Caring for a family member with dementia may involve a lot of “juggling” to manage the demands of caregiving as well as your personal responsibilities. Feeling stress is natural, but if left unchecked, continuous stress can negatively impact your physical and mental health and hinder your ability to provide proper care.

Here are some tips to help manage the stress associated with caregiving:

**Self-care is crucial.**
Prioritizing the well-being of the person you are caring for while sacrificing your own is noble but can be detrimental. Failing to care for yourself increases risk of caregiver burnout, which compromises your ability to provide quality care and negatively impacts the person for whom you are caring. Self-care is critically important. Find ways to reduce stress: Working out and breathing exercises are helpful. Make time for yourself, too. Even short breaks go a long way to help recharge your mind and your body.

**Ask for help.**
Support is vital. Family, friends, community and professional caregivers can all lend a helping hand in different ways, but if left unchecked, continuous stress negatively impacts your physical and mental health. It’s important to consider what services are available in your community today. Contact AFA’s Helpline at 866-232-8484 to speak with a licensed social worker. Ask for help.

**Prepare as much as possible.**
Caring for someone with dementia often involves a complex array of long-term medical, legal and financial issues. Deal with these decisions as early as possible, with strong consideration for personal wishes, to help reduce stress later. Addressing these matters early also gives the individual the opportunity to have a more active role in their care and the decision-making process.

**Build your skills.**
Key skills for any care partner include communication, understanding safety considerations, recognizing behaviors as a form of communication, and managing activities of daily living. Get to know doctors and other care team members. Ask questions, express concerns and be involved.

**Be flexible.**
While you can’t control every situation, you can work to better manage your reactions. While it may seem impossible at times, try to have a positive and accepting attitude; be flexible and understand the need to adapt. Take things one day at a time and handle challenges as best you can. Don’t feel that you have to deal with everything at once.

**Connect with others.**
Hugs, gentle touch and compassion help you and the person you are caring for feel connected and loved. Kindness, humor and creativity are essential. Manage your expectations and remain patient. Find your support network and surround yourself with positive connections, both old and new!

**Build empathy.**
Building empathy and maintaining compassion is essential for both you and the person you care for. Try to comprehend what it is to have this type of illness. Putting yourself in their shoes, while also recognizing your own losses, can help place things in perspective and alleviate stress.

**Feeling stressed? We’re here to help.**
Contact AFA’s Helpline at 866-232-8484 to speak with a licensed social worker.
A MESSAGE FROM
CHARLES J. FUSCHILLO, JR.
AFA PRESIDENT & CEO

With more than 5.8 million people living with Alzheimer’s today, I don’t believe that there are any American families who aren’t personally affected by it or don’t know someone else who has been. AFA aims to reach everyone with Alzheimer’s awareness, and we believe that it’s never too early to start talking about it when someone you love is impacted. That’s why we just published our new children’s book, Dancing with Grannaddad: An Alzheimer’s Story for Children and Their Families. (You can learn more about it on pp. 12-13.) We hope that you will share it with the children in your life.

Staying on the topic of our youth, we congratulate and share the touching stories of how Alzheimer’s affected the three top winners of AFA’s Teens for Alzheimer’s Awareness College Scholarship Essay Contest, on pp 18-19.

The wonderful Teepa Snow, a leading advocate and educator and founder of Positive Approach to Care (PAC), reminds us of the importance of caregiver observation skills in “Recognizing Symptoms of Anxiety and Depression in Persons Living with Dementia” on pp. 4-5.

We took on the important topic of “Racial Disparities and Their Impact on Dementia,” pp 16-17, with a special virtual webinar featuring Rep. Maxine Waters (D-CA), Dr. Jennifer Manley, Dr. Roland Thorpe, and AFA Board member Luisa Echevarria.

The COVID-19 pandemic changed many facets of life for us, including how to obtain and provide services. AFA now offers free virtual memory screenings every Monday and Wednesday, 10 a.m. to 4 p.m. (ET), and every Friday from 10 a.m. to 2 p.m. (ET). Learn more by reading “Memory Screenings Go Virtual,” p. 24. (A Spanish translation of this important article is on p. 23—please share with a friend!)

Nearly a decade ago, the federal government made Alzheimer’s disease a national priority by passing the National Alzheimer’s Project Act (NAPA). “Has Washington Fulfilled its Promise?” on pp. 9-10 shares expert insight from Sen. Roy Blunt (R-MO), Rep. John Garamendi (D-CA), Dr. Allison Reiss, and Dr. Mony de Leon.

We hope this new issue of Alzheimer’s TODAY provides you and your families with the tools and inspiration you need. We’re here for you.

All the best to you and your families,

Charles J. Fuschillo, Jr., AFA President & CEO

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EDITORIAL

W e’re having a difficult, but much needed, conversation in America right now about race and equality.

Tragic events throughout the country, including senseless deaths and acts of violence, have sparked outrage and anger nationwide. We strongly condemn racism and violence in any form and reaffirm the right for all Americans to live in a peaceful society, with full equality and respect, free from prejudice, discrimination, and hate. Intolerance against anyone should be intolerable to everyone.

