Finding Our Truth: Dr. Oz Reveals His Mother’s Alzheimer’s Diagnosis
MISSION: TO PROVIDE SUPPORT, SERVICES AND EDUCATION TO INDIVIDUALS, FAMILIES AND CAREGIVERS AFFECTED BY ALZHEIMER’S DISEASE AND RELATED DEMENTIAS NATIONWIDE, AND FUND RESEARCH FOR BETTER TREATMENT AND A CURE.

AFA’s Dementia Experience

is a virtual reality (VR) educational tool that shows how someone living with Alzheimer’s may experience common symptoms.

To learn more or purchase, visit the Professional Training and Education section of AFA’s website, alzfdn.org, or call 866-232-8484.

See through the eyes of a person with dementia.
A MESSAGE FROM OUR PRESIDENT & CEO

Dear Friends,

“As long as the actions you take come from a place of love, they feel it.” This wise reminder is from 25-year-old Emmy German whose mom Linda Larsen German was diagnosed with young-onset Alzheimer’s five years ago. Emmy shares advice on long-distance caregiving (p. 24) in this new issue of Alzheimer’s TODAY. As always, we bring you inspiration and resources for your days with the people you love and care for. This month’s highlights:

- “Finding Our Truth: Dr. Oz Reveals His Mother’s Alzheimer’s Diagnosis” (pp. 8-9). It’s a poignant reminder to be open to the signs you may be seeing in a loved one that suggest a dementia—and to take action.

- Meet AFA’s Dementia Care Professional of the Year, Pam Leonard, Program Director of CJFS Cares in Birmingham, Alabama. Pam shares great caregiver tips in “Finding Your Caregiver Happy Place” (p. 23).

- Dealing with the changes that occur when an individual has a dementia can be challenging. That’s why we pull together resources in every issue to help. Check out “Dementia’s Impact on the 5 Senses” (pp. 10-11), “Behaviors as Forms of Communication” (p. 22), “What to Do About Wandering” (p. 25), and “Travel Tips” (p. 5).

- If you’re looking to spark some activity with a loved one or someone you care for, take a look at “Using Art to Create Memories Together” (p. 4) and “Therapeutic Activities for the 3 Main Stages of Alzheimer’s” (pp. 18-19). Both provide lots of ideas to bring fun and purpose into every day.

- “Never say never” is an important lesson and one entrepreneur and author Rick Itzkowich has learned in his life more than once. He shares how his father’s Alzheimer’s changed everything for him and his family in “My Story” (pp. 20-21). In the end, it was all for good.

- Looking for new ways to have an impact in the world? Consider the “Gift of Securities” (p. 13). Your gift will help AFA fund care, education and research for treatment and a cure while potentially having financial benefits for you, too.

We love hearing from you. Don’t hesitate to send us feedback and story ideas to info@alzfdn.org. What would you like to see in the next issue of Alzheimer’s TODAY?

Let us know.

All the best to you and your families,

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

P.S. Interested in getting on our mailing list for Alzheimer’s TODAY? Go to our website www.alzfdn.org to the Media Center tab and click on Alzheimer’s TODAY to sign up.

EDITIORIAL

Thank You, Dr. Oz

“A gut punch.”

That’s how television talk show host and physician Dr. Mehmet Oz described finding out his mother had been diagnosed with Alzheimer’s disease (you can read more about that on pp. 8-9). He was referring to two things: the fact that his mom is now living with Alzheimer’s disease and realizing that he and his family had missed the early warning signs.

Recognizing the symptoms in someone you love can be hard, even for a trained physician. When something does seem amiss, people often attribute it to another cause, like “old age.” That’s understandable: No one wants to think about Alzheimer’s affecting them or someone they’re close with.

But with hindsight being 20/20, how many family caregivers wish they had the benefit of an earlier detection? Dr. Oz does.

In sharing his family’s Alzheimer’s story, Dr. Oz highlights an important point that can never be repeated enough: No one should be ashamed or embarrassed to talk about memory concerns. While they can be difficult or uncomfortable conversations, they’re for the person’s benefit. Early detection of Alzheimer’s disease potentially enables someone to begin medications sooner, which may help slow the disease’s progression, enroll in a clinical trial, participate in therapeutic programs and take a more active role in making health, legal and financial decisions. All of this plays a key role in helping the person achieve the best quality of life possible.

The Centers for Disease Control and Prevention (CDC) projects that the number of Americans living with Alzheimer’s disease could nearly triple, from over 5 million to 14 million, by 2060. As the number of individuals affected by Alzheimer’s continues to grow, so, too, will the need to have these conversations. Fear of them is common, but we must continue to help and encourage people to talk about memory concerns as quickly as possible.

Dr. Oz has done a great service in doing that. Being so candid and open in the public eye about something so deeply personal takes courage. We applaud him for bringing attention to this issue.
Using ART to Create Memories

“I just love the feeling in the room,” exclaimed Jodie Berman, CTRS, at the final art show of an AFA artist-in-residency program. Each week, for four weeks, participants, with their care partners, were encouraged to reflect and reminisce. Through the use of paint and collage on large-scale window frames, participants created an abstract “self-portrait” that expressed their memories and emotions. For some, each pane became decades, which eventually grew into the story of their whole life. At the close of the program, one participant gleefully shouted, “We did it!” which made the room erupt in applause.

Art can be a powerful tool to improve quality of life for people living with Alzheimer’s and dementia-related illnesses. It stimulates memories and creates opportunities for self-expression and social engagement. It can also uplift mood, improve self-esteem and be a welcome reprieve from an individual’s daily routine.

A caregiver can introduce art materials into a home setting fairly easily, says Marnie Herlands, MS, ATR-BC, LCAT, a Board Certified Art Therapist. “You can keep it simple; a sketch pad, pencils and some water color paints is enough...”

Artmaking can potentially be beneficial to individuals living with dementia and their caregivers as well. However, as the disease progresses, specific adaptations should be made. Before you embark on your trip, consider the difficulties and benefits of traveling for the individual you are caring for.

