Landmarks Light Up Teal for Alzheimer’s Awareness

Junior Golfer Takes the Cause to the Course

Sportscaster’s Advice to Alzheimer’s Caregivers: ‘Don’t Go it Alone’
MEMORY CONCERNS?
YOU’RE NOT ALONE.

CALL

ALZHEIMER’S FOUNDATION
OF AMERICA

866-232-8484

NATIONAL MEMORY SCREENING
LEARN MORE AT WWW.NATIONALMEMORYSCREENING.ORG
MISSION: “TO PROVIDE OPTIMAL CARE AND SERVICES TO INDIVIDUALS CONFRONTING DEMENTIA—AND TO THEIR CAREGIVERS AND FAMILIES—THROUGH MEMBER ORGANIZATIONS DEDICATED TO IMPROVING QUALITY OF LIFE”

FEATURING

PAGE 8
ALZHEIMER'S CAREGIVERS NEED CARE TOO

PAGE 12
SPECIAL SECTION

PAGE 18
A TEEN'S PERSPECTIVE
American Junior Golf Association Member on a Mission to Fight Alzheimer's Disease

WE'D LOVE TO HEAR FROM YOU
Please send your comments, questions or feedback on AFA Care Quarterly to Amanda Secor asecor@alzfdn.org. We may include your note in a future issue.

IN EVERY ISSUE

2  A MESSAGE FROM OUR PRESIDENT AND CEO
5  RESEARCH CLIPS
6  CONNECT
15  HEART AND SOUL
21  BEST FOR LAST

Cover Art:
Anthony Collins Photography
Here at AFA, fall is the most important season of the year and this year is no exception. With the arrival of November comes National Alzheimer’s Awareness Month—a time to shine a spotlight on this disease that affects so many, yet is still so often discussed in hushed tones or altogether ignored. As always, AFA has a host of programs and events scheduled throughout November to help raise awareness of Alzheimer’s disease.

First and foremost is our National Memory Screening Program. Traditionally, we’ve observed National Memory Screening Day on the third Tuesday of November. This year, to meet an increased demand for screenings and afford people more options to take advantage of this free, confidential service, we’ve expanded National Memory Screening Day to a whole week—National Memory Screening week—November 1–7.

Allisyn Vachon, our national program manager, has been hard at work reaching out to sites across the country to encourage their participation and provide the tools they need to conduct the screenings. She can also help refer people to local screening sites, so if you’ve been thinking about having a screening yourself—or taking a loved one—contact Allisyn at 866-232-8484 x 161 or visit www.afascreenings.org to search by city and state or zip code.

In addition to our National Memory Screening Program, for the second year, landmark buildings across the nation—and for the first time, around the world—will be lighting up teal (the international color of Alzheimer’s disease) to raise awareness of Alzheimer’s disease. You’ll find a full listing of AFA Light the Nation sites committed as of press time on page 12.

And, as any caregiver will tell you, a healthy helping of humor can help lighten the caregiving load...at least temporarily. To that end, AFA is hosting “For the Love of...Joseph DiSanto,” a special night of comedy with Sebastian Maniscalco. DiSanto was Maniscalco’s grandfather and lived with Alzheimer’s disease from 1999 until his passing in 2005. The event will be held November 11, at New York’s Gotham Comedy Club. For more information or to purchase tickets, visit http://gothamcomedyclub.com/event.cfm?id=415366&cart.

Finally, the holidays are a time during which many people first notice changes in their loved ones’ memory and behavior—especially if we live some distance from those loved ones. This fall, AFA is introducing two new services to help caregivers. A new, telephone-based support group—specifically for long-distance caregivers—will kick off on November 7. In addition, AFA has teamed up with the National Alliance for Caregiving to create a #TalkBrainHealth social media campaign and tip sheet to help caregivers broach a conversation about memory or behavioral concerns with their loved ones during the holidays. For more information or to register for the support group, call Heather at 866-232-8484 and check our Facebook and Twitter pages for the memory concerns tip sheet.

Take good care,

Charles J. Fuschillo, Jr.
President & CEO
Alzheimer’s Foundation of America
Helping to fund research toward a cure and toward programs and services that help improve care for individuals with Alzheimer’s disease and their families is important to us here at AFA.

We are often asked

“How Can I Help?”

Here are just a few of the many ways you can help contribute to the cause:

Care Partners – Our care partners are philanthropic leaders dedicated to addressing the crisis of Alzheimer’s disease head on. By making generous annual gifts of $1,000 or more, AFA’s Care Partners make a significant contribution to the financial resources that fuel our programs and services across the country.

The Legacy Society – Making a planned gift is a special way to help ensure that individuals with Alzheimer’s disease and related illnesses and their families have access to optimal care and support services for years to come. Bequests, insurance and pension plans, and charitable trusts are creative ways to facilitate charitable giving, while also offering potential estate tax benefits.

The Sustainer’s Circle – Our sustainers generously contribute monthly gifts that help us provide care for individuals and their families who are living with dementia, while saving time, banking fees and paper. When you become a sustainer, we never need to send you a reminder about contributing to our cause. Your pledge renews annually and you may cancel at any time.

Friends of AFA – Want to contribute but not sure where to begin? Become a friend of AFA! For a donation of just $35, you can help AFA fund critical care programs such as respite, which provides social engagement for individuals with Alzheimer’s disease as well as a much-needed time-out for their caregivers.

Volunteer – join an AFA events committee, start a high school or campus chapter to raise awareness or reach out to one of our local member organizations to see if you can lend your time or talent.

