Creating a Dementia-Friendly Home
A MESSAGE FROM
CHARLES J. FUSCHILLO, JR.
AFA PRESIDENT & CEO

As I write this, many of the challenges caused by the COVID-19 pandemic are thankfully easing. Gaining greater knowledge and understanding of the virus empowered medical and health professionals to develop solutions and create hope. This issue of Alzheimer’s TODAY aims to do something similar—empower you with information and solutions that can help you today and provide hope for the future.

Some highlights from our new issue of Alzheimer’s TODAY:

• We value your feedback. Please take five minutes to let us know how AFA’s Alzheimer’s TODAY is serving you. Fill out the Reader Survey that follows and drop it in the mail using the enclosed pre-paid envelope. We would be grateful.

• Almost every part of a home can impact the quality of life for a person living with dementia. To help families create dementia-friendly spaces for their loved ones, AFA built The Apartment, a full-scale model residence that teaches about features and technology that can make a difference. Read all about it in “A Guide to Creating a Dementia-Friendly Home,” pp. 12-13.

• The public announcement of legendary singer Tony Bennett’s Alzheimer’s diagnosis earlier in the year brought important reminders about brain health and the value of music. Check out “A Symbol of Hope,” p. 5, to learn more.

• AFA spent some time with Sanjay Gupta, MD, CNN Chief Medical Correspondent and practicing neurosurgeon, to discuss what he’s learned from researching and writing his new book Keep Sharp: Build a Better Brain at Any Age, pp. 6-8. You may be surprised by how much you can contribute to your own brain health.

• “Sometimes he needs the smiles; but most days I do,” says family caregiver Nicole Nightingale, who spends many of her mornings creating fun breakfast-food smiles for her 87-year-old dad, Cyril. You’ll be delightfully inspired by “Care Partner Creativity: Brekkie Smiles,” p. 11.

• Alzheimer’s disease research funding is more than an investment in science. It’s an investment in hope. AFA has awarded over $400,000 in new research initiatives over the last year alone. Check out AFA’s research update, “Investing in Hope,” pp. 24-25.

We hope you find this new issue of Alzheimer’s TODAY chock full of information you can use. Please, pass on articles to friends and family who may be able to benefit. Remember, if you need support, resources, or even just a sympathetic ear to listen, connect with our licensed social workers, seven days a week, through the AFA Helpline at 866-232-8484 or through our website chat at www.alzfdn.org. We are here for you. Whenever. Wherever.

Sending the best to you and your families,

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

Alzheimer’s TODAY Reader Survey
We value the feedback from our readers. Please take a minute to let us know your thoughts about Alzheimer’s TODAY so that we can better serve you!

1 In general, how would you rate Alzheimer’s TODAY?
   ○ Very helpful
   ○ Somewhat helpful
   ○ Not that helpful

2 How would you rate the amount of content in each issue?
   ○ Good amount of content
   ○ Would like more content
   ○ Too much content

3 What story topics do you find most beneficial?
   Check all that apply.
   ○ Caregiving tips
   ○ Available support programs and services
   ○ Legal/financial/healthcare planning
   ○ Recipes
   ○ Personal and human-interest stories
   ○ Medical/research/scientific updates
   ○ Governmental/legislative updates
   ○ Other

4 Is there a story topic that you would like to see more of in the magazine that we are not currently addressing?

5 Are any of these topics not beneficial to you?
   Check all that apply.
   ○ Caregiving tips
   ○ Available support programs and services
   ○ Legal/financial/healthcare planning
   ○ Governmental/legislative updates
   ○ Personal and human-interest stories
   ○ Medical/research/scientific updates
   ○ Other
6. Is including Spanish translations of articles in Alzheimer’s TODAY helpful to you?

- Yes, it is.
- No, it has no impact on me.

7. What led you to subscribe to Alzheimer’s TODAY?

- My family member/friend has Alzheimer’s disease/other dementia-related illness
- I have Alzheimer’s disease/other dementia-related illness
- I’m a professional who works with families affected by dementia-related illnesses
- I work at an educational institution/library
- Other ___________

8. Do you still wish to receive Alzheimer’s TODAY?

- Yes, continue sending me Alzheimer’s TODAY.
- No, I no longer need a subscription.

9. If yes, how would you prefer to receive Alzheimer’s TODAY?

- Paper copy in the mail
- Paperless copy through email
- Both

Any additional comments? ____________________________________________________________________________________________
Common Misconceptions About Dementia

“I heard someone whisper the other day, ‘My father has Alzheimer’s.’ I just gave him a big hug and said, ‘You don’t have to whisper—shout it out loud,’” said Gary. I am not ashamed of having Alzheimer’s. All my neighbors are aware I have a problem and there’s no ridicule, no stigma, and so I wish we would get it out of our minds that we’ve done something; that we need to go under the table and hide.”

This personal story shared in the new edition of the Mayo Clinic on Alzheimer’s Disease and Other Dementias, written by Jonathan Graff-Radford, MD, with Angela Lunde, MA, demonstrates that despite the fact that Alzheimer’s and dementia are more common than ever before, we still have many common misconceptions about them. Here are five of the most common myths and stereotypes followed by the truth, according to the Mayo Clinic:

MYTH #1
Memory loss means dementia

People naturally forget from time to time, but dementia is much more than occasional lapses. It’s memory issues that are affecting daily functioning. Also, memory loss isn’t the first dementia symptom. Unexplained changes in mood, behavior or ability should warrant a visit to the doctor. People with dementia become agitated, violent and aggressive—not all people with dementia do. Dementia affects everyone differently. Changes in the brain can create confusion and fear, and often expressions such as agitation are really the result of an unmet need.

