

For caregivers of individuals living with *Alzheimer's Disease* and related illnesses
A publication of the *Alzheimer's Foundation of America*

Seasonal Safety – Take Care This Winter

Coping with
Caregiver Isolation

Sportscaster Len Berman
Shares Lessons Learned as
an Alzheimer's Caregiver



Winter
2016

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WINTER 2016 VOL. 11 NO. 1

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FEATURES



PAGE 3 **WASHINGTON UPDATE**

The latest Hill happenings from Eric Sokol, AFA's vice president of public policy



PAGE 6 **SEASONAL SAFETY**

Tips to Help You Take Care This Winter



PAGE 9 **SPORTSCASTER LEN BERMAN SHARES CAREGIVING LESSONS**



PAGE 10 **GUEST COLUMN** *Coping with Caregiver Isolation*



PAGE 12 **BOOK CLUB** *'Finding Joy in Alzheimer's' by Learning to Listen*



PAGE 15 **CRACKING THE CODE** *A Look at Clinical Trials*

IN EVERY ISSUE

- 2 A MESSAGE FROM OUR PRESIDENT AND CEO
- 4 RESEARCH CLIPS
- 5 CONNECT

- 8 GIVING CORNER
- 18 TO YOUR HEALTH
- 20 HEART AND SOUL

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As we present our first issue of AFA Care Quarterly,™ in 2016, I want to take this opportunity to wish all of you a happy and healthy new year! I'm proud to tell you that we have greatly expanded our programs and services to better serve families in need. We are thrilled that the Alzheimer's Foundation of America's (AFA) national toll-free helpline is now open from 9 a.m. to 9 p.m. EST, Monday through Friday, offering assistance in both English and Spanish. And we're not stopping there! In 2016, we're looking to further expand the helpline's hours of operation and continuing to grow our programs and services nationwide.

I encourage you to take advantage of these programs and services, including AFA Care Connection—our free, monthly educational teleconference for family and professional caregivers of people with Alzheimer's disease and related illnesses. If you're a healthcare professional, consider joining our Dementia Care Professionals of America division and availing yourself of the wonderful professional education programs and trainings we offer.

In addition, AFA's membership continues to grow, with more than 2,400 member organizations nationwide providing hands-on programs and services to you in your community. Last year, we expanded our National Memory Screening Day to a full week and offered year-round screenings as well. I'm truly excited to see where 2016 will take us.

In preparing my message, I bear one thing in mind—You. AFA Care Quarterly is written for you. In each issue, we strive to provide practical strategies and tips to help you better navigate your caregiving journey. We share stories from professional and family caregivers alike to help reinforce that you are not alone. We are your caregiving companion, offering information and inspiration.

With that in mind, I want to hear from you. What topics would you like to see covered in these pages? What information would be most helpful to you?

I encourage you to take a few moments to let me know what you think.

Please send me your comments and suggestions:

Chuck Fuschillo
President & CEO
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You can also e-mail me at: cfuschillo@alzfdn.org.

All the best in 2016,



A handwritten signature in black ink that reads "Charles J. Fuschillo, Jr." The signature is fluid and cursive.

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

The latest Hill happenings from Eric Sokol, AFA's vice president of public policy



National Institutes of Health Releases Strategic Plan for FY'16-FY'20

The National Institutes of Health (NIH) has released its strategic plan for fiscal years 2016-2020. The plan focuses on four essential, interdependent objectives that will help guide NIH's priorities over the next five years. The objectives are:

1. Advancing opportunities in biomedical research in fundamental science, treatment and cures, and health promotion and disease prevention;
2. Fostering innovation by setting NIH priorities to enhance nimbleness, consider burden of disease and value of permanently eradicating a disease, and advance research opportunities presented by rare diseases;
3. Enhancing scientific stewardship by recruiting and retaining an outstanding biomedical research workforce, enhancing workforce diversity and impact through partnerships, ensuring rigor and reproducibility, optimizing approaches to inform funding decisions, encouraging innovation, and engaging in proactive risk management practices; and
4. Excelling as a federal science agency by managing for results by developing the "science of science," balancing outputs with outcomes, conducting workforce analyses, continually reviewing peer review, evaluating steps to enhance rigor and reproducibility, reducing administrative burden, and tracking effectiveness of risk management in decision making.

In comments submitted to NIH on the plan this past August, the Alzheimer's Foundation of America (AFA) called for increased focus on cognitive screening, including evaluation of impact and utilization of screens, and further research into person-centered

care as well as caregiver training. AFA will continue to monitor NIH as it works to achieve its goals during the next five years.

FY'16 Budget Includes Increases For Alzheimer's Disease Research and Caregiver Supports

Prior to their holiday recess, Congress passed and President Obama signed a federal budget package for fiscal year (FY) 2016 that includes an unprecedented increase in federal funds for clinical research into Alzheimer's disease. Under the spending plan, the National Institute on Aging (NIA) will devote \$936 million for Alzheimer's disease and related dementias research, a \$350 million or 60 percent increase above FY 2015.

