November is Alzheimer’s Disease Awareness Month, and that may get you thinking about your memory. Just like you exercise the muscles in your body, you need to exercise your brain to keep your memory sharp, said Dr. Cong Foley, a geriatrician and senior vice president of Parker Jewish Institute for Health Care and Rehabilitation in New Hyde Park. Here are a few ways to do that:

1. **STAY ACTIVE IN GROUPS**
   - No matter what your interest—photography, crafts, music, etc.—you can find a group for it. Group involvement keeps your mind engaged and your memory sharp.

2. **EXERCISE REGULARLY**
   - Marilyn Cleary, an occupational therapist at St. Charles Hospital in Port Jefferson, recommends physical activity, which increases blood flow to your brain and improves mood and well-being. Plus, if you exercise with others, you’re contributing to that social involvement that’s so important as we get older.

3. **ENGAGE IN SOME MENTAL GAMES**
   - Puzzles and board games can give your brain a workout, said Chuck Fuschillo, President and CEO of the Alzheimer’s Foundation of America in New York. In fact, here’s a mental challenge Fuschillo recommends: Brush your teeth or your hair with your non-dominant hand. That forces your brain to think outside of your normal routine.

4. **PUT ON YOUR DANCING SHOES**
   - Learning certain kinds of dancing, such as ballroom dancing, forces you to pay attention both mentally and physically, Fuschillo said. That keeps your mind engaged and your memory sharp.

5. **BE A LIFELONG LEARNER**
   - Take classes, expand your vocabulary, and constantly give yourself new challenges. You’ll get more out of life and help your brain, Cleary advised.

6. **WATCH YOUR MEDICATIONS**
   - There are certain medications that can affect memory. If you take medications and don’t feel as sharp as you once did, ask your doctor if what you take could affect your memory, Foley said.

By the way, you may be wondering if any “senior moments” of forgetfulness that you’ve had are normal. If you sometimes forget where you left the keys or the name of something from long ago, that’s normal. Forgetting the name of a family member or forgetting how to do a part of your routine is something you should discuss with your doctor, Foley said. The Alzheimer’s Foundation also offers memory screenings across the U.S., Fuschillo said.

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**A MESSAGE FROM**

**CHARLES J. FUSCHILLO, JR.**

**AFA PRESIDENT & CEO**

Dear Friends,

The most important piece of advice that we give at AFA is beautifully summed up by actor David Haydn-Jones in this issue of Alzheimer’s TODAY: “Don’t carry the load alone. Take the time to build your support group. Be strong through vulnerability.” (Read David’s story on pp. 6-7). That’s what we try to offer everyone at AFA, a safe haven where you can be vulnerable with your cares, gather resources and strength, and be empowered to make the most of every day with the people you love and care for.

Some of this issue’s special features:

- Technology! It’s everywhere today—including the world of caregiving. Our cover story, “Today’s Technology: Caregiving Support at Your Fingertips” (pp. 10-11) reveals the many ways you can use it—from care coordination to self care, remote monitoring, and engagement. “Technology can give a great sense of wellbeing and peace of mind, knowing that there is one less thing you have to do as a caregiver,” says Leda Rosenthal, founder and CEO of AlzYouneed.com. She and her team help caregivers find solutions for their particular needs.

- Do you know folks who would benefit from talking with AFA’s licensed social workers, but English is not their primary language? AFA has a new multilingual online chat system that enables people to speak in their native tongue. Learn more at “New Helpline Chat System Will Provide Care in 90+ Languages” (pp. 12-13). And help us spread the word!

- Check out our new Q&A column, “Ask the AFA Medical Advisory Board” (pp. 16-17). This month, Dr. George Perry of The University of Texas at San Antonio and the Editor-in-Chief of the Journal of Alzheimer’s Disease will address the impact some drugs and anesthesia may have on dementia risk.

- We understand that sometimes visiting a person in a long-term care facility can be emotionally challenging for you and the person you are visiting. But there are ways that you can make the most of this time together. Don’t miss “6 Tips for a Meaningful Visit in a Care Facility” (pp. 8-9).

And so much more. Don’t hesitate to send us feedback, story ideas, potential questions to address with our Medical Advisory Board or social workers for future columns to info@alzfdn.org. We love hearing from you.

All the best to you and your families,

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

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

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**EDITORIAL**

It’s a presidential election year, which means this November, we’ll be voting to decide who will lead our country for the next four years.

Over the next several months, there will be numerous town hall events, debates and campaign rallies where each presidential candidate will lay out their vision for the country if they are elected and offer their stances on numerous issues of national importance. Alzheimer’s should be one of those issues.

Alzheimer’s is a public health crisis right now that is projected to grow tremendously in the years ahead. The Centers for Disease Control and Prevention (CDC) estimates that more than 5 million Americans are living with Alzheimer’s right now, a number which will nearly triple to 14 million by 2060. It is the sixth leading cause of death in the United States and the only one in the top 10 without a cure or disease-modifying treatment.

It is a fiscal issue as well. According to the CDC, the costs of treating Alzheimer’s disease were projected to be as high as $215 billion in 2010. By 2040, these costs are projected to jump to more than $600 billion annually.

Certainly, we believe every candidate supports people with Alzheimer’s and finding a cure (who doesn’t support those things?). But we’d love to hear their proposed plans on how to get it done.

Will they continue working with Congress in a bipartisan manner to further increase federal Alzheimer’s research funding for the National Institutes of Health (NIH)?

Do they support changes to Medicare that will allow families affected by Young-Onset Alzheimer’s to access Alzheimer’s support services that they would be entitled to if they were over age 65? How do they propose to enhance support services for family caregivers?

Between now and Election Day, as candidates ask for your vote, ask them their plans to address the Alzheimer’s epidemic. Let them know why this is an important issue to you.

