer’s disease, but vaccination brings us another step closer to the end of this terrible pandemic.”

Vaccination helps protect you.

Alzheimer’s disease primarily impacts older adults, who are at higher risk of developing serious, sometimes fatal, complications from COVID-19, especially if they also have an underlying health condition. The overwhelming majority of COVID-related deaths in the U.S. have been among individuals ages 65 and over, according to the Centers for Disease Control and Prevention (CDC).

Getting a loved one vaccinated helps protect them from the COVID-19 virus as well as becoming seriously ill if they do contract it. Caregivers should get the vaccination as further protection because contracting the virus will impact their health and ability to provide care. Mental and physical stress, which have been significantly increased during the pandemic, can also impact the body’s immune system.

Your physician

You cannot get COVID-19 from the vaccination itself. FDA-authorized vaccines currently used in the U.S. do not contain the live virus that causes COVID—meaning you cannot get sick with COVID-19 from the vaccine. While there may be minor side effects as with any vaccination, such as fever, fatigue, or pain/swelling at the injection site, they are normal signs that your body is building protection and pale in comparison to the dangers of contracting COVID-19.

Don’t be afraid to ask questions. As with anything new, it’s understandable to have questions—don’t be afraid to ask them! Speak to your physician about any questions or concerns you may have regarding the COVID-19 vaccination.

Learn more about the COVID-19 vaccination.

CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC): www.cdc.gov

OUR AFA HELPLINE IS HERE FOR YOU.

9 a.m. to 9 p.m. ET
7 days a week
Connect Via
PHONE: 866-232-8484
TEXT: 646-586-5283
WEBCHAT: www.alzfdn.org

Our dementia-trained licensed social workers are here for you.

The COVID-19 pandemic has been one of the most significant public health crises in recent memory, and it has been extraordinarily hard for families affected by Alzheimer’s disease. The development of the COVID-19 vaccination has helped improve the situation, but continued progress depends on as many people receiving it as possible—especially with the emergence of variants such as Delta. AFA’s Medical, Scientific, and Memory Screening Advisory Board urges individuals affected by Alzheimer’s disease, their family members, and caregivers to get vaccinated.

IMPORTANT INFORMATION ABOUT THE COVID-19 VACCINATION

Food and Drug Administration (FDA) has
Vaccines authorized for use in the U.S. by the
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Alzheimer’s disease, but vaccination brings us another step closer to the end of this terrible pandemic.”
The Emotional Rollercoaster of Dementia

By Pam Ostrowski

Remember when you were a kid and you’d “lose your stomach” on the rollercoaster rides? Well, being a family member of a loved one with dementia is a bit like that. I certainly had emotional highs and lows throughout the months and years of my parents’ dementia and Alzheimer’s, through fear, sadness, grief, frustration, and confusion, along with some moments of joy. Keep in mind, you aren’t the only one experiencing the emotional rollercoaster ride. As your loved one declines in cognitive health, they may become angry and frustrated with themselves and you.

HERE ARE SOME TIPS TO KEEP IN MIND

Be forward-thinking about trying to avoid frustrating experiences. Be careful not to humiliate your loved one. Your relationship will benefit from those efforts. I’ve heard so many family members ask their loved one, “Don’t you remember?” Avoid saying that.

Let. It. Go.
We tend to correct our loved ones, to stubbornly fight to “bring them back” by trying to reason with them and “help them” remember memories. Those with dementia don’t need a dose of reality. They need kindness, compassion, respect, and for us to meet them where they are. Do you want to be happy or right?

Don’t take things personally.
It’s common for a person with dementia to get angry and paranoid and perhaps accuse you of stealing from them. Understand that this fear comes from disorientation and the lack of ability to remember recent events. Just start searching for the item and reassure them so they can have peace of mind that they are safe. Another driver of anger (yours or theirs) is loss of control of the situation. My father saw his life companion slowly disappear. He expressed his loss and frustration by raising his voice at everyone. All the while, he was also angry with himself, as he was starting to show signs of dementia, too.

Take care of yourself.
Your loved one needs you, and your being worn down or sick will not help them. Remember that they can sense your emotions. Know that this journey is likely to last several years (my journey with Mom lasted 14). That can be very wearing and exhausting, so it’s best to learn and develop coping skills early on.

The most important emotion is love.
It’s amazing how good you’ll feel when you notice your loved one is happy, laughing, and enjoying the moment. I think the most exhausting part of this journey is the sheer number of emotions happening all at once. Grief can show up as anger, sadness, or a multitude of other emotions. We all handle pain and loss differently, and we shouldn’t judge another for what is right or wrong for them in how they grieve. Just keep this in mind, when tempers flare or a family member doesn’t want to talk, it’s not about you. It’s how they’re processing the loss. Unable to change the outcome of an event or unable to understand the full scope of the situation and the possibilities this disease brings with it, everyone, loved ones and family members, experiences a lot of fear. Their world is changing as their past is erased; and we fear one day, we’ll be erased, too.

Loss, whether it comes one piece at a time or all at once, is never easy.

ABOUT THE AUTHOR
Pam Ostrowski is author of It’s Not That Simple: Helping Families Navigate the Alzheimer’s Journey and Founder of Alzheimer’s Family Consulting.