In addition, some programs and services to help family caregivers also saw some modest increases in funding. The Administration for Community Living (ACL) will receive \$14.7 million for its Alzheimer's Disease Prevention Education and Outreach program. The program encourages people experiencing memory loss to seek medical advice, addresses stigma, and funds new grants to states that expand specialized services and supports targeting certain categories of individuals living with Alzheimer's disease or related dementias. Also, ACL's Lifespan Respite Care Program will receive an additional \$1 million for a total of \$3.36 million and ACL's National Family Caregiver Support Program will receive an increase of \$5 million, reaching \$150.6 million in FY 2016.

AFA urges all Alzheimer's stakeholders to contact their members of Congress and thank them for their support. AFA will remain committed and, by building upon this success, will continue to work to increase federal funding for research and resources for caregiver services and supports in the coming year.

RESEARCH CLIPS

Alzheimer Disease and Associated Disorders • December 10, 2015

A recent study revealed that chronic stress in older adults could lead to mild cognitive impairment, which is often a precursor to Alzheimer's disease. The research is based on data gathered from more than 500 participants aged 70 and older from the Einstein Aging Study, at the Albert Einstein College of Medicine. The study found that individuals who had high stress levels were more than twice as likely to develop cognitive impairment than those who did not.

Neurology • December 2, 2015

The speed at which older persons walk may be related to the amount of amyloid they have accumulated in their brains. The study involved 128 people with an average age of 76 who did not have dementia but were considered at high risk for developing it because they had some concerns about their memory. The participants had scans of their brains to measure amyloid plaques. Of the participants, 48 percent had a level of amyloid often associated with dementia. Researchers found an association between slow walking speed and amyloid in several areas of the brain.

Health Affairs • December 2015

An evaluation of a specific Medicare Advantage home visit program recently showed that participants receiving such visits had reductions in admissions to hospitals and decreased risk of nursing home admissions compared with individuals who did not receive home visits. These results suggest that a detailed home-based clinical assessment of an individual's health and home environment—combined with referral services—can support aging in place, promote physician office visits, and preempt costly institutional care.

Neurology (online) • December 10, 2014

A study from the RAND corporation found that health care costs for individuals with dementia far surpassed costs of other illnesses (heart disease, cancer and other causes) during the last five years of life. Although Medicare expenditures were similar across groups, average out-of-pocket spending for individuals with dementia was more than 80 percent higher than that for individuals without dementia.

Caring for someone with Alzheimer's?

You may be able to help.

A local research center is conducting a research study for people with mild-to-moderate Alzheimer's disease.

To qualify, participants must be:

- Between the ages of 55 and 85
- Diagnosed and treated for Alzheimer's disease
- Have an available and reliable caregiver

Learn more. Call 1-866-847-4414

Qualified participants receive all study-related visits and medications at no cost.

SEASONAL SAFETY

Taking Care This Winter

Although much of the country has not yet experienced winter's wrath, it is inevitable that the season's cold temperatures and hazardous conditions will soon set in from coast to coast. Winter can pose a host of challenges for people with Alzheimer's disease and related illnesses and their families. Fires, hypothermia and slips and falls, are just a few of the seasonal situations that could have an even greater impact on individuals with cognitive impairment.



HERE ARE SOME TIPS TO HELP KEEP YOUR LOVED ONES SAFE:

KEEP WARM

Hypothermia is a medical emergency that occurs when the body loses heat faster than it can produce, resulting in a dangerously low body temperature. Men and women aged 65 and older—the at-risk age for Alzheimer's disease—are at much greater risk of dying from hypothermia. And some of the behaviors associated with Alzheimer's disease, such as wandering, may make a person more susceptible. Look to this checklist to help reduce the risk of hypothermia:

- Make sure chimneys and heating equipment are cleaned and inspected annually to reduce the risk of fire and help ensure optimal performance. In addition, ensure there is plenty of fuel. Finally, check the batteries on smoke and carbon monoxide detectors and make sure they are working properly.
- Keep thermostats set to a temperature that is comfortable for all who reside there. Dress in layers for optimal comfort.
- Be sure to place anything flammable at least three feet from all heat sources including fireplaces, wood stoves, radiators, space heaters, and candles.
- Turn off and/or unplug space heaters when going to bed or leaving a room.
- If your loved one is going outside, make sure he or she is dressed appropriately. A hat will help keep heat from escaping the body. A warm coat, gloves, a scarf and warm socks are also essential.
- Pay particular attention to your loved one's wandering triggers to help ensure he does not go out in the cold. If you sense he is restless, try redirecting his attention to an activity he enjoys.

HYDRATION

Hydration can often be overlooked during the winter months, but is just as important as in the summer. People with dementia may not realize they are thirsty, so think about ways to help them reach the recommended six to eight medium-sized glasses of liquid per day.

- Be proactive. Instead of asking "Can I get you something to drink?" have a beverage ready and say, "I brought you a cup of peppermint tea."
- Change it up. Fruits and vegetables are chock-full of water. Soups can also be a way to sneak in some additional hydration.

