Major Progress in Treating Behavioral Changes in Alzheimer’s Disease

Washington Update: Alzheimer’s-Related Public Policy Developments

From Broadcast Booth to Advocate—Ken Dashow Shares His Journey

Jeffrey L. Cummings, M.D., Sc.D.
Director, Cleveland Clinic Lou Ruvo Center for Brain Health

Ken Dashow
MEDICAL BREAKTHROUGHS MAY COME OUT OF THE LAB.  
BUT THEY BEGIN IN THE HEART.

For more than a century, a very special passion has driven the people of Merck. Our goal is to develop medicines, vaccines, and animal health innovations that will improve the lives of millions. Still, we know there is much more to be done. And we’re doing it, with a long-standing commitment to research and development. We’re just as committed to expanding access to healthcare and working with others who share our passion to create a healthier world. Together, we’ll meet that challenge. With all our heart.
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Do what you can, with what you have, where you are. – Theodore Roosevelt

These words, spoken by Theodore Roosevelt, are words for caregivers to live by. Too often, caregivers ask themselves: “How am I going to get everything done?” “Am I doing enough for my loved one?” “I’m spending so much time caring for mom, how will it affect my children?” We all need to take a moment, recognize the concerns that come with caregiving, and truly do what we can, with what we have, where we are.

At the Alzheimer’s Foundation of America, our national toll-free helpline (866-232-8484), staffed by licensed social workers, is here to assist caregivers. Our social workers listen to caregivers’ concerns and frustrations and celebrate their successes; they acknowledge the challenges caregivers face and provide support, referrals to local resources and an impartial point-of-view.

And indeed, we strive to do better, to do more, each day. For Dr. Jeff Cummings and his team at the Cleveland Clinic Lou Ruvo Center for Brain Health, that means working tirelessly on research toward a cure.

For family caregivers, like DJ Ken Dashow, it means taking his experience and his well-known voice and using them as a way to raise awareness of the disease.

For our leaders in Washington, it means advocating for increased funding for research and caregiver services to put Alzheimer’s on the same level as diseases like cancer and HIV/AIDS to make eradicating this disease a national priority.

So, as we celebrate the arrival of spring and the feelings of renewal it brings, let’s remember to be gentle with ourselves. Let’s “do what we can, with what we have, where we are.” Yet let’s continue to strive to make this world a better place for people with Alzheimer’s disease and the people who love them.

Take good care,

Charles J. Fuschillo, Jr.
President & CEO
Alzheimer’s Foundation of America
JAMA Neurology • April 2016
Research indicates that elderly people who regularly take proton-pump inhibitors (PPI)—a specific type of antacid—are 44 percent more likely to develop dementia than those who do not. The study examined 73,679 participants who were 75 years of age or older and who did not have dementia at the onset of the study. Individuals who regularly took PPIs had a significantly increased risk of incident dementia compared with those who did not.

Trends in Cognitive Sciences • March 2016
Scientists may have uncovered the area of the brain in which Alzheimer’s begins. The locus coeruleus is responsible for releasing norepinephrine, a chemical that helps regulate heart rate, cognition, attention, and memory. New research indicates that this area is subject to damage—including the plaques and tangles associated with Alzheimer’s—decades before people begin to show symptoms of the disease.

Journal of Physiology • February 24, 2016
New research in rats suggests distance running may be the best type of exercise for brain health. The study compared running, weight training and high-intensity interval training and found that sustained aerobic exercise, such as running, had positive effects such as adult hippocampal neurogenesis (AHN). AHN results in the production of new neurons, which can help improve brain structure and function.

Neurology • February 3, 2016
A new study suggests that people with traumatic brain injury may have a build-up of amyloid plaques in their brains. The study examined nine middle-aged people who had a moderate to severe TBI 11 months to 17 years before the start of the study. Study participants were given PET and MRI brain scans and were then compared to 10 people with Alzheimer’s disease and nine healthy participants. Both the people with brain injuries and the people with Alzheimer’s disease had plaques in the posterior cingulate cortex, which is affected early in Alzheimer’s, but only those with brain injuries had plaques in the cerebellum.

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.
The Alzheimer’s Foundation of America (AFA) has called upon the Obama Administration to appropriate an additional $1 billion in funding for Alzheimer’s research at the National Institutes of Health (NIH). AFA also requested $40 million in enhanced investments for caregiver supports and services administered by the Administration on Community Living (ACL) in FY’17. The ACL administers many programs for older Americans, including dementia caregiver training and support, family respite care and senior nutrition services, like “Meals on Wheels.”