MYTH #3
People with dementia become agitated, violent and aggressive

Not all people with dementia can affect people at an earlier age. Young-onset Alzheimer’s disease, for example, can affect people in their 50s—and even earlier in some cases—as well as frontotemporal dementia.

MYTH #4
People with dementia can’t enjoy new activities, learn new things or have a good quality of life

People with dementia can and do continue to have meaningful, active lives. It’s important that they try to continue to enjoy their usual activities for as long as they can, making some adaptations, and relying on help from others. Many people in the earlier stages of dementia—and even into the middle stages—can learn new routines and habits. Most importantly, during all stages of dementia, people are capable of giving and receiving love, able to share moments of joy and laughter.

MYTH #5
Nothing can be done for dementia

It’s important to overcome the idea that “nothing can be done for dementia.” The sooner a dementia diagnosis is made, the more opportunity there is for treatments and therapies that may actually slow the progression. Conversations with family and friends should focus on what the person living with dementia is still able to do and what brings them joy, rather than declines and losses. This will help ensure they are able to enjoy the best quality of life possible.

COUNTLESS STUDIES HAVE NOW REPORTED THE BENEFITS OF MUSIC FOR PEOPLE LIVING WITH A DEMENTIA, EVERYTHING FROM SPARKING MEMORIES TO IMPROVING MOOD.

Jackie Gatto, MS, R-DMT, LCAT-LP, CDP, AFAs Manager of Therapeutic Programming, recommends incorporating music and songs with day-to-day tasks:

During transitions: Play favorite music or songs by beloved singers as you travel from home to an appointment.

Mealtime: Incorporate music with meals to help with focus and rhythm to help with chewing.

Walking/balance: Rhythm in familiar music, with a steady beat, can help individuals stay motivated and focused.

Self-care: Play soft or favorite music of choice when feeling stressed or anxious.

Make simple instruments using a small container with popcorn kernels or a bag of dried beans; use a plastic or tin food container as a drum—then play along with favorite songs.

Use hands for clapping and tapping the legs and chest; stomp the feet.

Drum on a table with plastic or wooden utensils.

Hum along or use kazoo.

If you say it, you can “play it.” Use names of people or objects. Simply find the rhythm and play it, clap it, tap or stomp it.

A Symbol of Hope

When Tony Bennett’s family members decided to break their silence surrounding the legendary singer’s Alzheimer’s diagnosis earlier in the year with AARP, they had one purpose in mind—the desire for a more hopeful message to be heard. Lady Gaga, who had become the singer’s personal friend after collaborating with him on two albums, one still to be released, told Bennett’s oldest son, Danny, that such a public revelation would be a “gift to the world.”

Gayatri Devi, MD, the neurologist who diagnosed Bennett’s Alzheimer’s in 2016, told AARP, “He is doing so many things, at 94, that many people without dementia cannot do. He really is a symbol of hope for someone with a cognitive disorder.” Dr. Devi is author of The Spectrum of Hope, which describes Alzheimer’s as a “spectrum disorder,” varying from person to person.

Quality of life and progress of the disease depend on what kind of brain one “brings to the situation,” the AARP article reported. “Tony Bennett brought an amazingly versatile brain,” Dr. Devi said.

In addition to strong family support, good nutrition (a Mediterranean diet), exercise, and social stimulation provided with love and care by wife Susan Benedetto of 14 years, Bennett still, remarkably, sings, which was strongly recommended by his neurologist. “It kept him on his toes and also stimulated his brain in a significant way,” she told AARP. In fact, despite being diagnosed in 2016, his last public performance was as recently as March 11, 2020 at the Count Basie Center for the Arts in Red Bank, NJ.

“Tony could seem utterly mystified about his whereabouts. But the moment he heard the announcer’s voice boom ‘Ladies and gentlemen—Tony Bennett!’ he would transform himself into performance mode,” the AARP article reported. Bennett continues to rehearse, twice a week, with his longtime pianist Lee Musiker.

Monique Morimoto of SoulWorks Rhythm suggests rhythm-based activities (think toe-tapping) to lift spirits. All you need to do is “find the beat of a familiar song and play along with it,” she says.

Simply find the rhythm and play it, clap it, tap it or stomp it.
1. WHAT HAS BEEN YOUR PERSONAL EXPERIENCE WITH ALZHEIMER’S?

I was young, in my early teens, when my grandfather, in his late 80s, was diagnosed with Alzheimer’s. He and I were particularly close, out of all the relatives. He was this wonderful guy, big storyteller; he had this fascinating life. And I was all ears.

The thing about Alzheimer’s and these types of dementia is it’s not like a car accident, where there’s a sudden change. It’s subtle. He would say certain things and I wouldn’t quite understand. I thought it was a joke that I just didn’t quite get. And it just started to progress into things that were very unusual. He could still write, but was having a hard time reading. It got to a point where he could write something and not be able to read what he just wrote.

There was a part of me that can’t help but wonder: This happened to my grandfather, is this going to happen to my mom? Is this going to happen to me? What’s the genetics of this?

All that informed my fascination with the brain and my desire to go into medicine, but also this underlying concern—what is the real risk here?

2. WHY DID YOU FEEL THE NEED TO WRITE THIS BOOK NOW?

There are so many interesting things coming out of the world of neuroscience. One of the big ones is the understanding of this process called neurogenesis, the growing of new brain cells.

One of the big takeaways is the idea of cognitive reserve and resilience. We use our brains the way we have been living our Covid lives—primarily at home, going to a grocery store, to our kids’ school. It’s just the same few things that we do over and over again. And we kind of have that down pat. It’s never been true that we only use a certain percentage of our brains. We use our entire brain. But we probably use 10% of our brain 90% of the time. We are not growing new brain cells as much as making the brain cells we have super efficient.