- Limit the intake of caffeinated coffee, teas and sodas, as they can actually flush fluids from the body.
- Recognize the signs of dehydration, which include agitation, excessive tiredness, dry mouth, vomiting, dizziness, concentrated urine, muscle cramps, and confusion. Be aware that certain medications may increase the risk of dehydration by causing excessive urination or decreasing a person's thirst. Seek medical attention if your loved one exhibits these signs.
- Protect your skin. Winter can really take a toll on skin, leading to dryness, itchiness, and cracking. To help keep your loved one comfortable, be sure to moisturize regularly. You may even want to consider switching to a soap or cleanser that contains moisturizer for the season. And, don't forget the sunscreen when outside for walks.

TREAD CAREFULLY

- It doesn't take much liquid to create an icy patch that can cause a fall. Help minimize the chances for your loved one taking a spill by clearing snow, ice and excess clutter (such as tools and children's toys) from walkways and pavement.
- Ensure your loved one is wearing suitable footwear when going outside. Consider boots with non-skid or weather-appropriate soles. Hold your loved one's hand when walking to and from the car and your destination.

FIGHT THE FLU

The flu can be one of the season's most dangerous elements. According to the CDC, people older than 65 years of age are at greater risk for complications from this virus. In fact, it is estimated that between 80 percent and 90 percent of seasonal flu-related deaths have occurred in people 65 years and older and between 50 percent and 70 percent of seasonal flu-related hospitalizations are attributable to that age group. The CDC recommends that adults aged 65 and older get the flu vaccine. But if the virus does pay a visit to your family, here are some suggestions to help care for your loved one:

- Contact his primary care physician as soon as you notice symptoms. Symptoms can include coughing, fever, fatigue headache, sore throat, nausea and vomiting.
- Before reaching for that remedy, discuss medications with your loved one's doctor. Certain prescription and over-the-counter drugs designed to treat flu symptoms may interfere with other medications your loved one is taking or worsen confusion. Tell the doctor all medications your loved one is currently taking so s/he can best recommend treatment.
- Look for behavioral changes, as the flu might cause such changes as confusion and irritability in individuals with dementia.
- Protect yourself and your loved ones. Wash hands frequently with anti-bacterial soap and water or an alcohol-based hand sanitizer and consider wearing a mask over your mouth and nose.
- Keep your loved one home from any social activities while he is ill.
- Monitor your loved one's condition. If symptoms worsen after three or four days, seek medical attention.

TAKING TO THE ICE TO RAISE AWARENESS

In December, the New York Islanders hockey franchise and the family of its longtime head coach Al Arbour teamed up with AFA to make the team's commemorative "AL" patch available to fans. Coach Arbour, who recently passed away, battled Alzheimer's disease for several years. People can purchase the patch for \$10 and proceeds go to AFA. The patches are currently worn on all three Islanders game jerseys.

"The Alzheimer's Foundation of America is grateful to the New York Islanders Hockey Club and the Arbour family for raising awareness of this devastating disease," said Charles J. Fuschillo, Jr., president and CEO of the Alzheimer's Foundation of America. "Coach Arbour's contributions will always be revered by coaches, players, and fans of the sport of hockey. The proceeds from the "AL" patch will help the Alzheimer's Foundation of America continue to provide care, education and services to people with Alzheimer's disease and their families."

Fans can purchase the patch online through the New York Islanders website*

<http://islanders.nhl.com/club/search.htm?q=al+patch> or at one of the following locations:

- Islanders Pro Shop at Twin Rinks: 200 Merrick Ave, East Meadow, N.Y. 11554, (516-394-8041), Monday-Friday: 10 a.m. – 9 p.m., Saturday/Sunday: 9 a.m. – 8 p.m.
- Islanders Pro Shop at Iceworks: 175 Underhill Blvd, Syosset, N.Y. 11791 (516-496-2910), Monday-Friday: 10 a.m. – 9 p.m., Saturday/Sunday: 9 a.m. – 8 p.m.
- Islanders Pro Shop at Dix Hills Rink: 575 Vanderbilt Pkwy, Dix Hills, N.Y. 11746 (516-394-8041), Monday-Friday: 3 p.m. – 9 p.m., Saturday/Sunday: 10 a.m. – 5 p.m.

The patch will be sold throughout the 2015/2016 regular season.

*Shipping and handling charge to be added to online purchases.





FIVE QUESTIONS *with* LEN BERMAN

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Len Berman is an Emmy award-winning sportscaster and New York Times best-selling author who has covered just about every major sports event during his 40-year career in broadcasting. He is co-host of “Len Berman and Todd Schnitt in the Morning” a general news talk show on WOR radio.

In addition, Berman is the creator of “Spanning the World,” a monthly collection of sports bloopers, which is a long time staple on NBC’s Today Show.

He has been inducted into the New York State Broadcasters Hall of Fame and the National Jewish Sports Hall of Fame.

A native New Yorker, Berman graduated from Syracuse University. He resides on Long Island with his wife Jill. They have three children.

Your career has literally “spanned the world.” How did you get into sports broadcasting?