AFA wants to build upon last year’s historic 60 percent increase in Alzheimer’s disease research spending. Leading research scientists have called for $2 billion in annual research funding to keep us on track to find a cure or modifying treatment for Alzheimer’s disease by 2025, as articulated in the national Alzheimer’s plan. With just eight short years until the deadline, we need to ensure there is proper investment in promising research today that will get us to a cure tomorrow.

In February, President Obama released his FY’17 budget, which kept research funding for Alzheimer’s disease the same as in FY’16. In a statement, Charles J. Fuschillo, Jr., AFA’s president and chief executive officer, noted that “The Administration has been a champion in the fight against Alzheimer’s disease; however, we are disappointed that, in his final budget, the President is at a standstill...”

To put us on a pathway to a cure by 2025, AFA is now turning its attention to Congressional appropriators, who are currently developing their spending plan for FY’17. AFA will be meeting with key members of the House and Senate Appropriations Committees to encourage increased spending on Alzheimer’s disease. In addition, members of the Congressional Bipartisan Task Force on Alzheimer’s Disease are circulating “Dear Colleague” letters to lobby their fellow legislators to support more funding for Alzheimer’s disease research and care support services.

Reauthorization of the Older Americans’ Act
The Older Americans Act (OAA) was introduced, in 1965, to address a lack of community social services for older adults. Key OAA programs include Alzheimer’s disease education, adult day services, caregiver training, senior nutritional services, and legal assistance—aimed at helping to alleviate some of the physical, financial and emotional burden of Alzheimer’s disease. OAA has not been re-authorized since 2011. Without reauthorization, OAA programs are subject to yearly budget requests and fluctuations in funding.

In July 2015, the Senate approved S. 192, the Reauthorization of the Older Americans Act (OAA), introduced by Sens. Lamar Alexander (R-Tenn.) and Bernie Sanders (D-Vt.). The bill reauthorizes the program for four years as well as updates and strengthens current OAA programs including: dementia caregiver training programs, Meals on Wheels and state grants subsidizing adult day care.

The House has approved an amended version of S. 192 and the Senate posed no objections. The bill now goes to the White House where the President is expected to sign it into law.

2016 National Alzheimer’s Plan
The Advisory Council on Alzheimer’s Research, Care and Services held its first meeting of 2016 in January. At the meeting, members heard from the three federal workgroups: research, clinical and long term care supports, and reviewed the process of how the workgroups develop their recommendations. In addition, the council heard updates on progress toward the goals of the National Plan to Address Alzheimer’s Disease, and recommendations for setting milestones and metrics for achievement of these goals. Also discussed was development of the “Research Summit on Care and Services for Persons with Dementia and their Family Caregivers.”
In conjunction with this meeting, the Veterans’ Administration (VA) released a report, “Veterans Health Administration (VHA) Innovative Dementia Models of Care: Patient-Centered Alternatives to Institutional Extended Care.”

Other legislation supported by the AFA in the 114th Congress includes:

- **S.857/H.R.1559** - the Health Outcomes, Planning, and Education (HOPE) for Alzheimer’s Act, introduced by Sen. Debbie Stabenow (D-Mich.) in the Senate, and Rep. Chis Smith (R-N.J.) in the House, provides Medicare coverage for comprehensive care planning services—for both the individual and his/her caregiver—following a dementia diagnosis. Providers would be required to document the diagnosis and care planning services in the individual's medical record. The federal government would conduct outreach to providers to educate them about the new benefit.

- **S. 1549** – the Care Planning Act, introduced by Sens. Johnny Isakson (R-Ga.) and Mark Warner (D-Va.), creates a new Medicare benefit for people with chronic illnesses, including Alzheimer’s disease. The care planning benefit would include team-based discussion of care goals and values, explanation of disease progression, exploration of a relevant range of treatment options, and a documented care plan that reflects the individual’s goals, values, and preferences.

- **S. 879** – the Americans Giving Care to Elders (AGE) Act of 2015, introduced by Sen. Amy Klobuchar (D-Minn.), to allow caregivers a tax credit for up to $6,000 of the eldercare expenses incurred for their parents (or ancestors of such parents).

- **H.R. 3090** – the Alzheimer’s Caregiver Support Act, introduced by Reps. Chris Smith (R-N.J.) and Maxine Waters (D-Calif.), authorizes grants to public and non-profit organizations to expand training and support services for families and caregivers of patients with Alzheimer’s disease.

- **H.R. 3091** – the Missing Alzheimer’s Disease Patient Alert Program Reauthorization Act introduced by Reps. Chris Smith (R-N.J.) and Maxine Waters (D-Calif.), reauthorizes a Department of Justice program that helps local communities and law enforcement officials quickly identify persons with Alzheimer’s disease who wander away from their homes and reunite them with their families. This program saves law enforcement officials valuable time and allows them to focus on other security concerns. It also reduces injuries and deaths among Alzheimer’s patients, and helps bring peace of mind to their families.