Here are steps family caregivers should take to make the trip more comfortable for someone living with dementia:

- Advise airlines and hotels that you’re traveling with someone who has memory impairment and inform them of safety concerns and special needs.
- Inquire in advance with airports/train stations about security screening procedures. This way, you can familiarize the person and their needs when making arrangements; if they travel better at a specific time of day, consider planning accordingly.
- Plan the travel mode and timing of your trip in a manner that causes the least amount of anxiety and stress.
- Take regular breaks on road trips for food, bathroom visits or rest.
- Preserve the person’s routine as best as possible, including eating and sleeping schedules. Small or unfamiliar changes can be overwhelming and stressful to someone with dementia.
- Consider utilizing an identification bracelet and clothing tags with your loved one’s full name and yours to ensure safety.
- Depending on the trip duration and/or the stage of the person’s illness, consult with their physician to make sure travel is advisable.

Recommended Art Materials for Persons with a Dementia

By AFA Recreational Therapist, Jackie Gatto, MS, R-DMT

- Collage – Have old magazines laying around? Flip through those magazines together and find images of objects, landscapes, quotes, and food that can be cut or ripped out. Collect all of these images and create a collage together. You can even frame the finished product.
- Scrapbooking – Find old photos that are sitting in a box and create a scrapbook together. Many craft stores have scrapbooking kits that include fun pages, colorful stickers, and textural materials. This project is a great way to reminisce and reflect on treasured memories.
- Flower arranging – In the warmer months, you can go for a walk through the garden and pick out flowers together. If a garden is not accessible, you can purchase flowers or speak to a local florist about leftover ones they may have and are willing to donate. After collecting them, find a vase or mason jar and arrange them as you both please.
- Painting – Simple, yet satisfying! Whether it is a paint-by-numbers book or a blank canvas, painting is a great creative arts activity that can be enjoyed by many. Pro tip: Find colored painter’s tape and tape off lines and shapes together on canvas. Encourage the individual to paint all of the white parts of the canvas. When the paint dries, peel off the tape together and watch the canvas transform! Talk about what the painting looks like now that the tape is off. May be a new image you both didn’t notice before will appear!
Dental Care & Dementia

By Amanda Tavouliaris, DDS, and Greg Grillo, DDS, EmergencyDentistsUSA.com

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When a person living with Alzheimer’s loses the autonomy that most of us take for granted, they start losing the means of maintaining their own health. As Alzheimer’s progresses, oral health can become more challenging. An individual may forget what to do with toothpaste or may be resistant to assistance from others. Regular dental checkups are only part of maintaining good oral health. Caregivers are encouraged to work on preventative home care which includes brushing two times daily and watching for changes in behavior.

Here are some tips for everyday care:

Give short, simple instructions.

The best way to explain dental care is by breaking it down into steps. Walk the person through the entire process: how to hold the toothbrush and put on the toothpaste.

Use the “watch me” technique.

It may be helpful for someone to see what to do. Hold a toothbrush and show them how you brush your teeth. Then, put your hand over theirs and guide their brush. If there appears to be any agitation, postpone brushing for another time.

Keep teeth and mouth clean.

If the person you are caring for needs assistance keeping their mouth clean, brush their teeth, gums and tongue very gently twice a day. If they wear dentures, be sure to rinse them with plain water after meals and brush them daily. Each night, remove them and soak in a cleanser. Use a soft toothbrush to clean the gums and tongue.

Be aware of potential mouth pain.

Investigate any signs of mouth discomfort during mealtimes. Refusing to eat or strained facial expressions while eating may indicate mouth pain or dentures that don’t fit properly.

Not maintaining proper oral hygiene can precipitate problems that require even greater care:

Cavities: If teeth aren’t cleaned properly, bacteria can build up and eat away the enamel.

Broken teeth: Chipped teeth are minor but should still be fixed. If the break goes into the inner part of the tooth, it’s more serious.

Abscessed tooth: An infection inside the tooth’s pulp can spread quickly to the gums and be painful. Take the person to the dentist right away if you notice any signs of mouth pain or red bumps on the gums.

Dry mouth: Medication for Alzheimer’s disease, blood pressure, depression, and allergies can cause dry mouth. Untreated it can lead to ulcers, sores and cavities. It can also affect taste.

Bad breath: Poor dental hygiene, dry mouth, infection or medication could be the reason.

Balancing the demands of caring for a family member who has dementia with other personal responsibilities can be challenging. Those challenges are compounded when the caregiver is also a parent with young children.

“Everyone has their own unique challenges and you must understand and balance the needs and perspectives of both the person with dementia and the child,” says Ali M. Molaie, M.A., a caregiver coach at the University of Nevada, Reno’s Caregiver Support Center.

To help make the situation better for everyone involved, Molaie suggests caregivers approach their dual roles in the following ways:

Set a good example.

Parents are role models. Children often follow the example set by their mother and father. Modeling excellent communication is critical; children take cues (intentionally or unintentionally) from how their parent interacts with the person living with dementia.

Take a step back.

Always remember that everyone in the situation is doing the best they can, including the person living with the illness. The deficits and limitations caused by dementia are something they are frustrated by as well. Keep all of that top of mind as you handle your caregiving responsibilities.

“Model understanding and communication, ask about and validate emotional experiences, and enjoy every moment you can,” adds Molaie.

Adapted from a Care Connection Webinar. View upcoming webinars and archives of prior ones at www.alzfdn.org.

Dr. Sue McCurry’s “P.O.L.I.T.E.” model:

Patience – Ask or say one thing at a time and speak slowly and clearly.

Organize and observe – Break tasks into simple steps. Use hand gestures and written signs/notes.

Laughter – Use a warm, friendly, respectful tone of voice. Give sincere praise.

Ignore what you can – “Pick your battles” and refrain from correcting unless a person is doing something unsafe or unhealthy.