I walked into the college radio station at Syracuse University my freshman year and thought I wanted to be a disc jockey. They told me, “Everyone wants to do that. Would you be interested in reading the sports news Saturday night?” I didn’t have a date. And the rest is history. From Syracuse I went on to work as a television newscaster in Dayton, Ohio, then as a television sportscaster in Boston before coming home to New York.

Tell us about your experience with Alzheimer’s disease.

My dad suffered from Alzheimer’s around 1990. It was heartbreaking. He would resort to saying “hi fella” when he saw me because he forgot my name. The only saving grace during his four or five year decline was that he was never in pain.

How did being a caregiver affect you?

From the experience, I realized how devastating Alzheimer’s is. People think it’s “old forgetful Uncle Harry.” Obviously, that doesn’t begin to scratch the surface.

What advice would you give to other caregivers?

My advice to other caregivers is patience. It’s easier said than done, but getting frustrated and thinking if you ask a question over and over the individual might “get it” right is the wrong way to go. Simply help your loved one become as comfortable as possible.

What are you most looking forward to in 2016?

I’m most looking forward to the end of the political campaign in 2016. Enough yak already! I think the Brazil Olympics will be a nice diversion. And a cure for Alzheimer’s would be a dream come true for all of us.

COPING WITH CAREGIVER ISOLATION

By Susan Kaden



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At times, being a caregiver can leave one feeling lonely and socially isolated. It is a demanding occupation that often leaves little time for one's own needs. Balancing caregiving duties with our own habits and lifestyles is a difficult task, especially if there are also children in the picture. In fact, studies show that 40 to 70 percent of family caregivers experience symptoms of clinical depression.

Social isolation stemming from lack of social activities and relationships outside of work can leave you feeling hopeless. It is important that you understand you're not alone in your struggles. The National Alliance for Caregiving estimates 43.5 million Americans—age 18 or older—have been a caregiver in the past year. That's more than one-eighth of the U.S. population!

HERE ARE SOME TIPS TO HELP MANAGE THAT FEELING OF LONELINESS WHEN CARING FOR A LOVED ONE:

1. STAY CONNECTED

Social media can be both a blessing and a curse. It can pull us away and distract us from important tasks and household chores. But, when we are stuck at home and feeling isolated, social media can be a positive outlet for connecting with people who lift our spirits.

Create an Instagram account or sign up for Facebook to connect with loved ones and friends

and build your social network. Instagram can be a great place to find that inspirational photo or quote that might just brighten your day. Other networks, such as Inspire.com and My Health Teams offer communities of peer support that can help put you in touch with other caregivers who "get it."

2. FIND A PASSION

A few years ago, I was sitting in a waiting room on Christmas Eve waiting for my husband to come out of the ICU. He had just undergone brain surgery and I found myself feeling entirely numb. I had to find a way to occupy my mind and decided to start writing my memoir. Once I started writing, I could not stop. I came to realize that not only had I found a creative outlet that I enjoyed but I also found a passion.

So find your passion! Maybe it is knitting, or baking or painting. If there is something that you like to do, use it to help relieve stress and serve as a creative outlet. Not sure what your passion is? Don't be afraid to try different activities until you find it.

Sites such as Pinterest, a photo-sharing website, can be a good source of inspiration. The site features ideas from food and drink to do-it-yourself crafts and home décor.



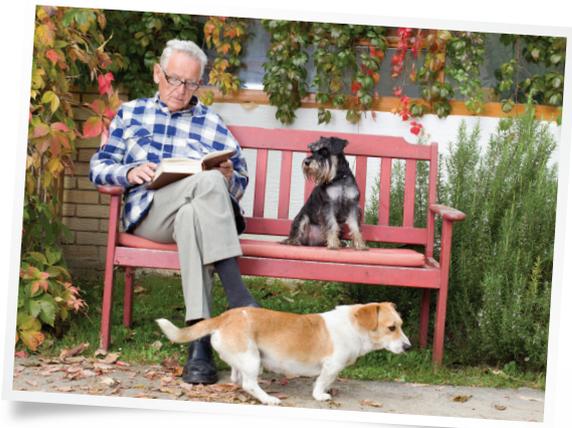
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3. REACH OUT TO OTHERS

At times, you may feel as if being a caregiver is the most challenging obstacle in your life, so it is important that you reach out to others for support. Reach out to family—or maybe even an old friend—whether via email, text, or a simple phone call

and ask them how they're doing. Lending an ear of support to others will not only make you feel wanted but will also help take your mind off of your own challenges.

Consider joining a support group. Often, local hospitals, assisted living facilities or adult day centers offer support groups for caregivers. You can ask your or your loved one's physician to recommend a group or contact the Alzheimer's Foundation of America's national toll-free helpline (866-232-8484) for referrals to resources in your area.



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4. READ AN INSPIRATIONAL BOOK OR WATCH AN INSPIRATIONAL MOVIE

There were times when I felt so down that I put on a non-fiction movie or read a book to keep me busy. Finding something inspirational to read or watch really lifted my spirits. It made me realize that I was not the only one with a challenge to weather.