- **H.R. 3092** – the Alzheimer’s Disease Semipostal Stamp Act, introduced by Reps. Chris Smith (R-N.J.) and Maxine Waters (D-Calif.), requires the U.S. Postal Service to issue and sell a semipostal stamp, with the proceeds helping to fund Alzheimer’s research at the National Institutes of Health. This bill will raise public awareness about Alzheimer’s and encourage concerned individuals to get involved and make voluntary contributions to Alzheimer’s research efforts. The bill is modeled on the popular and successful Breast Cancer Research Semipostal Stamp.

- **S. 1979/H.R. 3099** – the Recognize, Assist, Include, and Engage (RAISE) Act introduced by Sens. Susan Collins (R-Maine) and Tammy Baldwin (D-Wis.) along with Reps. Greg Harper (R-Miss.) and Kathy Castor (D-Fla.) calls for creating an integrated national strategy to recognize and support family caregivers. Specifically, the bill creates an advisory board, modeled on the advisory board established under the National Alzheimer’s Project Act, to advise and make recommendations to shape a national family caregiver strategy.

- **S. 2067** – the Ensuring Useful Research Expenditures is Key for Alzheimer’s (EUREKA) Act would authorize the National Institutes of Health to work with other federal agencies to establish prize challenges informed by the research milestones contained in the National Plan to Address Alzheimer’s Disease. Prize challenges enable government sponsors to pay only when a prize team achieves specified goals or milestones. Additionally, EUREKA would permit the receipt of donations from the private sector and from individuals to fund the competition and build the award fund.

- **S. 2614** – Kevin and Avonte’s Law of 2016, introduced by Sens. Charles Schumer (D-N.Y.) and Charles Grassley (R-Iowa) would reauthorize the Missing Alzheimer’s Disease Patient Alert Program, and also promote initiatives to reduce the risk of injury and death relating to the wandering characteristics of children with autism.
For PJ Davis, creating one-of-a-kind cars is a labor of love.

“I’ve been addicted to cars since I was little,” Davis said. “It started with Matchbox and then models. My dad took me under his wing and taught me and I just went with it.”

Now owner of Chimera Customs, Davis makes his—and his customers’—dream cars a reality each and every day. Recently, however, he embarked on a passion project truly near and dear to his heart.

For more than a year, the Chimera Customs team has been working on “Betty,” a custom, 1970 Camaro that Davis will be auctioning off to raise money for the Alzheimer’s Foundation of America (AFA). The car is named for his mom, who was diagnosed with Alzheimer’s disease at age 62. To date, Davis and Chimera Customs have raised more than $1 million for five different charities.

Asked how he came to choose AFA for this, his final charity car, Davis said: “My mom passed away, at age 69, from Alzheimer’s disease and my partner’s parents both have the disease. We decided to do one last charity car and it seemed fitting that the proceeds should go to [the Alzheimer’s cause].”

In the years between his mother’s diagnosis and her passing, Davis’ family was transformed. Because of the level of care their mom required, his sister sold her house, quit her job and moved in with their mom in West Virginia. Through a local senior center, he and his family found an in-home sitter, three days per week, so that his sister could do the shopping, pick up their mom’s medications and have a bit of respite. A sitter also came one evening per month so that Davis’ sister and her husband could go out to dinner. Insurance didn’t cover any of the care costs, and the Davises learned first-hand how trying a role caregiving can be, especially when their mom no longer recognized them.

Davis has owned Betty for several years and built her completely from scratch. Recently, he invited Chuck Fuschillo, AFA’s president and CEO, to take a sneak peek at Betty. He hopes to complete the car in the next couple of months and then will unveil her and put her up for auction.

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- Features dementia care experts, families, and individuals living with dementia
- Opportunity for AFA Certification & CE’s for Social Workers

To purchase the Training DVD call AFA at 866-232-8484 or visit www.careprofessionals.org
The ‘Forget It All’ Disease

By Cynthia Mullins

Think of an emotional dam, blocking out the old memories.
The dust is inches thick, placing a weight on the mind;
and every bang to the head causes these thoughts to float around, only to settle down in a different place, causing even more confusion.
Knowledge is becoming dim and slowly, faces are fading, little by little.
Names fly through the air alongside the particles, but there is nothing to identify them with.
Slowly the brain loses importance.
Everything is gone, nothing brings it back, and the pain restricts the effort to remember.
The pain is surrounding the brain, and the body, and those around, watching their loved one wither away.
Tears don’t flow from certain eyes, and the clenching of the jaw so tight, only a crowbar could pry it open.
Food has no taste, and the appetite is gone.
The back becomes hunched and the head hangs forward, no support to hold it up high.
The tale has come to an end, the slow death, finally set free from the sympathy and pity in staring eyes.
Now once again, names will match with faces, like a backwards memory game;
Cards will be turned over, and the game of trials and tribulations will reset.
It’s another chance, a time to start anew, with the same game, but a different piece.