The federal government has made substantial progress in the fight against Alzheimer’s disease in recent years, and it is encouraging to see Republicans and Democrats work together on this issue. Since the unveiling of the National Plan to Address Alzheimer’s Disease in 2012, federal Alzheimer’s research funding has grown from approximately $500 million a year to $2.82 billion for fiscal year 2020.

Additional legislative advancements, such as the adoption of the Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer’s Act, created new resources to provide care and support. But as we continue to say, while these are positive steps, more work remains to be done.

America must continue moving forward in the fight against Alzheimer’s disease. The direction we take is greatly influenced by leadership from the top. Those who are running for our nation’s most important job should let us know the course they plan to chart. ■
Lifelong Intimacy

“Without intimacy, we lack the buffer to survive the losses associated with aging.”
—Dr. Gayle Appel Doll

“Thank you so much. No one has touched me since my wife died nine months ago.” That was the response of an elderly man in a long-term care facility who was gently touched on the shoulder by Gayle Appel Doll, M.S., Ph.D., Director of the Center on Aging in Kansas State University’s College of Health and Human Science. As we age, sexuality and intimacy are human needs that start to get erased by society, our families, even ourselves.

Dr. Doll wants us to change that. The common hesitancy to broach these topics, which often stems from lack of understanding and stigma, led her to write Sexuality in Long-Term Care: Understanding and Supporting the Needs of Older Adults. “Similar to the way touch is important to infants, we find a failure to thrive in older adults who are not held or touched,” she says. “Without intimacy, we lack the buffer to survive the losses associated with aging.” Sexuality, the quality or state of being sexual, and the expression of the need for intimacy, has many forms. “It is much more than just sex,” says Dr. Doll. Sexuality involves one’s feelings about their gender, body image, need for intimacy, touch and connection. Acknowledgement of sexuality is a positive validation of our whole selves as human beings.

Dr. Doll reminds us that, years ago, Sandra Day O’Connor, Supreme Court Justice, publicly acknowledged she reported that they held hands. O’Connor allowed this private story to become public to draw attention to the fact that sometimes these attachments happen in a care facility. Today, Sandra Day O’Connor, 88, is also living with dementia.

Dr. Doll Laments that many nursing homes don’t address this topic until there is a problem. Inappropriate behavior does sometimes reveal itself in the form of unwanted advances, verbal or physical, to other long-term facility residents or even staff. Reasons for this type of problem are usually revealing an unmet need, says Dr. Doll. The inability to express sexuality and intimacy in healthy ways can sometimes lead to problems in care facilities. These needs never go away, although how they are experienced can change over time due to changes in mobility, energy levels, and libido. The most important thing care settings can do is provide quality, consistent assignment of staff to particular people and relationships. This will enable staff caregivers to experience and understand changes as they are occurring.

“Intimacy can occur at every stage of a person’s life,” says AFA Social Worker Kara Rogers, LMSW. “It is something as humans that we need. There is a lot to be said for the power of touch and the feeling that you belong.”

Adapted from an AFA Care Connection Webinar.
To learn more about upcoming sessions or to view past webinars, go to the Caregiving Resources tab on our website, www.alzfdn.org.
He’s starred as Arthur Ketch in the hit TV series *Supernatural*, is a Hallmark Channel holiday movie leading man, and plays “super-agent” Gabe Gabriel alongside NFL stars Patrick Mahomes and Aaron Rodgers in a series of popular State Farm commercials. But a role that is truly special for the quick-witted actor David Haydn-Jones is that of Alzheimer’s advocate. Haydn-Jones and his loyal fans are extraordinarily passionate about the cause.

As a young boy growing up in Canada, Haydn-Jones witnessed his grandmother, Annette Elizabeth White, live with Alzheimer’s disease during the 1980s. She was only in her mid-50s when the names of her three daughters began eluding her. One of Haydn-Jones’ lasting memories is the unconditional love that his grandfather, mother, aunts, and his grandmother’s nurse aide provided “Nana” throughout the course of her illness. His grandfather, Stuart Hanson White, was a WW II veteran and seven years Nana’s junior. He retired early, at the age of 62, because his wife needed the support.

“My grandfather was a hero twice,” said Haydn-Jones. “I was still very young at the time, so didn’t fully understand what was happening, but I knew Nana was different. My Granddad was completely devoted to her. He would still take her out to dinner, getting her dressed in her Sunday best. As she got to the later stages of the disease, he would bring a full apron with them to the restaurant and help her eat,” said Haydn-Jones. “One time my mom looked and saw she was eating her napkin. My Granddadd gently helped her, and another patron commented to him, ‘You’re doing God’s work.’ It was really something to see the magnitude of love, compassion and tenderness for her.”

Haydn-Jones also cherishes the moments of lucidity that he was able to experience with his beloved grandmother, even as the disease was progressing. When he was five or six, she would read to him and everything would come back. His grandmother was a well-educated woman who attended Simmons College in Boston, Massachusetts, during The Great Depression and received a degree as a professional librarian, specializing in children’s literature. During Christmas 1985, before she died, she received a Rachmaninoff tape. When his aunt played it, Haydn-Jones recalls how she lit up. “The music obviously sparked something in her,” he said. “It was amazing.”

Haydn-Jones devotion to his grandmother and his sensitivity to other families going through similar experiences has inspired him to want to bring attention to Alzheimer’s disease and raise funds to support those impacted by it. He launched a t-shirt campaign, “<3 = Love,” after good naturedly learning that the “less than 3” emoji (<3) that his fans were sending him via his social media feeds was not a math equation as he always supposed but a heart (and a sign of love). What started as a limited edition run was so popular that Haydn-Jones created additional designs and products, including coffee mugs, beanies and tote bags. He also recorded a single, “Makin’ Bacon,” born out of a humorous improvisational jingle he did while on a panel at a *Supernatural* fan convention (available at the online independent music store CD Baby) and created a charm replica of his *Supernatural* character’s cross tattoo.