Some of my favorite movies that are *The Theory of Everything* (2014), *Billy Elliot* (2000), *The Pursuit of Happyness* (2006) and *Forrest Gump* (1994).

Books I would recommend include *The Glass Castle* by Jeannette Walls, *Man's Search for Meaning* by Viktor Frankl, *Tuesdays With Morrie* by Mitch Albom, and Randy Pausch and Jefferey Zaslow's *The Last Lecture*.

Susan Kaden, of New York, N.Y., holds a Bachelor's Degree from New York University and is certified as a Health Coach by the Institute For Integrative Nutrition through Columbia University's Teacher's College. She became a caregiver, unexpectedly, two years ago when her husband was diagnosed with brain cancer. She has used her health coaching skills to create a better way to deal with her new role. For more information, visit www.susankaden.com.

‘FINDING JOY IN ALZHEIMER’S’ THE ART OF LISTENING

Neurologist Daniel C. Potts, M.D., F.A.A.N., and Marie Marley, Ph.D., a well-known author on dementia issues, recently published a book, “Finding Joy In Alzheimer’s,” designed to provide hope to caregivers of individuals with Alzheimer’s disease and related illnesses by helping them come to terms with their loved one’s condition and in so doing, giving them the power to experience positive interactions.

The following story, from Dr. Potts, is excerpted from the book and encourages us to “tune in” to a skill that is essential to any caregiver’s toolbox: the art of listening.



“The deepest level of communication is not communication but communion. It is wordless—My dear, we are already one.” – Thomas Merton

In medical school and during residency training, we were taught the importance of listening. Granted, by observing some of the master clinicians who were my teachers, I came to understand what good listening skills were like, but honing them myself was a different matter altogether. That skill developed primarily from my relationship with people who have Alzheimer’s.

The disease affects one’s ability to communicate with words. Not only can words become more difficult to think of and produce in speech, but also word meanings may be lost, causing all sorts of communication problems.

In some cases of dementia, the loss of semantics, or word meaning, may make it difficult for a person to understand and express the emotional content of words. At one time or another, most of us have had trouble recalling someone’s name. This phenomenon, as well as difficulty naming objects or parts of objects, quite commonly shows up as a symptom of Alzheimer’s disease.

The problems just described come under the term aphasia, which is the inability to understand or express language. This is one of the core

characteristics of Alzheimer's disease, and it renders communication challenging, at best.

But we communicate in ways other than through language, don't we? In fact, at times, non-verbal communication may be more expressive or truthful than verbal. This form of communication becomes especially important in persons with Alzheimer's disease and other dementias and in those of us who seek meaningful, joy-filled relationships with them.

We have to learn to develop the skill of non-verbal communication and to become good listeners.

I teach a course called "Art to Life" at the University of Alabama Honors College. In this course (inspired by my father's story and artistic gift), students are paired with persons who have Alzheimer's disease in an art therapy experience. Students learn about the disease, about art and other expressive therapies and benefits, and about person-centered caregiving and the importance of life stories in the delivery of such care.

During the semester, students learn and document the life stories of their participants. More importantly, they develop empathy for people with Alzheimer's disease and build relationships with them.

Recently, the students and I got to practice good listening techniques, and in doing so, we received a great gift.

John, a participant in his early 70s with moderately advanced Alzheimer's disease, has fairly prominent expressive aphasia. There are long pauses when he is trying to share his thoughts.

At first, I could detect some frustration and discomfort in the students, who weren't sure what to do when he was struggling for words. After the first art therapy session, we talked about this and discussed our strategy for handling it during the next session.

I shared with them what I had been told by several people with Alzheimer's disease over the years: they did not want to be interrupted and helped to complete their sentences if they were searching for words. Instead, they wanted to be given time to come up with the words

themselves, and they expressed their frustration at being denied the opportunity to actually say what they meant despite the good intentions of the 'helpers.'

In a subsequent session, we were able to practice our skills. The art activity in which John was participating reminded him of an experience he wanted to share. As he started telling us about it, he was having a hard time coming up with the words. There were long pauses during which we all had an urge to supply words for him.

But it seemed these pauses were only awkward to us. John did not look frustrated. He continued telling his story at his own pace. The students and I had talked about mindful listening: engaging actively and non-judgmentally in the moment and the content



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contained therein, being completely present in mind, body and spirit, and listening for anything that was being communicated verbally or nonverbally.

So we waited for him to speak, being careful not to express anxiety or impatience in our facial expressions or other body language while maintaining intense attention to what he was telling us with his whole person. And this soon paid off.

The further John got into his story, the better he was able to verbally express himself. The students and I could see this clearly and it was a beautiful thing to experience.

When John finished telling us his story (which happened to be about an important event in his life in which he had been able to offer assistance to others in need), he had a look of satisfaction and joy on his face. He seemed proud of himself, and we were proud of him, too.

In our later discussions about this, we realized that our mindful listening practice had given John the space and encouragement he needed to express himself, and he

had been validated as a person in the process. What he had to say was important enough to wait for.

This kind of listening had required us to step out of ourselves and into his world, and we had been enriched by the experience.