Try to be in good spirits.
Remember, they can sense your emotions and state of mind. You need to stay positive and happy when you are with them. No matter your emotional state internally, physical expression is very important; so be liberal with your hugs, smiles, hand holding, and kisses. If you’re visiting and not sure what to do, bring coffee and treats and find a nice place to sit and just enjoy the scenery. It will be one of the moments of joy that you’ll remember in the years to come. It will also bring you peace of mind and perspective.

Be forward-thinking about trying to avoid frustrating experiences. If you get upset, too, then your relationship can be damaged, which can lead to guilt and regret. The better their journey, the better yours is. You’ll experience a wide range of emotions throughout this journey. It’s best to accept them and learn how to move your attention away from the painful ones and toward creating happiness in your loved one’s life.

Loss, whether it comes one piece at a time or all at once, is never easy.
Using Aromatherapy

Scents and smells can be powerful. No, not just when someone is wearing too much perfume or cologne (though that can be powerful tool). Familiar scents from a positive time in the past can help with memory recall. Smells of favorite foods can stimulate appetite.

There’s an entire therapeutic intervention based on smell called aromatherapy—the inhalation of fragrant essential oils for therapeutic purposes. Essential oils are what give plants their characteristic odors—they are extracted from flowers, fruits, and herbs, bottled in a highly concentrated form, and then sold for use.

In the case of Alzheimer’s disease and other dementia-related illnesses, aromatherapy is generally used to support positive behaviors, either by itself or in conjunction with other therapies, and to aid with reminiscence. But keep in mind that Alzheimer’s disease can also diminish a person’s ability to smell, or change how things smell, so be aware of each person’s preferences and that preferences can change over time.

How can aromatherapy help?

Different aromas have different potential effects on the body. Common “essential oil” scents and their uses include:

- Lavender: Calming and balancing strong emotions
- Peppermint: Energizing and stimulating the mind, calming nerves
- Rosemary: Uplifting mood and stimulating the mind and body
- Bergamot: Alleviating anxiety, agitation, and mild depression
- Lemon: Calming and relaxation, reducing anxiety and insomnia, improving memory, easing digestion
- Ylang Ylang: Easing depression, promoting sleep
- Ginger: Promoting good eating habits and aiding with digestion issues, loss of appetite, and constipation

Before you begin using aromatherapy or essential oils

Speak to your doctor: Essential oils are generally considered safe (though they are unregulated by the U.S. Food and Drug Administration). However, like any plant, they may contain compounds that can cause side effects. Consult with the person’s physician before using essential oils for aromatherapy. If using a diffuser or humidifier, which vaporizes the oil into the air, also consider any potential allergies or side effects to other people in the home. Essential oils should not be ingested.

Choose wisely: Not all essential oil products are the same—some include chemical additives; others are harvested improperly. Review the product label for information about the oil’s purity and look for ones that are 100% oil with no other fillers. Avoid “fragrance or perfume oils,” which include chemical additives. Purchase products from well-known, established aromatherapy companies.

Follow the instructions: Closely adhere to any instructions provided by the manufacturer to ensure that you are using the product safely.

Companions in Care

Using Dolls and Robotic Pets as Therapeutic Tools

Among the many heartwarming things in this world, babies, puppies, and kittens are at the top of the list. Cradling an infant or petting a lovable furry friend can be joyful and soothing—bringing smiles and lifting spirits.

That’s the goal behind using therapeutic dolls and robotic pets as dementia caregiving tools—to mimic the positive characteristics of their real-life counterparts (without having to worry about any of the hassles, such as changing diapers or litter boxes!)

Therapy dolls are detailed, lifelike baby dolls designed to be cuddled and held. They are often textured to feel like a real infant, with features such as smooth skin and fine hair. Some are calibrated to be similar in weight.

Robotic pets are soft to the touch, mimic the animal’s natural movements and sounds, and often include sensors that respond to user touch and voice. Someone petting a robotic cat may hear and feel it purr; just as they would with a real one.

The Benefits

Companion dolls and pets, which are predominantly used in the middle- and late-stages of Alzheimer’s, have numerous potential benefits:

- Helping calm and soothe someone who is agitated
- Bringing back happy memories, such as early parenthood or having a pet
- Creating a sense of purpose and/or structure by “caring” for it
- Encouraging nurturing behavior
- Improving communication
- Building connections and empathy
- Decreasing feelings of isolation and loneliness

The last point became increasingly important during the COVID-19 pandemic, when families were often unable to visit a loved one with dementia in person and the problem of social isolation grew tremendously.

“Robotic pets and therapy dolls can help fill a void, where people cannot do things like hug or touch—tactile stimulation which is critical for all people, regardless of age,” said Dr. George Perry, Professor and Semmes Foundation University Chair in Neurobiology at the University of Texas San Antonio and an AFA Medical, Scientific, and Memory Screening Advisory Board member.

Another benefit—they are a non-pharmacological intervention, meaning individuals don’t need to worry about potential health complications or side effects that might arise from taking medications. That’s particularly true with the powerful behavior-modifying sedatives and anti-psychotic drugs which are often used to treat aggression or agitation in individuals living with dementia.