Tone of voice – Use pleasant, matter-of-fact statements instead of commands.

Eye and body contact – Look directly at the other person when speaking or listening. Gentle touch can help orient someone to you.

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Consider the age and gender of both the child and the person with dementia when it comes to caregiving and the intimacy of the tasks at hand. While a child may have no problem helping out with preparing meals, more than likely they’ll feel very uncomfortable if they are asked to bathe the individual with dementia.

Molaie recommends referring to psychologist Dr. Sue McCurry’s “P.O.L.I.T.E.” model:

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Dr. Mehmet Oz, TV talk show host and heart surgeon, kicked off the first episode of his 11th season with a deeply personal story. His mother, Suna Oz, 81, had Alzheimer’s, and he had missed the signs. It was a “gut punch” to him. “The biggest lies we tell are the ones we tell ourselves,” he confessed.

Alzheimer’s TODAY invited Dr. Oz to get at the heart of the truth and invite his family to join him. He wanted to “come out” with his mother’s story, so that others won’t make the same mistakes as he did.

When Things Started to Change
Dr. Oz noticed changes in his mother last year when her stubborness started to accelerate. Despite his father’s serious illness, she would no longer listen to his son’s rational advice regarding medical treatment. His parents denied timely care even when Dr. Oz would plead with them. His father, Dr. Mustafa Oz, a Turkish-American cardiothoracic surgeon, was also in denial over his wife’s illness.

Then Mustafa passed away in February 2019. Suna’s immediate, known, comfortable environment was now permanently disrupted. Her condition further deteriorated. Dr. Oz saw that she was struggling to find her words, while his sisters noticed that she was dressing oddly and misapplying her make-up. Suna persistently requested that her son swing by for a visit, as though he lived across town instead of 11 hours away by plane.

“I would suddenly explain that I could not just ‘pop by’ but began to realize that she had forgotten our earlier conversations. Mom was completely unaware that her memory and intellectual capability were failing, in part because the process was episodic. On lucid days, she understood; she forgot that she even had the weaker days.”

Like many people facing dementia, Dr. Oz explained that his mother was realizing she periodically forgot; but could not process that she was, in fact, becoming like other past family members who also lived with a dementia.

“When I’d make the comparison and explain to her what is going on, her cognitive wheels got stuck,” said Dr. Oz. “I have tried several times, but have taken a lesson from Maria Shriver. She advised that I stop trying to prove that I am correct and let her live in the comfort of periodic ignorance.” Maria Shriver’s father, Sargent Shriver, was also diagnosed with Alzheimer’s in 2003 and died, at 95, in 2011.

Watch out for these 6 signs of a problem, says Dr. Oz, and seek out an evaluation.
- Challenges in planning
- Confusing time and place
- Problems with words
- Difficulty completing tasks
- Trouble understanding visuals
- Inability to retrace your steps

Family Life in This New Reality
Since his mother’s diagnosis, one of his sisters has moved back to Istanbul, Turkey, to help manage her care and hired a professional staff, including a nurse, to ensure daily continuity of care. Vegetarian meals and hour-long walks on the Bosphorus, seem to help her mentally, he says. Suna Oz’s life is an amazing one. She left her Turkish homeland to follow her live in the comfort of periodic ignorance.” Maria Shriver’s father, Sargent Shriver, was also diagnosed with Alzheimer’s in 2003 and died, at 95, in 2011.

Reduce Alzheimer’s risk with prevention
“Prevention strategies should start as early as possible to arrest the pathways to clinical Alzheimer’s,” says Dr. Oz. “The disease starts with the formation of amyloid plaque, which leads to neuron cell death and resulting tangles. This cascade culminates in inflammation that rages like a fire through healthy parts of our brains. Breaking the cycle at any point will slow progression of the disease. As a collateral benefit, your brain will perform like a younger person’s within 18 months if you follow these suggestions, even though you may have to wait years to prove the benefit of delaying Alzheimer’s.”

Know your waist size and keep it less than half your height. A big waist will shrink your brain. As long as you are focused on your diet to lose weight, eat lean protein with lots of veggies and pick healthy omega-3 fats like those in salmon and walnuts.

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Among the things Dr. Oz remembers most about his mother, as her own memories continue to fade: “She always provided me with unconditional love, which is what I mirror in caring for patients. She had a great imagination for telling fairy tales to us as children, and I have done the same for my kids. And she is the most diplomatic woman that I have ever met. We would joke that she could run the world from our living room overlooking her beloved Bosphorus.”

Dr. Oz Reveals His Mother’s Alzheimer’s Diagnosis

Finding Our Truth

Dr. Oz Reveals His Mother’s Alzheimer’s Diagnosis

Dr. Mehmet Oz with his parents, Suna Oz (left) and Dr. Mustafa Oz (middle).

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The five senses of the body’s nervous system (sight, smell, taste, sound and touch) are how we receive and process information about our surrounding environment. Dementia-related illnesses change these senses over time, and these changes can impact quality of life. Here are ways the five senses are affected by dementia and how to help someone deal with those changes.

**SIGHT**
Images travel from the eyes to the brain where they are then interpreted alongside information provided by thoughts and memories. Dementia can impact the brain’s ability to interpret images, potentially resulting in confusion, disorientation and the inability to recognize familiar people, places and things. It is important to understand that this change is caused by dementia itself and not poor eyesight.

**TIPS**
- Regularly check smoke and carbon monoxide detector batteries.
- Ensure rooms are well ventilated.
- Consider pleasant scents that may offer an opportunity to reminisce with the person.

**SMELL**
Sense of smell is often impacted in the early stages of a dementia-related illness. For some, smells can be intense and overpowering, while others may have a significantly diminished or total loss of smell. These changes can impact a person’s safety in the event that they are not able to smell smoke, for example. This change can often go unnoticed, making it difficult to plan accordingly for care.