For more information on these and other ways you can give to AFA, please contact us at 866-232-8484 or visit www.alzfdn.org.
“Sudden outbursts of crying or laughing can be a sign of fine acting. But for people with Alzheimer’s, it could be PBA.” —Danny Glover

People with brain injuries or certain neurologic conditions like Alzheimer’s disease or dementia, may experience frequent outbursts of uncontrollable crying or laughing called PseudoBulbar Affect (PBA).

In a recent national registry of more than 5,000 patients with a variety of neurologic conditions, 29% of the 1,799 patients with Alzheimer’s disease had PBA symptoms.*

‘PBA FACTS’ is a FREE KIT that explains the facts and science behind this treatable neurologic condition. For yours, call 1-800-810-3188 or go to pbafacts.com.

Choosing to cry or laugh should be up to you, not PBA.

*PRISM was a nationwide registry of adult patients with brain injuries or certain neurologic conditions, including 1,799 who have Alzheimer’s disease. PBA symptoms were defined as a Center for Neurologic Study Lability Scale (CNS-LS) score ≥13. This CNS-LS score may suggest PBA symptoms and merits further diagnostic assessment. Patients or caregivers completed the assessment. The CNS-LS has been validated in ALS and MS patient populations.
Patients or caregivers completed the assessment. The Center for Neurologic Study-Lability Scale (CNS-LS) has been validated in ALS and MS patient populations.  

de/f_i  ned as a Center for Neurologic Study-Lability Scale (CNS-LS) score ≥13. This CNS-LS score may suggest PBA symptoms and merits further diagnostic assessment.  

In a recent national registry of more than 5,000 patients, people with brain injuries or certain neurologic conditions like Alzheimer’s disease or dementia, may experience frequent outbursts of uncontrollable crying. 

PseudoAffect (PBA).  

A recent study suggests that sleeping on one’s side, as opposed to on his back or stomach, may help stave off Alzheimer’s disease. This is due to the fact that the side-sleeping position may be more conducive to efficient removal of waste from the brain.

Recent research out of Rush University in Illinois suggests that African Americans are less likely to have Alzheimer’s disease alone. Instead, 71 percent of study participants had Alzheimer’s disease mixed with another type of brain change that can cause dementia, such as infarcts resulting from stroke, dementia with Lewy bodies or Parkinson’s and blood vessel disease. Only 51 percent of European Americans, on the other hand, exhibited Alzheimer’s disease with one of these other conditions. These findings could signal the need for different treatment and prevention protocols for African Americans.

A recent study shows that Type 2 Diabetes takes a toll on the brain. The disease negatively affects the regulation of blood flow in the brain, which resulted in cognitive test scores of people with diabetes declining 12 percent during the two years of the study. By contrast, the scores of individuals without diabetes stayed the same.

A recent study suggests that scoring low on memory and thinking tests could signal a risk of developing Alzheimer’s disease years before diagnosis. The study followed more than 2,000 people of European-American and African-American descent, who had an average age of 73. The study took place over an 18-year period. Participants were required to take cognitive tests every three years. During the study, 23 percent of African-American participants and 17 percent of European-American participants developed Alzheimer’s disease. Those who scored poorly on the first test had 10 times increased risk of developing Alzheimer’s disease than those who scored well.
**QUESTION:** My mother has mild/moderate Alzheimer’s disease. She lives in a facility, though still in an independent capacity, with some help from my brother and me. I call her every night to check in but it is difficult to have a conversation with her because she has difficulty remembering what she did that day. If I offer highlights from my day as a conversation starter, she has trouble comprehending and asks a lot of questions. The answers seem only to confuse her more so I now avoid telling her about my day. When we finish this very short talk, I hang up feeling badly for her and I have a feeling she does the same. Any advice?

**ANSWER:** In terms of general tips on how to communicate successfully with an individual who has Alzheimer’s disease, the expression of “It’s not what you say, but how you say it” rings true. Alzheimer’s disease and related illnesses impair a person’s ability to understand words and also to speak. However, they can still benefit from non-verbal communication—body language, voice tone and facial expressions. As an individual’s ability to process verbal information declines, the importance of how caregivers communicate with them, verbally and non-verbally, increases. In this case, your mother does not have the ability to see these cues, since the conversation is taking place by phone.

Your phone conversations with your mom were probably once effortless—talking about anything and everything. Now you notice that due to this disease, your mother can no longer recall nor stay on task. This is your mother’s new norm, and you noted that your current communication style needs to change. While there is no golden dialogue I can provide you to have a fulfilling conversation, I can say that some planning can go a long way.

For example, perhaps you can call at the time of day that she is at her most alert; perhaps this is first thing in the morning. Also, instead of asking questions of her day, which she cannot recall or talking about your day—have specific topics already planned. Reminiscing can be fun and engaging. Talk about past family events or memories. Remember, we are not looking for ‘right’ answers—just hearing each other’s voices can be fulfilling. As the disease progresses, your conversation will sometimes just be a simple hello. And while it may often feel one sided, feeling loved is all she’s seeking.

**QUESTION:** My father has moderate Alzheimer’s disease. He was living with my husband and me; however, he became more and more disoriented and confused. We both work hectic hours, and it became difficult to provide my father the level of care he needed. We decided to put him in a skilled nursing facility so he could receive appropriate care. I am feeling guilty about it, especially because he keeps asking when he will be able to go home. I realize I can no longer care for him, but in my culture, it’s expected for me to care for him at home. This is really weighing on me. I still visit him every day, but it’s hard. I am worried he will decline further…was this the right decision?