Continued on following page
Companions in Care

In general, don’t directly point out that they are presenting the doll or pet and asking them if they want to engage with it. Another can dementia. That way, they can decide on their own time into consideration can help make the decision for you. If they get comfort and joy from having one, great. If a doll or robotic pet upsets or offends them, then you know to try something different.

WHERE TO BEGIN?
One of the best ways to introduce a doll or robotic pet is to do so casually—such as placing it in a location where it can be discovered by the person living with dementia. That way, they can decide on their own whether they want to engage with it. Another can be presenting the doll or pet and asking them if they would like to hold it.

In general, don’t directly point out that they are dolls or robots. If asked whether it is real or not, don’t lie, but try to redirect into asking them a question about their own experiences (i.e., “Did you once have a dog?”). If they identify it as a “fake,” don’t lie, but try to redirect into asking them a question about their own experiences (i.e., “Did you once have a dog?”). If they identify it as a “fake,”

FINDING THE RIGHT ONE
Not any doll or stuffed animal is suitable for use as a therapeutic tool. Consider the following when making your purchase:

- Make sure its eyes can open, so that the person doesn’t think that it has passed away.
- For dolls, avoid ones that cry, as the person may find that upsetting or startling.
- Stay away from ones that “make messes” which necessitate diaper changes or cleanups.

A variety of therapeutic dolls and robotic pets are available over the internet. Do your research and shop around before buying to find one that’s most suitable for your person.

Have additional questions about using therapy dolls or robotic pets with someone who has a dementia-related illness? Contact AFA’s helpline by calling 866-232-8484 or visiting www.alzfdn.org.

PERCEPTION IS REALITY
Often the individual will believe that these therapeutic tools are the real thing. You should treat them that way, too.

For example, items need to be handled in a similar manner as a child. Taking the person and their preferences at the time into consideration can help make the decision for you. If they get comfort and joy from having one, great. If a doll or robotic pet upsets or offends them, then you know to try something different.

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WHITING RESTING WITH HER MOTHER, BETH, IN 1999

By Lonna Whiting

Moments
Meaningful
Make

When my mother was diagnosed with young-onset Alzheimer’s in 2013 at age 61, I thought her life was over.

In my mind, her future was a downhill tumble from diagnosis to death. She’d never get better or improve. She’d stop being able to cook on the holidays. We’d never take that trip to Ireland. I was focused on what we were going to lose slowly over the course of several years. As a result, I spent so many years preparing myself for what to expect that I missed out on the many meaningful moments I could have made with Mom.

Although the truth that Mom would progress in her disease was a reality I couldn’t escape, I eventually discovered that even though we didn’t get to take that trip to Ireland, we did (and still do) have many amazing moments together that I will cherish forever.

I wish I could tell you when this change in my perception occurred, but I’m not sure when or how it did. It would certainly save you some of the stress, sadness and heartache that weighed me down. But what I can do is describe ways in which I now maximize meaningful moments with my mother and how you can do the same.

Share the good moments, not the clinical milestones.

If you’re like me, one of the most difficult questions people ask is, “How’s your mom doing?” In the earlier years, I would reply to this question about my mother’s dementia based on the clinical stage of her progression. “She’s about mid-stage now because she needs help dressing and bathing,” I’d say.

Because I was so focused on the medical side of things, I wasn’t perceiving Mom as a person anymore. I was perceiving her as a patient with a terminal disease. Over time, as I spent less of my own energy worried about when the next progression would happen and more time focused on little moments that put a smile on my mom’s face, I realized I was going about answering the question in all the wrong ways.

My advice for when people ask you how your loved one is doing is to relay a meaningful moment. Instead of, “She’s no longer walking on her own,” say something like, “We enjoyed a strawberry shake together the other day.” I’ve found that in doing so, the person who asks about my loved one is much more comfortable with my answer. I’m much happier, too.

Continued on following page
How to Make Meaningful Moments cont’d from p. 9

Spend time observing your loved one and take note of what seems to bring them joy.

It would be dishonest of me to dismiss the difficult parts of dementia: the hallucinations, mood swings, behavioral changes, outbursts, etc. Until efficacious medical interventions are discovered and approved, it will continue to be a devastating reality.

In between the difficult, though, there is opportunity for joy: you just may have to look a little harder and be more observant to discover it. Your loved one is still communicating with you, just in different ways.

Look for cues, such as:
- smiling
- raised eyebrows
- clapping or patting hands

Accept that what they once enjoyed might not be what they enjoy now.

My mother loved classic rock, especially The Beatles, Led Zeppelin and Pink Floyd. So naturally, I was horrified when she once would meet me out for sushi, she now preferred a ham and cheese sandwich.

The same went for some of her food preferences. When she once would meet me out for sushi, she now preferred a ham and cheese sandwich.

For a long time after that, I would play Led Zeppelin for her, even after it was clear the music no longer resonated. When she once would meet me out for sushi, she now preferred a ham and cheese sandwich.

I encourage you to individualize your own loved one’s three stages. It brings perspective that might not have been there otherwise. It also brings great joy and comfort, knowing that even though your loved one may not “remember” a memorable moment the way you do, the important thing is that it happened and you were present as a loving, kind and caring witness.