**TIPS**
- Regularly check smoke and carbon monoxide detector batteries.
- Ensure rooms are well ventilated.
- Consider pleasant scents that may offer an opportunity to reminisce with the person.

**TASTE**
Due to changes in taste bud sensitivity, someone living with a dementia-related illness may not be able to experience flavors as they once did. These changes can impact eating habits, food preferences and nutritional health. For instance, an individual may experience weight loss or gain as a result of not being able to taste or recognize when they are no longer hungry.

**TIPS**
- Cook with a variety of herbs and spices.
- Review medications that may have side effects which impact taste.
- Offer food with texture, as chewing can produce even more flavor.
- Be mindful of changes in eating habits and seek assistance as needed, such as working with a nutritionist to identify food options.

**SOUND**
Dementia-related illnesses can cause difficulties with processing sounds, and/or lead to hypersensitivity to noise. Diminished hearing can lead to increased disorientation, anxiety, fear, and overstimulation. These changes are not related to whether or not a person has hearing loss, but rather the impacts of dementia-related illness itself.

**TIPS**
- Be aware of tone, pitch, and volume when addressing someone with dementia.
- Minimize background noise.
- Offer sounds or music that may speak to the person’s preferences (i.e., classical music, ocean sounds).

**TONE**
Dementia can impact fine motor skills, interfering with a person’s ability to button/unbutton clothes or use eating utensils. Someone with a dementia-related illness may also be unable to recognize being hot or cold. They may experience a decreased ability to identify and verbalize pain and/or experience increased sensitivity to pain.

**TIPS**
- Offer things for a person to hold or touch that may be engaging for them based on their preference. For example, a person may enjoy using molding clay or dough.
- Be aware of temperature.
- Consider offering therapeutic touch to soothe the person.
When it comes to your finances, it’s always important to plan. But did you know there are ways to be charitable with your money that can also be beneficial to you financially?

Combining a charitable contribution with overall financial, tax, and estate planning goals (known as “planned giving”) can optimize the financial benefits to you and your family, as well as leave a meaningful and lasting impact on the lives of others. One such method is by donating long-term appreciated securities (i.e., stocks, bonds, mutual funds, exchange-traded funds).

How can giving the gift of securities benefit me financially?

If you’ve been holding a stock or other security for at least one year that has appreciated in value, you will have to pay tax on the appreciation (known as capital gains tax) when you sell it. Donating the stock/appreciated security to charity can be financially beneficial in two ways.

First, it eliminates the capital gains tax because you are giving the security to charity rather than selling it on the open market. Second, it allows you a charitable income tax deduction for the fair market value of the gifted securities as of the date of the gift. For example, if the fair market value of your shares is $10,000, you can claim a $10,000 charitable contribution deduction on your income tax return the year of your donation.

Giving the Gift of Securities to AFA

AFA accepts gifts of stock/securities to support its programs, services and research initiatives. Here’s how to make a gift:

Step 1: Send us an email at info@alzfdn.org to let us know of your intended gift with the name of the donated stock, the number of shares, and the expected transfer date.

Step 2: Provide your broker with the following security transfer information:

- Account Name: Alzheimer’s Foundation of America
- Account Number: 782159560
- Broker Phone: 800-669-3900

*If you manage your own securities, include AFA’s transfer information in your initial correspondence (see Step 1).*

Step 3: We will sell your securities and apply the proceeds to advance AFA’s mission.

Step 4: We will promptly send you a tax acknowledgement letter.

If you’re interested in making a planned gift to AFA and want to discuss giving options, please contact AFA, 866-232-8484, to learn more.

Please note: This content is for educational and informational purposes only and is not given as legal or tax advice, or intended to replace it. If making estate or financial arrangements, please consult a professional tax advisor, lawyer, and/or financial planner to make sure it is in your best interests.

Dining out, shopping or going to the bank are excursions most people take for granted, but these “routine” trips can be challenging for a caregiver bringing along someone with dementia. Alzheimer’s Family Services of Greater Beaufort (AFSGB) in South Carolina is launching a new program to change that.

The Purple Haven Project will train and educate staff at Beaufort County restaurants and businesses on how to interact with a person with dementia. By alleviating some of the stress involved when caregivers bring a person with dementia to these establishments, AFSGB aims to make it easier for them to get out into the community.

“Our goal is to provide safe and stress-free establishments for our caregivers to be able to frequent with their family members or care partners,” explained AFSGB’s Executive Director, Arlene Hull. “They face enough hardships and interruptions in their normal daily routines.”

Staff at participating establishments will learn tips on how to interact with a person who has dementia, ways to make them feel comfortable and actions to avoid that can be negatively impactful.

“For example, in a restaurant, it’s important not to serve food on a hot plate or fill water glasses to the rim,” Hull explained. “In a bank or department store, employees should be aware not to rush people or talk to them without making eye contact.”

Businesses that complete the training will receive a window decal indicating they are a Purple Haven establishment. AFSGB will provide their caregivers with cards to hand to restaurant hostesses, bank tellers and retail store clerks alerting them that a person they are with is living with dementia. A list of Purple Haven establishments will be made available to caregivers and on AFSGB’s website. AFA awarded grant funding to AFSGB for the Purple Haven project.

“Patience, understanding or assistance from an employee can make a big difference in the outcome of an outing. These simple actions are powerful opportunities to create more good memories,” Hull added.
RECIPE FOR YOUR HEALTH

2-MINUTE CHOCOLATE BANANA PUDDING

What to do with bananas that have ripened too quickly? Make this delicious and healthy pudding with four simple ingredients! All you need is a small bowl, a spoon and a strong stirring motion to make it under two minutes! P.S. Top with sliced candied ginger if you happen to have it on hand.

This no-cook, guilt-free sweet treat is incredibly healthy. It’s full of antioxidants from the cocoa—that’s if you use natural cocoa powder that has not been alkalized. Evidence from scientific literature indicates that natural cocoas are high in flavanols, but when the cocoa is processed with alkali, also known as Dutch processing or Dutching, the flavanols are substantially reduced. Bananas are brimming with potassium, which is needed for the muscles of your body to work. All of the ingredients contribute to the high fiber content, essential for gut health and beneficial for cholesterol and blood sugar control.

