Something Special
Anne Brodsky’s Legacy Continues to Change Lives 20 Years Later
Caregiver Advocacy: Whatever It Takes

Baseball Reminiscence Program Catching On

Something Special: Anne Brodsky’s Legacy Continues

20 Years of Making a Difference: AFA Helpline Chairman of the Board
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Visit alzfdn.org/tour for more information.
Navigating a New Caregiver Role

Caring for a loved one with Alzheimer’s often comes with unexpected challenges. Boston University experts neurologist Andrew Budson, MD, and neuropsychologist Maureen O’Conner, PsyD, in their newly published book Six Steps to Managing Alzheimer’s Disease and Dementia provide a comprehensive guide for families navigating this caregiver role:

STEP 1: UNDERSTAND DEMENTIA
Dementia has stages and can be caused by different disorders. Talk to your primary care provider about your loved one’s behavioral changes. They may refer you to a neuropsychologist or neurologist for testing.

Alzheimer’s is the most common cause of dementia. Family history increases chances of disease development, but you can reduce your risk by following a healthy diet, exercising regularly, and staying social.

STEP 2: MANAGE PROBLEMS
Most severe stages of dementia look alike, but each person has a different experience. Maintain routines and use visual cues to cope with memory changes and increased nonverbal communication. When caring for a loved one, take your time and follow the 4Rs: reassure, reconsider, redirect, and relax.

Observe changes in behavior, emotions, communication, and bodily functions. Keep a log for you and your care team to reference over time. Talk to your health care provider about sleep difficulties or symptoms of anxiety and depression as these can be treated with medication.

STEP 3: ASK ABOUT MEDICATIONS
Make a list of all medications and take note of possible side effects. Dosages need to be reviewed or adjusted by your health care provider. Certain medications may cause memory impairment, confusion, and drowsiness which worsen symptoms of dementia.

Continued on following page
NAVIGATING A NEW CAREGIVER ROLE  cont’d from p. 3
There are some medications to help enhance cognitive function and reduce problematic behaviors. You should always consult your health care provider before lowering or stopping a medication altogether.

STEP 4: BUILD YOUR CARE TEAM
Many caretakers follow a “whatever it takes” attitude, but this can result in burnout. Ask friends and family for help when you need a break, and enlist professionals depending on the needs of your loved one. Remember to care for your own health, too.

Different types of support groups, day programs, and adult day centers can be beneficial. Be sure to ease your loved one into different care options to prevent anxiety and problematic behaviors resulting from the transition. Always share new updates with your care team.

STEP 5: SUSTAIN YOUR RELATIONSHIP
The relationship between you and your loved one will undoubtedly change over the course of their dementia; however, it’s important to maintain one outside of your caregiver role. Pursue new activities that you’ll both enjoy, such as listening to music or engaging in arts and crafts together.

Physical touch becomes increasingly important as communication declines, and it’s known to reduce anxiety. Learn and follow nonverbal cues to offer comfort through touch.

STEP 6: PLAN FOR THE FUTURE
End-of-life care and death are sensitive subjects, but essential to plan for. Ideally your loved one can be involved early on to ease your decisions as their dementia declines. Be prepared to make future plans for their health care, ceremony, and physical body.

In the time after death, move forward even if you simply go through the motions of life at first. Look to support groups or seek therapy to process and understand your grief and rebuild friendships that may have been lost. Remember that no one can manage dementia and grief alone.

Seek advice from your health care provider about the type of care that will be most appropriate at the end of life. Invite conversations about death itself to understand your loved one’s wishes for their care, ceremony, and physical body.

Nothing can replace seeing, touching, and spending time with a loved one in person. COVID-19 impacted that more than anything in recent history—especially for those with loved ones living in a professional care setting. Facilities nationwide were forced to close their doors to outside visitors to protect their residents’ health and safety, but that prolonged separation has been extraordinarily hard for families.

Mary Daniel of Jacksonville, Florida, is one of the many who were affected. Her husband, Steve, lives with young-onset Alzheimer’s in an assisted living facility, RoseCastle at Deerwood. Both looked forward to their daily visits, but that changed once the pandemic began—they went months without being together in person. Visits through the window sadly made things harder. Steve would get upset and not understand why they had to be separated. Desperate to find a way to be with Steve and make him feel comfortable and loved, Mary was willing to try anything.