Cynthia Mullins is 16 years old and attends Centennial High School in Columbus, Ohio. Her grandfather, Carl Robert Mullins, lived with Alzheimer’s for three years before passing away in early March at the age of 79. Mullins wrote this poem for him and read it at his funeral.
QUESTION: This May, my family has planned a reunion which will take place about an hour away from where I live. There will be a lot of family members and many different events, including a family concert. Do you think my father with Alzheimer’s can go? He loves family and music—I am torn.

ANSWER: Family reunions are joyful occasions, and with careful planning, it may be possible to include your father. Given the fact that the family reunion is only an hour away from your home, there are several ways you may be able to include him in the celebration. One option is to have him attend only certain events at the reunion. As a general rule, individuals with Alzheimer’s disease fare better in known environments and routines. If you decide to bring him to the family reunion (an unknown environment), it is important to try to mimic his daily routines as much as possible (e.g., getting up, eating and going to sleep at the same time he normally does). You also may want to consider whether it would be less disorienting for him to be driven back and forth from your home at the conclusion of each day, as opposed to staying at a hotel or other unfamiliar location.

Individuals with Alzheimer’s disease are often sensitive to environmental stimuli. Family reunions—with crowds of people, loud music and flash photography—can be an over-stimulating experience for a person with Alzheimer’s disease. If you decide to bring him to all, or a part of, the family reunion, talk with other family members to see if it is possible to create an area that can be used as a “quiet room” for him to retreat to should he become overwhelmed during the event. This way, should he become overwhelmed during the event there will be someone “on-call” to tend to his needs so that you can enjoy the reunion as well. Having close family members take turns spending time with him can help to ease his interactions with other more distant relatives, who may not be aware of his dementia. If you have a home health aide, you may want to see if it is possible for this person to join you at the reunion.

You may also want to consider asking a family member to act as an intermediary to “introduce” your father to more distant relatives, so that he won’t have to worry about not remembering who people are. For example, the family member could say, “This is Aunt Betty. She wants to say hello.” Encourage family members to be watchful for signs your dad is becoming overwhelmed, such as increased confusion, anxiety, or irritability, so that they can bring him to the quiet room. You may also want to alert family members to information about his triggers and which “tricks” work best. As you can see there are a lot of things to consider with this event. If you have additional questions, please don’t hesitate to reach out to our national toll-free helpline at 866-232-8484. Our team of licensed social workers is available from 9 a.m.–9 p.m. Monday–Friday and is happy to help.
**QUESTION:** My wife was once part of a horticultural club, and due to her advancing dementia she cannot attend any longer. Spring is approaching, do you have any ideas on how I can recreate this club in my own backyard?

**ANSWER:** Your idea of recreating a horticultural club in your own home is wonderful! You are recognizing that this club was an important part of your wife's life, and that you want her to continue to enjoy this hobby, even though she is unable to attend her former club because of her illness. With this in mind, try to structure your club so it meets your wife where she is in the disease continuum and gear the gardening activities toward her current abilities and strengths.

Perhaps you can start by selecting one day each week to meet with your wife and mark “Garden Club” as a reminder on a wall calendar to help her look forward to it. On garden club day, serve your wife’s favorite snacks to make it festive. It may also be nice to have a gardening basket, filled with tools that are safe for her to use, such as a small, handheld shovel and gloves. You can personalize the basket with your wife’s name.

In addition, you may want to consider getting some flower pots, soil, seeds and labels. You and your wife can fill the pots with soil and seeds, and can make decorative labels for each pot, perhaps using stickers, to identify what is planted in each. Your wife can place the stickers on the pots that correspond with each seed.

The purpose of this club is for your wife to enjoy getting her hands dirty, so to speak. Have fun with her and your new club!

**HAVE A QUESTION?** AFA’s licensed social workers are available Monday through Friday, from 9 a.m. to 9 p.m. EDT and beginning May 7, on Saturdays, from 9 a.m. to 1 p.m. EDT, via AFA’s National Toll-Free Helpline—866-232-8484. They are also available by e-mail, live chat and Skype.

The answers provided here should not be considered a replacement for consultation with your healthcare professional. As every individual and every situation is unique, be sure to consult your or your loved one’s care professional for advice best-tailored to your needs.