The nut butters are a sustainable source of healthy fats and plant-based protein!

INGREDIENTS

(Choose organic ingredients when available.)

- 1 very ripe banana
- 1 teaspoon tahini
- 2 teaspoons natural peanut butter
- 1 heaping teaspoon of cocoa powder

DIRECTIONS

Place all ingredients in a small bowl. Cover and microwave for 30 seconds. Remove from microwave and stir rapidly to combine into a pudding texture. Let it rest for a few minutes and devour!

Nutrition facts (serving size 1): 205 calories, total fat (16 g), saturated fat (5 g), trans fat (0 g), sodium (29 mg), total carbohydrate (31 g), protein (5.8 g), sugar (15.2 g), dietary fiber (4.8 g), potassium (488 mg), calcium (29 mg), iron (2 mg).

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.

ASK AN AFA SOCIAL WORKER

“My father was diagnosed with dementia two years ago; however, he still continues to drive and is adamantly about his ability to continue to do so. My family is fearful that he will harm himself or others. How do we decide as a family when it’s time to take the car keys?”

Valerie Damon, LMSW

The transition process

This change impacts your father as well as the family and care team. The key here is to ensure that there is communication within the care team and planning for positive options and alternatives. Some ideas may include having dad join when running errands, making decisions, if possible, on where to stop first, or which direction to take. This may help him feel like he is still a part of the driving process and needed. Families could also arrange for car services to take him where he needs to go, whether to appointments, religious services or activities within the community. Scheduling delivery services for food or medication could be beneficial as well.

The Conversation

If families are noticing these signs, it may be time to have a conversation and start the transitioning process. It’s crucial to include your father in this conversation instead of just taking his keys away or removing the car. Validate how good a driver your father has been for years and how much the family has appreciated him. However, let him know your concern for his safety.

Allow him to discuss how he’s feeling about this transition. It’s important to be aware and validate his feeling of loss. The idea with all of this is to be respectful, recognize this change and loss of independence, while still maintaining his dignity.

When having the initial conversation, it might be helpful to involve a person in an authoritative position such as a doctor. Your father’s doctor should be apprised of your concern and could speak to him about his driving abilities. Keep in mind, depending on where you live, your doctor may also be required to report a diagnosis of a dementia to the Department of Motor Vehicles. The reporting requirements may vary in different states.

Last-Resort Strategies

If your father remains adamantly about not giving up driving, you may need to remove all car keys or provide a false key that won’t start the car. Another option would be to disable the vehicle and tell your father that it has to go for repair. Selling the vehicle might even be an option.

Safety for your father and others should be your main concern.
What to Know if Hospitalization Happens

Hospital visits and stays are common among people living with dementia. Each year, on average, 49% visit the ER and 26% are hospitalized, according to Dr. Angela M. Allen, RN, of Banner Alzheimer’s Institute and Arizona State University. Bringing a loved one to the hospital can be stressful, but being prepared can help make things a little easier.

When you arrive
Dr. Allen recommends immediately explaining to staff that your loved one has dementia (which specific type/stage), the symptoms leading up to the visit, and identifying yourself as the primary caregiver to help avoid problems or confusion. Ask a family member or friend to meet you at the hospital, Dr. Allen advises. “Having someone there to help you will positively impact the person; whether they wear glasses, primary language; a list of key words that can negatively or positively impact the person; whether they use dentures or hearing aids; and other general behavioral concerns (e.g., if the person was a mechanic, they may try to tamper with machines). Give this sheet to the doctors and/or hospital staff so they are aware.

Hospital “care pack”
Dr. Allen recommends preparing a hospital care pack which includes:
- Health insurance cards
- A list of the person’s current medications and allergies
- Primary healthcare provider’s name and phone number
- Copies of healthcare advance directives
- A personal information sheet which includes preferred name; primary language; a list of key words that can negatively or positively impact the person; whether they wear glasses, dentures or hearing aids; and other general behavioral concerns (e.g., if the person was a mechanic, they may try to tamper with machines). Give this sheet to the doctors and/or hospital staff so they are aware.
- Comfort objects, such as a favorite blanket or special pajamas
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- Health insurance cards
- A personal information sheet which includes preferred name;
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Adapted from an AFA Care Connection Webinar.
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Qué Saber si Ocurre la Hospitalización

Las visitas al hospital y las estadías son comunes entre las personas que viven con demencia. Cada año, en promedio, el 49% visitan la sala de emergencias y el 26% son hospitalizados, según la Dra. Angela M. Allen, RN, del Instituto Banner Alzheimer y la Universidad Estatal de Arizona. Traer a un ser querido al hospital puede ser estresante, pero estar preparado puede ayudar a facilitar las cosas.

Cuando llegues
La Dra. Allen recomienda explicar inmediatamente al personal que su ser querido tiene demencia (qué tipo/etapa específica), los síntomas previos a la visita, e identificarse como el cuidador principal para ayudar a evitar problemas o confusión.

Pídale a un familiar o amigo que se encuentre con usted en el hospital, le aconseja la Dra. Allen. “Tener a alguien allí para ayudarlo lo hará sentir más cómodo y menos estresado.” Para evitar una afluencia abrumadora de preguntas de familiares y amigos preocupados, pídale a alguien de confianza que transmita información y proporcione actualizaciones periódicas a otros en su nombre.

Debido a que los hospitales a menudo están muy poblados, solicite un personal de hospital limitado para evitar que la persona se sienta abrumada, si es posible. Mantenga a la persona informada sobre lo que está sucediendo y pregúntele a los médicos sobre procedimientos ambulatorios para evitar estadías innecesarias.