As of the time of this writing, Haydn-Jones and his fans have collectively raised more than $16,000 for AFA. “I am so grateful to be able to pay it forward. It’s my little drop in the ocean,” he says. His greatest piece of advice to others living with Alzheimer’s in their families, “Don’t carry the load alone. Take the time to build your support group. Be strong through vulnerability.”

—David Haydn-Jones

**“Don’t carry the load alone. Take the time to build your support group. Be strong through vulnerability.”**

—David Haydn-Jones

In State Farm commercials, David Haydn-Jones playing “super agent” Gabe Gabriel with NFL stars Patrick Mahomes (L) and Aaron Rodgers (R).

Haydn-Jones plays leading role in <3 = Love t-shirt campaign for Alzheimer’s awareness.
6 Tips for a Meaningful Visit in a Care Facility

Visiting a loved one living with Alzheimer’s or another dementia in a long-term care facility may be challenging at times. It also can be a very special and memorable experience. Joanna LaFleur, a certified recreational therapist, former family caregiver, and the CEO of a care facility in Michigan, offers advice to make the most of these visits for you as well as your person.

1. Acknowledge the grief both you and your loved one may feel

Having someone in your life with Alzheimer’s or another dementia can be difficult to fully grasp. “You are both experiencing a lot of grief,” says LaFleur. It’s essential to acknowledge this grief to be mentally and emotionally prepared for the days to come. Be mindful that you are experiencing losses.

2. Develop empathy and understanding

To connect with your loved one, you need to understand how they may be feeling at certain moments. “Once you realize and understand the losses they’re experiencing, you can move past some of your own sadness,” says LaFleur. Empathy fuels connection. The individual with dementia is the same person you’ve known your whole life. Try to appreciate this time together and use it in the best way that you can.

3. Be positive and approach appropriately

Often times when visiting a loved one with dementia, they will feed off of your energy. That’s why it’s crucial to always approach them with positive emotions and a good attitude. LaFleur recommends these tips to create an encouraging environment:

- **Tell them who you are.** Don’t ask them if they know you. That only reminds them that they are forgetting things.
- **Be on their level.** People with dementia often have a visual field problem (they can only see what is directly in front of their faces).
- **Bring them a favorite drink, snack or a picture of a fond memory.**

A typical visit could begin like this: Enter the room with a smile, kneel down to their level and say something like, “Hi mom, it’s Joe. I am so happy to see you today. I love your pink shirt, and I brought you your favorite doughnut.”

4. During your visit, engage your loved one with therapeutic activities

Therapeutic activities, simple activities with a purpose, are great tools for a more enjoyable visit. You can turn almost anything into a therapeutic activity. Just know what their passions are and try to include them during your visit. Some ideas include an arm, hand or neck massage; going for a walk or stroll in a wheelchair; doing a small art project; listening to music; reading poetry or putting on make-up and fixing hair. Remember, many people who no longer have verbal skills can still sing songs. So use favorite songs generously. Avoid asking your person directly if they want to participate in an activity. Just bring the activity out and show it. If you are reading a book say, “I brought you this great book and I’m really excited to read it to you.” Then start reading and see their reaction. Spurts of activities work best (15 minutes on, 15 minutes off) because of their short attention spans. Bring options.

5. Use redirection techniques

Redirection is a technique where you attempt to shift a person’s attention away from a situation that is causing anxiety, fear, anger or unsafe behavior. If they say they need to go to work, you could say, “Oh mom, it’s Saturday. You have the day off today. Since you are free, let’s go for a walk.” Realize if your loved one expresses a true concern, do not just redirect them to something else and ignore the issue. Instead, address the problem and then redirect, if needed.

LaFleur calls redirection an art and says it requires practice and being intentional. Understand what your loved one’s needs, difficulties and triggers are and prepare some possible solutions. Below are examples of ways to redirect:

- **Engage in a therapeutic activity (noted above)**
- **Offer a favorite food or beverage**
- **Ask for help with a project** (putting pictures in a photo album, folding socks)
- **Talk about someone they love reminisce**. Bring up a story you know they enjoy talking about.
- **Move to a different area or room.**
- **Go for a walk or a drive if you can.**

6. How to end your visit

Leaving your loved one can be as traumatic for them as it is for you. Actually, saying the phrase “goodbye” can sometimes make the situation worse. Use phrases like “I will see you soon” or “I have to run an errand; I will be right back.” Once you tell them you are leaving, redirect their attention to someone or something else before you depart. For example, “I enjoyed spending time with you. I love you. Let’s go get ready for dinner. I heard they’re having beef stroganoff—that sounds delicious.”

Adapted from an AFA Care Connection webinar. To learn more about upcoming sessions or to view past webinars, go to the Caregiving Resources tab on our website, www.alzfdn.org.
Today’s Technology: Caregiving Support at Your Fingertips

“T
technology can give a great sense of
well-being, knowing that there is one less thing you
have to do as a caregiver,” says Leda Rosenthal,
founder and CEO of AlzYouNeed.com, an online
technology-matching service to help caregivers
find the right solutions for their particular needs.
“Even small improvements can make the world
of difference in your days.”

When Rosenthal’s mother was diagnosed with
young onset Alzheimer’s in 2015, she started
to see changes in her mother’s everyday life—an
inability to navigate short dog walks or to
remember to turn off the stove. A tech-savvy
millennial, Rosenthal was determined to find
the best assistive caregiving technologies to help
combat these new challenges. Then realizing
that she and her family were not alone in needing
these supports, she founded AlzYouNeed.com.

Most importantly, make sure you are getting
the technology that will be successful in your
home or care setting, advises Rosenthal.
The first thing you should ask is, “What am I
trying to accomplish through technology?” (See
“6 Ways Technology Can Make Caregiving Easier”
in our guide below.)