Alzheimer’s disease and other dementia-related illnesses affect individuals of all races, ethnicities, genders, and economic backgrounds, but they have a disproportionate impact on minority communities. There are a number of factors involved, including lack of health insurance, distrust of the medical system, and socioeconomic status (you can read more about this in our article, “Racial Disparities and Their Impact on Dementia,” later in this issue, pp. 16-17), but the fact remains that we as a country need to do more to change that. As America has an important and much-needed national discussion about race and equality, breaking down barriers to care for Black and Hispanic-Americans, once and for all, must be part of the conversation.

Time and time again, we’ve said in these pages that Alzheimer’s is a public health crisis, not a political issue, and applauded Republicans and Democrats in Congress and the White House for treating it that way, coming together to make significant progress in the fight against Alzheimer’s disease, including significantly increasing federal funding for Alzheimer’s research. They’ve put politics aside before to further the fight against Alzheimer’s before. They need to do it again.

Dr. Martin Luther King, Jr., was once quoted as saying, “We must accept finite disappointment but never lose infinite hope;” We strongly believe in never giving up hope, because without it, all is lost.

When people come together with good intentions and work constructively in good faith, good things happen. ■
Recognizing Symptoms of ANXIETY and DEPRESSION in Persons Living with Dementia

One of the most important things you can do as a caregiver is use and build your observation skills,” says Teepa Snow, a leading advocate and educator on dementia and founder of Positive Approach to Care (PAC), at a recent AFA webinar. “We make a lot of assumptions rather than making assessments. We do a lot of moving forward before making sure we have people on the bus with us. Notice when someone is showing us signs of distress and depression. Don’t miss these cues in your interaction with the people you care for.”

In this time of the COVID-19 pandemic and increased isolation, observation is more important than ever. Those living with dementia, as well as caregivers, have isolation, observation is more important than ever. In this time of the COVID-19 pandemic and increased interaction with the people you care for.

HOW TO ASSESS YOUR INTERACTIONS
Remember, every interaction with a person living with dementia is an opportunity to observe, assess, and respond to what is really going on. Some tips to keep in mind, from Snow:

- Use your greeting to screen for affect.
  * Start with “How are you?” Use visual cues and simplified words or sounds, such as thumbs up, thumbs neutral or thumbs down.
- Use empathy, acknowledge reactions.
  * Use reflection to confirm. If they say, “I need something,” you would respond, “You’re needing something?”
  * Affirm the message. If they say, “No, I don’t like that!” you would respond, “OK, you really don’t like that!”
  * Sometimes saying “I’m sorry” helps: “I’m sorry I disappointed you.” “I’m sorry this is making you feel…” “I’m sorry this is happening; it shouldn’t have,” “I’m sorry this is so hard.”
- Listen and try to figure out the meaning of the message.
  * Consider what need is unmet or emotion is being shared: “More coffee?” “Are you missing home?” Use fewer words whenever possible to make comprehension easier.
  * Consider a response.
  * Offer options: “This or that?” or “This, or something else?”
- Affirm you got the message. If they say, “I need something,” you would respond, “OK, you really don’t like that!”
  * Sometimes saying “I’m sorry” helps: “I’m sorry with emotion, “OK, you really don’t like that!”
- Use reflection to confirm. If they say, “I need something,” you would respond, “OK, you really don’t like that!”
- Affirm you got the message. If they say, “I need something,” you would respond, “OK, you really don’t like that!”

WHAT TO LOOK FOR
Keep in mind that anxiety is a symptom of distress. Beyond feeling stressed, anxiety is the more persistent, worrying, fearful feeling articulated in a statement such as, “I don’t know what to doooon.” Depression, on the other hand, reveals itself in statements like, “Why are you bothering me with this?” “I don’t care.” or “I can’t take this,” often initially with a flat affect but can turn into irritability or even anger. Many elders with depression are resistant to seeking help and describe themselves as having “memory problems” or complain of “pain” rather than “sadness.” But if situational depression is not addressed, it often escalates—try to alleviate it when you see it.

But is it even possible to distinguish between anxiety, depression, and dementia? Snow believes it is possible and important to take the time to try. Why? “Because if we can help people control their symptoms of anxiety and depression, often the dementia symptoms will seem less severe.”

WHAT DEGREES OF EMOTIONAL DISTRESS
irritated vs. angry vs. furious
blue vs. sad vs. hopeless
missing someone vs. lonely vs. abandoned
missing freedom vs. trapped vs. imprisoned
anxious vs. scared vs. terrified
not engaged vs. bored vs. purposeless
distracted vs. antsy vs. exit-seeking

LOOK FOR CHANGES IN BEHAVIOR
- appetite
- sleep
- self-care
- pleasures
- irritability

LOOK FOR POTENTIAL CAUSES
- therapy
- physical activity
- schedule changes
- environmental support
- medication

BE PROACTIVE ABOUT MENTAL HEALTH
Caregivers should be proactive about maintaining the mental health of the people in their care.