**ANSWER:** Placing a loved one in a long-term care facility is a personal decision. But, it’s important to keep in mind that when a loved one’s safety is at stake, and when life circumstances such as work, financial issues or caregiver burnout prevent a person from providing an individual with the level of care that they require, moving that person to a long term care facility will help ensure their needs are provided for.

The move will certainly be a major adjustment for your dad. Keep in mind that his frequent request to go “home” is a common symptom of the illness, and is not necessarily an indication of maladjustment or unhappiness. What he may actually be looking for is a feeling of comfort and security. Express your love and concern for him as frequently as you can, so he feels valued. You can also try redirecting his attention to other topics that may spark positive conversation between the two of you.

Many caregivers experience feelings of guilt when it comes time to move their loved one to a long term care facility. This is particularly true in cases in which a family member, due to cultural beliefs or familial obligations, is expected to look after his loved ones or if that family member promised never to put his loved one in a nursing home. Consider it in this context: if you no longer have the stress of managing your loved one’s activities of daily living, it opens the door to spending more quality time together during visits.

Support groups are a truly wonderful resource for family caregivers as they not only provide a source of helpful information and care strategies, but also offer a safe and confidential place to vent some of the intense emotions brought on by the caregiving role. You can also reach out to AFA’s social services team through our national toll-free helpline at 866-232-8484. The helpline is staffed by licensed social workers and offers assistance in both English and Spanish from 9 a.m. – 9 p.m. ET, Monday – Friday.

Have a question for our licensed social workers? Call 866-232-8484 or send an e-mail to info@alsfdn.org.
For our readers who are not based in New York, can you tell us a little bit about how your donation came to be?

This past June, SportsNet New York (SNY) hosted a game show, called “Beat the Booth,” pitting TV announcer Gary Cohen and me against two pairs of avid fans in a trivia contest. Gary and I won and were each awarded $5,000 for the charity of our choice. I chose the Alzheimer’s Foundation of America.

How did you come to choose AFA as the recipient of your donation? Do you have a personal connection to the disease?

My dad, Robert “Bob” Rose, had Alzheimer’s disease way back before it was identified as such. He became ill in 1971-72 and passed in 1978, just shy of his 62nd birthday.

At the time, they diagnosed him with low-pressure hydrocephalus. They performed surgery and implanted a shunt, which they hoped would help drain fluid from his brain. In reality, his regression continued, resulting in a second surgery in just a four-month period. The words Alzheimer’s disease were not even uttered prior to its use on his death certificate.

How did the experience affect you?

It was a harrowing experience watching him go through it. At the time he got sick, I was 17 or 18 years old and my younger brother and sister were only 13 or 14. It had a profound, life-lasting effect on all of us. You witness things that scare you—seeing your parent behave in ways you’re not accustomed to. My dad was short-tempered to begin with, but this took it to a whole new level. And, although we knew it wasn’t meant maliciously, it still left scars.

Many of us who have had a parent with Alzheimer’s disease live in fear that we will also get the disease. We worry over menial forgetfulness—not remembering certain details, not being able to find the keys, etc.

What advice would you give our readers, many of whom are caregivers for their family members who have Alzheimer’s disease?

Don’t try to do it alone! Lean on people. Take advantage of support groups. There wasn’t much available to my mother, my siblings and me when my dad was ill. We had no support system.

In January of 1973, my father was no longer able to live at home and was moved into the VA hospital in Manhattan. My siblings and I had limited contact with him from that point on—just visits to the hospital. A social worker there suggested my mom bring my siblings and me in to talk with someone and get support. I regret not having done that because I think it would have helped.

I urge everyone living with a loved one with this disease—especially teens—don’t go it alone. Reach out for support. Communicate.

Shifting gears, and on a lighter note, lots of New York baseball fans are quite excited about their National League East Division Champions. What are the top three things you’re looking forward to this fall?

Watching the Mets win the World Series.

Helping out with the ceremonies at the championship parade.

Spending as much time as possible playing golf in Florida.
I observed my wife’s first symptoms of Alzheimer’s disease in 2007. In 2009, Clare was officially diagnosed with early- or young-onset Alzheimer’s, and by 2010, her decline had progressed to the point where I could no longer leave her alone. I became her 24/7 caregiver. Sometime in 2011; however, I realized that I needed some respite time. Initially I enrolled Clare in an adult day program for four hours a day, one day a week, but eventually, that grew to 22 hours of day care each week. Outside those 22 hours, I was with Clare almost every second of every day, and all my needs—including health-related ones—were placed on the proverbial back burner.

Clare was my number one priority, which meant that whatever I could not get done during the hours she was attending the day program just did not get done. When her needs were such that I had to place her in the dementia unit of an assisted living facility in September 2013, I slowly, but surely, morphed from 24/7 caregiver to 24/7 advocate. Because the staff at Clare’s residence now oversees her activities of daily living except when she accompanies me outside, I no longer view my role as her primary caregiver. Instead, I am her advocate, making sure that she is receiving the best possible care.

To be clear, Clare remains my number one priority. Our time together is sacrosanct and I visit every day, with few exceptions. However, unlike those years when I was her primary caregiver, I am now able to do almost anything I want or need to do each day—whether it be running an errand, going to the doctor or visiting our family. For example, I recently started taking occasional weeklong trips to visit our son and family in Michigan.

But whether home or away, I am now able to care for myself in ways I simply could not do before. Daily advocacy has its stress, but it’s nothing like the stress of daily caregiving.