Instead, we want you to be traveling new roads, and going to new cities, in your brain. How do you do that? You have to do new things—and that’s how you build reserve. Practice makes perfect is true, but it is change that builds resilience.

And it doesn’t have to be huge changes. I talk to these neuroscientists and they say simple things: Eat with your non-dominant hand tonight; don’t just focus on crossword puzzles; take up something like pottery or painting. We typically think of those as recreational, relaxing things, and they can be, but they can also be really good for building new brain cells. So think about mixing it up.

3. YOU DESCRIBE CAREGIVERS AS THE “INVISIBLE SECOND PATIENT.” WHAT DO YOU MEAN BY THAT?

During the time that my grandfather was going through this, I can tell you that was our entire life. That’s what we did. Every family conversation revolved around my grandfather and what he was doing and what kind of care he was getting and what was this all going to mean.

When this happens in your family, if you leave aside for a second the impact that it will have on you financially, the impact that it will have on you in terms of your time is all-consuming in every way imaginable. I’m really, really empathetic to this.

Caregivers who are taking care of loved ones with dementia provide the highest levels of unpaid care in the country. Because they are doing it all the time and it’s typically a family member, you are not getting paid.

Also, caregivers are at higher risk of developing not just dementia themselves compared to the general population; they are also at higher risk of most chronic diseases—heart disease, diabetes, obesity. So it’s a group of people who are not compensated and putting themselves at tremendously increased risk of developing these problems.

4. WHAT CAN CAREGIVERS DO TO HELP PREVENT THE “SECOND PATIENT” SYMPOD?

I do think there needs to be a recognition that given the number of people in our society that are likely to be diagnosed with dementia over the next few decades, how are they going to be cared for in a way that will be really sympathetic to their needs, but also sympathetic to the caregiver’s needs as well?

Right now, short of that, understanding that there probably is a lot of help out there. One of the things that prevents people from seeking out the help is the concern about the stigma of the dementia in the first place.

It becomes a deeply personal thing. Again, I saw this in my own family. My mom did not want to talk about it. She didn’t want to alert friends and family and other people about what was happening with her dad because he was developing dementia—something that really robbed him of his personality. We need to recognize that there are a lot of people out there who have this. We need to try and decrease the stigma around this and, most of all, encourage people to ask for help.

For most people, I think it’s a binary thing. Either I’m going to create some sort of living situation that outsources the entire care or I’m going to take on everything. There are mediums in between. It’s not the care of your loved one that’s the problem. It’s the relentless nature of it. So how do you really, truly, get a break from it. I think that’s the key.

It’s hard the first time you do it, but focus on taking a week off, a night off, or a few hours off, and feel good about it. Let other people step in. Once you do that, a lot of those people who really want to help out, help. It really can make a world of difference.

5. YOU MENTION THE IDEA THAT ANYONE WITH A BRAIN NEEDS TO BE THINKING ABOUT THE POSSIBILITY OF ALZHEIMER’S. HOW IS THIS TRUE?

What I didn’t fully realize until I started researching Keep Sharp: We have between 40 and 50 million people in the United States alone who if you were to look inside their brains would have evidence of plaques and tangles associated with Alzheimer’s disease, but they don’t have any cognitive dysfunction. Their function is totally normal. So it has to have something to do with our lifestyle. Because changing our lifestyle does seem to make a difference. We were not designed to sit for 23 hours a day and go to the gym for an hour. We were not designed to consume more calories than we expend on a daily basis.

What this does tell me is that you can have a brain that has plaques and tangles in it that still functions normally. Focus on that fact. How do you keep the brain functioning normally even as plaques and tangles are developing. That’s really key.

You can also have a brain that gets sharper throughout your entire life. I know that sounds crazy because people just think, “Ah, I’m getting old. My memory’s not so good.” That’s just become the vernacular of the United States. You go to Okinawa, Japan, and places like that, and they’re like, “What are you talking about?” The smartest people in our society are the oldest, because they have sharp brains and they have a ton of judgment and experience. It’s just a different way of looking at the future and our own old age.

Continued on following page
5 PILLARS OF BRAIN HEALTH

Dr. Sanjay Gupta recommends these to keep your mind sharp, no matter your age.

MOVE.
Exercise, both aerobic and nonaerobic (strength training), is not only good for your body; it’s even better for your brain. Movement can increase your brainpower by helping to increase, repair, and maintain brain cells, and it makes you more productive and alert throughout the day.

DISCOVER.
A study from the University of Texas at Dallas tells us that picking up a new hobby, like painting or digital photography, or even learning a new piece of software or language can strengthen the brain. Seeing a 3D movie, joining a new club, or even brushing your teeth with a different hand count, too.

CONNECT.
Connect with others, in person and face-to-face. Many studies show us that having a diverse social network can improve our brain’s plasticity (its ability to reorganize its synapses in response to stimuli) and help with cognitive abilities.

NOURISH.
We now have evidence that consuming certain foods (e.g., cold-water fish, whole grains, extra virgin olive oil, nuts and seeds, fibrous whole fruits and vegetables) while limiting certain foods, high in sugar, saturated fat, and trans-fatty acids) can help avoid memory and brain decline, protect the brain against disease, and maximize performance.

RELAX.
Relaxing is not solely a physical thing for your body; your brain needs to chill, too. Many studies show that poor sleep can lead to impaired memory and chronic stress can impair your ability to learn and adapt to new situations.

THE CONVERSATION:
How do you talk to children about Alzheimer’s?