- Have a daily routine
- Help to fill days with a balance of meaningful activity
  * productive activity (feeling valued)
  * leisure activity (having fun)
  * self-care activity (wellness, health, personal care)
  * restorative activity (sleep, rest, reenergizing)
  * large group, small group, 1:1 time, and alone time
  * active vs. passive time
- sensory options: visual, auditory, tactile, olfactory, gustatory

Adapted from an AFA Care Connection Webinar, “Recognizing Symptoms of Anxiety & Depression in Those Living with Dementia” led by Teepa Snow, Founder, Positive Approach to Care. Visit www.alzfdn.org to learn more about upcoming webinars. Contact AFA’s Helpline at 866-232-8484, seven days a week, with any questions about anxiety or depression.
INGREDIENTS
(Choose organic ingredients when available.)
• ¼ cup cold-pressed extra virgin olive oil
• 2 cloves garlic, minced
• 1 small white onion, chopped
• 2 stalks celery, chopped
• 5 large carrots, chopped
• 1 large potato, chopped
• 3 cups broccoli florets
• 3 cups low-sodium vegetable broth
• 2 cups 1% (low fat) milk
• Sea salt to taste
• Freshly ground black pepper to taste
• Pinch of cumin
• Freshly grated Parmesan cheese (optional)

This is a delicious and healthy vegetarian broccoli soup recipe that can be served year-round with crusty whole grain bread. If you want to increase the protein, add one cup of prepared white beans at the same time that you are adding the broccoli. This plant-based soup is brimming with vegetables that are full of antioxidants, fiber, vitamins, and minerals.

DIRECTIONS
1. In a large soup pot, heat oil, add garlic, onion, celery, carrots, and potato. Sauté for 10 minutes or until softened.
2. Add broccoli, broth, and milk. Simmer for 5 to 7 minutes.
3. Allow to cool slightly. Then transfer soup to a food processor and pulse a few times. Do not puree! Broccoli pieces should be visible.
4. Return to soup pot; season with salt, pepper, and cumin.
5. Reheat and serve with grated Parmesan cheese.
6. Buon appetito!

When you have a family member living with Alzheimer’s in your home there will likely come a time when you will need additional support to provide quality care. The idea of bringing someone new into your situation may be anxiety producing for you or your loved one, but it need not be if you take the process slowly, knowing that home health assistance can be the best thing for the entire family.

How do you find a home care agency? What types of services do they provide? How do you introduce home care to someone who may not feel they need it? All of these are common questions for families caring for a loved one with a dementia-related illness. Grace Townley-Lott, LMSW, Director of the True Bridge Program at True Care Home Care in New York City, leads us through some of the answers.

Let’s start with one of the most important considerations: introducing home care to someone who may be reluctant to accept it. Townley-Lott shares this advice on how to begin:

 Ease into it. The introduction of a new care person into your home setting may feel like an unwelcome loss of independence for a loved one. Consider introducing new help as a “temporary situation” for just a few hours a week. Perhaps you need a little extra help over the holidays or while you are getting through a big project at work. This will also give you a chance to try out a new arrangement on a more limited basis.

 Help the change feel less intimidating. Introduce the new aide as a friend who is coming over to share an engaging activity, such as sharing an afternoon of music, going for a walk or playing a game. Start with a few of your housekeeping tasks first. Wait until your loved one gets more comfortable before introducing personal activities, such as bathing and dressing.

 Take the “blame.” If your loved one remains resistant to the new change, suggest that this person is helping you. “This puts your loved one in the position of doing a favor for you instead of putting themselves in the weaker position of having care imposed on them,” says Townley-Lott. “You are asking them to help you out by accepting this extra help in your home.”

 Give the “blame” to another professional. You can always ask a trusted doctor to write a note that recommends extra support in the home. Make a few copies of that note and be sure to share it or remind them, kindly, as needed.
Has Washington Fulfilled Its Promise?
Experts Discuss Progress Made Since Alzheimer’s Declared a National Priority

Early a decade ago, the federal government made Alzheimer’s disease a national priority by passing the National Alzheimer’s Project Act (NAPA). This led to the creation of a National Plan to Address Alzheimer’s Disease that, among other goals, called for the development of a cure or disease-modifying treatment by 2025. So, how much progress have we made?

That’s the question discussed during an AFA webinar featuring a panel of federal elected officials and research experts: Senator Roy Blunt (R-MO), Congressman John Garamendi (D-CA), Dr. Mony J. de Leon of Weill Cornell Medicine, and Dr. Allison B. Reiss of NYU Winthrop Hospital and a member of AFA’s Medical, Scientific and Memory Screening Advisory Board. Former Congressman Steve Israel, Director of the Institute of Politics and Global Affairs at Cornell University and a member of AFA’s Board of Directors, moderated the discussion.

One major point of progress all panelists agreed upon was the consistent, significant increases in federal funding for Alzheimer’s research. Since the adoption of the National Plan to Address Alzheimer’s Disease, federal funding grew from approximately $500 million a year to $2.82 billion in fiscal year 2020. All stressed, however, that federal policymakers must remain committed to building on that progress and making sure that these resources are allocated in the right way.