The availability of so many products in the marketplace makes it a necessity that caregivers do
their own research. Alz You Need is a jumping off point, with a quick online survey that helps caregivers
identify their needs, level of confidence, cost considerations, and possible solutions. (Note: Alz
You Need receives no commission for the vetting or the suggesting of these products.) Below is a
sampling of products, provided by Rosenthal, that could be suitable for use during the three main
stages of Alzheimer’s. This is not an all-inclusive or exhaustive list.

EARLY STAGE

6 Ways Technology Can Make Caregiving Easier

Safety
Communicate quickly during emergencies, provide
remote monitoring and prevent accidents.

Care coordination
Help you gather and make happen all the tasks that need to get done on
behalf of the person you are caring for—sharing notes within a care circle,
coordinating care rides to appointments and finding a paid caregiver.

Cognitive engagement
Maintaining your person’s behavioral and emotional health,
including social skills, cognitive ability, and general mood,
and helping reduce social isolation.

Self care
For the caregiver, managing your own wellbeing and improving your own mental
health, including networking with other caregivers and meditation apps. “You
can’t care for someone if you are not caring for yourself,” says Rosenthal.

Health tracking
Monitoring both long- and short-term cognitive and physical health,
such as tracking changes and ensuring medication adherence.

Planning for the future
Navigating the care journey proactively, including managing your
person’s finances and important legal documents.

Technology for All Stages & Many Purposes

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EARLY STAGE

BRAIN TRAINING

Neurotrack A cognitive training
program (i.e., “exercise” for the brain)
designed to improve mental abilities
such as memory, attention, decision-
making and awareness.

LOST & FOUND

Tile Bluetooth-enabled device and app to
put on keys, inside wallets, pocketbooks,
TV remotes and anything that often gets
“lost.” It will play a sound when it is in
range. (Rosenthal puts one on her dogs’
collars because her mother was often
taking their dogs out for walks.)

Orbit Bluetooth Glasses Attach
the Orbit Bluetooth tracker to your
frames so you can find them just by
using your phone.

ORGANIZATION

Evernote, Google Calendar
Organization apps for sharing scheduling
and reminders.

MANAGING MEDICATION

Pillo Intelligent pill dispenser and companion that can store up to four
weeks of medication and serve as a
communication device between
family members.

Pilxy A “smart cap” that automatically
tracks when a pill bottle is opened and
will mark the dose as “taken”; beeps
and blinks when it’s time to take your
dose if you’ve missed it; and will warn
you if it thinks you are double dosing.
You can also setup “take as needed”
medications and go into the app to see
your entire history.

VOICE ASSISTANTS

EliQ An artificially intelligent companion
that becomes even more helpful as it learns
what you like and need. Features video calls
and messaging, stimulation games, curated
music and videos, calendar, daily routine
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Amazon Echo Show Virtual assistant
Alexa and a home tablet allow you to
manage your day at a glance: voice
test TV shows and movies, music, have a
“drop in” with your loved one, control
your smart home (lights, lock doors).

PLANNING FOR THE FUTURE

Lifesite, Everplan Secure document
and storage online for multiple family
caregivers to access.

Silver Bills An online financial service that
will pay your bills for you or a loved one.

CAREGIVER SELF CARE

Headspace A meditation app for
caregivers to live more mindfully and
reduce stress.

Being Patient A news source for everything
Alzheimer’s and dementia-related.

THERAPY OPTIONS

Joy for All Companion Pets Fosters a person’s emotional well-being through
reminiscence therapy, animals that
gently vibrate and can be interactive and
comforting.

Simple Music Player MP3 music box
that you can preload with favorite songs.

LATE STAGE

REMOTE MONITORING

Safe Wander A wearable sensor for
nighttime use that activates when your
person sits up at night, alerting you
to the fact that they may fall out of
bed or wander.

Reolink A wireless camera that you can
put in the home and see what is going on;
voice driven on both sides.

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New Helpline Chat System Will Provide Care in 90+ Languages

A new online chat feature available through AFA’s Helpline will now allow licensed social workers to provide assistance and support to families affected by Alzheimer’s disease and other dementia-related illnesses in more than 90 different languages.

“Alzheimer’s disease doesn’t recognize language barriers, ethnic or geographical boundaries: It impacts people from all over the world who speak a wide variety of languages. Families affected by Alzheimer’s disease need to be able to access support, regardless of the language they speak. Adding this new feature to our Helpline enables us to break down language barriers and serve a greater number of people,” said Charles J. Fuschillo, Jr., AFA’s President & CEO.

By clicking on the blue and white “chat” box in the lower right-hand corner of AFA’s website, www.alzfdn.org, or by sending a text message to a mobile device to 646-586-5283, individuals can type questions in their native language and send it to the Helpline. The system is translatable for more than 90 different languages, including Spanish, Chinese, French, German, Russian and Italian. More than 37 million people over the age of 18 living in the United States speak a language other than English, according to 2018 data from the United States Census Bureau.

As an example, someone can ask, “What are some ways to help prevent my family member with Alzheimer’s from wandering?” in Spanish, and the system will recognize the foreign language text. The Helpline social worker will then type their response, which is then translated into Spanish for the user on the other end. Because the translation occurs instantaneously, conversations can be had in real time.

English-language speaking individuals can also utilize the system to have chat conversations with a licensed social worker through the Helpline.

Individuals who have questions about Alzheimer’s disease, need caregiver support or would like to be connected with services in their area can visit AFA’s website, www.alzfdn.org, and click on the blue chat icon on the lower right-hand side of the page or send a text message to 646-586-5283 to connect with the Helpline. The AFA Helpline is open seven days a week, 9 a.m. to 9 p.m. (ET) on weekdays and 9 a.m. to 3 p.m. (ET) on weekends.