A lo largo de la hospitalización
Aunque ya haya notificado al personal del hospital sobre el diagnóstico de demencia de su individuo a su llegada, no asuma que todos lo saben. “Por ejemplo, si un flebotomista viene a extraer la sangre de papá, explique que tiene demencia. Puede cambiar su enfoque,” dice la Dra. Allen.

Sea paciente, tranquilo, y positivo. “Permita que la persona haga todo lo posible,” dice la Dra. Allen. “Instale el cepillo de dientes de mamá y pídale que se cepille los dientes, pero luego brinde ayuda si no tiene toda la boca. Luego aplaude y hágale saber que hizo lo mejor que pudo.”

“Paquete de atención” hospitalaria
La Dra. Allen recomienda preparar un paquete de atención hospitalaria que incluya:
- Tarjetas de seguro médico
- Una lista de los medicamentos y alergias actuales de la persona
- Nombre y número de teléfono del proveedor de atención médica primaria
- Copias de instrucciones anticipadas de atención médica
- Una hoja de información personal que incluye el nombre preferido; lenguaje principal; una lista de palabras clave que pueden impactar negativamente o positivamente a la persona; si usan anteojos, dentaduras postizas o audífonos; y otras inquietudes generales de comportamiento (p.e.g., si la persona era mecánica, podrían intentar manipular las máquinas). Entregue esta hoja a los médicos y/o al personal del hospital para que estén al tanto.
- Objetos cómodos, como una manta favorita o un pijama especial

Actividades Terapéuticas para las 3 Etapas Principales de la Enfermedad de Alzheimer

L a enfermedad de Alzheimer generalmente progresa gradualmente en tres etapas diferentes: la etapa leve y temprana, la etapa media y más moderada, y la etapa avanzada. Es esencial saber qué esperar de la enfermedad, también es muy importante comprender que las personas se ven afectadas de manera diferente, y que a medida que la enfermedad progresa, las terapias específicas pueden no ser suficientes para la persona.

A continuación se presentan estrategias terapéuticas beneficiosas para los cuidadores que se pueden usar en todas las etapas de la enfermedad de Alzheimer:

ETAPA TEMPRANA (LEVE)
En la etapa inicial, los síntomas incluyen un aumento en el olvido y la confusión. Los ejemplos son olvidar cosas como detalles a lo largo de horarios, temporadas, fechas y lugares, tener problemas para cocinar y pedir comida de un menú, y la incertidumbre sobre qué ropa usar. Los síntomas incluyen la necesidad de tener un propósito o cuidar algo; trastornos del sueño; así como problemas de higiene e incontinencia. En esta etapa, la mayoría de las personas necesitarán ayuda para comenzar o continuar las actividades.

ETAPA MEDIA (MODERADA)
En la etapa media, las personas experimentan un aumento en la pérdida de memoria y la confusión. Los ejemplos son olvidar cosas como detalles a lo largo de horarios, temporadas, fechas y lugares, tener problemas para cocinar y pedir comida de un menú, y la incertidumbre sobre qué ropa usar. Los síntomas incluyen la necesidad de tener un propósito o cuidar algo; trastornos del sueño; así como problemas de higiene e incontinencia. En esta etapa, la mayoría de las personas necesitarán ayuda para comenzar o continuar las actividades.

ETAPA AVANZADA (SEVERA)
Hay casi una pérdida total de memoria en la etapa avanzada. Una persona puede reconocer caras pero olvidar nombres o confundir a una persona con otra persona. Pueden surgir ilusiones, como pensar que necesitan ir a trabajar, aunque ya no son empleados. También puede haber una gran necesidad de mantener algo cerca para la estimulación táctil, el cuidado, el compañeroismo y la comodidad. Las habilidades como comer, caminar y sentarse se desvanecerán; y la persona ya no identificará la sed o el hambre y necesitará apoyo con todas las actividades básicas de la vida diaria.

Therapeutic Activities for the 3 Main Stages of Alzheimer’s Disease

Alzheimer’s disease usually progresses gradually in three different stages: the mild and early stage, the moderate stage, and the later and severe stage. While it is essential to know what to expect from the disease, it is also important to understand that individuals are impacted differently by it and as the disease progresses, specific therapies may no longer be sufficient for the individual.

Below are beneficial therapeutic strategies for caregivers that can be used throughout the stages of Alzheimer’s:

EARLY STAGE (MILD)
In the early stage, symptoms normally include forgetfulness, misplaced objects, and confusion. Examples are forgetting things like details about times, seasons, dates and locations, having trouble cooking and ordering items from a menu, and uncertainty about what clothes to wear. Other symptoms include needing to have a purpose or care for something; sleep disorders; as well as hygiene issues and incontinence. At this stage, most individuals will need assistance in starting or continuing activities.

MIDDLE STAGE (MODERATE)
In the middle stage, individuals experience an increase in memory loss and confusion. Examples are forgetting things like details about times, seasons, dates and locations, having trouble cooking and ordering items from a menu, and uncertainty about what clothes to wear. Other symptoms include needing to have a purpose or care for something; sleep disorders; as well as hygiene issues and incontinence. At this stage, most individuals will need assistance in starting or continuing activities.

LATE STAGE (SEVERE)
There is almost a total loss of memory in the late stage. A person may recognize faces but forget names, or mistake a person for someone else. Illusions may arise, such as thinking that they need to go to work even though they are no longer employed. There may also be a strong need to hold something close for tactile stimulation, nurturing, companionship, and comfort. Skills such as eating, walking, and sitting will fade; and the person will no longer identify thirst or hunger and need support with all basic activities of daily living.