Senator Blunt and Congressman Garamendi were optimistic that would happen, noting that both Republicans and Democrats recognize the overwhelming physical and financial burden of caregiving and the importance of easing it. Garamendi indicated that virtually everyone he speaks with in Congress has some tie to the disease and that he, himself, was a caregiver.

“It is personal. My wife’s mother suffered with Alzheimer’s and spent the last three years of her life living with us in our home. We watched the progression of the disease over the previous years, slow and steady, and eventually she passed away,” Garamendi stated. “The experience is one that my wife and I said we want to deal with. We also recognize that we are not alone.”

Tomasz Szymanski | Dreamstime.com

Adapted from an AFA Care Connection Webinar, “An Introduction to Home Care,” led by Grace Townley-Lott, LMSW, Director of the True Bridge Program at True Care Home. Visit www.alzfdn.org to learn more about upcoming webinars. Contact AFA’s Helpline at 866-232-8484, seven days a week, with any questions about home care.
Blunt noted the dire need for state and federal programs to provide caregiver relief such as supporting in-home care, both for quality of life and economic reasons, as the tax costs of caring for individuals with Alzheimer’s could reach the trillions by 2050.

“The caregiver issue is a big one,” Blunt said. “Caregiver income loss is almost never covered by insurance.”

Blunt and Garamendi also noted other public policy advances, the Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer’s Act. The BOLD Act, which became law at the end of 2018, will create a pathway toward treatment for millions by funding the establishment of centers for brain health and diagnosis across the country.

On the research side, Reiss and de Leon noted that much has changed over the last decade, particularly in identifying risk factors for Alzheimer’s disease, such as cardiovascular disease, racial ethnicity, and gender. New research is exploring the risk factors of diabetes, sleep disorders, and head trauma. “Forward movement of this field [today] is in internal medicine...where the whole body is part of the story of the degenerative disease,” said de Leon. “It’s not simply a brain disease.”

Reiss stressed that “science needs to be done differently.” She has observed “the use of incredible amounts of resources that keep repeating the same ineffective approaches.....We need to think outside the box.”

De Leon pointed out the growth in the biomarker fields due to technological advances. “In the past, CT and MRI scans were the primary diagnostic tools, but were not as effective.”

“Technologies have evolved into ones more specific for pathologies such as amyloid PET, amyloid tau, and other markers. This arena is a hot one,” said de Leon.

To help ensure continued progress, the panelists encouraged families to share their personal Alzheimer’s stories with their federal representatives in the House and Senate, stress how the disease impacts and affects them, and urge continued support for further funding increases for research, direct care services, and supportive programs.

Overall, the panelists believe that we are on the right path. “Alzheimer’s research is propelled and encouraged by a four-legged word, HOPE....There are opportunities and success somewhere out there in the future,” said Garamendi.
Talking to Young Children About Alzheimer’s

When a member of a family is diagnosed with Alzheimer’s, everyone is affected, including our children. Young children, in particular, may sense that something is amiss, but not be able to understand the subtle changes that are occurring early on in the progression of the disease. You may wonder, when is it a good time to talk to children about Alzheimer’s?

“The best time to talk to children about Alzheimer’s or any dementia-related illness is as soon as you can,” says Jennifer Reeder, LCSW, AFA’s Director of Educational & Social Services. “This conversation is about nurturing and maintaining the bonds between the family members while also helping to eliminate the fear of the unknown for children. We want to talk about this with the children in their lives, usually with the help of another family member. But that may not be possible.

One of the easiest ways to begin a conversation about Alzheimer’s disease with a young child is with a picture book. That is why AFA created Dancing with Granddad: An Alzheimer’s Story for Children and their Families. Written for children, ages five through eight, by Linda Bozzo and illustrated by Mudassir M. Abid, the new book takes young readers on the journey of learning in an age-appropriate way that the granddad of seven-year-old Nia has Alzheimer’s and will need to move to a new home. They also learn that while Nia’s granddad is changing, the love between them never will. The book gently introduces her grandfather’s behavior changes (such as retelling stories, wandering, agitation and confusion), but also shares the constant of the loving relationship between Nia and Granddad as well as her caring parents who arrange a transition to an assisted living facility where he will be safer. The book, which includes a message from AFA about how to talk with children about Alzheimer’s disease, is a jumping off point for every family.

Says Reeder, “Young children are very egocentric, so it is effective to explain complicated topics through situations and analogies that can relate to the child’s world.” Some of her suggestions:

- A person with a dementia could say, "You know how I tell you all the time that I’m so amazed by the way you remember just about everything? Well, I’m going to need your help to remember things, like people’s names, things I’m supposed to do for you, maybe even how to tie my shoes! That’s what happens when someone has Alzheimer’s like me. If ever you forget your face or your name, just remember, it’s the Alzheimer’s that’s getting in my way; it’s not me. So just hold my hand and remind me that I am safe with you."

- "It’s just like when you are swimming with your friends and you try to talk to each other under water. Using only words doesn’t work very well; you have to make gestures with your arms and hands. Grandma may have a hard time hearing and understanding all your words, so you may need to act out your stories, too."