El Chat Nuevo de la Línea de Ayuda les Brindara Asistencia y Apoyo en 90 Idiomas

Un nueva función de nuestro chat será disponible a través de la Línea de Ayuda de Alzheimer de la AFA. Ella le permitirá que los trabajadores sociales con licencia brinden asistencia y apoyar a las familias afectadas por la enfermedad de Alzheimer y otras enfermedades relacionadas con la demencia en más de 90 idiomas diferentes.

“La enfermedad de Alzheimer no conoce barreras de idiomas y tampoco conoce razones de etnicidad o límites geográficos. Ella impacta personas de todo el mundo entero y personas de diferentes idiomas. Familias afectadas por la enfermedad de Alzheimer necesitan tener disponibles el apoyo a pesar de su idioma. Agregando esta nueva característica a nuestra Línea de Ayuda permite romper barreras de idiomas y nos permite servirle a personas a nivel números,” dice Charles J. Fuschillo, Jr., Presidente y CEO de AFA.

Haciendo clic al botón de la caja color azul y blanco del “chat” a la esquina abajo hacia la mano derecha en la esquina de nuestra página web, www.alzfdn.org, o mandando un mensaje de texto de un teléfono móvil a 646-586-5283, personas podrán escribir sus preguntas en su idioma nativo y mandarla a la Línea de Ayuda. Nuestro sistema podrá traducir 90 idiomas incluyendo Español, Chino, Francés, Alemán, Ruso y Italiano. Más de 37 millones de personas mayores de 18 años o más que ubican en los Estados Unidos hablan otros idiomas además de Inglés, según las estadísticas del Departamento del Censo de los Estados Unidos de 2018.

Como ejemplo, alguien pregunta, “¿Cuáles son las maneras de impedir que un miembro de mi familia con Alzheimer se vaya a deambular?” en Español, nuestro sistema reconocerá el idioma y le comunicará en inglés a nuestra trabajadora social. Cuando nuestra trabajadora social de nuestra Línea de Ayuda recibe su mensaje y le contesta, el sistema le contestará en Español. Como la traducción ocurre instantáneamente, las conversaciones son en tiempo real.

Personas de habla Inglés también pueden utilizar el chat para conversar con una de nuestras trabajadoras sociales por medio de nuestra Línea de Ayuda.

Toda persona, sea cuidadora o familia de personas con la enfermedad de Alzheimer o demencia, pueden buscar ayuda, apoyo, o necesitar servicios en su propia zona, pueden encontrarse a través de nuestra página web www.alzfdn.org y hacer clic al botón azul del chat que se encuentra abajo en la esquina a mano derecha o manda un texto a 646-586-5283 para conectarse a nuestra Línea de Ayuda. La Línea de Ayuda está abierta los siete días de la semana, 9 a.m. a 9 p.m. (ET) y de 9 a.m. a 3 p.m. (ET) los fines de semana.
Manejo y cambios en la vida diaria

Los cambios en la vida diaria son importantes para el cuidador y la persona afectada. Algunos de los cambios que se pueden encontrar son:

- Cambios en apetito: Las personas con demencia pueden no tener hambre o desear alimentos nuevos. Es importante evitar que se olviden de comer y asegurarse de que sigan comiendo.

- Cambios en la vida diaria: Los cambios pueden ser sutiles, como cambiar la temperatura del agua durante el baño o la cantidad de comida disponible en casa. Es importante adaptarse a estos cambios.

- Cambios en el cuidado personal: Las personas con demencia pueden tener dificultades para cambiar de ropa o bañarse. Es importante encontrar soluciones para estos problemas.

- Cambios en el comportamiento: Las personas con demencia pueden volverse más agresivas o tener cambios en sus comportamientos. Es importante entender la razón detrás de estos cambios.

En el papel de cuidador, es importante adaptarse a estos cambios y asegurarse de que la persona se sienta segura y cómoda. Es importante tener paciencia y ser empático. También es importante buscar ayuda profesional, como el médico o la psychologically care, si se necesita.
of dementia among some people, particularly the elderly. That doesn’t mean that all of these medications are “bad” and should never be taken, but, rather, that each patient in consultation with their doctors needs to assess on a case-by-case basis the potential benefits and risks.

Anticholinergic drugs block the action of the neurotransmitter acetylcholine, which is needed to send signals to other cells. Common drugs in this category include some antihistamines, antidepressants, medications for gastrointestinal and bladder disorders as well as antiparkinson, antiepileptic and antipsychotic drugs.

A study in JAMA Internal Medicine suggested that 10% of dementia diagnoses are attributable to anticholinergic drug exposure, so it could be important to modify the intake of some of these types of drugs for some people. Keep in mind, the JAMA study found greater increase in risk associated with people diagnosed with dementia before the age of 80, which indicates that anticholinergic drugs should be prescribed with caution in middle-age and older people. Also, long-term use of anticholinergic medications (three years or more) was linked to a higher risk of developing dementia than taking the same dose for three months or less.

Taking drugs is always a balance of benefit vs. side effect that each person should discuss with their physicians.

Q: I have a 69-year-old friend who has had many hours of back surgeries over the years. After his most recent one, there seemed to be some serious changes in his behavior (making drastic changes in his family life) and memory (forgetting and misunderstanding things). I’ve heard that anesthesia can trigger dementia. Is there any truth to that?

A: Major surgery (for knee and hip replacements, heart conditions and back surgery) is common for many older adults, so this is a concern worth addressing. General anesthesia changes your brain, clearly, but, according to recent studies, the lasting effects are mixed. There are two types of disturbances associated with elderly folks following surgery and general anesthesia: postoperative delirium (POD) and postoperative cognitive dysfunction (POCD).

POD occurs early after surgery and lasts days to weeks. It is characterized by a fluctuating mental state of inattention and altered levels of consciousness. There are three types of POD delirium: hyperactive (when a person is restless, irritable, combative or agitated); hypoactive (when a person is lethargic, lacks alertness and is unaware); and mixed (characteristics of both types). The incidence of POD increases with age and surgery complexity.