Therapeutic Activities for the Early Stage
- Trivia games, word puzzles and memory games
- Passing a balloon in the air with a group
- Reminiscing with family picture albums
- Listening to favorite music
- Storytelling
- Flower arranging
- Conversations with friends

Therapeutic Activities for the Middle Stage
- Aromatherapy and/or light therapy
to help with sleep
- Small tasks like folding towels, or putting socks together
- Family pictures, stories and conversations
- Stuffed animal therapy (adult-appropriate, like dogs and cats) to help with tactile stimulation, comfort, and play
- Baby doll therapy since nurturing can become beneficial

Therapeutic Activities for the Late Stage
- Listening to familiar songs from the person’s past
- Aromatherapy
- Stuffed animals continued for comfort and companionship
- Doll therapy will help with the need to nurture empathy, human touch and love
When Rick and his two sisters, Rebeca and Carla, realized that their dad could no longer manage on his own, they agreed to go to Mexico on a rotating basis for a week to 10 days at a time. Rick said that it was key to his dad’s ongoing care how Rebeca took on the responsibility of scheduling all the siblings’ caregiving visits. “The first lesson for us was to become educated and to understand what our role in the illness was,” he reflected. For Rick, his initial role would be often helping his dad understand and navigate a world he understood less and less. Going out to a restaurant would set him off when the bill arrived because he thought the prices were too high. To help his dad through this, Rick would meet with the manager beforehand and pay half the bill. When the meal was over and the bill arrived, which was now half the actual amount, his father was more amenable to the cost. “You can only do what you can do; and sometimes when there are no good options, you have to get creative and make the best choices with what you have,” said Rick.

There was a softer, more vulnerable side to his dad that he also got a chance to experience for the first time in his life. Waking up in the middle of night, his dad was scared and Rick was able to comfort him. A silver lining was the support that he found from a renewed relationship with both his younger sisters. “When you lean on one another, you don’t feel so isolated and burdened,” said Rick. “Together, you can find ways to get help and, at the same time, to take care of yourself in order to be able to provide the best possible care for a loved one.”

After a brave battle with Alzheimer’s, Moises Itzkowich passed away in January 2018 at 85. “This final chapter really allowed me to come full circle with my dad. Throughout my whole life I wanted to be independent, get his respect, and be my own person—I never wanted to work with or for him. But when he passed away, I ended up running his business and respecting and appreciating him more than I ever imagined possible.” Rick thought he would sell the business after six months, but now it’s already two years later, and he’s realized that he is having the time of his life. “It’s brought me much closer to my dad; his vision for what he wanted for me is now being realized. I feel that everything I’ve done during my adult life has prepared me to be able to do this.”

Also, for Rick, who lives in La Jolla, California, being able to help other people going through similar challenges is also an important mission. He’s doing that by going back on another “never,” the decision to write a book after years of many people urging him to while he insisted that he wasn’t interested. The final product, The Referral Playbook: How to Increase Sales with Proven Networking Strategies, published October 2018, reveals how to bridge the gap between the worlds of face-to-face networking and online marketing. It’s dedicated to his father, Moises Itzkowich, with all of the proceeds going to the Alzheimer’s Foundation of America.
A s Alzheimer’s disease and dementia-related illnesses progress not only does an individual’s memory change but their ability to communicate as they once did may also be impacted. If a person loses their ability to speak and explain how they feel, they may show frustration and anger. What we need to do as caregivers is understand the unmet need. Here are examples of situations that may spur a change in the “behavior” of someone you care for (please note, if a person ever poses an immediate threat to themselves or others, call for emergency assistance right away):

Basic needs
- Is the individual hungry or thirsty?
- Do they need to use the bathroom?
- Is the room too hot or too cold?
- Are they bored?

Pain
- Is the individual grimacing?
- Are they favoring/clutching a specific part of their body?
- Are they sensitive when touched on a particular body part?

Environmental stimuli
- Are there noises that may be alarming to the individual?
- Are lights bright or flashing?
- Is the room too cluttered?
- If children are around, is their play unsettling?

Improve communication with this 3-step approach
This three-step approach can help improve communication, which can potentially enhance both the individual and caregiver’s quality of life. First, validate the person’s feelings. Show them that you understand and respect where they are coming from. This, in effect, will help to reduce any anxiety and resistance. Second, reassure the individual that you’re here to help them. People with dementia may experience multiple losses which may lead to feelings of fear and anxiety around the simplest of tasks. But by understanding these underlying feelings, you will be better equipped to meet the unmet need. Finally, once you’ve validated these feelings and reassured the person that you’re present for them, try turning their focus to something positive like having a snack, playing their favorite music or going for a walk.

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Finding Your Caregiver Happy Place

“Being there for someone in the darkest and hardest part of this disease is something that I feel is my strength because of the skills I have gained through my career in social work, as well as my personal experience with family members I have lost to this disease,” Leonard said. “Regardless of the situation, I am guided by the knowledge that there are times when we all need to be reassured that we are not alone; and we all need to have our feelings and experiences validated.”

Leonard has spent much of her 21-year career helping seniors to remain independent. Some of her top tips for good caregiving follow:

- You become the person who helps them to navigate through their world. This can be very draining, but it can also be very rewarding when you have found a way to help them to succeed and find joy in completing a task.

- Give simple assurances like, “You are safe,” “You are doing exactly what you are supposed to be doing,” and “I am happy you are spending time with me today.” Oftentimes that is enough to validate, calm fears, and allow someone to feel loved. The people we care for are no different than us: We thrive when we know we are safe and loved.

- When the person you are caring for is exhibiting challenging behaviors, they may have lost their ability to express their basic needs, such as toileting, hunger, being over or under stimulated, and confused. Once you successfully help them meet those needs, they are more likely to cooperate in their care.

- Embrace the reality of what your individual or loved one is experiencing in any given moment. Avoid power struggles.

- Find the humor even in the challenging times.

- Take care of yourself. Do not say no to offers of help. Seek out respite and support group opportunities that give you a break and the person in your care a pleasant experience with a stimulating and supportive community. Exercise and stay connected to friends and family. It’s important to prioritize your own medical appointments, too.

- Trust your instincts. This is the most powerful tool you have.