Partnering with RoseCastle, she found a solution—working there part-time as a dishwasher. As an employee, she could be allowed inside and see Steve.

“‘When they offered this to me, I let them know I’d be the best dishwasher they ever had,’” Mary said. “I wanted and needed to be there more than anything, because it meant I could be with Steve.”

Working with members of the Florida State Legislature, she advocated for new legislation that requires care facilities and hospitals to allow patient visitation with touching from family members during public health emergencies such as the COVID-19 pandemic, as long as visitors adhere to required health protocols. The law passed with bipartisan support. With the help of a 14,000 member Facebook group she runs—“Caregivers for Compromise—Because isolation kills too!”—similar legislative efforts have reached all 50 states.

“We understand the well-intentioned reasoning behind these restrictions—to protect our loved ones. But prolonged isolation and loneliness harms them too, as well as us,” Mary said. “To me, it’s about finding the balance—if it’s ok for me to touch Steve as a dishwasher, I should be allowed to as his wife if I follow the same protocols. That’s what we’re working towards.”

Looking for a caregiver support group, resources in your area or a listening ear?

Dementia-trained social workers are available 7 days a week at 866-323-8484 or via webchat at alzfdn.org.

CAREGIVER ADVOCACY: WHATEVER IT TAKES

ADVOCACY:

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Following her first shift on the job, 114 days after their last visit, Mary and Steve were reunited. The creative solution became national news.

Mary’s efforts didn’t stop there. Florida Governor Ron DeSantis appointed her to the state’s Task Force on the Safe and Limited Re-Opening of Long-Term Care Facilities, where she’s used her experiences to work towards creative solutions to help prevent prolonged caregiver and family separation in the future.

Seek advice from your health care provider about the type of care that will be most appropriate at the end of life. Invite conversations about death itself to understand your loved one’s wishes for their care, ceremony, and physical body.

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ART MUSEUMS OFFER ALZHEIMER’S PROGRAMS

We know that art therapy and creativity stimulate the mind and provide comfort for people living with dementia. But what about opportunities to engage with art outside of the home or your care facility? Check out three museums that offer free, specialized tours and programs for people living with dementia and their caregivers.

Frye Art Museum, Seattle, WA

The Frye Art Museum has presented its Creative Aging Program for over 10 years to engage people with dementia in creative, lifelong learning. The museum offers a variety of programs, including the Alzheimer’s Café, personalized art-making sessions led by museum educators and artists; movie programs, presenting classic and contemporary films; small-group arts discussions for adult and their care partners; and a lecture series for community members.

Most recently, the museum opened an exhibit showcasing the stories and works of art by program attendees called “Art on the Mind: Ten Years of Creative Aging.” “Their experiences are testimony to the success of arts engagement programs in bringing joy, respect, and dignity to people living with dementia while destigmatizing the disease.” The museum also provides downloadable art projects on its website for at-home use with caregivers.

Nasher Museum of Art, Durham, NC

The Nasher Museum of Art at Duke University began its Reflections Program in 2014 and has expanded it to include events for individuals at all stages of Alzheimer’s disease. The program offers museum tours, guided discussions, musical performances, and hands-on art experiences for visitors with dementia and their caregivers.

The goal of the program is to provide an opportunity to engage the senses and spend time with others without fear or stress.

The Met Museum, New York, NY

The Met Museum in New York City offers two programs for visitors with dementia and their caregivers: Met Escapes and Met Memory Café. Met Escapes is led by museum educators to engage visitors with dementia in art discussions, art making, and other interactive activities throughout the museum. Met Memory Café encourages visitors to chat and share their thoughts about art over a cup of tea or coffee. This program promotes a sense of community and lifelong learning.

Other museums across the country may offer similar programs. Check with your local art museum to see if they have one or are interested in creating one.

Baseball has a way of creating memories—trips to the ballpark with loved ones, rooting for a favorite team or player, having a catch with a parent, sibling, or child, and playing the game with friends—that last for generations. America’s national pastime is also helping families affected by dementia-related illnesses through “Baseball Memories,” a sports reminiscence program created by members of the Society for American Baseball Research (SABR).
BASEBALL REMINISCENCE PROGRAM CATCHING ON (cont'd from p. 7)

Sports reminiscence programs invoke pleasant memories of the past and promote socialization. One of the first programs began in Scotland in 2009, centered around soccer, and the concept has grown in popularity ever since. SABR volunteers started their first baseball reminiscence program in Austin, Texas, in 2015, based upon an earlier program in St. Louis.