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**As of May 7, 2016, AFA’s National Toll-Free Helpline will be open Saturdays!**

**AFA’s National Toll-Free Helpline**

866-232-8484

Call us Monday-Friday, 9 a.m. - 9 p.m. EDT and Saturday, 9 a.m. - 1 p.m. EDT
Neuropsychiatric—or behavioral—symptoms are common in Alzheimer’s disease and include agitation, depression, apathy, hallucinations, delusions, anxiety, disinhibition, irritability, wandering and pacing, appetite changes, and nighttime behavioral alterations. These symptoms—especially apathy and depression—can begin early in the course of the disease and become progressively more common as the disease worsens.¹ Eventually, up to 80 percent of individuals with Alzheimer’s exhibit agitation, 70 percent have apathy, 40 percent have depression, and 20 percent have evidence of psychosis with delusions (false beliefs such as paranoia) and hallucinations.

Biological evidence using brain scans and other investigations suggests that behavioral symptoms occur when the pathological changes of Alzheimer’s disease, including plaques and tangles, invade the areas of the brain responsible for mediating normal behavior, known as the limbic system.² In individuals with behavioral changes, an overabundance of neurofibrillary tangles has been identified in the limbic system cortex. Neurochemical changes in the brain’s transmitter systems implicated in mood and behavior disorders may also contribute to neuropsychiatric symptoms observed in Alzheimer’s disease. Environmental disturbances, including upsetting circumstances, environment changes, and challenging interpersonal interactions may further contribute to agitation and other behavioral changes observed in people with Alzheimer’s disease.

Behavioral changes in Alzheimer’s disease worsen the quality of life of the individual affected and adversely affect the quality of life of caregivers who are struggling with agitated or depressed family members.³ Such symptoms contribute greatly to the decision that families can no longer care for someone at home and are a major reason that individuals with Alzheimer’s disease are transitioned to long-term care settings. The increased likelihood of the need for residential care and the use of medications in individuals with behavioral changes can be costly. And there can be an added physical toll, as well. Individuals with behavioral symptoms exhibit more rapid cognitive decline, a possible reflection of the greater involvement of the brain.

To date, finding ways to treat the behavioral symptoms of Alzheimer’s disease has been a challenge. But emerging research is showing progress, some of which I will share here. There are both nonpharmacologic and pharmacologic—or drug—interventions for treatment of behavioral changes in Alzheimer’s disease.³ Nonpharmacologic approaches include educating the caregiver about the disease, such as how to avoid precipitating or aggravating behavioral changes and how to calm a distressed individual. When these strategies fail, drug therapies are often used.
A Look at the Pharmacologic Treatments Landscape

Currently, there are no Food and Drug Administration (FDA)-approved treatments for any behavioral disturbances in any neurodegenerative disease except Nuedexta™, a combination of dextromethorphan and quinidine, which is used to treat pseudobulbar affect (PBA). PBA refers to uncontrollable or inappropriate laughing and crying that occurs in individuals with frontotemporal dementia (FTD), amotrophic lateral sclerosis (ALS), multiple sclerosis (MS), traumatic brain injury (TBI), stroke, Alzheimer’s, and other neurological disorders. All other psychotropics used in Alzheimer’s are prescribed “off label.” In fact, some widely-used agents, such as anti-psychotics, have “black box” warnings alerting clinicians to increased risk of stroke and death among people with dementia. While that may sound scary, it is important to note that in some cases, using anti-psychotic drugs cannot be avoided as it may be the only means of keeping an individual from hurting himself or others.

It is also important to keep in mind that a clinician’s decision to use a psychotropic agent is based on a careful consideration of the potential benefit and potential harm to the individual. Such decisions should include an informed discussion with family members and, if possible, the patient.

Calming Agitation

There is an encouraging amount of progress in the development of new therapies for behavioral changes in Alzheimer’s. A recent trial of Nuedexta showed a marked reduction in agitation over a 10-week treatment period.4 It has now been advanced to Phase 3 studies in preparation for presentation to the FDA. The safety profile of Nuedexta™ is well known because the drug is already approved for the treatment of PBA. A recent trial of another drug, citalopram, in Alzheimer’s disease also showed a reduction in agitation; however, in this study, there was a slight decline in cognition with treatment and a slight increase in heart rhythm abnormalities, raising questions on whether the dose of citalopram used in the trial (30 mg) is an entirely safe approach to the treatment of agitation in patients with Alzheimer’s.5 Further studies are ongoing. Another drug, an anti-psychotic called brexpiprazole, is being studied for calming agitation in individuals with Alzheimer’s. If the brexpiprazole development program succeeds, then this anti-psychotic could be approved for the treatment of agitation; it would be the only anti-psychotic agent approved for this use by the FDA. A study of lithium for agitation and psychosis in Alzheimer’s is also underway and may provide additional valuable information regarding its usefulness in treating behavioral changes in people with Alzheimer’s disease.