But POCD becomes apparent over months and even years as subtle changes in memory, attention, and comprehension begin to appear. According to the Journal of Anesthesia, POCD was reported to affect 26% of patients over 60 years in the first week after surgery but actually fell to 10% in the following three months. A long-term follow up study found only 1% of elderly subjects suffered from persistent POCD up to two years after surgery.

What does that mean for you? The connections are inconclusive and we still have more to learn. Actually, cognitive performance prior to any major surgery are stronger indicators of potential problems. (Does a person already have a mild cognitive decline, been diagnosed with Alzheimer’s disease or possibly have undiagnosed Alzheimer’s disease?) The general understanding now is that POCD has multiple causes—the choice of anesthesia, the seriousness of the surgery as well as the overall health and age of the patient at the time of the surgery. But it is a medical field priority to lower its incidence. When considering major surgery, again, the risks need to be balanced with the rewards and should be discussed with your doctor.

AFA Medical Advisory Board Member George Perry, PhD, is a Professor and Semmes Foundation Distinguished University Chair in Neurobiology at The University of Texas at San Antonio. He is also the Editor-in-Chief of the Journal of Alzheimer’s Disease.

Do you have a question for the AFA Medical Advisory Board? Please email it to info@alzfdn.org.
HEALTHY CHICKEN PICCATA WITH MUSHROOMS

Traditionally, Italian Piccata is made with veal or chicken. This recipe calls for chicken cutlets or chicken tenders. It can also be used with mild fish filets, scallops or shrimp. I like the addition of mushrooms, which contain selenium, an antioxidant trace mineral that helps strengthen the immune system.

INGREDIENTS

(Choose organic ingredients when available.)

• 4 chicken cutlets (4 to 5 ounces each) or 1 pound of chicken tenders
• Sea salt (or rock salt) to taste (optional)
• Freshly ground black pepper to taste
• 1 ½ cups low-sodium chicken broth
• 3/4 cup whole-wheat flour, divided
• 3 tablespoons fresh, cold-pressed extra-virgin olive oil
• 1 clove garlic, minced
• 1 10-ounce package of mushrooms, sliced
• 1 10-ounce package of mushrooms, sliced
• Juice from 1 large lemon or 3 to 4 tablespoons fresh lemon juice
• 2 tablespoons capers, drained and rinsed (optional)
• 1/4 cup chopped Italian parsley, fresh

DIRECTIONS

1. Season both sides of the chicken with salt and pepper (optional).
2. In a bowl, whisk together chicken broth with 5 tablespoons of flour until smooth, and set aside.
3. Place remaining flour in a dish.
4. In a large skillet, heat 3 tablespoons of olive oil over medium heat.
5. Coat the chicken with the flour. Arrange the chicken in the pan and cook until browned on both sides, 2 to 3 minutes per side.
6. Transfer the chicken to a plate and set aside. Add the mushrooms and garlic to the pan and sauté for about 5 minutes. Then add the chicken broth mixture and the lemon juice. Bring to a boil. Add the chicken back to the pan along with the optional capers. Bring back to a boil. Reduce the heat to low and simmer for 2 to 3 minutes.
7. Garnish with fresh chopped parsley and slices of lemon. Serve over whole wheat pasta or egg noodles with steamed spinach.

NUTRITION FACTS

SERVINGS 4

AMOUNT PER SERVING

372 CALORIES

total fat (13.9g), saturated fat (1.7g), cholesterol (73mg),
sodium (345mg), total carbohydrate (24.4g), dietary fiber
(1.7g), total sugars (1.6g), protein (34.9g), vitamin D
(250mcg), calcium (18mg), iron (5mg), potassium (710mg)

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.

The Power of Story

Who doesn’t love a great story? That point hasn’t been lost on Pete and Joyce Vanderpool, founders of the Creative Story Project in Cleveland, Tennessee. They make the art of oral storytelling and story creation accessible to people with Alzheimer’s and dementia by “replacing the pressure to remember with the encouragement to imagine.”

Once a week for 10 weeks, an 8x10 color picture, either silly or thought provoking, is given to each person in a small group. Everyone gets exactly the same picture. Then open-ended questions are asked by a leader and the ensuing conversation is captured by a scribe who turns it into a story. The following week a new story is created and each participant receives a printed copy of the previous week’s creation. The technique, called Story Power, is successful in its own right, but the Vanderpools added Intergenerational Story Power as a second exciting program.

The Intergenerational Story Power program enables the Vanderpools to work with students in schools and youth organizations, educating them about aging and the elderly, Alzheimer’s and dementia. These students then get first-hand experience in a care facility.

“It is a great experience for both the students and the residents. Sessions always include lots of laughter, hugs and invitations to return. And the students do return to visit their new friends and bring them love and hugs, and an enthusiasm for life that youth can provide,” says Joyce Vanderpool, who serves as the program’s Executive Director.

Janice Allen, Activity Director of Bradley Healthcare, a nursing and rehab center in Tennessee, which has experienced the program firsthand, says, “It’s a delight to watch our residents open up and contribute creative stories. They make jokes. They interact with other residents and staff. They just have a wonderful time.”

Both programs, which were recently supported by an AFA grant, help build community and pride, reduce feelings of isolation as well as improve understanding of dementia among participating staff and youth. “Activities that stimulate the mind are critical to happiness and quality of life during times of declining cognizance and health,” says Joyce Vanderpool. “And laughter is contagious. It can really brighten the lives of people with dementia.”
Wisconsin Summer Camp Supports Youth Impacted by Alzheimer’s

They arrive hoping to figure out how to laugh with Grandma again, throw a ball with Dad or communicate with Mom who repeats the same question over and over again. When Alzheimer’s and cognitive impairments touch our loved ones, every member of the family is affected. That is why the Alzheimer’s and Dementia Alliance of Wisconsin (ADAW) decided to address a sometimes overlooked group in need of support—youth and teens.