“We use baseball as a means to create community and friendships and improve our participants’ quality of life,” said Jon Leonoudakis, who chairs SABR’s Baseball Memories national initiative. “Our goal is to create community and connection by talking baseball and help participants have fun and feel good together—all of which helps enhance socialization, communication, mood, and self-esteem.”

Before the pandemic, Leonoudakis and his co-leaders organized free meetings with Alzheimer’s Los Angeles that would take individuals living with Alzheimer’s and their caregivers through the familiar structure of a baseball game, starting off with the national anthem, introducing players, and ending with everyone singing “Take Me Out to the Ballgame” before taking a few swings at bat. Now, SABR organizes virtual sessions for participants to engage and share stories.

“We ask attendees to bring in a piece of memorabilia and just tell us the story behind it. When we’re in person, everybody gets a baseball with 108 magical red stiches. That’s a big part of the magic,” said Leonoudakis.

Participants are encouraged to dress up in their favorite team’s gear, share artifacts, and talk about their favorite players. SABR volunteers often recount specific games or historic plays, using photos, videos, and audio clips to trigger memories in participants.

“For more information, visit www.sabrbaseballmemories.org.

Sugar reminiscence programs invoke pleasant memories of the past and promote socialization. One of the first programs began in Scotland in 2009, centered around soccer, and the concept has grown in popularity ever since. SABR volunteers started their first baseball reminiscence program in Austin, Texas, in 2015, based upon an earlier program in St. Louis.

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CARE PARTNER CREATIVITY:

Life (and Love) with Grams

Five years ago, Kris McCabe, 34, became the primary caregiver for her grandmother, MaryAnn Padovani, 84, affectionately known as Gram. She is living with Alzheimer’s. Based in Chicago, McCabe regularly shares her experiences as a full-time caregiver for Grams and the ups and downs of the disease on Instagram and TikTok @LifeWithGrams.

“At first, I just wanted to share our adventures and show my friends and family who always loved Grams what we were up to, but it unexpectedly turned into so much more. I soon realized how many others were out there like me, clueless on what to do to provide the best possible care for their loved ones with dementia,” she said.

McCabe now uses her platforms to help educate and support other caregivers, whether it’s offering tips and tricks, sharing the reality of the day-to-day unpredictability of living with Alzheimer’s, or sharing videos. “Whenever I meet a fellow caregiver online it’s like a virtual hug. There is something truly special about the connections I have built and knowing that other caregivers really seem to understand us.” McCabe often emphasizes the importance of looking after your own mental health in order to provide the best care and support possible.

“A little patience, guidance, and love can truly go a long way. Whenever I meet a fellow caregiver online it’s like a virtual hug. There is something truly special about the connections I have built and knowing that other caregivers really seem to understand us,” said McCabe. "I had to let go of expectations and meet her where she was." McCabe understood that her grandmother always kept up with her hair—and McCabe encouraged that. Over the years, McCabe has shared videos of her grandmother styling her hair, wearing makeup, and dressing up in costumes for Halloween. "As her disease continually progresses, I still find ways to keep her involved with her hair. I adjust the equipment we use and how we do certain styles. I think it’s really important as a caregiver to keep your loved one involved in activities they love." Caregiver health and support is often a topic in McCabe’s videos. "Whenever I meet a fellow caregiver online it’s like a virtual hug. There is something truly special about the connections I have built and knowing that other caregivers really seem to understand us.” McCabe often emphasizes the importance of looking after your own mental health in order to provide the best care and support possible.

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something special

“When you leave this earth, if you’ve left it a better place, then you’ve done something special with your life.”

Anne and Irving Brodsky instilled that guiding principle in their son, Bert. Pillars throughout his life, Bert adored them and could always count on them for guidance and support.

In their later years, when they moved from New York to Florida, Bert would regularly visit them. In the early 1980s, there were moments that would foreshadow a looming problem.

“My father loved the movies; so during one visit, he and I decided to go. We let my mother know our plan. When the movie was done, we decided to stay for a second one; so I called mom and told her we’d be home later,” Bert remembered.