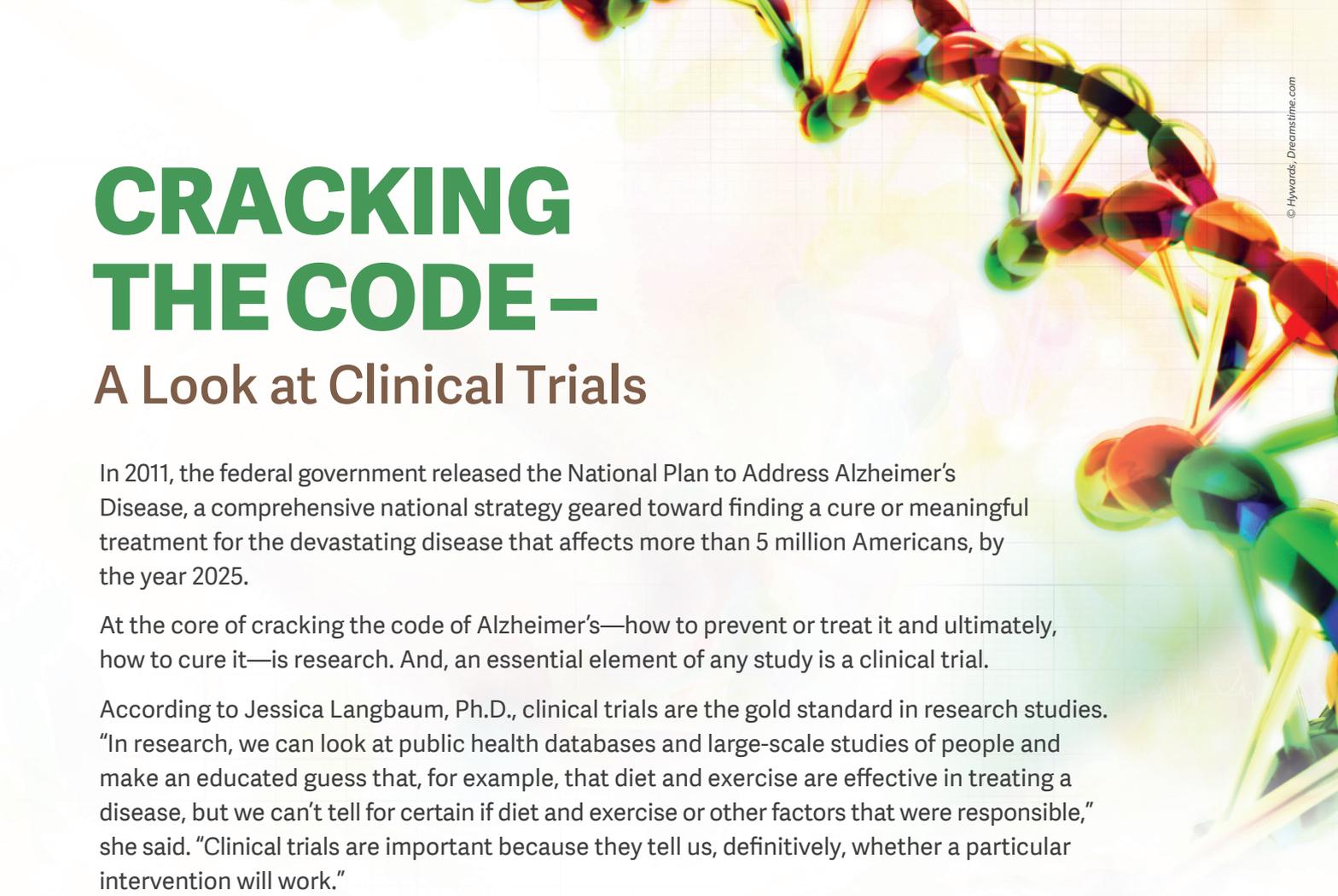
Learning to be good listeners will increase our capacity to experience joy and share it as we develop relationships with people who have Alzheimer's.

Daniel C. Potts, M.D., F.A.A.N., is a fellow of the American Academy of Neurology and staff neurologist at the Tuscaloosa, Ala. VA Medical Center. He founded Cognitive Dynamics, a foundation dedicated to quality of life improvement in people with Alzheimer's and dementia through arts & storytelling. Potts draws inspiration from his late father, Lester, who became an acclaimed watercolor artist after being diagnosed with Alzheimer's. In addition, Dr. Potts is one of the dementia care experts featured in AFA's new professional training DVD, "AFA Partners In Care: Supporting Individuals Living With Dementia."

Reprinted, with permission, from "Finding Joy in Alzheimer's: New Hope for Caregivers," by Marie Marley, Ph.D. and Daniel C. Potts, M.D., F.A.A.N. The book is available in paperback and electronic form through Amazon.



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CRACKING THE CODE – A Look at Clinical Trials

In 2011, the federal government released the National Plan to Address Alzheimer's Disease, a comprehensive national strategy geared toward finding a cure or meaningful treatment for the devastating disease that affects more than 5 million Americans, by the year 2025.