It’s no secret that caregivers often sacrifice their own care when they are responsible for a loved one with Alzheimer’s. It was true of me, and also was true of others in my Alzheimer’s spouse support group. I also know, first-hand, the feelings of guilt that can come with even thinking about doing something for oneself while caregiving.

I want to share some of the lessons I’ve learned during my caregiving journey in the hope that they might help others who find themselves in similar situations.
THE CHALLENGE: Making Time for Self-Care

Every caregiver gives up some favorite activities in favor of caregiving responsibilities. I used to love playing golf. Once Clare could no longer be home alone, golf was one of the first things that went out the window. On a couple weekends, our daughter volunteered to stay with Clare so I could play, but I felt guilty being away from home for so long. I also knew that Clare wanted to be with me, not our daughter, so I couldn’t even enjoy myself. After trying twice, I thanked our daughter and put my clubs away.

Even simple home activities, like chores, often go out the window. For example, at a certain point I could not do anything at home by myself if Clare was awake. She would sit and watch TV all day long, and if I was not by her side, she would get up, find me and hover next to me until I joined her on the couch.

So, how can one make time for one more thing in a 24/7 caregiving routine? Here are my “core four” tips:

1. Make Room for Respite.
   For me, initially, I found respite time by placing Clare in adult day care programs. For others respite may take the form of hiring part-time health aides or companions who stay with loved ones in their homes. Still others may depend upon a trusted friend or relative to provide some weekly respite relief. Caregivers must find ways to provide themselves at least some respite time to do what they need to do, by themselves, each week. Studies have shown that such “time-outs” from caregiving can help reduce stress and prevent caregiver burnout.

2. Change Your Venue.
   Many assisted living and long-term care facilities permit a person with Alzheimer’s disease to stay up to one week, at a reasonable cost, to provide additional respite for caregivers. Facilities may do this to entice caregivers into considering full-time residential placement for their loved ones somewhere down the line, or simply to fill up empty bed space. Regardless, if there is a suitable place near where you live, I encourage you to look into this as an opportunity to leave your loved one in a safe and secure environment while you take time to visit relatives or friends and recharge your batteries.

3. Find an Outlet.
   Some caregivers go for manicures and pedicures to take their minds, temporarily, off of caregiving. Others may catch a movie, visit the library or go to a park to read a good book in peace and quiet without any distractions. Still others may enjoy yoga, tai chi or another form of exercise. Whatever works, all caregivers should try to find some outlet to help reduce their stress on a regular basis.

   For me, writing articles for publication enables me to take care of many of my emotional needs. Writing allows me to vent my emotions and feelings. After completing each article—even if battling tears while writing—I feel better. When I receive feedback from readers, it feels good to learn that I may be helping others through my writing. To this day I still find emotional release through writing, and more and more I am enjoying my correspondence with fellow caregivers who comment on my articles.
Visit your doctor.
As with hobbies and household chores, many caregivers sacrifice their own health needs if they interfere with their caregiving responsibilities. In my situation, I had severe left hip and leg pain and had to walk with a cane for nearly a year. I was walking so lopsided to try to reduce the hip pain that my left knee was aching and my leg was swollen. I waited to address the issue until Clare was no longer residing at home so I knew that she would be well cared for if I needed hospitalization. Unfortunately, I had put it off for so long that by the time I went to the orthopedic surgeon, I needed complete hip replacement surgery, followed by rehabilitation therapy.

Similarly, some caregivers in my support group scheduled their chemotherapy sessions during times their spouses were attending day care programs, not because it was the best time for the treatment, but because it was the only time their spouses would not be impacted.

Caring for a person with Alzheimer’s can easily lead to health issues for caregivers. Caregivers often find themselves suddenly having to deal with the effects of high blood pressure, weight gain or loss due to newly developed poor eating habits, stress headaches, or difficulty sleeping. Other ailments may be incurred from the physical strain of lifting a loved one in and out of a wheelchair, car or bed. In short, many caregivers find themselves in a continuous state of mental, physical, and emotional exhaustion at the end of every day.

A doctor may be able to suggest some diet modifications, exercise, or treatment that caregivers can do during respite time or when loved ones are asleep. Doctors may also recommend over-the-counter or prescription medication, or the name of a helpful therapist. At the very least, caregivers should make time for an annual physical examination to ensure they are receiving necessary health screenings, vaccinations (if desired) and advocating as much for their own healthcare as for their loved ones.

THE BOTTOM LINE
I know of no ways to completely eliminate the daily stress that caregivers find themselves facing when placing the needs of their loved ones ahead of their own. But there are some steps that caregivers can take to reduce some of their daily stress and improve their own self-care.

Most caregivers will always place the needs of their loved ones ahead of their own. One would expect this to be true for caregivers in a loving relationship with the person who has Alzheimer’s, but it is often also true even for caregivers who do not have a particularly loving relationship with the person who has Alzheimer’s disease. People who resent having to spend time as caregivers frequently still place that person’s needs ahead of their own due to feelings of guilt or from a sense of duty.

My closing thought is that as caregivers, we need to tend to our own needs as best we can. After all, if we “go down,” who will be there to care for our loved ones?

ALLAN S. VANN, of Commack, N.Y., is a retired public school principal. His wife, Clare, a retired high school teacher, was diagnosed with young-onset Alzheimer’s disease in 2009 at age 63. Vann also writes blog posts for Alzheimer’s caregivers in the Healthy Living section of The Huffington Post, which can be found at www.huffingtonpost.com/allan-s-vann.
“what did I want?”