One of the best things I did recently was take some of those meaningful moments and individualized the three stages of Alzheimer’s so they better reflect my mother’s journey, not just the clinical stages she’s experienced.

If I share the story of my mother’s journey in personal stages, here is what it looks like:

- **STAGE ONE:** Busts out of the facility with me for pizza dates. Dances with my partner, Kevin. Drinks a beer. Sits with me. Holds my hand. Listens to me repeat, “I love you.”
- **STAGE TWO:** Goes for drives with me. Hums along to The Beatles. Shares a mocha.
- **STAGE THREE:** Sits with me. Holds my hand. Listens to me repeat, “I love you.”

ABOUT THE AUTHOR

Lonna Whiting is the owner of lonna.co, a growth strategy and communications consultation agency located in Fargo, ND. Whiting writes frequently about her experiences as a care partner to her mother, Beth. You can read more of her work at www.lonna.co and/or reach her at lonna@lonna.co.

Individualize the three stages of Alzheimer’s.

As Alzheimer’s disease and other dementia-related illnesses progress, many facets of daily living become more difficult. Everyday tasks an individual routinely performed for decades can suddenly become challenging. That includes managing finances.

Someone in the early stages of Alzheimer’s disease may still be able to continue handling some financial responsibilities, such as paying bills or writing checks, but have trouble with more complicated tasks such as balancing a checkbook or reviewing bank statements.

According to the National Institute on Aging (NIA), basic financial tasks become even more challenging for the person as the disease progresses, and eventually someone else will need to oversee them.

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Managing Alzheimer’s Impact on Finances

IT’S NOT JUST ABOUT MONEY

Losing control of the ability to manage finances is also a loss of independence for many individuals—some may even try to hide financial problems out of fear of having to relinquish that self-sufficiency. They may feel suspicious or resentful of another person trying to take that control away from them, even if it’s a trusted loved one acting in the person’s best interests.

To help the individual living with Alzheimer’s retain the feeling of independence, while still protecting their finances, consider the following tips:

- Lower spending limits on credit cards or cancelling them entirely
- Provide dummy or voided checks
- Give the person a small cash allowance

If it becomes necessary to take over the person’s finances, take every possible measure to do so in a sensitive manner that treats the person with respect and dignity.

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Q&A with Filmmakers Seth Rogen & Lauren Miller Rogen
Founders of HFC

• CAN YOU SHARE YOUR PERSONAL EXPERIENCE WITH ALZHEIMER’S DISEASE?

Lauren: My mom, Adele Miller, was diagnosed with young-onset Alzheimer’s when she was 55 years old. I was 25 and much younger than I thought I’d be when faced with losing my mom to a disease like Alzheimer’s. None of my friends or peers were navigating anything like that at the time, so I just felt super alone. I was angry and depressed and really devastated. I started talking about it because I needed to and I’m so glad I did. I found that I was so far from alone and that connecting with people who understand can feed your soul and your journey.

• WHEN WAS HILARITY FOR CHARITY (HFC) FOUNDED AND WHAT WAS ITS PURPOSE?

Seth: We founded Hilarity for Charity (HFC) in 2012. We started by hosting fundraisers to raise money for other folks doing great work toward curing Alzheimer’s. As we grew, we really saw a need to focus on young people for whom, at the time, there was really no dedicated space. No place where it was okay to be like, “This sucks.” To be fresh out of college or just starting out on your own, having a parent diagnosed with Alzheimer’s really hits you in the face.

Lauren: We also wanted to acknowledge that, while finding a cure is critical, there are millions of people struggling to handle this disease right now. That’s how “Care for Caregivers” became a programmatic focus for us. HFC has awarded over 350,000 hours of free, professional, in-home respite relief for caregivers.

• WHAT’S YOUR DAY-TO-DAY INVOLVEMENT IN HFC?

Seth: We are hands on in the work every day. We’ve really grown up with the organization. We may not say we’re “kicking Alz in the ballz” anymore, but we remain deeply committed to our vision. That said, we’ve been very fortunate to grow into an amazing team of board members, science advisors, caregivers and providers, and a professional staff.

Lauren: Plus, Alzheimer’s is awful. It’s really just the worst, and finding humor in a dark situation is both a necessary coping mechanism and good for your own health.

• HOW AND WHY IS COMEDY A CORNERSTONE OF HFC’S EFFORTS?

Seth: Comedy is what we do. I like to joke that if we were chefs, we’d be cooking for Alzheimer’s. But comedy is our expertise, so it was natural to incorporate levity into our organizational values.

Lauren: Another priority for us is to inspire the next generation of Alzheimer’s advocates and be a leader in brain health research and education. This year, HFC will launch HFCUniverse: a digital platform of original, evidence-based coursework designed to shift the knowledge and behaviors of high school and college students around Alzheimer’s and related dementias. The only way we’re going to change the trajectory of this disease is to get young people thinking and caring about it.

• HAVE YOUR COLLEAGUES IN HOLLYWOOD GOTTEN INVOLVED IN SUPPORTING HFC?

Seth: Yes. We have called in many favors! Everyone has been really amazing and generous with their time and talent. Elizabeth Banks, Billy Eichner, Craig Robinson, Anna Faris, Jim Gaffigan, Bruno Mars, Post Malone, Miley Cyrus, Sarah Silverman…..