Addressing Psychosis

Psychosis, which can manifest itself as false beliefs of theft, infidelity, or abandonment, can be a major challenge for patients and caregivers. Pimavanserin is a new class of anti-psychotic that has undergone a successful clinical trial for the treatment of psychosis in Parkinson’s disease and is now being tested as an anti-psychotic for patients with Alzheimer’s.6 The experience with Parkinson’s disease suggests that pimavanserin may be a new and important intervention for psychotic disturbances in neurodegenerative disorders.

Overcoming Apathy

Apathy—or lack of interest—is a common symptom in Alzheimer’s and can be disabling. Apathetic individuals are less likely to engage in exercise, mental activities, or social gatherings, all of which could benefit their cognitive function. They are also less likely to interact with family members, and families are often frustrated by
the behavioral disengagement of patients with Alzheimer’s disease and apathy. A recent trial of methylphenidate (Ritalin™) showed that psycho-stimulants can help reduce apathy; however, this study did not meet all of its predefined outcomes and the use of psycho-stimulants in individuals with Alzheimer’s disease must be further investigated.

Managing Depression
Depression is a common symptom in Alzheimer’s disease. It may begin early in the illness, even in the Mild Cognitive Impairment (MCI) stage, and is common throughout all phases of the illness. None of the existing anti-depressants has been proven to reduce mood symptoms in patients with Alzheimer’s and all use of anti-depressants in Alzheimer’s is currently off-label. A study of venlafaxine, a dual norepinephrine and serotonin reuptake inhibitor, is now being conducted to investigate its effect on mood symptoms in Alzheimer’s disease. The outcome of this study will help inform the use of anti-depressants in Alzheimer’s disease and identify the chemical classes that may assist in relieving mood symptoms in this brain disorder.

Cognition-Enhancing Agents with Behavioral Benefit
Another approach to treating behavioral disturbances in Alzheimer’s is to use drugs that improve cognition and simultaneously may affect behavior. Currently approved cholinesterase inhibitors (Aricept™, Exelon™, Razadyne™) and memantine (Namenda™) have been shown to have behavioral effects in human trials in Alzheimer’s disease. Cholinesterase inhibitors reduce apathy and may benefit depression, psychosis, and hallucinations. In several studies, memantine has been associated with reduced agitation and irritability. Newer agents, being developed for treatment of cognitive disturbances in Alzheimer’s disease, may also have behavioral benefits. One class of drugs being tested to gauge its effectiveness in relieving behavioral disturbances in Alzheimer’s is 5HT-6 antagonists. Idalopirdine has been associated with reduced anxiety, and RVT-101 is being tested for its ability to improve cognitive symptoms and hallucinations in patients with dementia with Lewy bodies, a disorder closely related to Alzheimer’s.

Other Areas of Progress
Another avenue of progress in developing new therapies for Alzheimer’s involves advances in clinical trial methodologies. Clinical trials are the only avenue for developing treatments for Alzheimer’s disease, as information gathered in such trials is the only type of information acceptable to gain FDA approval of a drug. For example, in order to pursue studies of agitation in Alzheimer’s disease, we needed to first establish a definition of agitation that is clinically relevant and easily grasped by practitioners. Until recently, no such definition existed. Then, the International Psychogeriatric Association (IPA) developed a definition of agitation that was evaluated through surveys that yielded nearly 1,000 responses. This definition has been reviewed as part of clinical trial protocols approved by the FDA and appears to be acceptable to the FDA for defining a clinical trial population of individuals with cognitive impairment and agitation.

This represents significant progress in providing a definition applicable to clinical trials across a wide variety of drugs that may reduce agitation and can help advance new therapies for patients with Alzheimer’s disease and its associated behavioral disturbances.

Similarly, clinical trials relating to apathy have faltered because of a lack of well-defined clinical
trial methodologies. There has been recent progress in advancing new approaches to defining apathy and also to advancing clinical trial methods that will assist in testing psycho-stimulants or other approaches to apathy symptoms in Alzheimer’s.10

Non-pharmacologic Interventions

Pharmacologic intervention for behavioral disturbances in Alzheimer’s is best coupled with non-pharmacologic treatment, including education and behavior-soothing activities from caregivers.3 These methodologies have also been explored in recent trials that typically have a psychosocial intervention lead-in period prior to the administration of a psychotropic agent. Individuals who respond to the non-pharmacologic intervention are not included in the pharmacologic trial. This ensures that individuals who do not need pharmacologic treatment are not selected for trials and spares them the risk of developing side effects from drugs which are not needed. Removing individuals who respond to non-drug interventions from clinical trials also allows researchers to better explore the effects of drugs in a population that has proven unresponsive to behavioral interventions. Thus, clinical trials are advancing non-pharmacologic interventions as well as improving understanding of pharmacologic treatments.