Time for Us Camp, which received an AFA grant this year, is a five-day summer camping opportunity for youth 10 to 18-years old who have a loved one with a cognitive impairment or neurological challenges. Priority is given to youth who have caregiving responsibilities in the home. While most of the camp days are spent on fun activities, like climbing rocks and canoe paddling, a portion of the time focuses on understanding Alzheimer’s and memory challenges. Campers gain knowledge, coping skills, peer support, and relationships that may assist in years to come.

“Time for Us Camp was conceived over 10 years ago by volunteers who were diagnosed with Mild Cognitive Impairment (MCI) at young ages and knew they needed to find a way to help their kids understand what was going on. According to ADAW, it is the only summer camp of its kind in the nation. “For youth in a family, this is typically a crisis, a crisis that may be kept secret from the community,” says Jennifer Bauer, Executive Director of ADAW. “The family members that are closest to someone with a cognitive challenge often feel alone, stressed, and depressed. Youth tend to hide their concerns from their peers and helping professionals. They often have no safe place to share their fears and pressing questions.”

When youth leave Time for Us Camp, they most importantly realize that they are not alone. They listened to others share what helped, asked questions about issues that had been bothering them, revealed frustrations, and practiced new ways to communicate that don’t require spoken words.

Each year, we see the campers come at the beginning very closed off about the person at home who has a dementia,” says Bauer. “By the end of the camp, they are expressing their feelings and sharing experiences with each other. They are leaving with new methods of coping and a new understanding about the disease impacting their loved one.”

A Time for Us camper, in Dodgeville, Wisconsin, learning coping skills.

Wisconsin Summer Camp Supports Youth Impacted by Alzheimer’s

History Repeats Itself

Washington Delivers Another Record-Breaking Appropriation for Alzheimer’s Research

By Eric Sokol SVP of Public Policy, AFA

H istory has been made in Washington, DC (the good kind). Democrats and Republicans in Congress worked together with the President to deliver $2.82 billion for Alzheimer’s disease research at the National Institutes of Health (NIH) as part of the fiscal year (FY) 2020 federal budget.

The landmark funding is the largest amount ever appropriated by Washington in a single year toward research to find a cure or disease-modifying treatment for Alzheimer’s disease. It breaks the previous record, set just last year in the FY 2019 federal budget, by $350 million. AFA strongly advocated for the funding increase.

“AFA applauds the federal government’s commitment to enhance funding for clinical research toward a cure or treatment for this relentless disease. Alzheimer’s is a growing public health crisis that affects more families every day. Continued scientific research is the only way we can make the breakthrough everyone is hoping for,” said AFA President & CEO Charles J. Fuschillo, Jr.

Since the adoption of the National Plan to Address Alzheimer’s Disease in 2012, which established the goal of finding a cure or disease-modifying treatment by 2025, funding for Alzheimer’s disease research has grown tremendously. In 2012, federal Alzheimer’s research funding was approximately $500 million. In less than a decade, it has risen by more than 400 percent.

Also included in the FY 2020 federal budget is a $10 million appropriation to the Centers for Disease Control and Prevention (CDC) to begin implementation of the Building Our Largest Dementia (BOLD) infrastructure for Alzheimer’s Act, which became law in early 2019, aims to close existing infrastructure gaps in our health care system and deliver valuable new resources for the prevention, treatment and care of Alzheimer’s disease. Under BOLD, the CDC will provide enhanced resources for state health departments and greater help for health and social services professionals, families and communities as a whole; establish Centers of Excellence in Public Health Practice to provide educational information about Alzheimer’s and brain health; and promote support resources for individuals with Alzheimer’s and their caregivers.

While appropriations for research were historic, allocations for caregiver support did not reach the same level. Funding for Alzheimer’s disease programs through the Administration for Community Living (ACL) totaled $16.5 million. These services, including the National Family Caregiver Support Program, provide critical assistance to families affected by Alzheimer’s disease. While the FY 2020 appropriation represents an increase over FY 2019 funding, a larger, more substantial investment must be a priority, given that more than 1.7 million Americans are living with Alzheimer’s disease now and the CDC projects that number to grow to 14 million by 2060.

“While AFA is also grateful for the $26.5 million allocation to the Administration of Community Living (ACL) for Alzheimer’s disease programs, we hoped that it would be more. Family caregivers are on the front lines in the fight against Alzheimer’s. Caregiving support services are critical to enabling people to live where they choose and maintain a quality of life,” Fuschillo added.

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PUBLIC POLICY REPORT
Dealing with the death of a loved one is challenging under any circumstances and can be especially so when you are wondering how to communicate that loss to a person who has dementia. It’s best to initially consult with others who know your mother well—a medical doctor, another family member, friend, or a caregiver who sees her daily.

There are a few things that could be helpful to consider when approaching this situation: First, will she be able to retain the information and, secondly, can she physically and emotionally handle all the following events? Another consideration is whether this relationship was a positive or negative one for her. While many people assume that a long-term partner relationship is perfect, that might not always be the case. If the relationship was a source of pain in her life, it might not be a good idea to tell her about the death. Just bringing up a name may bring up bad memories.

Does your mother currently have the lucidity to grasp this news? If you are certain that she does not, then it may be best not to tell her. If she is only going to forget, telling her will cause unnecessary pain. Keep in mind, we want to be sensitive to the vibes and energy we carry in a situation like this. As cognitive abilities start to decline, people with dementia can be more attuned to feelings and emotions than words. Your mother might have the ability to sense this change in your presence and could become agitated without your knowing why.