Lauren: Michelle Wolf, Hannibal Buress, Tony Hawk, Tiffany Haddish, Ilana Glazer, Paul Rudd, Busy Philips, Adam Devine, Nick Kroll, Anderson Paak, Yvette Nicole Brown, Kimberly Williams-Paisley, Ashley Williams, Sarah Rafferty…..

Seth: We really can’t even name all of the cool people who have very generously supported HFC and who genuinely care about the mission.

• WHY IS GETTING YOUNG PEOPLE INVOLVED IN RAISING AWARENESS AND DRIVING CHANGE SO IMPORTANT TO YOU?

Lauren: Research suggests that Alzheimer’s begins in the brain up to 20 to 30 years before the onset of symptoms. It’s really not the “old person’s disease” many think it is. So another priority for us is to inspire the next generation of Alzheimer’s advocates and be a leader in brain health research and education. This year, HFC will launch HFCUniverse: a digital platform of original, evidence-based coursework designed to shift the knowledge and behaviors of high school and college students around Alzheimer’s and related dementias. The only way we’re going to change the trajectory of this disease is to get young people thinking and caring about it.

Continued on following page
Lauren and Seth center levity and encourage brain healthy activity to raise awareness among people aged 50 and younger, including brain healthy lifestyle interventions so that one day we can prevent or delay onset. Lauren: We’re also supporting efforts to build and grow the pipeline of future leaders, encouraging medical students and other emerging professionals to explore and commit their area of focus to neurology, Alzheimer’s, and cognitive health. And, of course, we wouldn’t let our 10th birthday pass by without having a ton of fun, so there are lots of activations and events coming up in 2022 that will continue bringing light to Alzheimer’s in true HFC fashion.

**IS THERE ANY ADVICE OR ENCOURAGEMENT YOU’D LIKE TO SHARE WITH OUR READERS?**

Lauren: Talk about it! Share your story. You are not alone. And if you’re a caregiver, please don’t be afraid to ask for help. HFC has virtual support groups with no commitment—it can be so helpful to connect with others who can empathize with your experiences and offer support or direction. The more we all talk about this disease, the better chance we have of ending it.

Lauren and Seth center levity and encourage brain healthy activity to raise awareness of Alzheimer’s among college students.

**CAN YOU DESCRIBE LIFESTYLE CHANGES YOU’VE MADE TO PROMOTE GOOD BRAIN HEALTH?**

Lauren: After some resistance, we both started taking steps to protect our own brains. We have a sleep routine that includes going to bed at the same time each night and keeping our room cool. In the past few years, we learned to make pottery, and now we are working on making our own glazes—which is kinda like science and, therefore, really good for our brains. We found exercise we enjoy (I like functional training and HIIT workouts, Seth likes hiking) and do those things pretty much every day. And, finally, we eat brain healthy foods such as green leafy vegetables, berries, and foods that are rich in Omega-3 fatty acids like salmon. And on Saturdays, we eat ice cream for happiness.

**HFC CELEBRATES ITS 10TH ANNIVERSARY NEXT YEAR. WHAT PROGRESS HAVE YOU SEEN OVER THE LAST DECADE AND WHAT’S YOUR HOPE FOR THE FUTURE?**

Seth: The progress over the last ten years has been really encouraging. From testing and early detection to treatment and prevention findings, we’re really hopeful. But as we say, until there’s a cure, there’s care. We are committed to supporting future research and projects that advance the understanding and effectiveness of Alzheimer’s prevention and control. We’re really hopeful that over time we’ll see real breakthroughs.

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Nutrition at the University of Illinois at Chicago and the Rush explained David Marquez, PhD, Professor of Kinesiology and is expected to grow by 832%—to 3.5 million by 2060, the progression, the number of Latinos 65+ with Alzheimer's. Unless a medical families facing a diagnosis of Alzheimer’s. According to the progression, the number of Latinos 65+ with Alzheimer's disease, which has been ongoing for 16 years. “Some days we persist and when the family sought medical support, Lesbia de depressed. But the difficulties endured and when the family sought medical support, Lesbia was officially diagnosed with Alzheimer’s disease at age 54. It was 2005. Sisters Perla Castro and Celita Castro, RN, joined AFA recently, which has been ongoing for 16 years. “Some days we are thriving, and some days, surviving,” the sisters said—and that’s why they were eager to share lessons learned so that others can have better days.

The Castros are among the growing number of Latino families facing a diagnosis of Alzheimer’s. Unless a medical breakthrough is discovered that prevents, cures, or slows the progression, the number of Latinos 65+ with Alzheimer’s disease is expected to grow by 832%—to 3.5 million by 2060, explained David Marquez, PhD, Professor of Kinesiology and Nutrition at the University of Illinois at Chicago and the Rush Alzheimer’s Disease Center. Why the large uptick? The “greying of America.” As the American population is getting older, Latinos—as our largest minority group—will end up facing the largest increase in Alzheimer’s disease and related dementia cases of any racial or ethnic group in the U.S., according to the National Institute on Aging.

Dr. Marquez, like the Castro sisters, is trying to help—by engaging more Latinos in these conversations about Alzheimer’s disease and inviting them to participate in research so that the Latino population is properly represented in findings about the disease.