- "Think about when you are listening to music and someone comes up behind you and taps on your shoulder to get your attention. That can scare you because you weren’t expecting them. Same with your granddad: Alzheimer’s sometimes distracts him from what’s around him, so you always want to approach Grandpa in a way that he can see you so you don’t startle him."

- "Draw lots of pictures that explain the stories you want to tell them.

- "Let them know you’re coming for a visit to draw a picture, tell a story, give a hug, etc.

- "Always ask them one question at a time and wait for them to respond.

- "Always ask them first if they would like a hug, if they say no, that’s ok. Explain, “Your grandma will always want a hug from you, but sometimes the Alzheimer’s doesn’t want a hug that day.”

- "Always remind the person who you are.

- "Talk slowly.

- "Always remember to give them a hug and tell them how much you love them.”

The book, which includes a message from AFA about how to talk with children about Alzheimer’s disease, is a jumping off point for every family.

AFA Publishes New Children’s Book Dancing with Granddad to Ease Into Conversation

We want to give children (and adults) the basic tools to communicate effectively so that they will have a positive experience.

Advice for children to help them talk to someone with a dementia:

- Always remind the person who you are.
- Let them know you’ve come for a visit to draw a picture, tell a story, give a hug, etc.
- Talk slowly.
- Always ask them one question at a time and wait for them to respond.
- Always ask them first if they would like a hug, if they say no, that’s ok. Explain, “Your grandma will always want a hug from you, but sometimes the Alzheimer’s doesn’t want a hug that day.”
- Draw lots of pictures that explain the stories you want to tell them.

Order Dancing with Granddad through the AFA e-store at shop.alzfdn.org, by calling 866-232-8484 or by filling out the order form on the back inside cover of this magazine.
Secrets to Caregiver Survival

Caregiving is hard. And when you are caring for someone with dementia, it’s especially difficult because you will never have any influence or control over the progression of the disease or the impact it will have on your loved one. So how do you deal with the anger, guilt, depression, and grief?

Caregiver and speaker Elaine K. Sanchez, founder of CaregiverHelp.com, and author of the unflinchingly honest and surprisingly funny book Letters from Madelyn: Chronicles of a Caregiver, recently addressed this question at an AFA virtual Educating America Tour conference.

Sanchez’s book, based on the letters her mother wrote to her during the six-and-a-half years she cared for Sanchez’s father after he suffered a debilitating stroke, is every caregiver’s experience: a wide range of challenging emotions on nearly a daily basis, including anger, frustration, fatigue, fear, guilt, depression, and grief.

But Madelyn realized that by controlling her thinking and her emotions, she could find her own peace and happiness from within. Early on, she developed a “detached” attitude toward the events and situations that were causing her the greatest amount of emotional stress. In time, her “detached” attitude morphed into what she called an “attitude of creative indifference.” Said Sanchez, “What this means is not allowing yourself to become emotionally ravaged by the disease or the progression of events.”

Sanchez encourages caregivers to practice being responsible for their own feelings and happiness. Using caregiver guilt as an example, Sanchez asks caregivers to apply the three steps.

1. Awareness: Sanchez recommends going to your computer or getting a pad and a pen and writing down exactly what is upsetting you.

2. Acceptance: This is a difficult step because it requires a caregiver to accept that who their person was, and what their life was like before the illness, is in the past.

3. Action: There are two parts to this. The first step is to determine if a problem you are facing has a solution. If it does, you need to make a plan, execute it, and move on. But it doesn’t, and sometimes that is the case in caregiving, the action step is to choose whether to obsess over it or release your emotional attachment to it.

Sanchez encourages caregivers to practice being responsible for their own feelings and happiness. Using caregiver guilt as an example, Sanchez asks caregivers to apply the three steps.

Examples include:

I regret that I sometimes get angry and say mean things to my care receiver.

I regret that I resent the amount of time it takes to provide for their care.

I regret that our relationship has changed.

I regret that there are days when I wish it would all just end.

I regret a lot of things, but I don’t do GUILT anymore.

Sanchez reminds caregivers, “When you get to the end of your caregiving journey and reflect on all you have done and all you have given, you will understand the magnitude of your gift to your loved one. You will realize that through it all, you have been stronger, smarter, braver, and given more than anyone could have ever reasonably asked for or expected. One day you will realize that through it all, you were growing in beautiful and unexpected ways, and eventually you will be able to release your role as a caregiver. You will never forget them, but you will be able to move forward and start a new life.”

Elaine Sanchez’s book, Letters from Madelyn: Chronicles of a Caregiver, is available on Amazon, in bookstores, and on her website, CaregiverHelp.com.

Have caregiving questions or need support? Contact AFA’s Helpline at 866-232-8484 or by web chat through www.alzfdn.org.

A study researching a different approach for mild Alzheimer’s Disease using a neurosurgical procedure called Deep Brain Stimulation (DBS) is seeking participants who:

- Are 65+ years old
- Have mild Alzheimer’s Disease
- Are currently taking or have tried an FDA-approved medication for dementia
- Have a caregiver or family member who can accompany the patient to doctor visits

Contact Info
Functional Neuromodulation
Phone: 1-866-296-4040
Email: info@fxneuromod.com

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“It is a persistent and tragic problem affecting minorities.” – Maxine Waters

Medical Center, said the “root cause is gaps” when it comes to dementia risk factors, accessing quality of care and caregiver burden. “It appears that the context in which people live, even in childhood, impacts the effects that biological changes in the brain have on cognitive function,” said Manley. She referred to racial inequalities in schooling, and, particularly, limited governmental investment in schools that serve minorities as causes that could lead to cognitive disorders later in life.