Audrey’s memory is letting her down. Even her lists are not helping her these days.

Audrey wants an answer.

If you find that forgetfulness is becoming a problem for you, people comment on your memory loss, or you have difficulty solving problems and planning, these could be early signs of Alzheimer’s disease.

The AMARANTH clinical research study is testing an investigational medication to see if it is safe and effective in slowing the decline in memory and mental functioning caused by Alzheimer’s disease. You may be eligible to join.

To find out more call 855-930-7546, or, visit www.theamaranthstudy.com.
PAINTING THE NATION TEAL FOR ALZHEIMER’S AWARENESS

As daylight fades to dusk on November 5, more than two dozen landmarks will be turning teal in support of Alzheimer’s awareness. In 2014, its inaugural year, AFA’s Light the Nation campaign was celebrated in eight cities across the U.S. This year, that number has nearly quadrupled.

Here’s a full listing of North American sites as of press time:

- RSA Battle House Tower, Mobile, Ala.
- RSA Tower Building, Montgomery, Ala.
- Renaissance Montgomery Hotel & Spa/Convention Center, Montgomery, Ala.
- Los Angeles International Airport, Los Angeles, Calif
- Willis Tower, Chicago, Ill.
- The Wrigley Building, Chicago, Ill.
- LaSalle Plaza, Minneapolis, Minn.
- Wells Fargo Duke Energy Center, Charlotte, N.C.
- Woodmen Life Tower, Omaha, Neb.
- Miracle Mile Shops at Planet Hollywood, Las Vegas, Nevada
- Rundel Memorial Library Building, Rochester, N.Y.
- The Shops at Columbus Circle, New York, N.Y.
- The Empire State Building, New York, N.Y.
- The Peace Bridge, Buffalo, N.Y. and Fort Erie, Ontario, Canada
- City Hall of Cleveland, Cleveland, Ohio
- Terminal Tower, Cleveland, Ohio
- Skydance Bridge, Oklahoma City, Okla.
- Allegheny County Executive Office and Courthouse, Pittsburgh, Pa.
- Carnegie Science Center, Pittsburgh, Pa.
- High Level Bridge, Edmonton, Alberta, Canada
- Sails of Light at Port Metro, Vancouver, British Columbia, Canada
- Sichuan Tower, Chengdu, China
- Trafalgar Square Fountains, London, England, United Kingdom
- Gateshead Millennium Bridge, Gateshead, England, United Kingdom
- Emirates Spinnaker Tower, Hampshire, England, United Kingdom
- The Convention Centre Dublin, Dublin, Ireland

And for the first time, additional sites around the globe will also light up teal to show their support for the Alzheimer’s cause. Those sites are:

- Los Angeles International Airport, Los Angeles, Calif
- Willis Tower, Chicago, Ill.
- LaSalle Plaza, Minneapolis, Minn.
- Wells Fargo Duke Energy Center, Charlotte, N.C.
- Woodmen Life Tower, Omaha, Neb.
- Miracle Mile Shops at Planet Hollywood, Las Vegas, Nevada
- Rundel Memorial Library Building, Rochester, N.Y.
- The Shops at Columbus Circle, New York, N.Y.
- The Empire State Building, New York, N.Y.
- The Peace Bridge, Buffalo, N.Y. and Fort Erie, Ontario, Canada
- City Hall of Cleveland, Cleveland, Ohio
- Terminal Tower, Cleveland, Ohio
- Skydance Bridge, Oklahoma City, Okla.
- Allegheny County Executive Office and Courthouse, Pittsburgh, Pa.
- Carnegie Science Center, Pittsburgh, Pa.
- High Level Bridge, Edmonton, Alberta, Canada
- Sails of Light at Port Metro, Vancouver, British Columbia, Canada
- Sichuan Tower, Chengdu, China
- Trafalgar Square Fountains, London, England, United Kingdom
- Gateshead Millennium Bridge, Gateshead, England, United Kingdom
- Emirates Spinnaker Tower, Hampshire, England, United Kingdom
- The Convention Centre Dublin, Dublin, Ireland

“We are honored to have the support of so many—near and far—in literally shedding light on this devastating disease that affects so many individuals,” said Charles J. Fuschillo, Jr., AFA’s president & chief executive officer. “It is our hope that the number of participating sites will continue to grow for years to come and that with it, leaders in this country and worldwide will make finding a cure for Alzheimer’s disease a global priority.”
In recent years, memory screenings—simple check-ups designed to gauge memory, thinking and language skills—have gained traction as a way to detect possible issues early on. In fact, recent studies, including one from the journal “Neurology” have suggested that Alzheimer’s disease may be detected up to 18 years prior to clinical diagnosis through regular cognitive screening (see Page 5).

AFA is among the organizations leading the movement, encouraging people to be proactive about their brain health. The organization has hosted National Memory Screening Day annually since 2003, offering free, confidential screenings across the country. The increased number of people screened—year after year—led AFA to expand the initiative, offering screenings year-round, at venues as diverse as state fairs, libraries, houses of worship, and care facilities. This year, to afford people even more opportunities to be screened, National Memory Screening Day has become National Memory Screening Week—November 1-7.

Age is the greatest known risk factor for Alzheimer’s disease, and taking a proactive approach to brain health may help bolster our brain health. J. Wesson Ashford, M.D., Ph.D., a clinical professor (affiliated) at the Stanford / VA Aging Clinical Research Center and director of the War Related Illness and Injury Study Center the VA Palo Alto Health Care System, and chairman of AFA’s Memory Screening Advisory Board, believes that memory screenings are a good idea for individuals over age 65—the at-risk age for Alzheimer’s disease.