**FAMILY IS EVERYTHING.**

Upon Lesbia Castro’s diagnosis, taking care of her beloved mom became the five siblings and dad’s top priority. They agreed that their father, Cesar Castro, would retire, so that he could be the full-time, primary caregiver. Then Perla started thinking about having her own company, so that she would have more flexibility with her time to better support her parents. She founded Communica Global, a project management company. Understanding the great need for information within the Latino community, she also founded a volunteer organization, Latino Alzheimer’s Coalition for Advocacy, Research and Education (LA CARE), enabling her to have a broader role in helping even more families.

Like Perla Castro, supporting families within the Latino community is a “personal and professional” passion for Dr. Marquez. His own father passed away from the disease just a year ago. He “dedicates” his life’s work, which involves Alzheimer’s research, to all the people who passed away, those living with the disease, and the “loved ones who provide the care, like [his] mom did for [his] dad.”

As a researcher, Dr. Marquez understands that Latino families often share cultural values that drive their decisions around important issues—though he wants to be careful about creating stereotypes and encourages individual sensitivity to every person met. Still, he admits, “We have come to see how shared cultural values are central to everything that happens when a Latino family member is living with Alzheimer’s disease.”

Among the values that stand out to Dr. Marquez: “familismo” (a strong loyalty to family members); “personalismo” (having a personal connection and rapport before “business” can take place); “mariánismo” (nurturing women within the extended family taking on the responsibility of care); and “fatalismo” (a belief that certain events or diseases are “meant to be” and not preventable).

The last value can be problematic for families because senior family members may perceive that their Alzheimer’s disease “was supposed to happen” and not welcome being proactive about brain health. Hearing about the experiences of another Latino family, like her own, or Perla and Celita’s, can make a real difference in understanding, he believes.

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To access the entire virtual Latino Healthy Brain Summit—Chicago, “Una Mejor Calidad de Vida” / “A Better Quality of Life,” available in Spanish and English, go to www.alzfdn.org/latinochicago
Do you have a loved one with agitation associated with Alzheimer’s dementia? Is their agitation becoming overwhelming?

Is someone you care for with Alzheimer’s dementia exhibiting excessive motor activity, verbal and/or physical aggression?

If so, they may qualify for the ASPECT™ clinical research study. The purpose of this study is to evaluate the safety and effectiveness of an investigational drug for agitation associated with Alzheimer’s dementia.

To be eligible for this study, a potential participant must:

✓ Be between the ages of 50 and 90
✓ Have a diagnosis of probable Alzheimer’s dementia
✓ Have moderate-to-severe agitation that interferes with their daily life
✓ Have a reliable caregiver who spends a minimum of 2 hours per day, 4 days per week with them and is willing and able to comply with all study procedures

Other eligibility criteria may apply.

The image depicted contains models and is being used for illustrative purposes only.

Those who qualify will receive study-required medical care and study drug at no cost. Health insurance is not required.

For more information visit: aspect306.com or call 1-877-592-2574.

The Course of Alzheimer’s Disease: Common Features with Individual Variations

BY DR. ALLISON B. REISS

If you or a member of your family have been recently diagnosed with Alzheimer’s disease, you may wonder what you can expect next.

Memory loss and trouble with language and communication—such as difficulty finding words, concentrating, or following a conversation—are common early signs. As the disease progresses, confusion, reading and writing problems, and difficulties managing finances are expected, followed by loss of basic motor skills and self-care abilities in the later stages, unfortunately.

While these features are nearly universal for everyone living with Alzheimer’s, at some point, many aspects of the disease are quite unique and vary from person to person. Some individuals move through the various stages of Alzheimer’s in just a few short years, while others have a prolonged period that stretches over two decades.

Emotional and behavioral symptoms differ among individuals as well. One person may become depressed but not agitated, aggressive, or violent, while a second experiences the opposite, and a third encounters none of those symptoms. Wandering may be an ongoing issue for some, but not others.

Different variants of Alzheimer’s, while still sharing the same long-term prognosis as the classical form of the disease, in general, also cause different effects.

The language variant may produce less memory impairment early on, but more prominent difficulty with language—trouble finding words, slowed speech and mispronouncing words.

The visual variant may preserve memory and cognitive ability, but create greater vision effects early on, such as poor depth perception; difficulty reading, driving, and recognizing faces; and problems finding objects that are right in front of them.

The rare frontal variant may leave memory intact early in the course, but cause behavioral symptoms such as apathy, loss of inhibitions, and socially inappropriate conduct.

One of the most important things of which a caregiver should always be mindful is that their person is unique; and to the greatest extent possible, care should be centered upon them and how they are experiencing Alzheimer’s. While we continue to search hard for a cure for Alzheimer’s, remember that treatments, therapeutic interventions, and lifestyle choices may improve symptoms and quality of life. Good nutrition, exercise, proper sleep, social interaction, and cognitive stimulation can all be helpful.

ABOUT THE AUTHOR

Allison B. Reiss, MD, is an Associate Professor of Medicine at NYU Long Island School of Medicine and a member of AFA’s Medical, Scientific and Memory Screening Advisory Board.