One of the easiest ways to begin a conversation about Alzheimer’s disease with a young child is with a picture book. That’s why AFA created Dancing with Granddad: An Alzheimer’s Story for Children and Their Families.

Written for children entering kindergarten through third grade by Linda Bozzo and illustrated by Mudassir M. Abid, the book, available in English and Spanish, takes young readers on the journey of learning in an age-appropriate way that the grandfather of seven-year-old Nia has Alzheimer’s and will need to move to a new home. They also learn that while Nia’s grandfather is changing, the love they have between them never will. The book gently introduces behavior changes (such as retelling stories, wandering, and confusion). Nia’s caring parents arrange a transition to an assisted living facility where he will be safe. The book, a jumping off point for every family, includes a message from AFA about how to talk with children about Alzheimer’s disease.

“All members of our families can love better when we understand our ailments, especially Alzheimer’s.”
—DR. MEHMET OZ, THE DR. OZ SHOW

“Both children and adults will connect with the tender relationship between Nia and her Granddad as they use this special book to begin or continue the often challenging conversations about Alzheimer’s.”
—DALE V. ATKINS, PHD, PSYCHOLOGIST

It’s never too early to start talking about Alzheimer’s. You can order AFA’s children’s book Dancing with Granddad (for ages 5-8) at shop.alzfdn.org or call 866-232-8484—available in English and Spanish.
Rich, savory chopped liver is a traditional Jewish dish that brings back fond food memories for many families. Here’s a healthier version that is rich and delicious without the artery-clogging saturated fat calories!

The word pâté means paste in French. In French cookery, pâté refers to a mixture of cooked ground meat and fat with added vegetables, herbs, spices, and either wine or brandy, which is then minced into a spreadable paste. It’s typically served as an hors d’oeuvre with sliced baguette or crackers. This vegan pâté recipe substitutes walnuts and mushrooms for the meat protein and olive oil for the animal fat.

This recipe is simple, delicious and nutritious; and makes a great appetizer, condiment or sandwich spread.

**INGREDIENTS**

Choose organic ingredients when available:

- ¾-pound (about 3 ½ cups) shitake, crimini and/or portabella mushrooms, cut into quarters
- 1 shallot, chopped
- 1 tablespoon fresh thyme, chopped
- 2 tablespoons cold-pressed extra-virgin olive oil
- 2 teaspoons fresh lemon juice
- 2 tablespoons unsweetened coconut water
- ½-cup walnuts, chopped
- Sea or rock salt and freshly ground pepper to taste (optional)

**DIRECTIONS**

1. Preheat oven to 375° F.
2. In a large bowl, toss mushrooms with shallot, fresh thyme, and olive oil. Season with (optional) salt and pepper.
3. Transfer to a rimmed roasting pan (or baking sheet) and roast for 25 minutes.
4. Remove from oven and cool to room temperature.
5. Using a high-speed blender, Vitamixer or food processor, transfer the mushrooms to the bowl of the blender and add remaining ingredients. Pulse until smooth or finely chopped (whichever you prefer). Adjust seasoning, if needed.
6. Serve with thinly sliced toasted whole grain baguette or pita chips and sliced turnips or jicama, at room temperature.

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.

**CARE PARTNER CREATIVITY**

**Brekkie Smiles**

“Sometimes he needs the smiles; most days I do.”

You will delight in the sunshiny cheerfulness of @brekkiesmiles. It’s an Instagram page started by Nicole Nightingale, of Toronto, Canada, which showcases the many smiles she lovingly and artistically creates using breakfast foods (yes, food!) for her dad, Cyril “Algie,” 87, who is living with Alzheimer’s.

It all started with a fast attempt to improve her dad’s sour mood and picky eating one morning (using scrambled eggs, bread, and small pieces of fruit) that has turned into an almost daily ritual of smile-making. The careful cutting and designing often soothes Nightingale in the early morning alone hours while her dad sleeps in, “allowing [her] to feel attached to something positive and not worry about all the negatives.” For her dad, the “brekkie smiles” bring smiles, chuckles, and sometimes comments or conversation.

Nightingale realized her dad’s appreciation of her creations all made sense. He was a former chef who had spent his career working in food service, including the kitchen of a children’s rehabilitation center. Nightingale has since learned to involve him in the food prep as often as she can, like the icing of cupcakes or mixing a batter, sometimes slicing a holiday roast.

Other things she’s learned is the importance of involving her dad in her small projects and allowable outings, like late-night Home Depot runs, when they are not on pandemic lockdown, and giving him opportunities that encourage him to learn and sing new songs, not just his “top 5 hits, over and over again,” many of them choir songs, from his years in many choirs.

Her greatest lesson: “Know your person. You are the expert when it comes to knowing what could work best.” And keep smiling.

Check out @brekkiesmiles on Instagram for inspiration.
A GUIDE TO CREATING A Dementia-Friendly Home

Almost every part of a home can impact quality of life for someone living with a dementia-related illness. Even seemingly cosmetic choices like color schemes, furniture patterns, and dishware make a difference, but most residences are not built with these needs in mind. So how do you adapt a home to make it dementia-friendly?

That’s the answer provided through The Apartment—a model, full-scale dementia-friendly studio residence AFA built as a teaching tool to help families across the country learn how to make a home safer and more comfortable for someone living with a dementia-related illness. The Apartment is located in AFA’s New York City headquarters and can be “visited” virtually anytime through AFA’s website at www.alzfdn.org/theapartment. Along with a video tour on the website, a 20-page companion guide which takes individuals through each room in detail is available in both electronic and print formats.