At the core of cracking the code of Alzheimer's—how to prevent or treat it and ultimately, how to cure it—is research. And, an essential element of any study is a clinical trial.

According to Jessica Langbaum, Ph.D., clinical trials are the gold standard in research studies. "In research, we can look at public health databases and large-scale studies of people and make an educated guess that, for example, that diet and exercise are effective in treating a disease, but we can't tell for certain if diet and exercise or other factors that were responsible," she said. "Clinical trials are important because they tell us, definitively, whether a particular intervention will work."

AFA Care Quarterly recently spoke with Dr. Langbaum to learn about clinical trials and how people can take part.

AFA Care Quarterly: What is a clinical trial?

Dr. Langbaum: In a clinical trial, volunteers are randomly assigned to an intervention, which could be a drug, diet or exercise, or memory and thinking exercises or assigned to a control or placebo.

Those volunteers are then followed for a period of time to see if the intervention is making a difference.

People often think that clinical trials are only for drug-related therapies, but in reality, there are many trials that are not drug-based.

AFA Care Quarterly: Who can participate in clinical trials?

Dr. Langbaum: Almost anyone can participate in a trial. Eighty percent of all research studies fail to meet their original recruitment goals because too few people are stepping up to participate in trials.

There are studies for healthy individuals, caregivers and people with Alzheimer's disease.

Each study has its own entry requirements—not every study is open to everyone—but there are always studies looking for participants.

Some studies can be done from the comfort of your own home.

There are even studies to gauge caregiver health. Caregivers can check in from a mobile phone or tablet and say how they are feeling. Another current study utilizes computer games to check memory.

People can visit www.clinicaltrials.gov or www.endalznow.org to search for a research study that suits their lifestyle.

AFA Care Quarterly: How is Alzheimer's prevention research different from research into treatments?

Dr. Langbaum: Alzheimer's prevention research is really exciting because we are looking for healthy adults who don't have memory or thinking problems yet, but who may be at risk for developing them later based on genetics, scans of their brain, etc. We are trying to intervene before they develop memory and thinking problems, using drugs that are thought to target the Alzheimer's disease pathology.

We now know that the pathology of Alzheimer's starts accumulating in a person's brain 10-20 years before the first signs and symptoms emerge. The idea with prevention is to stop the disease in its tracks before memory and thinking problems have an opportunity to present themselves.

Most people don't think about participating in a clinical trial with an experimental drug when they don't have any signs or symptoms of a disease. But here, we are asking healthy volunteers to step forward and participate – for a loved one, for a future generation or for their future selves. It's truly an exciting time.

And researchers are also striving to find trial participants to help patients and families who already have mild cognitive impairment or Alzheimer's disease. There are studies seeking to slow down the progression of the disease or stop or reverse the problems of the disease altogether.

AFA Care Quarterly: Why hasn't there been a major breakthrough in Alzheimer's research to date?

Dr. Langbaum: It has been quite a long time since we have had a new drug approved for Alzheimer's disease. Scientists have been learning a great deal about the disease, but there haven't been any major breakthroughs.

Part of the reason for this is that the drug development pipeline is quite lengthy. Drugs that are currently in trials have been very focused on amyloid pathology (plaque build-up in brain). Now, we are starting to wonder if drugs may be more beneficial in very mild stages of the disease or used preventatively instead of as mid to late stage treatment. More and more drugs are being developed that target other aspects of the disease – BACE inhibitors, Tau therapies, etc.

Enrollment criteria for Alzheimer's studies is getting much better. For example, researchers are looking for brain scans and other biomarkers to ensure the disease is Alzheimer's and not another dementia before enrolling participants in trials.

We have hope that one day, we will find an effective treatment.

AFA Care Quarterly: What makes it difficult to launch a clinical trial?

Dr. Langbaum: Recruitment is by far one of the biggest challenges. Finding people for studies is a very lengthy and time-consuming process. In addition, in drug-based studies, it takes time to make sure a drug is safe to be used in humans and it takes time to collect enough data to show whether or not a drug is making an impact. There are also other factors at play, including working with regulatory authorities and working with trial sites to make sure they have the infrastructure to run the trial.

AFA Care Quarterly: How did you become involved in Alzheimer's prevention research?

Dr. Langbaum: I have a long-standing interest in memory and thinking issues. Around the same time I was completing my Ph.D. research, my grandfather developed mild cognitive impairment. I saw the toll it took on him, on my grandmother, who was his primary caregiver, and on my mom and her siblings.

I feel very fortunate in that I have a personal connection to the disease – it certainly helps motivate me to ensure that my mom, me and my children don't develop the disease.

FIND A RESEARCH STUDY:

For more information or to find a research study, visit the Alzheimer's Prevention Registry at www.endalznow.org or the National Institutes of Health's (NIH) clinical trials registry at www.clinicaltrials.gov.