“Afterwards, we came back to the house, and she was hysterical. She didn’t know where we were, thought something terrible happened to us, and was ready to call the police. Her reaction made no sense to me. I had kept her informed the whole time, and when I explained that to her, she just kept telling me that I never said anything!”

Situations like this happened more frequently as time went on. Anne would ask the same question repeatedly, even after it was answered. Bert would have a conversation with her, and then a few minutes later she would ask him why she hadn’t heard from him in a long time.

The turning point came when Anne could no longer take care of Irving, her husband. During one visit, Bert noticed that Irving’s health was declining. When Bert took his father to the doctor’s office, Irving’s doctor explained that the problem was he wasn’t taking his medications properly.

“When I talked to my mother and told her, ‘Mom, you’re not giving Dad the right medications,’ she denied it and told me I was wrong. At that point, I realized that she had a bigger problem, especially taking care of my father.”

Bert wanted to hire a nurse to come in and help. Anne adamantly refused. Desperate, he took a drastic step—hiring an attorney and filing a lawsuit asking a judge to order her to accept an at-home nurse.

“It was an incredibly difficult and painful thing to do. Mom was very upset and hired her own lawyer to stop it. My brother and cousins wouldn’t speak to me, not realizing and understanding the problem as I did—all they could focus on was that I sued my mother. But I knew in my heart that she needed help; and this was the only way for me to make sure she got it. I did what I thought was right.”

Ultimately, the judge convinced Anne to listen to Bert and accept the help on her own, without forcing the court to decide the matter.

Eventually, Anne was diagnosed with Alzheimer’s. Over the years, things got progressively worse. Anne passed away in 1992.

“Describing the difficulties, Bert said, “In the early 1980s, when Alzheimer’s came into our lives, society generally viewed it as a very taboo thing with a stigma attached to it. No one wanted to talk about it, and there was nowhere to go. When the disease started making her volatile, all the doctor wanted to do was give her sedatives. There was nothing I could do. I had no experience with anything like this.”

In her memory, Bert set out to create a place where people like Anne and their families could turn for help, support, guidance, and answers—so that none of them ever had to deal with Alzheimer’s all on their own. That vision led him to create the Alzheimer’s Foundation of America in 2002.

“Feeling helpless and alone, as we did, is something no one else should experience. Resources like this would have made an enormous difference for our family, so we created it to be the helping hand for others in their time of need,” said Bert.

In the two decades since AFA first opened its doors, the Foundation’s services have grown tremendously—“exceeding any vision I originally had,” Bert said. What began with a Helpline that people could call during normal weekday business hours has grown into an organization which provides help seven days a week in more than 90 different languages, holds daily enrichment and therapeutic programs, offers support groups, educational classes, professional trainings, and provides free memory screenings across the country.

“Watching someone you love go through this and not knowing what to do to help felt absolutely horrible. Knowing what I know now, I would’ve done so many things differently for her,” he said.

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Did You Know?

AFA Helpline social workers pride themselves on spending as much time helping and listening as a caller needs—the record for a single Helpline call is over two hours long.

FREQUENTLY ASKED AFA HELPLINE QUESTIONS

- How can I get my loved one to a medical provider when I can see significant cognitive decline, and they are resistant to going?
- My loved one insists on driving though he/she gets lost frequently and is becoming a hazard on the road. What can I do?
- What are things we can do to make the transition to assisted living/memory care easier?
- My loved one refuses to take a shower. What can I do?
- Where can I find a caregiver support group?
- Why does my person say they want to go home when they are already home? How can I address this?
- My loved one is unable to manage their finances anymore. What steps can I take?

How to Connect with the AFA Helpline

Phone: 866-232-8484
Webchat: www.alzfdn.org
Text message: 646-586-5283

“During the Coronavirus pandemic, I often felt alone and invisible. Thank you AFA for helping me give the best care possible to my loved one—while taking care of myself.”
—David J., Caregiver

When Alzheimer’s disease enters your life, it’s impossible to be prepared. From trying to figure out what to do following the initial diagnosis to navigating the legal, financial, and family issues that can arise throughout the course of the illness, living with Alzheimer’s disease or caring for a loved one with Alzheimer’s comes with a variety of emotions, stresses and questions that change as the disease progresses. Having a trusted place to turn to get help in these situations is critical.