“Most homes are designed for young, active individuals, not for the changing needs of older adults—especially those with dementia,” said Rosemary Bakker, the Interior Designer of The Apartment, President of Age Friendly Design, Inc., a gerontologist, and a former caregiver for her mother who lived with Alzheimer’s disease. “Dementia-friendly design is about creating a living space that improves the well-being and safety of the person living with dementia, while making caregiving less difficult and more fulfilling for their families.”

Each area of The Apartment—including the kitchen, bedroom, bathroom, living room and dining area—showcases different steps, designs and adaptations that can improve quality of life for individuals with dementia and their caregivers. Many tools families can utilize in their own homes—whether they live in a house, apartment, condominium or townhouse. Technology, for example, can be a friend to caregivers. Interactive virtual assistants (i.e., Google Assistant or Amazon Echo/Alexa) allow caregivers to schedule reminders and events that will be audibly played for a loved one, such as “it’s lunchtime now” or “time to take your medication.” Thermostats, lighting, smoke and carbon monoxide alarms, and alert systems can be controlled and monitored by an app—especially useful for caregivers who don’t live with their person.

For safety, smart burners can replace electric stove coils to guard against kitchen fires (and are easily installed). Special temperature control technology prevents smart burners from reaching the temperature at which most cooking oils autoignite. Automatic fire extinguishers can magnetically attach to the inside of a stove hood to dispense baking soda if a cooking fire occurs.

“Labeling dresser drawers and storing nonperishable food in clear plastic containers aids with memory. Utilizing color contrast can improve sight. Covering sharp furniture edges with clear rubber corner protectors enhances safety. These are just a few examples of things that can be done at minimal cost.”

Dementia-Friendly Design Features to Consider in Your Home

Colors matter. Colors aren’t just for show—they can actually influence mood. Blue often has a calming effect and is great to use in places that promote relaxation, such as lounge areas, bathrooms and bedrooms. Brighter colors like red, purple and orange can be energetic and stimulating; and, therefore, may not be the best choice to use in these rooms.

Contrast is key. Dementia can negatively impact vision, depth perception and spatial orientation (which can also increase the chances of injuries from bumps or falls). Color contrast can help offset some of these impacts. Simply swapping out a white toilet seat for a sunny yellow or royal blue one will be much easier for someone with a dementia to see as opposed to a white toilet seat on a white floor.

Let there be (good) light. Just like color choices, lighting can affect the body and behavior. Lights which produce glare may hinder vision for someone with dementia. Flickering lights can increase agitation. During the day, blue light rays stimulate the brain, increase alertness and elevate energy levels, but also negatively impact sleep quality in the evening. Utilizing glare-free lighting, along with circadian lighting or light bulbs which mimic natural night-day patterns of blue light can be helpful to improve sight, state of mind and sleep quality. Another option is to use a single low-blue light bulb, known as a “sleep bulb,” on the bedside, for a softer, more restful light at night.

Décor—not just for show. Décor can serve a purpose beyond making a home aesthetically pleasing—it can promote familiarity, aid with disposition, and assist with memory recall. For example, if your person likes the beach, having seascape artwork can help promote positive mood and memories. Displaying vintage magazines can help remind someone about a familiar time period from their past. Family photos reinforce the faces of familiar time period from their past. Family photos reinforce the faces of familiar time period from their past. Family photos reinforce the faces of familiar time period from their past. Family photos reinforce the faces of familiar time period from their past. Family photos reinforce the faces of familiar time period from their past. Family photos reinforce the faces of familiar time period from their past.

The Kitchen
It is a common concern among family caregivers—offering help to a loved one with Alzheimer’s, only to be rebuffed and told “I don’t need help.” They can no longer manage their personal finances or drive safely. Personal hygiene might become less important. Medication remains untaken. Dementia can bring memory problems, confusion, behavioral changes, and impaired judgement.

It seems obvious to others when a loved one needs help. Why would a loved one not only refuse help but refuse to recognize that help is even needed? Or that there are self-care steps they need to take?

One possibility is a medical condition called anosognosia, where individuals genuinely cannot recognize their own impairment. Because of changes in the brain, they are unaware that they need assistance; the ability to understand their own impairment is affected. This is not the same as denial.

Those with Alzheimer’s disease or other forms of dementia, as well as traumatic brain injury, stroke, bipolar disorder, and schizophrenia, can truly believe there is nothing wrong with them. According to Anosognosia by Aninda Achary and Juan Carlos Sánchez-Manso, 81% of individuals with Alzheimer’s disease and 60% of individuals with Mild Cognitive Impairment (MCI) exhibit signs of anosognosia. To compound the difficulty, there can be varying degrees of self-awareness. Common responses to this condition are rationalizing impairments, disbelief that there is an impairment, and anger. Because a loved one must be cared for and kept safe, intervention is needed. Remember that strategies need to keep evolving as the illness progresses, and finding solutions is often a process of trial and error.

Tips for helping a person who is experiencing anosognosia

- Consult with your medical provider for advice.
- Understand that your loved one truly believes there is nothing wrong with their functioning.
- Don’t take things personally. Your person has an illness.
- Offer choices so that some autonomy is maintained.
- Let your loved one do what they can (e.g., if they want to pay bills, have dummy checks made. If they enjoyed homemaking, let them fold laundry or set the table).
- If your person can no longer drive, you drive to their destination, reminding them that it is to “give them a break.”
- Find activities close to things they once did but simplify them.
- Take an individual approach; use your best judgement. If one approach does not work, try another.
- If a Power of Attorney is needed for medical and/or legal affairs, say it is being done “in case anything ever happens to you.”
- Join a caregiver support group for feedback and resources.
- Contact the AFA Helpline at 866-232-8484 to speak with a licensed social worker specifically trained in dementia care for support.
Creating a Long-Term Care Team

The concept of a “team” usually connotes a group of individuals working closely together to achieve a common goal. When it comes to health care, the “team” members don’t all necessarily work together, but they ideally coordinate their efforts and share information, even though they may not meet or communicate regularly. Their common goal? Enabling the person living with dementia to exercise their choices, sense of independence, and social and community involvement to the greatest extent possible.