Jessica Langbaum, Ph.D., is a principal scientist at the Banner Alzheimer's Institute (BAI) and Associate Director of the Alzheimer's Prevention Initiative (API). Dr. Langbaum is responsible for the Alzheimer's Prevention Registry, the API APOE4 Genetic Testing and Disclosure Program, and provides administrative and scientific oversight of the API clinical trials. Dr. Langbaum earned a bachelor's degree in neuroscience and psychology with high honors from Oberlin College and a Ph.D. in psychiatric epidemiology from the Johns Hopkins University Bloomberg School of Public Health.

Classic Minestrone Soup



Perfect for fortifying our bodies during the cold winter months, this hearty soup is packed with protein, antioxidants and lycopene. Got extra veggies in your fridge? Add them in! If you like garlic, chop a clove and sauté it with the onion. Serve with a slice of hearty whole-grain bread for a balanced, nutrient-rich meal.

Serves 6

INGREDIENTS:

- 1 tablespoon extra-virgin olive oil
- 1 medium onion, diced
- 2 carrots, diced
- 1 ½ cups Savoy or Napa cabbage, chopped
- ½ pound green beans, cleaned, ends removed and cut in thirds
- 1 (14 oz.) can diced tomatoes
- 1 (15 oz.) can kidney or pinto beans, drained and rinsed
- 1 large potato, peeled and diced
- 1 cup peas, fresh or frozen (thawed, if frozen)
- 2 cups strained tomatoes
- 2 cups low-sodium vegetable broth
- 1 teaspoon dried oregano (or 1 Tablespoon fresh)
- 1 teaspoon dried basil (or 1 Tablespoon fresh)
- 1 bay leaf
- ½ teaspoon red pepper flakes
- Freshly-ground sea salt to taste (optional)
- Freshly-grated Parmesan cheese (optional)

METHOD:

- Heat oil in large stockpot over medium heat and sauté onions for 2 minutes.
- Add carrots and cabbage and sauté 2 minutes.
- Stir in green beans and sauté 1 minute. Add diced tomatoes, kidney or pinto beans, potato, peas, strained tomatoes and broth and bring to a boil.
- Lower heat, then add herbs and pepper and simmer for 20 minutes.
- Remove bay leaf before serving and top with freshly grated Parmesan cheese, if desired.

Nutrition facts per serving (482 grams, about 2 cups): 220 calories, 3.2 grams fat, 312 milligrams sodium, 38.4 grams carbohydrates, 12.3 grams dietary fiber, 11.4 grams protein

Recipe and photo adapted from the book "Beyond the Mediterranean Diet: European Secrets of the Super-Healthy," by culinary nutritionist and award-winning author Layne Lieberman, M.S., R.D., C.D.N. For more information and recipes, visit her website at www.WorldRD.com.

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Hearts of Care Lapel Pin - \$10
3/4" (diameter) sterling silver pendant



HEART & SOUL

Written in remembrance of Uncle Lou

HE LEFT US

He Left Us.....

Though he was 94 years old when he died, he left us too soon.

He left us when he was ready

He left us knowing we loved him

He left us with each one of us knowing we were the "special one" to him

He was the best.....

He was the best example of what a brother, husband, father, Boompa, uncle, best friend and real man should be

He was best at making us laugh and he made us laugh often

He was the best teacher to us all

He loved.....

He loved watching cowboy movies, bowling, baseball & golf

He loved watching the ladies as they went by

He loved his family, best friend, Florida, whiskey & water, fishing, poker, and the Oyster Bar

He taught.....

He taught us fairness and forgiveness

He taught us unselfishness

He taught us respect

He left us.....

He left us at home, on his own terms with his children by his side

He left us with all these lessons to learn. To be our best, to laugh, to enjoy life and how to be a good friend.

He left us to love each other and be strong

He left us to carry on smiling without him and raised his arm as he waved goodbye.

Though he was 94 when he died, he left us too soon.

Written with love by Patricia L. Clarkson

Lou Breisinger lived in Sarasota, Fla. after retiring from Chrysler, in Trenton, Mich. He returned to Michigan each year at Christmas and again each summer for a weeklong family vacation to Carpenter Lake in Ontario, Canada. Those trips were filled with fishing, cards, hikes, and good times spent together. Lou passed in April 2014, at the age of 94, with his children by his side. This poem was submitted by his niece, Patricia L. Clarkson (pictured top, right), and printed with her permission.



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Have a question?

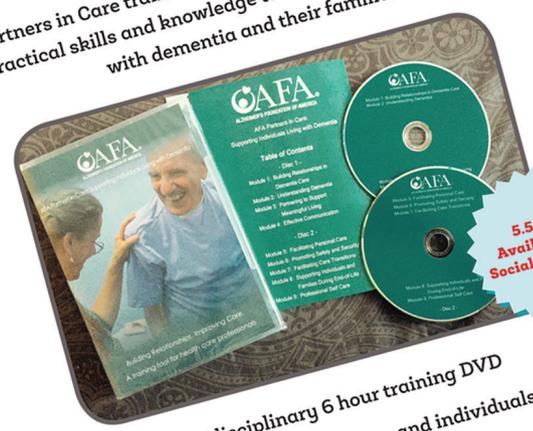
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