A family caregiver founded AFA to ensure other families always had somewhere to turn for help with these types of issues—something which did not exist when his mother lived with the disease. To help carry out this vision, AFA launched a national telephone number, staffed by licensed social workers, to provide guidance, answers, and compassionate support, as well as connect callers with local resources in their community.

When AFA first opened its doors in 2002, its Toll-Free Hotline (now known as the Helpline), was available during business hours, 9 a.m. to 5 p.m. ET, Monday through Friday, to answer questions as basic as “What do I do now?” and “Where do I go for help?” to more in-depth concerns about behavior, stress, and care planning.

Over the years, this important support service expanded significantly. As AFA grew, evening hours were added—because Alzheimer’s doesn’t just impact families during regular business hours. Saturday hours followed, and, ultimately, the Helpline became the seven-days-a-week resource it is today. Technological advances enabled the Helpline to serve families in additional ways beyond just the telephone—Skype, webchat, and text messages.

One of the most significant changes to the Helpline took place in February 2020, with the implementation of a new multilingual chat feature enabling non-English speaking individuals to access support in their primary language through webchat and text message. Through this feature, people who speak Spanish, Chinese, French and 90 other languages can chat in real time with an AFA Helpline social worker. Questions and answers are translated instantly, ensuring that language is not a barrier to much-needed support.

Since its inception two decades ago, the Helpline has provided hundreds of thousands of minutes of support to people in their time of need—over 38,000 minutes in 2021 alone. It’s here for you, too, if you need it—just reach out!
Did you know that a frittata is an egg-based Italian dish? It means omelet in Italian and is popular in the Mediterranean diet, served from breakfast to dinner, hot or cold. Frittatas are typically cooked in the oven, but here it’s cooked entirely on the stovetop. It comes out tasting more steamed than fried, which makes it a healthy vegetarian favorite! Feel free to get creative with the vegetables.

**INGREDIENTS**

Choose organic ingredients when available.

- 1 teaspoon extra virgin olive oil
- 1/2 large white onion, chopped
- 4 large eggs
- 4 egg whites
- 1/4 cup ricotta cheese, part-skim or whole milk
- 1/8 teaspoon red pepper flakes
- 2 cups baby spinach
- 8 cherry tomatoes, cut in half
- 4 pitted kalamata olives, cut in half
- 1 slice Jarlsberg lite cheese, chopped

**Optional Substitutions**

- Use low-fat milk or a plant-based beverage if you don’t have ricotta cheese
- Add 1 cup chopped mushrooms when cooking the onions

**DIRECTIONS**

1. In a large (10-inch) non-stick sauté pan*, on medium-high heat, heat oil and sauté onions until slightly brown and fragrant, 3 to 5 minutes.
2. In a large bowl, whisk eggs, egg whites and ricotta cheese until frothy and smooth; set aside.
3. To the sauté pan, add spinach and tomatoes, and sauté for 3 to 5 minutes. Pour in egg mixture and evenly combine with vegetables. Let set for a minute.
4. Using a spatula, carefully begin to separate egg mixture from side of the pan, tilting pan while doing this so that egg mixture fills the space. Do this all around the pan so that frittata cooks up evenly. Continue to do this until most of egg mixture is spread and only a small layer is left on top.
5. Dot with kalamata olives and cheese. Lower heat, cover and cook for 5 to 7 minutes until eggs are set.
6. Slide frittata out onto a plate or cutting board and slice into quarters.
7. Serve warm. Serves 3 to 4.

*Note: use a non-stick sauté pan with a lid

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**Recipe 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 WorldRD.com.**

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**NUTRITION FACTS**

**SERVES 3, PER SERVING:**

- 292 CALORIES
- TOTAL FAT 16 G
- SODIUM 560 MG
- CARBS 19 G
- PROTEIN 21 G
- DIETARY FIBER 5 G

**See your loved one as a person rather than a victim of disease**

Don’t define your loved one solely by their disease state. “Negate stigma and attitudes actually push along people’s neurological diminishment,” says Rev. Casteel. “We envision people with dementia often as having disappeared from themselves.” Instead of focusing on the person’s memory loss or behavioral changes, encourage what they can do.