Someone with dementia may feel a formal and detailed “care team” is unnecessary, at least early on; but having a care team—even an informal one—is beneficial in the long run:

• The person with dementia should be the center of the team, making care and other decisions, and being encouraged to do so, consistent with their capacities.

• The person’s key family member(s) and/or friend(s), primary health professionals and specialists should be team “members.”

• Support groups, even if involved only with the person’s family caregiver(s), should be seen as part of the person’s care team as well.

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By Michael C. Parks, Esq., an attorney with Senior Citizens Law Office, a civil legal services organization that serves persons aged 60 and older in Central New Mexico.

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Creating a Long-Term Care Team

A lawyer is unlikely to be considered a member of the core team. However, a lawyer has a critical obligation to the team as a whole: to provide confidential advice and assistance to a client—in this case, the person with dementia. While the lawyer may need to exchange information with team members, they must have the client’s permission to do so. Generally speaking, the lawyer’s role is to: (1) help the person with dementia and their family and friends to be better aware of the person’s legal rights and options; (2) prepare documents that help them carry out the person’s choices and responsibilities; and (3) possibly pursue legal actions on the person’s behalf, if ever needed.

Preparing Important Documents: Advance Directives Including POAs

The two most important types of documents upon which a person with Alzheimer’s and their families commonly rely are advance directives and powers of attorney; and, to a lesser extent, government benefits forms.

**Advance Directives**

1. Declare things that a person does or does not want to happen to them or their property in the future.
2. Authorizes one or more other persons to make specified decisions on their behalf in the future. Two of the most widely used types of advance directives are both “Power of Attorney” documents.

**Powers of Attorney**

A Power of Attorney (POA) is a written, legal document, by which one person (“the Principal”) can authorize one or more other persons (“the Agent(s)”) to take actions on their behalf during their lifetime. The two types most commonly used:

**Financial POA**

A financial POA enables a person or persons to act on someone else’s behalf regarding “financial interests,” such as issues involving banks and other financial institutions, as well as real estate, government benefits and taxes. The “Principal” has the option of deciding whether they want a POA to go into effect immediately or sometime in the future, when they become unable to manage financial responsibilities on their own (i.e., “incapacitated”).

**Health Care POA**

Essentially an advanced health-care directive or living will, this POA provides for the appointment of a person or persons to make healthcare decisions on the “Principal’s” behalf when they become unable to do so. Such decisions may involve end-of-life preferences, pain relief and anatomical gift designations.

One major difference between financial and health care POAs are the consequences of not having one. If a person without a financial POA becomes incapacitated, it may be necessary to pursue a guardianship and/or conservatorship proceeding in court to have an agent appointed. When someone without a health care POA becomes incapacitated, state law specifies who is entitled to make healthcare decisions on their behalf.

**Important Reminder: Government Benefits Require Government Forms**

Keep in mind, different agencies that administer government benefits have their own forms that must be used to obtain various results. For example, agencies like Social Security, Medicare, and the Veterans Administration have forms that must be used instead of state-recognized POAs. Agencies will have their own forms for applications, appeals, appointment of representatives, appointment of representative payees, and more. Lawyers regularly help clients and members of the community cut through this maze of forms, to help people be more aware of them, and better understand and complete them.

When to seek legal advice?

When a person first learns that they are experiencing symptoms of dementia, they should seek the assistance of an elder care lawyer. Why? Because if they haven’t already done so, they should start considering how to protect their income and assets to optimize future care and assistance and enable their family or others to help manage their affairs when their own capacity to do so diminishes.

Individuals with substantial financial resources may seek the services of lawyers specializing in trusts and estates. Many others may consult with lawyers about wills and other estate planning options. Many consult lawyers who specialize in “Medicaid planning” to consider lawful ways of preparing for possible nursing home or home-based care.

Some civil legal services will help prepare wills and related documents for persons with limited assets, as well as educate seniors on matters such as simple “life planning” and the often-bewildering offering of government benefits. Those efforts range from information about steps to take—and forms and procedures to use—to help manage the person’s affairs—to highlighting areas of misinformation that can cause needless depletion of financial resources or denial of benefits.

Changing Places

When is the “Right” Time to Move a Family Member to a Care Community?

It can be years that a family manages at home, sometimes with the help of homecare aids, the slow changes that are occurring in the physical, cognitive, and daily-living abilities of a loved one diagnosed with Alzheimer’s or another dementia-related illness.

Are they safe?

Pam Ostrowski, author of it’s Not That Simple: Helping Families Navigate the Alzheimer’s Journey, and Founder of Alzheimer’s Family Consulting, LLC, says, “Safety is the biggest driver for moving into a care community (assisted or memory). When we refer to safety, we’re talking about a person who takes their purse (full of flammable things) and puts it in the oven and turns it on. Or walks out of their home when it’s 100 degrees out and can’t find their way back.”

“Eating and drinking are the second key drivers for a move, particularly if the loved one with Alzheimer’s lives alone,” adds Ostrowski. “If someone with mid-stage Alzheimer’s has no family to bring them groceries, how do they get food? The next problem is that they don’t know if they’ve eaten.”

“Their hunger cues are askew, and so they tend to lose weight,” says Ostrowski. “They also don’t know if they’re eating spoiled food. Nutrition declines rapidly. The situation is exacerbated further by the lack of proper hydration. Seniors tend to drink less water.”