If you are not certain about your mother’s ability to completely comprehend, you could try to have a conversation with her about it and see how she responds. Make sure you are clear and concise while allowing her time to process. For example, in this case, you could say, “I’m so sorry to tell you this, mom, but I have some sad news that might be hard to hear. Dad had a heart attack last night and died.” If she is not able to retain this information and forgets the news within the next hour or day, this might be an indicator that it will not be helpful to mention it to her again. That would be inhumane to inflict more pain. Every time she hears the news, it will be like the first time.

You may make a decision to have your mother participate in the affairs if she is in the early stages of the disease. If this is the case, you should inform her as far in advance as possible, so she will have time to allow it to sink in. Then check in with her periodically until the day of the service. How she answers each day will help inform you about bringing her to the service on the actual day.

If you plan to bring your mother to the services, make sure you have a back-up plan. Be aware of a quiet place to take her if she needs time away from others or be prepared to leave early, which may be necessary. We want to be flexible because we cannot predict how she’ll respond.

In addition, it could be helpful to think about how your mother handles being in public. Has she been out in public recently? Attending any type of services can be taxing and incorporate many moving parts. Traveling is another factor, as it can be difficult for a person with dementia to travel back and forth. This can then disrupt their routine, which will need to be watched. Also, will being at a funeral home or cemetery trigger past unhappy memories? Is it worth it?

“Compassionate Lies”

Some caregivers feel uncomfortable about “massaging the truth” or not being completely honest about sharing difficult information. We advise caregivers to consider two things: Is it kind to tell them? And is it necessary? For someone with this disease, what’s important is the role that the deceased person played in their life and the fact that they are now gone and will be unable to fulfill that role. As a caregiver, you want to figure out how to help your loved one fill that loss now that her special person will be missing.

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.
NIH Awards $4.3 Million to Develop Next-Generation Alzheimer’s Treatments

The National Institutes of Health (NIH) awarded a $4.3 million research grant to Stony Brook University to pursue a study over the next five years to develop treatments that can potentially arrest and reverse memory loss in people living with Alzheimer’s. The team received an initial grant of more than $500,000 from the Alzheimer’s Foundation of America (AFA) to prove the potential of their approach, which involves both human imaging and examination of a mouse model of Alzheimer’s disease.

The team of cross-disciplinary faculty spanning biomedical engineering in the College of Engineering and Applied Sciences and psychiatry in the Renaissance School of Medicine aims to develop an approach to find the source of the damage to the cholinergic neurons that results in Alzheimer’s disease.

Principal investigator Dr. Christine DeLorenzo’s lab at Stony Brook University focuses on the neurobiology of mental illness using brain imaging, artificial intelligence and technology to obtain the most comprehensive views of the brain possible. “If we know exactly what is altered in the biology, then we can develop the next generation of treatments,” Dr. DeLorenzo said.

It has been known since the 1970s that cholinergic neurons are responsible for memory cognition in the human brain. They employ a neurotransmitter, acetylcholine (ACh), to communicate with each other for memory retrieval. It has also been known for some time that decreased levels of ACh are found in Alzheimer’s patients. Prevailing treatments for the disease have focused on boosting the levels of ACh, but these have been minimally effective in arresting the progression of memory loss.

Dr. DeLorenzo said, “Medical science has known for some time that Alzheimer’s is a result of the ‘memory network’ in the brain falling apart. What we intend to discover is how the network deteriorates and how to fix it.”

To examine the cholinergic system in higher resolution than possible in a living human brain, Dr. DeLorenzo, her collaborator Dr. Lorna Role, Scientific Director of the National Institute of Neurological Disorders and Stroke, and their team perform microscopy and PET imaging in rodents. This inset demonstrates the complexity and density of these cholinergic axons (green lines). These high-resolution images improve our understanding and interpretation of the human imaging. Here, they are projected onto the walls of Stony Brook University’s Reality Deck using algorithms developed by Arie Kaufman, PhD, and his student Saeed Boor Boor. (Image created by Mala Ananth, PhD)

College Student Runs 100 Days of 5Ks for Grandma

Ethan Widrig was well aware of the impact of Alzheimer’s disease; his grandmother passed away from it when he was a junior in high school. Fast-forward five years and the New Hampshire native is now a senior at St. Joseph University in Philadelphia and raising awareness and funds for AFA’s research efforts toward a cure.

During the fall semester of his senior year, Widrig finished his first fundraising campaign, “100 Days of 5Ks,” where he ran a 5K every day from August 26th until December 3rd. Over the course of his 100-day campaign, Widrig ran more than 310 miles, the equivalent of running from Philadelphia to Canada, and raised $13,700 to support the more than 5.7 million Americans impacted by Alzheimer’s every day.

While balancing the heavy class load of a college senior, Widrig never took a day off or missed a run. To avoid classes and other commitments interfering with the campaign, he would often run at 11 p.m. so that he stayed on pace to achieve his goal, “I thought that would demonstrate my commitment to the cause,” he said. Needless to say, Widrig’s commitment was quickly known throughout campus and the community.

During the campaign’s entirety, Widrig constantly reached out and encouraged his friends, classmates and the community to participate in the runs to further raise recognition of a disease that younger generations like Widrig’s are not as familiar. He used social media platforms like Instagram and Facebook to further assist his outreach as well. By the time his campaign ended, Widrig regularly had individuals come out to participate in the run with him when time permitted them to do so.

When asked about Alzheimer’s, he reflected upon its devastating effects and his memories of how they had impacted his grandmother, “With Alzheimer’s you have to watch their condition deteriorate over time and it was hard to experience that firsthand with my grandma,” he continued. “But I know she would think what I’m doing is pretty cool. She was always very active and I know this is something she’d be very supportive of.”

Alzheimer’s awareness is something that Widrig has taken to heart over the years, and he is not done supporting it to improve the lives of others. He has future goals of putting together more fundraisers such as an organized 5K event or community walks for those who may be intimidated by the idea of running a 5K.
The memories that matter to you, matter to us.

See our new public service video at www.alzfdn.org.
Helpline: 866-232-8484