A Final Note

In past years, there have been many unsuccessful Alzheimer’s drug trials in and it is easy to become discouraged by these failures. However, in research pertaining to the treatment of behavioral and neuropsychiatric symptoms, there is promise on the horizon. Drugs are moving toward Phase 3 testing and eventual approval by the FDA is likely; more treatments are entering the drug development pipeline; and advances have been made in trial methods. There is good reason for individuals with Alzheimer’s disease, caregivers and society—at-large to be optimistic about the emergence of new and better treatments for behavioral disturbances in Alzheimer’s. These advances can help improve quality of life for individuals with the disease and their caregivers.

References

Spring Fusilli with Asparagus and Walnuts

Asparagus, a spring staple, is the star of this light and flavorful main dish. This perfect pasta is a complete, vegetarian meal. Walnuts provide protein, ALA/omega-3 fatty acids and fiber.

SERVES 4

INGREDIENTS:
8 ounces dry whole-wheat fusilli
1 pound fresh asparagus
2 Tablespoons extra-virgin olive oil
1 clove garlic, minced
½ cup walnuts, chopped
Juice from 1 lemon (or 3 Tablespoons fresh lemon juice)
1 teaspoon dried oregano (or 1 Tablespoon fresh)
½ cup flat-leaf parsley, chopped
¼ cup freshly grated Parmesan cheese
Freshly ground black pepper to taste

METHOD:
• Cook pasta according to package directions and set aside in a large mixing bowl.
• Trim off tough ends of asparagus and discard. Cut asparagus into 1-inch diagonal slices.
• Heat oil in a large nonstick skillet over medium heat. Sauté garlic and asparagus for 3 minutes and add 2 Tablespoons water if needed. Add walnuts and cook 2 to 3 more minutes.
• Add asparagus mixture to the pasta and then add lemon juice, oregano and parsley. Gently toss and sprinkle with Parmesan cheese and black pepper to taste. Serve at room temperature.

Nutrition facts per serving (232 grams): 418 calories, 20.8 grams fat, 142 milligrams sodium, 43.4 grams carbohydrates, 9.3 grams dietary fiber, 18.7 grams protein

When did you know you wanted to be a broadcaster?

Even as a kid, I knew. Growing up, there were two main AM radio stations in New York—WABC and WMCA. I loved listening to “The Good Guys” at WMCA, and my two career choices, at that time, were baseball player for the New York Mets or DJ.

Your “Breakfast with the Beatles” program is a Sunday morning staple for so many people in the New York–tristate area. How did you become such a Beatles aficionado?

I just love them! I’m of that era where I was buying the records as they were coming out. It was new to me. And I love that now, it’s not just people my age who love the Beatles. They are loved by several generations. My favorite e-mail came from a teen who wrote: “George Harrison is sexiest man in the world.” It just struck me as so insightful. Even though he is no longer of this world, his spirit and his music live on and that’s just incredible.

Tell us something people would be surprised to learn about you.

I play golf, I enjoy going out to eat and concerts, but my true passion is being a weekend warrior. I love doing construction projects around the house. I’ve put down my own floors, built a tiki bar in my apartment, installed moldings, and built a home studio. My prized possession is my tool closet—an entire closet filled with power tools. On weekends, I watch “This Old House” and other home shows, and drool over their workshops.

You are a staunch advocate for Alzheimer’s awareness—you participated in AFA’s radiothon last year, and voiced public service announcements encouraging memory screenings. What is your personal connection to the disease?

Alzheimer’s is my own personal worst nightmare. To me, the horror of losing who you are is worse than any physical disease or loss of a body part or organ.

I have a dear friend whose father was diagnosed with Alzheimer’s in his late 50s and declined rapidly. My mother–in–law, Phyllis, also had the disease. She was diagnosed at the age of 77, declined fairly quickly and passed away about eight months later. The hardest thing, as a caregiver is trying to figure out the need behind what the person is asking.

For example, when my mother–in–law would say, “I want to go home,” and she was at home, my wife, Jane, and I found ourselves trying to determine was she longing for her childhood home and a feeling of safety? Was she uncomfortable? And if she was uncomfortable, what could we do to make her feel comfortable?