Is it realistic?

“When aging in place, that is, staying at home for as long as possible, is the ideal scenario for most families these days, it can be impractical or unrealistic for many,” says Suzanne Hanas, RN, BSN, CEO/Owner, Premier Life Planning Care Management, Newport Beach, CA, and Premier Geriatric RN, based in Virginia and Washington, DC. “When home health aids are needed, family members are also needed to be around to supervise.” If relatives are living long distance, this becomes untenable. “It’s like running a company,” says Hanas. “You have to make sure the aides show up; and when they don’t, you need to have alternative agencies as backup.” Hanas’ consulting firm provides registered-nurse clinical assessments that help families determine what their loved one is capable of managing on their own, so that they can find the best care possible.

Importance of Planning Ahead

Faraz Kayani, Executive Director at The Bristol at York Avenue in New York City, explains that “it will start with the family member having sudden changes that require more care and attention; and this will lead to the family caregiver being more exhausted, both physically and mentally. This juncture then prompts that phone call to an assisted living facility. It’s best for the family caregiver to proactively consider a transition to assisted living prior to reaching that state or situation. When we look for help only in case of a crises, we may end up having little time to make a sounder decision.”

Adds Hanas, “The best way to plan is to know how hard it is in the beginning. To be presented with the what ifs. What should I have as an alternative? You are never 100% sure of what’s going to happen, regarding your health and your safety—or that of your loved ones. You should always have a plan.”
AFA has already begun advocating for greater investments in federal research funding and caregiver services and supports, including:

- $3.4 billion, a $289 million increase, for Alzheimer’s research at NIH
- $20.5 million at CDC to fully fund BOLD Act Provisions

As of press time, the House and Senate have not yet released their budget proposals, but Congress is holding hearings and drafting their own spending packages with an eye toward finalizing the budget by October 1.

YOUR VOICE IS A POWERFUL ONE IN ENCOURAGING FEDERAL OFFICIALS TO BUILD ON THE PAST PROGRESS THE FEDERAL GOVERNMENT HAS MADE IN THE FIGHT AGAINST ALZHEIMER’S DISEASE.

Contact your Congressperson and two U.S. Senators and urge them to support more resources to combat Alzheimer’s disease by increasing research funding at NIH and caregiver supports at ACL. Visit www.house.gov and www.senate.gov to find out who your federal representatives are and to reach them via email. You can also contact the Capitol Hill switchboard at 202-225-3121 to be connected by phone.

Prior to adjourning last December, the 116th Congress and the President continued to build on past progress by approving a federal budget for fiscal year (FY) 2021 that included a historic $3.12 billion for Alzheimer’s research at the National Institutes of Health (NIH); $20.5 million for the BOLD Act, an Alzheimer’s public health initiative at the Centers for Disease Control and Prevention (CDC); $27 million for Alzheimer’s disease programs to support caregivers at the Administration for Community Living (ACL); and $3 million at the Department of Justice (DOJ) to fund Kevin and Avonte’s Law that provides grants to first responders to combat wandering.

The new year brought a new Congress and new Administration, and the FY 2022 budget process is already underway.

The White House released a spending proposal that includes a $115 million increase for aging research (not specifically Alzheimer’s) at NIH; $30 million—a $3 million increase—in Alzheimer’s caregiver services under ACL; and full funding for BOLD Act provisions at CDC ($20.5 million) and $3 million for Kevin and Avonte’s Law at DOJ.

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WORLDWIDE ICON SHINES BRIGHT FOR ALZHEIMER’S AWARENESS

New York’s Empire State Building is one of the most famous and recognizable buildings anywhere on Earth. Standing more than 1,400 feet tall, it was at one time the world’s tallest and most photographed buildings. Named one of the seven greatest engineering achievements in American history, it holds iconic status in architecture and pop culture. It also has another special role: Alzheimer’s awareness symbol!

On November 5, 2020, teal was added to the bright lights of the New York City skyline when the Empire State Building illuminated in the color to raise awareness about Alzheimer’s and show support for all those who are affected by the disease. The lighting was done as part of AFA’s Light the World in Teal program, an annual awareness event held each November as part of Alzheimer’s Awareness Month, where places and people around the world “go teal” on a single day.

More than 300 sites worldwide joined the Empire State Building in “going teal” on November 5, 2020. Other participating sites included some of America’s tallest buildings—Chicago’s Willis Tower (formerly the Sears Tower) and 875 North Michigan Avenue (formerly the John Hancock Center), Philadelphia’s One Liberty Place, Seattle’s Columbia Center, and Dallas’ Bank of America Plaza; major sports arenas in Atlanta (Mercedes-Benz Stadium), Boston (TD Garden), Miami (American Airlines Arena), Minneapolis (US Bank Stadium), Nashville (Bridgestone Arena), and New Orleans (Mercedes-Benz Superdome); as well as government buildings, museums, residential and office structures, care settings and other sites in the United States and 10 countries.

For a complete list of 2020 participating sites as well as more information about Light the World in Teal 2021, scheduled for Thursday, November 4, 2021, visit www.lighttheworldinteal.com.

RECOMMENDED READING from LINDA’S LIBRARY
Looking for some good dementia-related reading? Here are a few recommendations from Linda Mockler, LMSW, AFA Licensed Social Worker

NON-FICTION

On Vanishing: Mortality, Dementia, and What It Means to Disappear
by Lynn Castell Harper
A philosophical and anecdotal exploration of how to relate to, and understand, someone with dementia, On Vanishing, a New York Times Book Review Editors’ Choice, is based on the author’s personal experiences with dementia caring for family members and working as a nursing home chaplain. The book provides a new perspective on dementia in part by examining our own fears, as well as our cultural and societal views. It offers comfort, insight and helps guide the way to compassion and empathy to ultimately improve care for individuals living with dementia-related illnesses.