Roland J. Thorpe, Jr., PhD, Professor of Health Behavior and Society at Johns Hopkins Bloomberg School of Public Health in Baltimore, MD, stressed the need for change in the health care system, estimating that 45% of the nation will be a racial minority by 2060.

“TWe need to open the communication gap,” says Thorpe. “There is a mistrust that people have with the medical system. We need to establish trust and communication. Listen to the patients.”

Luisa Echevarria, Director of Community Empowerment for Univision in Chicago, IL, and a member of AFA’s Board of Directors, cared for her grandmother and mother when they lived with Alzheimer’s disease. She said that Latinos tend to have higher levels of stress, and that being part of a family impacted by a dementia-related illness causes even greater anxiety. “There is a stigma associated with cognitive disorders. We need to de-stigmatize it simply by talking about it,” she said.

All panelists stressed the importance of lifestyle changes in reducing the risk of developing a dementia-related illness, but also noted inequalities in accessibility to practicing wellness. Exercise, for example, is something that everyone should do, but not all neighborhoods have gyms or health clubs.

Proper diet is essential for good brain health, and good health overall, but in some minority communities there is limited access to affordable and nutritious food. In some cases, there may not even be a grocery store.

“At a local level, you need to think about developing programs that ensure you get fruits and vegetables into these food deserts,” Thorpe said. “We need a top-down approach and bottom-up approach working together at the same time….If you invest in the community, the stores will come.”

All agreed that addressing these important issues will take a collaborative effort.

“We have made a lot of progress on Alzheimer’s issues over the past several years. But we still have a lot more work to do,” Waters said.
A competition began in 2008. Since then, college scholarships have been awarded every year. Nearly $300,000 in scholarships were awarded, the largest single mentions through the 2020 contest. A total of more than 1,700 students have been awarded scholarships ranging from $5,000 for first prize to $400 for honorable mentions through the 2020 contest. A record 59 students were awarded college scholarships for college.

Thousands of students write emotional and heartfelt essays to share their stories through AFA’s College Scholarship Essay Contest. Each year, high school seniors across the country are encouraged to work with in Memory Care, thank you—thank them for their hard work, compassion, and dedication.

A common misconception about Alzheimer’s is that young people are immune from its affects. On the contrary, children and young adults across the country are deeply impacted by the disease: They serve as caregivers for loved ones living with Alzheimer’s disease, volunteer their time at care settings, raise awareness and funds, and, in some cases, even conduct research toward a cure.

First-place winner Pilar Elaine Carson from Bend, OR, who won a $5,000 scholarship, wrote about her grandfather who lived with Alzheimer’s disease and her experiences working in a memory care facility. She recalled fond memories with her grandfather before and after Alzheimer’s disease and how things changed as the disease progressed and he moved into a retirement home. Pilar also described working in a local memory care facility where she participated in art projects, gardening, exercise, “Coffee Talks,” and numerous other activities with the residents.

“Thank you for teaching me not to be afraid of the brutal word ‘Alzheimer’s.’”

“Your grandfather’s Alzheimer’s Disease changed me. Upon first entering Memory Care, I was expecting to find the fragile shells of people, shells with whom I wouldn’t be able to relate. Instead, the unexpected occurred: I discovered that people living with dementia and Alzheimer’s Disease were, in fact, just like everyone else I knew: compassionate, funny, insightful, and chatty.”

Pilar’s experiences taught her many life lessons and inspired her to study psychology and political science at Occidental College in Los Angeles. She will focus on how best to interact with individuals in varying stages of Alzheimer’s disease and to help bring more urgency to Alzheimer’s research and finding a cure through the legislative process.

Second-place winner Emma Civello of Southampton, MA, who received a $2,500 scholarship, wrote about her experiences volunteering to play cello for nursing home residents, many of whom had Alzheimer’s disease, as part of her high school’s community service requirement and the joy that the music brought them.

Emma’s experiences and the many bonds she formed motivated her to continue volunteering at the home even after her school’s required volunteer community hours were met. She plans to continue performing in her free time while attending Smith College in Northampton, MA.

Connor Bramhall, from Wilmington, DE, whose third-place winning essay earned him a $1,500 scholarship for his education at Embry-Riddle Aeronautical University in Daytona Beach, FL, recounted the changes he saw in his grandfather due to Alzheimer’s disease over the course of several Thanksgivings. As his grandfather, “PopPop,” changed from leading the table discussion and telling jokes and stories to having to move into a memory care facility, Connor and his family did their best to celebrate his favorite holiday by talking and laughing just as much as they had years ago to “make that memory a reality again” for him.