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Caregiving that Goes the Extra Mile

Emily (Emmy) German was only 20-years-old when her mother, Linda Larsen German, a former fashion industry executive, was diagnosed with young-onset Alzheimer’s at 65. Five years later, Emmy German, 25, has turned into a passionate advocate of Alzheimer’s awareness and brain health. But it wasn’t always like that for Emmy. “I wanted the first year feeling sorry for myself instead of understanding that my mother was the best she would ever be,” she said. Now, she wants to remind others to “be grateful for every day and for every moment.”

Like many family members, Emmy German is a long-distance caregiver for her mom, who lives in New York while Emmy lives in New Orleans. Long-distance caregiving has its unique set of challenges, but it’s also full of its own rewards. Emmy is lucky to be able to return “home” almost monthly to spend time with her mother and calls her regularly to connect with her loved one, “I know that my Mom has and will always love me no matter what parts of her are still able to outwardly express it. You have the opportunity to give yourself in a way to your loved one that you never thought possible. As long as the actions you take come from a place of love, they feel it. My Mom thanks me all the time these days; it is an unexpected joy for this stage of the disease.”

Emmy is the primary caregiver in booking doctor appointments and helping coordinate aides’ schedules. “I find that helping my Dad truly does help my Mom. Creating calm and clarity in the primary caretaker’s life helps them show up for your loved one,” says Emmy.

When you take care of yourself, “in every way that you want to give to your loved one, you must give to yourself as well,” says Emmy. “Caregiving is emotionally and physically draining.”

• Approach every visit with gratefulness for the things that your loved one still can do. “When you live in another state, you miss out on the every day decline. A month or two may go by and the changes in your loved one may suddenly seem kind of shocking. Don’t focus on that. Appreciate every moment.”

• Take care of yourself. “In every way that you want to give to your loved one, you must give to yourself as well,” says Emmy. “Caregiving is emotionally and physically draining.”

• Remove the guilt. “Trust me, no matter how far or close you are, you will always feel guilt. Take your experience and your story out of the picture and solely focus on your loved one. The emotions that you bring into what is ‘right’ or ‘wrong’ in your caregiving only take away from the time with your loved one,” says Emmy.

Everything happens for a reason, believes Emmy. “You will learn a lot about yourself and a lot about those around you during this process. You will learn who is there to stick it out through some bumpy times and what is truly important in life. Take a moment to reflect on what has prepared you for this in your own life.”

my Mom stopped driving to begin the process of encouraging more people to visit her,” said Emmy. Family conference calls or maintaining a family Facebook page or group text to provide updates is helpful, too. “Facebook is a great tool to engage with some of my Mom’s friends who I do not know as well. I try to be as honest and open as possible. The more I have shared, the larger community of supporters I have found around me.”

• Help manage the day-to-day care. Emmy supports her dad, David, who is Linda’s primary caregiver in booking doctor appointments and helping coordinate aides’ schedules. “I find that helping my Dad truly does help my Mom. Creating calm and clarity in the primary caretaker’s life helps them show up for your loved one,” says Emmy.

• Phone your loved one. “People ask me all the time if my Mom ‘remembers’ me,” says Emmy. “I know that my Mom has and will always love me no matter what parts of her are still able to outwardly express it. You have the opportunity to give yourself in a way to your loved one that you never thought possible. As long as the actions you take come from a place of love, they feel it. My Mom thanks me all the time these days; it is an unexpected joy for this stage of the disease.”

• • •

What to watch for

Keep in mind that an individual may have difficulty expressing themselves with words as the disease progresses. Issues to watch out for include:

- confusion
- social disengagement
- boredom or pain
- hunger or thirst
- in need of a restroom
- anxiety
- emotional distress
- searching for something from the present or past

What can you do

- Pay attention to the individual’s patterns—frequency, duration, time of day, etc., and prepare activities that can be used to redirect their attention, as needed.
- Ensure current photographs of the individual and their medical information are available.
- Provide opportunities for socialization and engagement for the individual. Keeping busy can help to stimulate and engage. Consider recreational or other therapeutic activities, such as art or music.
- Familiarize yourself with your state’s public alert (Silver Alert) service, a notification system that broadcasts information about missing persons, especially seniors with Alzheimer’s, dementia or other cognitive disorders—in order to solicit aid in locating them. Understand how to contact your police department and how to call 911 in an emergency situation.
- Keep a list of local hospitals in case the individual is admitted to one.
- Know the individual’s phone carrier and number to track them by phone.

Families affected by Alzheimer’s disease who have questions or need support can contact AFA’s National Toll-Free-Helpline at 866-232-8484 and speak with a licensed social worker or connect through the Internet at www.alzfdn.org. The helpline is open seven days a week: 9 am to 9 pm (ET) on weekdays and 9 am to 3 pm (ET) on weekends.

What to Do About Wandering

No doubt you have seen or heard news reports like this: “The sheriff’s office is asking for the public’s help in finding a missing 82-year-old man [or woman] who has Alzheimer’s.” Wandering is one of the most common behaviors among people living with Alzheimer’s, occurring in some 60% of individuals. So it’s important for caregivers to be aware of this unique behavior and try to understand why it’s happening. Wandering often stems from an unmet need or desire for purpose and sometimes is a form of communication. Individuals may leave their homes because they believe they need to go to work, even if they are retired. Others are looking for something or someone.

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- Ensure the person’s basic needs (food, beverages, utilizing the restroom, etc.) are met. Utilize medical identification bracelets, necklaces, and tracking devices for monitoring.
- Install electronic chimes or doorbells on doors so someone is alerted if the individual tries to exit; but be mindful of how this alert can impact the individual.
- Reduce environmental stimuli, such as loud noises or crowds, which can be disorienting.

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$8.2M Awarded in grants for Alzheimer’s and dementia education, care and research.

5M Memory screenings conducted.

2M Individuals, caregivers, and families served through more than 2,800 member organizations.

Help us to continue to make a difference. Donate today at www.alzfdn.org/donate National Toll-Free Helpline 866-232-8484