“A very important part of overall health is mental health,” Ashford said. “And a very important part of mental health is memory. So when thinking about screening, the question becomes not ‘what if I have Alzheimer’s disease?’ but ‘how can I optimize my memory health?’”

He suggests activities such as learning a new language, taking adult education classes that really challenge the mind, socialization, taking a cooking class to learn how to eat more healthfully, and engaging in exercise such as swimming, yoga and pilates.

Ashford also notes that there are benefits to early detection of memory problems. Identifying a memory problem early on can help put a person on the path to proper care. There are a number of reasons a person can be experiencing memory problems. Vitamin deficiencies, thyroid issues and depression can cause memory issues and are readily treatable. A poor result
A memory screening can signal whether a person should follow up with a physician for a thorough evaluation.

If a memory problem does turn out to be Alzheimer’s disease, a person may be able to participate in clinical trials or take advantage of drug or mental health therapies that may help slow the progression of symptoms.

Early detection also opens the doors to future planning. For example, if a memory problem does turn out to be a function of Alzheimer’s disease, but is detected while an individual’s cognitive functions are relatively intact, that person can discuss legal and financial implications of the disease with loved ones and put plans in place for the future. It also paves the way for conversations about long-term care and end-of-life wishes, which can help avoid family members having to guess at a loved one’s wishes when that person is no longer able to make decisions for himself.

For more information about memory screenings, or to locate a screening site, visit www.nationalmemoryscreening.org.

---

**A Memory Screening is**

- a safe, non-invasive test, consisting of a series of questions and tasks designed to assess thinking, language and other cognitive functions. AFA-sponsored memory screenings are administered, face-to-face, by qualified healthcare professionals.

- a process that more often relieves an individual’s concerns about their memory rather than suggests memory problems that were not suspected beforehand.

- can be used as a benchmark to monitor future memory function.

- included in the annual Medicare wellness visit—a fact many people don’t realize.

- a first step in identifying an issue and putting a person on a path to proper treatment.

---

**A Memory Screening is Not**

- something that requires a lot of time; most screenings last only about 10 minutes.

- a diagnosis of any particular condition. There are a number of reasons a person could experience memory problems, including depression, vitamin deficiencies and thyroid issues. A person who scores below the normal threshold will be advised to contact his or her physician for a thorough evaluation.

- a process that causes any harm if the procedure is followed.
Personally, and as a former teacher, analogies have always been useful in helping me understand and explain information when learning something new. When my husband was diagnosed with early-stage dementia, I sought information about the disease to guide our future decisions. The characteristics of the disease reminded me of the multiple facets of a glacier. The comparison grew in my mind as I experienced more effects of the disease and heard accounts from others, resulting in the decision to write and share the perspective.

As people age and memory lapses emerge, a concern about Alzheimer’s and dementia starts to build. How does it start? What does it look like? Viewing a glacier twisting down a slope to the sea brings similar questions. The glacial surface is spiked with sharp edges, smooth humps, and blankets of snow; at the sea, arched caves scallop the massive ice wall. Both the glacier and dementia progress slowly. If we examine and compare the features of glaciers to observable behaviors in a person with early Alzheimer’s or dementia, it may help frame the experience in a way we can better understand.

By sliding and creeping a glacier flows downward; it is slow and relentless. Alzheimer’s disease and dementia slowly alter the brain’s ability to retrieve information, initiate decisions, discern actuality, and, eventually, control life functions. Although, like a glacier, each person’s journey is different, being aware of possible behaviors may signal a action. During the early stages of the illness, people often create excuses rather than address the changes. As a result, the disease may advance for years before treatment is sought by—or for—the person.

When viewing a glacier, a first impression includes expansive fields of ice. However, a journey over the glacier reveals perilous facets. Once-soft snow crystals accumulate and pack, bonding together to form the hard ice. The underlying layer of the mass flows slowly, with its movement seldom noticed, yet it creates cracks that deepen into crevasses. Snow spreads across the cracks, creating a thin bridge hiding the chasm below. While traversing a glacier, probing for solid footing is important, as crevasses open and close. Although the typical speed is slow, there are bursts of speed causing displacement of material.

Just as glaciers have many facets, there are many types of dementia and variations of symptoms. Difficulty with short-term memory, reasoning, making decisions and confusion or disorientation are noticeable conditions. Dementia is a general term under which Alzheimer’s is one type of illness. Once dementia is diagnosed, care plans can then be established and will change and evolve—like a glacier—as dementia symptoms progress.

When ascending a glacier, the ice becomes more and more fissured and confused. As dementia progresses, confusion and lapses in memory also increase. For example, when attending a meeting
at a site with multiple buildings, Eric* was unable to find the correct building, even though it was directly across from the parking lot. The number of choices added to his confusion and inability to recall the designated building. Another example is when a person recalls the overall circumstances of an event, but specifics are missing or altered. As Matt told a story about an event in 1985, he changed the place of the event and the roles of a few participants. At first these incidents may be rationalized as happening because of unclear directions or overlooked as the result of a preoccupied mind. The excuses, denial or concealment of incidents might be compared to snow bridges that form over crevasses in a glacier, making the path seem regular. Without a solid base, a traveler or person will find their world breaking apart beneath them. A person who normally attends to the details of a business or job may become inconsistent in performance, creating shortages of inventory, issues with records of transactions or missed opportunities. As the lapses continue or increase, a business or job is lost.