“After last Thanksgiving, I’ve learned that it takes a certain kind of acceptance to properly interact with people with dementia. You have to accept that your fundamental relationship will change,” wrote Connor. “You can’t make more memories fishing or walking in Rehoboth or exploring Longwood anymore; a relationship with someone with dementia is more about what memories you keep rather than make.”

Visit www.alzfdn.org and click on the “Teen Scholarship Essay Contest” tab to read these three essays in their entirety and to learn more about the contest.

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By Linda Mockler, LMSW, AFA Social Worker

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

A:

It’s easy to forget your own needs when you are subsumed in caring for others. But it is really important to take care of yourself! Caring for yourself will provide you with new energy to be a better caregiver. As a great poet once said, “No man [or woman] is an island.” The human condition is such that we need each other.

Sharing important feelings and events and connecting with others who understand what you are going through provides comfort and the strength to continue as a caregiver. Group members bond over shared concerns and issues and can help each other problem-solve approaches.

While some caregivers might feel reluctant revealing personal problems or feel that talking about a loved one is a betrayal, remember, all shared information in a support group is confidential. A group experience is an ongoing process. Trust will grow over time, and information is shared as the trust develops.

Support group participants report a significant easing of pain and anxiety as they talk to group members. They discuss adjusting to a “new normal” and the challenges this presents. Group members can discuss the good, the bad, and the ugly, and the beauty of this is that everyone is going through similar situations and experiencing similar feelings. Feelings of isolation are reduced. You have the support, concern, and attention of the group. Caregivers who are in support groups often say it is a lifeline for them.

Typically, caregiver support groups are facilitated by licensed mental health workers who are trained in both group process and the understanding of Alzheimer’s disease. Because of COVID-19, most group meetings are currently virtual or telephone-based. Groups can meet weekly or monthly, can be short- or long-term, and can be comprised of people in your community or be national in scope. Assess both your needs and the amount of time you have available. If possible, talk to the group facilitator beforehand to address your questions or concerns so that the process is comfortable.

The Alzheimer’s Foundation of America currently provides several different telephone-based caregiver support groups, all facilitated by licensed social workers. Visit our website at alzfdn.org under the Caregiving Resources tab to get more information about them. Call us at 866-232-8484 to speak with a social worker about registering for a group.

The website www.communityresourcefinder.org is another good way to look for caregiver support groups (enter your zip code and a list of groups in your area will come up). Psychology Today (www.psychologytoday.com) can also provide helpful information about locating a group. You can also reach out to your local Area Agency on Aging at www.eldercare.gov. These are local divisions of your state’s Department of Aging. Speak to an agency representative about the different services offered to caregivers.

Take a deep breath and start the process of finding your group today.

Q: I am overwhelmed with my caregiving responsibilities. How would a caregiver support group help me?

STRAIGHT TALK from the AFA HELPLINE
Es fácil olvidar sus propias necesidades cuando está sobrecargado en el cuidado de los demás. Pero es muy importante que te cuides. Cuidar de sí mismo le proporcionará nueva energía para ser un mejor cuidador. Como dijo una vez un gran poeta, “Ningún hombre [o mujer] es una isla.” La condición humana es tal que nos necesitamos unos a otros.

Compartir sentimientos y eventos importantes y conectarse con otras personas que entienden por lo que está pasando brinda consuelo y la fuerza para continuar como cuidador. Los miembros del grupo se unen por preocupaciones y problemas compartidos y pueden ayudarse mutuamente en enfoques de resolución de problemas.

Si bien algunos cuidadores pueden sentirse reacios a revelar problemas personales o sentir que hablar de un ser querido es una traición, recuerde que toda la información compartida en un grupo de apoyo es confidencial. Una experiencia grupal es un proceso continuo. La confianza crecerá con el tiempo y la información se compartirá a medida que se desarrolle.

Los participantes del grupo de apoyo informan un alivio significativo del dolor y la ansiedad mientras hablan con los miembros del grupo. Discuten cómo adaptarse a una “nueva normalidad” y los desafíos que esto presenta. Los miembros del grupo pueden discutir lo bueno, lo malo y lo feo, y la belleza de esto es que todos están pasando por situaciones similares y experimentando sentimientos similares. Se reducen los sentimientos de aislamiento. Tienes el apoyo, la comprensión de la enfermedad de Alzheimer. Debido a la pandemia de COVID-19, la mayoría de las reuniones de grupo son actualmente virtuales o telefónicas. Los grupos pueden reunirse semanalmente o mensualmente, pueden ser a corto o largo plazo; y puede estar compuesto por personas de su comunidad o tener un alcance nacional. Úntale tanto sus necesidades como la cantidad de tiempo que tiene disponible.

Si es posible, hable con el facilitador del grupo de antemano para abordar sus preguntas o inquietudes y conocer al facilitador para que el proceso sea cómodo.

La Alzheimer’s Foundation of America actualmente ofrece varios grupos de apoyo telefónicos para cuidadores, todos facilitados por trabajadores sociales autorizados. Visite nuestro sitio web en alzfdn.org en la página Recursos de Cuidado para obtener más información sobre ellos. Llámenos al 866-232-8484 para hablar con un trabajador social sobre cómo registrarse en un grupo.