Learning to Speak Alzheimer’s: A Groundbreaking Approach for Everyone Dealing with the Disease
by Joanne Koenig Coste
Written by a caregiver whose husband was diagnosed with young-onset dementia in his early 40s and later suffered a debilitating stroke, this book is a tool for care partners as they move through the progression of the illness, providing an understanding and practical coping advice for each stage of Alzheimer’s, as well as underscoring the importance of self-care. Utilizing her self-devised philosophy, the “habilitation approach,” which emphasizes relating to patients in their own reality, Coste describes Alzheimer’s as a disease of the emotions, with behavioral changes reflecting the frustration of being unable to master emotional and physical environments that feel foreign. Working with and partially controlling these emotions, behaviors can be made more acceptable and productive. Issues such as helping the individual talk about the illness, driving, making mealtimes and bath times as positive as possible, adjusting room designs, and dealing with wandering, paranoia, and aggression, are thoroughly discussed.

FICTION

Elizabeth is Missing
by Emma Healey
Written from the perspective of Maud, an 82-year-old woman with dementia, readers travel back and forth with her between the past and a constantly shifting present in this multidimensional book. Maud is determined to find out what happened to her best friend, Elizabeth, who she believes is missing. Elizabeth is one of Maud’s last emotional connections in an increasingly puzzling world. To remember things, Maud writes notes to herself. How can she solve a mystery if she cannot remember clues? And not coincidentally, this can be seen as a metaphor for dementia itself. As she works to “solve” the mystery and deal with the progression of her illness, readers enter Maud’s world and see the impact it has on her day-to-day life, emotions, and familial relationships.

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Alzheimer’s disease research funding is not just an investment in science—it is an investment in hope. Over the last year alone, AFA has awarded $400,000 in new grants for research initiatives aimed at finding new treatments for Alzheimer’s disease and enhancing early detection of dementia-related illnesses.

NYU Langone Hospital—Long Island
AFA awarded a $250,000 grant to NYU Langone Hospital—Long Island, in Mineola, NY, to expand and accelerate research being conducted to uncover the underlying causes of Alzheimer’s disease, with the goal of developing new treatments and slowing the progression of the disease. This AFA award follows a $100,000 grant in 2019 that began the cutting-edge research project. The NYU Langone research study enables a team of clinicians and researchers to conduct the following: (1) Collect blood samples and genetic information from individuals that will be used to perform machine learning analysis to develop personalized treatments. (2) Develop a clinical cohort, with the ultimate goal of improving early detection at the pre-symptomatic phase and developing personalized treatment plans.

Gateway Community Service Board
Supported by a $50,000 AFA grant, this study examines the relationship between behavioral impairment and early markers of cognitive decline using the Mild Behavioral Impairment (MBI) scale. MBI measures five components: apathy (impaired drive/motivation); mood and anxiety; inhibition/self-regulation (agitation, impulse control problems); impaired social cognition (social inappropriateness); and psychosis (abnormal thoughts/perception). The study also explores the impact of COVID-19 on MBI, as well as the mediating influences of factors such as lifestyle, exercise, sleep, social supports, and overall health.

Hadassah Medical Organization
AFA awarded $100,000 in grant funding to the Hadassah Medical Organization to purchase a semi-automated Quanterix SIMOA system to use at the new Hadassah Center for Healthy Brain Aging. The system will be used to screen the aging population in order to identify “at risk” patients and assemble a clinical cohort, with the ultimate goal of improving early detection at the pre-symptomatic phase and developing personalized treatment plans. Hadassah’s hope is that early intervention using state-of-the-art tools and medical practice will delay Alzheimer’s disease and reduce its large medical and socio-economic burden, as well as facilitate the development of future personalized treatments.

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Dr. Nathaniel Chin Appointed to AFA Medical, Scientific and Memory Screening Advisory Board
Congratulations and welcome to the newest member of AFA’s Medical, Scientific and Memory Screening Advisory Board, Nathaniel Chin, MD. Dr. Chin is the Medical Director for the Wisconsin Alzheimer’s Disease Research Center (ADRC) and the Wisconsin Registry for Alzheimer’s Prevention (WRAP) study, as well as the Associate Director of the Geriatric Memory Program, University of Wisconsin Hospital and Clinics. Dr. Chin grew up in Watertown, Wisconsin, and earned undergraduate and medical degrees from the University of Wisconsin-Madison. While completing his internal medicine residency at the University of California San Diego, Dr. Chin’s father was diagnosed with Alzheimer’s disease at an early age. His father’s condition influenced the way Dr. Chin began to look at his life’s work, and he decided to pursue a career as a geriatrician and scientist focused on dementia, specifically Alzheimer’s disease.

In addition to seeing patients in the UW Health Memory Clinic, Dr. Chin studies modifiable risk factors and biomarker disclosure within the Wisconsin ADRC and WRAP study. He collaborates with many of the researchers at the Wisconsin ADRC and oversees the clinical care provided to the research participants. His memory clinic focuses on creating a dementia care pathway, designed to help those with cognitive impairment navigate and best utilize the health care system by aligning patient goals with medical care.

“The intersection of care and research is an important one, with caring for our fellow person being the foundation of what we do and research being one of the key ways of doing it right,” said Dr. Chin. “I look forward to my time with AFA and working toward both care and cure.”
Enjoy free daily virtual activity and therapeutic programming for care partners

The AFA Teal Room

www.alzfdn.org/afatealroom