**Support familiar routines**

Familiar routines that engage the senses are important. Going for a walk at the same time each morning or attending a music class every Thursday are examples of routines people can rely on and expect. Accept that your person may develop new rituals over time.

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Utilize faith resources
If you have a connection with a faith community, invite them to stay involved with you and your loved one. Familiar rituals, prayers, holiday celebrations, and songs offer important touchstones of meaning and care that don’t hinge on cognitive capacity.

Redirect anxieties
During moments of anxiety, your loved one may say that they’re scared or can’t remember where they are. Reassure them and ask, “What do you see, hear, feel?” to redirect the conversation away from the anxiety.

Engage and communicate to reassure
It’s important to meet your person where they are in the moment. People living with dementia may communicate in ways that we’re not used to. Remember, all actions and speech are meaningful even if we don’t understand. Observe cues (smiling, swaying to music) and assume that your person is trying to express something important. We know that when we’re communicating with someone with dementia it’s best to ask yes or no questions that don’t hinge on recall.

Don’t rush to fill the silence
“We’re trained from an early age to fill the silence,” says Rev. Castel. “We must be willing to sit in silence to receive responses.” Instead, slow down your breath. Sit with your person. Hold their hand to reassure them of your presence. Enjoy the silence, together.

The greatest gifts
Ask yourself: “What gifts may I offer this person, and what gifts is this person offering me?” A gift may be as simple as a smile or a hug. Acknowledge what your loved one brings to their world. Above all, Rev. Castel reminds caregivers, “Take time when you need it. You’re doing the best you can. Know that that’s enough.”

*Questions to ask when considering a memory care community*
Let’s say you’ve been taking care of your loved one with dementia and their care needs have exceeded your skills. Perhaps your health is being affected, or it’s just time for a change in their care plan. Maybe you’ve lost your relationship with them because of your role as caregiver and you want that back. It may be time to start looking for a memory care community.

Care for individuals with dementia and Alzheimer’s can range from assisted living in the earliest stages, when less personalized care is needed, to memory care in mid-to-late stages. Use these questions to guide your search:

**Who’s running the place?** You’ll most likely tour with the community’s marketing and sales director. Talk with the executive director about how you will engage as a family member, how issues are resolved, how staff are trained and what certifications they have, as well as COVID policies and resident security.

**How big or small?** Consider the number of resident rooms, the size of the room, whether they are private or companion rooms, the number of dining rooms, and indoor and outdoor activity spaces.

Continued on following page
What type of medical care is available? Most memory care communities have at least one registered nurse or licensed nurse practitioner on the floor 24/7. Speak to the nursing staff and the medical director before choosing your community to understand their level of engagement with family members.

How do staff interact with residents? All staff should be trained in dementia care. A common caregiver ratio is one caregiver to five or six residents. Some facilities assign residents to the same caregiver every day. All of this may vary. Ask how caregivers are trained to manage dementia behaviors, especially distress, anger, and aggression. It’s important to understand their approach and decide if you feel comfortable with it.

What’s to eat? Yes, food is a factor. What is the meal setting and cleanliness level? Meet the registered dietician and ask about how they’ll address your loved one’s nutrition needs. Find out if there’s an alternative if your loved one doesn’t like a particular meal. Most communities offer sandwiches or some other palatable option to each hot meal.

What types of stimulation are available and how often? Do they have specific areas to accommodate higher-functioning and lower-functioning individuals? How do they ensure activity participation? How much time do residents spend in their rooms, if any? I favor no TV in the resident rooms because it requires them to leave their room to seek stimulation.

Are companion rooms available? If a private room is not available or if budget is a concern, a companion room is a great option. The executive director will match the information of your loved one with another resident and they’ll observe the compatibility. They want your loved one to be happy. My mom had a private room and it always felt empty. When I switched her to a companion room, both women seemed happier.

Are they regulated? Regulation varies by state, not by community, and is typically overseen by the state’s Department of Health. Search your state’s Department of Health website for a list of regulated facilities.

Is there a waiting list? Unfortunately, waiting lists are common, especially at the best communities. When they’re at capacity, you have to wait for an opening. To me, this is the key reason to start your search when symptoms are first observed. You can get on waiting lists and then pass if you’re not ready. Find out if there are any consequences to passing.