Respire profundo y comience el proceso de encontrar su grupo hoy.

Por Linda Mockler, LMSW, Línea de Ayuda de AFA

F: ¿Estoy abrumado con mis responsabilidades como cuidador. Cómo me ayudaría un grupo de apoyo para cuidadores?

R: HABLA DIRECTA desde la LÍNEA DE AYUDA DE AFA

La pandemia de COVID-19 cambió muchas facetas de la vida de nosotros, incluida la forma en que nos movemos o brindamos servicios. Las cosas que normalmente se harían en persona tuvieron que adaptarse y cambiarse para que las personas pudieran acceder a ellas. El Programa Nacional de Evaluación de la Memoria de la AFA no es diferente. Cumbió a un formato virtual para que las personas aún pudieran aprovechar las evaluaciones de memoria sin tener que viajar a un sitio de evaluación.

AFA ahora ofrece evaluaciones gratuitas de memoria virtual los lunes y miércoles de 10 a.m. a 4 p.m. (ET) y todos los viernes de 10 a.m. a 2 p.m. (ET). Cualquiera puede hacerse la prueba de detección: No hay requisitos mínimos de edad ni de seguro. Todo lo que se necesita es un teléfono inteligente, computadora portátil, tablet o cualquier otro dispositivo con cámara web y capacidad de Internet, así como una cita, que se puede hacer llamando a AFA al 866-232-8484.

"Los exámenes de memoria son una parte importante de una buena rutina de salud y bienestar, incluso en medio de la pandemia de COVID-19."

La evaluación de memoria virtual se realizan a través de tecnología de videocferencia segura, como FaceTime, Zoom o Skype (el modo que sea más fácil para la persona que se somete a la evaluación). Cada examen es confidencial y se realiza individualmente por un profesional calificado.

La proyección se lleva a cabo tal como se haría en persona, el evaluador le hará una serie de preguntas diseñadas para evaluar su memoria, lenguaje y habilidades de pensamiento crítico. Los resultados se le proporcionan y explican al final de la evaluación, que dura aproximadamente de 10 a 15 minutos. Los resultados no son un diagnóstico, pero pueden sugerir si debe consultar a un médico para una evaluación completa.

Las proyecciones se ofrecen tanto en inglés como en español. “Queremos que este servicio sea lo más accesible posible,” dijo Fuschillo. “No queremos que el idioma sea una barrera.”

Programe una cita de evaluación llamando a AFA al 866-232-8484.

Llegue a su cita de evaluación cada vez un gran poeta, “Ningún hombre [o mujer] es una isla.” La condición humana es tal que nos necesitamos unos a otros.
The COVID-19 pandemic changed many facets of life for all of us, including how we obtain or provide services. Things that would normally be done in-person had to be adapted and shifted so that people could access them. AFA’s National Memory Screening Program is no different. It shifted to a virtual format so that individuals could still take advantage of memory screenings without having to travel to a screening site.

AFA now provides free virtual memory screenings every Monday and Wednesday from 10 a.m. to 4 p.m. (ET) and every Friday from 10 a.m. to 2 p.m. (ET). Anyone and everyone can get screened: There are no minimum age or insurance requirements. All that’s needed is a smartphone, laptop, tablet or any other device with a webcam, Internet capability, and an appointment, which can be made by calling AFA at 866-232-8484. “Memory screenings are an important part of a good health and wellness routine, even in the midst of the COVID-19 pandemic,” said AFA President & CEO Charles J. Fuschillo, Jr. “We want to make sure that individuals can obtain them from the safety and comfort of their own homes.”

Virtual memory screenings are conducted through secure video conference technology, such as FaceTime, Zoom or Skype (whichever method is easiest for the person getting screened). Each screening is confidential and performed one-on-one by a qualified professional. The screening is conducted just as it would be in-person. The screener will ask you a series of questions designed to test your memory, language, and critical thinking skills. Results are provided and explained to you at the end of the screening, which takes approximately 10- to 15-minutes. Results are not a diagnosis, but can suggest if you should see a physician for a full evaluation.

Screenings are offered in both English and Spanish. “We want to make this service as accessible as possible,” Fuschillo said. “We want to make sure that individuals can obtain them from the safety and comfort of their own homes.”

“Memory screenings are an important part of a good health and wellness routine, even in the midst of the COVID-19 pandemic.”

Screenings are offered in both English and Spanish. “We want to make this service as accessible as possible,” Fuschillo said. “We don’t want language to be a barrier.”

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Schedule a screening appointment by calling AFA at 866-232-8484.

“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, Ph.D., Psychologist

Young readers learn in an age-appropriate way that the Granddad of seven-year-old Nia has Alzheimer’s and will need to move to a new home. Readers also learn that while Nia’s Granddad is changing, the love they have between them never will.

The book includes a message from AFA about how to talk with children about Alzheimer’s disease.

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2020 has been a year of unthinkable for caregivers and individuals living with Alzheimer’s.

WE ARE HERE FOR YOU.
WHENEVER. WHEREVER.

For caregiving support every day, go to www.alzfdn.org
or call AFA’s Helpline at 866-232-8484