During the early stages of dementia, the changes in demeanor or episodes of memory lapses or illogical thought processes may be scarcely noticed, similar to glacier ice formation. Eventually the snow becomes packed into impermeable ice with individual bubbles, unconnected to each other. In the brain of a person with dementia, it is thought that plaques and tangles form and pockets of memories become disconnected, making involvement with current reality or conversations difficult. Retrieval may be as impermeable as the ice. No matter how hard the person tries, the information cannot be accessed. Irritation, annoyance, exasperation or frustration may occur. For instance Todd, always mechanically competent, bought a new watch to help him remember the day and date as well as the time, but he found himself unable to set the features. After considerable effort, he became annoyed and frustrated with himself as he realized the loss of his previous abilities.

**Just as ice can lose substance by evaporation even when temperatures are so cold that it can’t lose it by melting, an active mind can lose information and memories.**

Bike riding and walking keep Karen physically active. Managing a household and involvement with civic and school activities require Karen’s thoughtful consideration of detail. However, Karen now finds preparing a meal for family holidays overwhelming. She can’t seem to coordinate the cooking of so many items or remember if she has added all the ingredients to a dish.

With dementia, a person’s short-term memory loss may appear with repetition of questions. The individual truly does not remember asking for the information, so asks again (and again) because she is seeking an answer for some relevant concern. During a conversation, the individual may attend to only the current focus, unable to link it to previous comments. In addition, the individual may extend the subject matter beyond the flow of the group’s conversation, especially if the topic triggers past memories which are more accessible. During a conversation the person may also experience difficulty understanding certain words, which will alter perception of the content or purpose of the discussion. Individuals may become less communicative, suddenly disappearing from a room, when difficulty of interacting becomes greater.

And, just as glacier flow is more rapid in the afternoon than the morning, some people with dementia experience sundowning, a shift in behavior that usually occurs as evening approaches, with the individual becoming restless, fatigued or overstimulated.
Dementia advances in segments with uneven intervals; the level and extent of decline may be slow or sudden. Glaciers typically poke along at a slow speed for decades, then have a short, sudden burst of speed. Certain events may trigger rapid or severe losses or changes in behavior/coping ability. After surgery on his shoulder, Todd experienced more difficulty communicating and functioning in his environment. In order to reduce household demands, a person with dementia may move to a smaller home with less maintenance to concentrate more on daily activities. However, the change can be upsetting and trigger advances in the person’s condition. Sudden surges may also occur after a traumatic event, such as the death of someone special to the person or from a divorce causing a major lifestyle change.

Since progression of dementia is unpredictable, a person with the disease or a caregiver must always be alert to changes and their implications. For example, as retrieving words becomes more difficult, more effort will be necessary during communication. The individual may need to consider responses longer to access desired words. The inability to find the correct word can cause frustration and make retrieval more difficult or impossible. If words are interchanged, such as sheet for towel, the listener will need to consider the gist of the discussion and surmise the appropriate word, ask for clarification, or give the word or a synonym of the assumed word—all with discretion.

Creeping means to slowly overcome or enter into something. Sluggishly, a glacier slides along its bed, just as changes to the brain and behavior slowly enter into a person’s life with dementia. Creepy is a slang term for something/someone triggering horror or fear. Fear may delay individuals from consulting a physician or neurologist. Since Alzheimer’s and dementia is not curable, many people worry that the progressive nature of the disease and the long-term consequences it will have on themselves and those close to them. Yet diagnosis is imperative so the type of dementia is identified, available treatment started, and support found.

Robert Scott, as he was crossing glaciers at the South Pole, described a crevasse as nature’s pitfall. Its light rippled snow bridge giving no hint of the hidden danger until one is floundering on the brink. Although the symptoms of dementia slowly appear, the realization of having it always seems sudden and leaves many floundering to understand and adjust to the changes. New pathways must be forged so the individual is able to sustain her/his lifestyle.

Consider this: one evening, Matt was to meet his wife for dinner. She was to call him at 5:00 to set a time that she would be finished at the office and arrive at the restaurant. However, Matt called her at five o’clock already at the restaurant wondering when she would arrive. In his mind, the call time became the meeting time. For future meetings his wife delayed telling him the place until she called with a time.

Living with dementia and caring for a loved one who has it is a new journey over uneven ground. However, understanding the symptoms, establishing baseline brain function levels, and implementing thoughtful changes can help smooth the path ahead.

CAROL MOUTRAY is a former teacher and current caregiver for her husband who has dementia from mild cognitive impairment.

* All examples are incidents told to the author by caregivers of a person with Alzheimer’s or dementia. All names are pseudonyms.

RESOURCES


Like many 16 year olds, Reece Sanders is a junior in high school and plays sports. Specifically, Reece plays golf. He made the varsity team in just the seventh grade and this past June, won the Minnesota State High School golf tournament, which he describes as “a wake-up call to get more serious about the sport.” Sanders joined the American Junior Golf Association (AJGA) and opted to participate in its Leadership Links program.

Leadership Links allows the AJGA to further its mission of helping develop young men and women by teaching charitable giving skills and service-oriented practices at an early age. This program gives juniors all the tools necessary to donate their time, talent and resources to local charities. Sanders chose the Alzheimer’s Foundation of America as his charity, as his paternal grandmother is in the early stages of the illness. AFA Care Quarterly recently spoke with Sanders:

“My father’s mom, Jane Sanders—Nana to me—is in the early stages of Alzheimer’s disease. She was diagnosed in her early 80s when I was in middle school. Since then, my family has been learning about the disease and educating one another. I thought, ‘why can’t Alzheimer’s disease have a treatment or cure?’ and decided to do my part. It’s pretty cool being able to tell my teachers about my involvement in Leadership Links and to share a cause that is close and personal to me. Plus, my grandmother is really proud.