How much does it cost? Many people sell their homes and use the profits to pay for memory care. Medicaid can help with expenses if the community accepts Medicaid payments and your loved one qualifies. Medicare does not pay living expenses, only medical expenses.

A side benefit to selecting the right community is the amount of relief you feel knowing that your loved one is being well cared for and encouraged to engage in a way that’s comfortable for them. They are being supported by professionals who are experienced in dementia behaviors. Most family members feel some level of guilt for not keeping their loved one at home. Knowing that they’re getting better care than you can provide makes that guilt sting less, allowing you to focus on your relationship with your loved one instead.

Seek Out Local Referrals

Search for a local senior living placement agency in your state (e.g., National Placement and Referral Alliance [NPRA]: npralliance.org). These agencies facilitate care community selection. As locals, they know more about which communities are best for specific needs.

AFA’s Helpline can also provide information about finding senior living facilities—call 866-232-8484 or visit www.alzfdn.org.

About the Author

Pam Ostrowski is author of It’s Not That Simple: Helping Families Navigate the Alzheimer’s Journey and Founder of AlzheimersFamilyConsulting.com

The United States does not have an official language designated by the federal government. Almost every language in the world is spoken here, and almost every known religion is practiced.

What does any of this have to do with dementia care? A lot, particularly if there are cultural differences or clashes that disrupt appropriate care.

Photo courtesy of Jennifer Lagemann

What is cultural identity?

It’s the feeling that we belong to a group of people. Cultural identities can be many: ethnicity, religion, birthplace, gender, language, profession, even music. Culture reveals itself through patterns of behavior that include our beliefs and values, how we use language, communicate with each other, and practice habits and customs.

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Continued on following page
Understanding of dementia differs among cultures
Not all cultures view dementia as an illness, so it’s important to be aware of common hurdles caregivers may face when working cross-culturally. Even the meaning of the word “dementia” is not universally understood. Some cultures consider it a normal part of aging and therefore not something to be concerned about. Others feel a stigma associated with dementia that may lead to a family postponing diagnosis or seeking medical attention. While dementia occurs across cultures, the experiences of non-Western settings has not been well-studied. Some groups may not have words for what we call “Alzheimer’s disease,” often instead using “crazy” or “mental” to describe changes in memory and behavior.

Importance of being “culturally competent”
Today’s caregivers and health care providers need to be “culturally competent”—that means having the ability to understand, appreciate and interact with people from cultures or belief systems different than their own. This may involve managing language barriers and taking time to learn about a person’s background to provide culturally responsive health care options.

“When caregivers fail to recognize cultural differences between themselves and the person they are caring for, misunderstandings can be perpetuated and sometimes even discrimination can occur,” warns Jennifer Reeder, LCSW, SIFI, Director of Educational and Social Services at the Alzheimer’s Foundation of America.

It’s important to acknowledge that minority groups are more likely to face discrimination when seeking health care. Also, lifelong discrimination may lead to an increase in risk factors related to developing dementia, such as type 2 diabetes and high blood pressure.

Most importantly, understand that there is no “one-size-fits-all” approach to care. “Caregivers—family and professionals—need to understand that cultures are constantly evolving. Think about how the views and practices of your own culture have changed over different generations,” says Reeder. “This is a lifelong process of learning.”

To address the important topic of cultural competency in caregiving, the Alzheimer’s Foundation of America is launching two new professional training webinars, each offering 2 continuing education (CE) credits this year: Micro-Level & Macro-Level Cultural Consideration in Dementia Care. To learn more, go to alzfdn.org, and click on the Professional Training & Education tab.

Steps Caregivers Can Take to Become More Culturally Competent
By Laurel Gumpert, MPH, MBA, CHES
Education Program Coordinator, AFA

1. **Keep Learning.** Cultural competence is not a one-time goal, but an ever-evolving, ever-changing way of living our lives. We do not just become culturally competent, but rather we constantly learn and grow to better understand others.

2. **Know That As Much As We Learn, We Will Never Fully Understand.** We want to be able to build empathy, but we will never truly know what others have lived and experienced. That is okay.

3. **Meet People Where They Are.** If someone does not speak the way you do, or learn the way you do, find a way to communicate that works best for them. This means being adaptable and flexible with our communication strategies.