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Live In the Moment

Six Teens Share Lessons They’ve Learned About Alzheimer’s

There’s no minimum age to be a difference maker. Teenagers across the country are serving as caregivers, volunteering, raising awareness, and even conducting research.

More than 2,000 of them shared their stories through AFA’s 2021 Teens for Alzheimer’s Awareness College Scholarship Essay Contest. Seventy-two students received more than $55,000 in college scholarships, the largest single-year amount to date. Over $350,000 in scholarships have been awarded since the program’s inception.

“Alzheimer’s residents filled me with inspiration,” wrote first place winner Sharada Vishwanath of Northborough, MA, whose grandfather lived with Alzheimer’s disease. Following his passing, she began volunteering in a nursing center to help others affected by dementia-related illnesses.

Interacting with and getting to know the residents impacted her tremendously. She learned their stories, formed relationships, and enjoyed seeing their smiles while doing their favorite activities. Her experiences taught her how to communicate more effectively and be at greater ease making conversation. They also changed her outlook on life—encouraging her to live in the moment and appreciate the things in front of her. “In simple activities such as playing bingo, ball games, or painting their nails, I saw the full embrace of the moment upon their faces,” wrote Sharada, who earned a $5,000 scholarship. “There were so many experiences here that opened my eyes and filled me with the fullness of compassion.”

Second place winner Sisy Chen of Chicago, IL, described how little moments became lasting memories. Her grandfather, Yéyé, made handmake Chinese dumplings every Friday night for the family. After his Alzheimer’s diagnosis, frozen dumplings from the grocery store became the replacement, until one Friday night when her mother decided to make them as Yéyé had. As she chopped and mixed the ingredients, with the familiar smell filling the air, Yéyé walked into the kitchen and began making dumplings for the first time in a long time. During dinner, he picked one up with his chopsticks, turned to Sisy and said slowly in Mandarin, “Try this dumpling, my love.” “Alzheimer’s disease does not erase a lifetime of love—it only amplifies it through small, ephemeral moments,” wrote Sisy, who earned a $3,500 scholarship and also volunteered at the Rush Alzheimer’s Disease Center and initiated a pen pal program matching volunteers with seniors at nursing homes in underserved Chicago communities. “Every moment that I could spend with my grandfather was another memory I could tuck away into the vast expanse of my own mind.”

Liana described wanting to take a more active role in caring for her great grandmother, Tai Tai, who has Alzheimer’s disease—preparing her meals, playing piano for her, and spending quality time with her. “Taking care of her and telling her about my day has allowed me to become closer to her,” Liana wrote. “I also remember telling her of the day I would go to college, the day I would buy a house, and the day I would travel to China on a solo trip and try every street food I could find. But now, all I want to do is be in the present and cherish it.”

For Eryn Edwards of Ladson, SC, who earned a $1,500 scholarship as the fourth place winner, Alzheimer’s disease taught her to be more patient, see things from a different perspective, and treasure her own memories as she helps care for her father, who is living with young-onset Alzheimer’s disease. “Although his moods influence me and my family, I have discovered that how we interact with him influences him to an even greater degree,” she wrote. “I’ve changed my tactics and ways of approaching him to be more positive and understanding even if I’m having a bad day or am frustrated.” “He, regardless of Alzheimer’s, is still my dad,” she continued. “On the days when he remembers who I am, I am hopeful that me spending time with him means something to him; and if nothing else, spending time with him means something to me.”

Mackenzie Wright of Gaylord, MI, who earned fifth place and a $1,000 scholarship, discovered the importance of going with the flow, keeping things simple, and being patient during his grandfather’s time with Alzheimer’s, but the best lesson she learned was “to be there, be in the present…you only have so much time before the clock runs out, and when it does, you can’t get wasted time back.”

Living in the moment is a lesson learned for third place winners Hunter Field of San Antonio, TX, and Liana Chen of Austin, TX, both of whom earned $2,500 scholarships. For Hunter, it was being able to spend quality time with his grandfather before he passed away from Alzheimer’s disease that became important to him. “Although he wasn’t the same grandpa I knew growing up, there were good days and bad days,” Hunter wrote. “On the good days, I took advantage of speaking to him about his life and we spent time reminiscing about the cool things he did when I was little, like when he taught me to shoot a BB gun and roasting marshmallows by the campfire. I sensed that we connected man-to-man for the first time and I got a chance to let him know I appreciated him and loved him very much.”

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Navigating a complex bureaucratic system can also be confusing and intimidating. That’s where the support of a Long-Term Care (LTC) Ombudsman can be helpful—someone who advocates for the health, safety, and rights of individuals in long-term facilities, and ensures residents are protected by the standards required under the Nursing Home Reform Law of 1987 (in most states, this law also covers assisted living and small board and care homes). Each state has an office headed by a full-time State LTC Ombudsman.

What can an Ombudsman help with?

Your loved one is entitled to the best possible quality of life and care. The Ombudsman program is one of the avenues created to ensure they receive both. Ombudsmen help by:

- Educating individuals about their rights
- Addressing concerns about quality of care
- Discussing and resolving grievances/issues with facility staff and family members
- Investigating suspected neglect or abuse (physical, emotional, mental, or financial)
- Reviewing inadequate staffing or training for the level of residents’ care needs

“Residents’ concerns often relate to their specific preferences, such as bathing times or food choices—things not directly attached to a regulation but should be honored by a facility,” said New York State Ombudsman Charlotte Royal. “Concerns like these often require mediation by the Ombudsman with the facility to work together to meet the resident’s desire and ensure that a resident-centered plan of care is in place.”