My involvement in Leadership Links has definitely given me perspective—this is bigger than just golf. I came off the course recently after a day that I hadn’t played particularly well. But, my donors pledge money for each birdie I make and I raised $25 for everyone who pledged on that day that was donated to AFA. My fundraising goal was $2,000 and I’m happy to say that so far, I have raised more than $3,200.

I am fortunate that all four of my grandparents are alive. My mom’s family lives in Naples, Fla., and my dad’s family lives in Sacramento, Calif. My grandmother’s illness has definitely brought us closer together. I’m e-mailing and calling her more. I think it’s been especially hard for my grandfather. My mom is going out to visit and help them in November. I’m glad I have a chance to do something to help raise money to support people living with Alzheimer’s disease.”

Visit Reece’s fundraising page at https://www.ajga.org/PIF/HomePages/index2.asp?UID=202993
AFA Partners In Care: Supporting Individuals Living With Dementia

TRAINING PROGRAM
Helping professionals build relationships and improve care.

ABOUT THE TRAINING PROGRAM
- Comprehensive, multidisciplinary 6-hour DVD program
- Provides practical skills and knowledge for paraprofessionals and professionals working with individuals who have dementia
- Features dementia care experts, families, and individuals with dementia
- Opportunity for AFA certification!

LEARN MORE
- Order AFA Partners in Care DVD training
- Learn about AFA Partners in Care
- View the AFA Partners in Care video trailer

www.careprofessionals.org

Inform Let your networks know why professional, person-centered dementia training matters. Share information about the training video in e-newsletters and on social media and your organization’s website.

Advocate Stay connected with DCPA as we work together to improve the quality of dementia care nationwide. Let us know how we can better serve you!

Approved for 5.5 CE contact hours from the National Association of Social Workers and New York State Education Department’s State Board for Social Work.

To purchase Program DVD or for more information call 866-232-8484.
TO YOUR HEALTH

One Pot Chicken, Broccoli and Whole-Wheat Couscous

Fall’s hectic schedules make it the perfect season for one-pot dishes. This dish is simple to prepare, great-tasting and requires minimal clean-up. The best part? The leftovers can be frozen and reheated for a no-fuss meal another night.

Serves 4

INGREDIENTS:

- 1 tomato, chopped
- 1 Tablespoon fresh basil, chopped
- 2 Tablespoons, balsamic vinegar
- 3 teaspoons cold-pressed extra-virgin olive oil, divided
- 1 clove garlic, minced
- 1 medium carrot, diced
- 1 pound boneless chicken breast, cut into 1-inch-wide strips
- 2 cups broccoli, chopped (discard thick stems)
- 1 ½ cups low-sodium chicken broth
- 1 cup uncooked whole wheat couscous

METHOD:

- Combine tomato, basil, vinegar and 1 teaspoon of oil and set aside.
- Heat remaining two teaspoons of oil in large nonstick skillet on medium to high heat.
- Sauté garlic, carrot, chicken and broccoli for five to six minutes or until chicken is cooked thoroughly.
- Pour broth into skillet and bring to a boil.
- Add couscous, cover and remove from heat. Let stand 10 minutes.
- Divide tomato dressing evenly on four plates and then evenly plate chicken, broccoli and couscous. Fluff the couscous with a fork as you serve it.

Nutrition facts per serving (318 grams): 390 calories, 7.4 grams fat, 118 milligrams sodium, 37.7 grams carbohydrates, 3.5 grams dietary fiber, 40.6 grams protein.

I SCREAM, YOU SCREAM...

One of America’s most popular desserts, ice cream, comes in dozens of flavors. From store bought to homemade, ice cream is a sweet treat that people of all ages enjoy.

For a fun (and appetizing) mental workout, answer the questions below.

1. Name at least three basic ingredients that give ice cream its delicious, creamy flavor.

2. Which type of ice cream is really not creamy at all? (Hint: it is based with water, giving it a lighter taste).

3. List at least three ice cream flavors that contain nuts.

4. Which decadent dessert is made with a banana, three ice cream flavors, toppings, and whipped cream?

5. Which edible device for holding ice cream was originally made from glass or metal (called a penny lick) or wrapped paper (called a hokey pokey)?

6. Although everyone has his or her favorite, which flavor of ice cream is America’s most popular?

7. Baskin-Robbins, the world’s largest ice cream franchise, is famous for having how many flavors?

8. What flavor of ice cream is a blend of chocolate ice cream mixed with marshmallow and almonds?

Answers:
1. Cream, milk, sugar
2. Ice milk
3. Black walnut, butter pecan, pecan praline, pistachio, rocky road
4. Banana split
5. Ice cream cone
6. Vanilla
7. 31
8. Rocky road

Excerpted with permission from “Strengthen Your Mind,” by Einberger & Sellick ©2007 by Health Professions Press, Inc.
On NOVEMBER 5TH landmarks from New York to Los Angeles, from Toronto to Vancouver and from the United Kingdom to China will be lit in TEAL in honor of the Alzheimer’s Foundation of America!

Thank you to all for helping us raise awareness! For more information call AFA at 866-232-8484 or visit www.alzfdn.org #AFALightTheNation