4. **Advocate!** No matter what your profession, where you live, or what you do, you can be an advocate for health equity so that everyone has equal access to the healthiest life possible. Speak to local representatives, health care providers, continue to learn and grow, ask questions, and help individuals become informed consumers of health services.
RESEARCH UPDATE:

Searching for New Psychosis Treatments

Hallucinations, delusions, and aggression are among the most common symptoms of dementia-related illnesses, as well as the most problematic—difficult to treat and highly challenging for caregivers and family members. Persistent psychotic symptoms and violence or aggression can be dangerous and emotionally devastating, both for caregivers and individuals with dementia. Often, these behaviors are an indication for placing a loved one in a residential health care setting.

Scientists at the Feinstein Institutes for Medical Research are working to find solutions—expanding research efforts into developing new treatments to address these troubling symptoms. Led by Dr. Jeremy Koppel, the new study, funded by a $998,156 grant awarded by AFA in January 2022, builds on previous research the team conducted from 2016-2021 which found a link between abnormal tau protein in brain regions and psychosis. A $500,000 AFA grant funded that research.

“The funding provided by AFA made our work possible; and the ongoing support is critical, allowing us to do the necessary research to translate these discoveries into safe and effective treatments for patients and caregivers,” said Dr. Koppel.

Over the next five years, researchers will further investigate the association between abnormal tau proteins and psychosis using advanced tau PET imaging technology. The study is comprised of three types of participants—those with both Alzheimer’s and psychosis, those with Alzheimer’s but without psychosis, and healthy controls between the ages of 65 and 85.

Interested in supporting research like this? Visit alzfdn.org/donate or call AFA at 866-232-8484 to donate.
Alzheimer’s TODAY Reader Survey

Thank you to the more than 500 participants who provided feedback to our reader survey!

Here’s what they said:

Survey respondents who indicated that the content of Alzheimer’s TODAY is helpful.

Survey respondents who indicated that they like the amount of content in each issue.

What Led You to Subscribe to Alzheimer’s TODAY?

- My family member/friend has Alzheimer’s 81%
- I’m a professional working with Alzheimer’s 20%
- I work at an educational institution 5%
- I have Alzheimer’s 1%
- I work at an educational institution 1%

Most Beneficial Topics

- Caregiving Tips 83%
- Medical/research/scientific updates 79%
- Available support programs and services 71%
- Personal and human-interest stories 63%

Here’s What Readers Are Saying:

“Alzheimer’s is a long journey for everyone involved. It is helpful to know you and your loved one are not alone. You normalize it a bit.”

“Thank you for all you do for all of us. You cover so many stories, topics, etc. I learn so much. All of these topics are very important to me.”

“You’re providing valuable information that I share with my caregivers.”

“I look forward to receiving each issue. Appreciate there is such a variety of articles, you cover all the bases.”

“Thank you for all you do for all of us. You cover so many stories, topics, etc. I learn so much. All of these topics are very important to me.”

“I look forward to receiving this because it helps me cope and deal with my mom who has Alzheimer’s.”

Didn’t complete the survey yet? Share your feedback with us at alzfdn.org/alztodaysurvey.

Have You Gotten Your Memory Screening Yet?

Memory screenings should be part of a good health and wellness routine for everyone! You can get one for free through the Alzheimer’s Foundation of America’s National Memory Screening Program.

A memory screening is a free, 10–15 minute healthy brain checkup, similar to other routine health screenings, such as blood pressure and cholesterol. Memory screenings consist of a series of questions designed to test memory, language, thinking skills, and other cognitive functions.

Memory screenings are noninvasive and confidential and are performed one-on-one by a qualified professional. AFA currently offers virtual memory screenings conducted through secure video conferencing technology. All that’s needed is a computer, smartphone or tablet, or any other device with a webcam and internet capability.

Results are not a diagnosis, but screenings can suggest whether further evaluations should be conducted by a physician. AFA’s memory screening program is offered in English and Spanish, and there are no minimum age requirements or insurance prerequisites. More than 5 million people have been screened nationwide!

The first 100 people to register for a memory screening test will receive a special gift from AFA!

Screenings are done by appointment, which can be scheduled by calling AFA at 866-232-8484 or visiting alzfdn.org.
The mission of the Alzheimer’s Foundation of America (AFA) is 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.

GIVE THE GIFT OF LOVE, CARE, & HOPE

Donate today at www.alzfdn.org/donate