Ombudsmen also coordinate with other agencies to solve problems on both individual and systemic levels, along with analyzing and recommending changes in laws, regulations, and policies.

Contacting an Ombudsman

If you cannot resolve your concerns or issues directly with the facility on your own, or don’t feel comfortable doing so, you can make a confidential report with the Ombudsman. With your permission, the Ombudsman then investigates and moves to resolve the issues presented.

“Federal and state law requires facilities to allow residents access to the LTC Ombudsman and to also work with the program to resolve issues and concerns. Most facilities do work with the Ombudsman program effectively,” Royal said. “If a facility denies access or refuses to work with the program to resolve issues, the Department of Health is notified; however, this is always a last resort.”

Residential care communities must post the area’s Ombudsman program contact information and responsibilities. You can also search by state, visit the Elder Care Locator website (eldercare.acl.gov), or contact the AFA Helpline (866-232-8484).

A lot of sensory products I saw were basic, poor quality, and unattractive,” explained Goddard. “I believe that people with dementia deserve to have nice things, and I try to incorporate that belief into each one of my designs.”

Her occupational therapy background guides her in creating designs that incorporate engaging, familiar tasks, bright and clear colors, and a mix of tactile objects and materials that would encourage exploration and create interest. She also designs blankets for people of different stages of dementia—some focused more on cognitive activities, such as lacing, weaving, fastening, and folding; others are purely tactile and comforting.

Each blanket is handsewn by Goddard at her home in Perth, Australia. View her different designs at www.tactilesbysophie.com and on Instagram at @tactiles_by_sophie.
Nearly 60 years ago, Sanford Finkel, MD, made a choice. He chose to specialize in geriatric psychiatry, a little-known field, with only a handful of professionals interested in it around the country. Having spent the weekends of his childhood with his father’s parents, Bella and Louis Finkel, since his own parents worked weekends in retail, specializing in older people was a comfortable choice for him, albeit one that was considered “far out” at the time. He loved his grandparents, and he and they were extremely close. What was not clear at the time was that this choice of profession would end up having a profound impact—on not just himself but on the field of psychiatry and subsequently millions of patients around the world.

“When I started in geriatric psychiatry in 1968, there was virtually no interest in aging,” said Dr. Finkel. On top of that, there was hardly anywhere to participate educationally among peers. One day in 1974, he decided to set up a geriatric mental health organization in Chicago where he lived. That organization was the Society for Lifecycle Psychology and Aging, and Dr. Finkel served as its founding president. From there, the field, thanks to his vision, grew exponentially.

Dr. Finkel went on to found or cofound three other groundbreaking professional organizations: the American Association for Geriatric Psychiatry (AAGP) in 1978 (and serving as its first president), the American Psychiatric Association (APA) Council on Aging in 1980 (and serving as its chair), and cofounding the International Psychogeriatric Association (IPA) in 1982 (and serving as its president). Because of AAGP, cities and states across the United States established their own mental health organizations specializing in geriatrics. AAGP was the model. AAGP also provided a conceptual basis for establishing the IPA, the international organization.

“Professionals all over the world were also looking for opportunities to collaborate with colleagues and talk about their patients, research, training, and public policy,” explained Dr. Finkel. “IPA then spawned more national organizations in Australia, Brazil, Canada, Israel, New Zealand, Spain—every continent except Antarctica. It’s been a lasting piece that impacted many thousands of health care professionals all over the world. It has also led to many professionals establishing their careers as a result of the educational initiatives of these organizations.”

“Probably more than any other field, geriatric psychiatry integrates the biology, the psychology, and the social. There are many dimensions, just like life—and that has always appealed to me,” Dr. Finkel said. Dr. Finkel went on to be the medical consultant who developed the first memory care facility, a critical component of Sunrise Assisted Living. Like so many others, Dr. Finkel was personally touched by dementia in his family. His paternal grandfather passed way from vascular dementia the month before he started his psychiatry residency and his maternal grandmother, Helen Kosins, developed Alzheimer’s when he was already a geriatric psychiatrist.

Dr. Finkel, a Clinical Professor of Psychiatry at the University of Chicago Medical School; an AFA Medical, Scientific, and Memory Screening Advisory Board member; and an AFA Executive Committee member, reflected on the changes in the field over the course of his career, describing the last fifty years as full of many advances, though much still remains to be done.

“On the positive side, there is far more focus on the subject—better programs for older people, increased understanding for people with dementia, and greater emphasis on caregivers and their needs. However, it’s very disappointing that we still don’t have a cure or anything that significantly arrests the illness,” he said.

“I am most proud and grateful that for over a half a century I have been able to take care of patients with Alzheimer’s disease and other dementias and their families,” he said.

And for his amazing contributions, we are grateful, too.
Light the World in TEAL
November 4, 2021

Join us! For more information, or to sign up, go to www.LighttheWorldinTeal.com

NOVEMBER IS ALZHEIMER’S AWARENESS MONTH