One of the moments that sticks with me during my mother–in–law’s illness happened at the hospital. She was in bed and restrained, after experiencing an episode of extreme agitation. There was a moment of clarity in which she looked at me, recognized me as her son–in–law and asked, “Do you think you could stop this merry–go–round? I want to get off.”
AFA CQ: Were there warning signs with your mother-in-law that signaled something was amiss? How did you and your wife first notice?
KD: We all forget where we put things or lose our keys. But when we began to see patterns emerging, it was hard to accept, but Alzheimer’s had come into our lives. In our case, my mother-in-law was always funny, sarcastic and aware of everything going on around her. Gradually, I started to notice little buzz words she would repeat when having a conversation. She would say “Oh my word,” over and over again, which signaled to me that she was having problems processing what was being said or didn’t quite know how to react.

AFA CQ: What have you learned about yourself and your family through the course of this disease?
KD: Many caregivers of people with Alzheimer’s disease describe their loved one’s passing as “she mercifully passed.” Indeed, that is the only peace that comes from this disease. And it is why I am a big proponent of stem cell and other research aimed at unlocking how we can intercept this disease and end it. There are so many smart, great kids studying science. We need to do everything we can to put a stop to Alzheimer’s. I have confidence in the fact that we are making progress.

There is also a guilt that comes from how much effort it takes to maintain someone’s health whether they live close or far away. As caregivers, so much of our lives is taken away—time with our children and our friends, work—and this can lead to feelings resentment, deep down. We all feel it, but there is such guilt around acknowledging it. We need to acknowledge these feelings and move on, together, to do what needs to be done to care for our loved one.

My wife and I shared the duties of caregiving. We agreed we would not snap at each other; we would not compare or keep score of who was doing more. We were and are a team. Both of us did as much as we could. And if there is a day we just can’t do it, we have to accept that with no recriminations.

AFA CQ: Where did you turn for information and support?
KD: We’re children of the 60s, when people didn’t talk about their problems. They just did what needed to be done. Looking back, if I had to do it over again, I would reach out to an organization like yours—to help with the: “Am I doing this right?” or “What can I do to make this more efficient, to work better?”

AFA CQ: What advice would you give to other families?
KD: You are not alone. Everything you are feeling, everything that frightens you, others have been there. Talk with someone—a friend, a family member, a professional—even if just to vent. It is so important to vent your feelings and emotions so you don’t take out your stress on a family member or co-worker.

I had a close friend who was caring for her parents and who would call me every day from the pharmacy. She would walk the aisles and tell me everything—good and bad—that had happened that day: her mom accused her of stealing her jewelry, sharing a cup of tea with her dad. And it was cathartic. You need a friend who understands when you just want to scream—that’s the most important safety valve.

We know how hard it is. You are not alone.

Brooklyn-born Ken Dashow is a graduate of NYU’s Tisch School of the Arts. A life-long Mets, Jets, Knicks and Rangers fan, he can still be found playing golf around the Metropolitan area. Since those days, Dashow has become a fixture of New York rock radio, having worked at WNEW-FM for 17 years, then joining Q-104.3, where he is the afternoon “drive-time” host, rated #1 in New York and nominated for a NY A.I.R. award for best afternoon show. He also hosts the wildly-popular “Breakfast With The Beatles” show Sunday mornings, on Q-104.3 FM, where he plays listener requests, shares stories of the Fab Four, and has interviewed everyone from Paul McCartney and Ringo Starr to Yoko Ono, May Pang, Olivia Harrision, James Taylor, and even Pete Best. His years of doing stand-up and performing with “Noo Yawk Tawk,” the acclaimed improv group, honed his skills for his numerous acting roles on-stage, off-Broadway and regional, as well as various TV shows, including multiple episodes of “Law & Order, C.I.”
Mother.me

I don’t know what to say to MOTHER. You will learn. There is not a golden dialogue for life. Be patient in tone. WORDS have escaped her. Evermore guide her with yours.

Please give me a solution. With patience and education, it will become easier. Never easy.

MOTHER is not herself. You are right. The disease does this. The outside. Does not match the inside. Find the beauty within. It is still and always will be there.


This poem, written by Heather Saposnick, L.M.S.W., one of AFA’s licensed social workers, was published as part of the University of Iowa’s School of Social Work’s national poetry contest. The competition was introduced in 2013, and has been held annually since. View this year’s submissions here: http://clas.uiowa.edu/socialwork/files/socialwork/Chapbook2016.pdf
Getting the Most Out of A Family Meeting

A family meeting is a specific time set aside to promote communication, decision-making, and problem-solving, and to encourage strong family relationships. When caring for someone with Alzheimer’s disease or a related illness, family meetings are important in ensuring information is shared, putting care plans in place, and helping divide tasks among family members.

**SET GOALS**

- Set realistic and attainable goals for each meeting. Remember, the key objectives to a family meeting are to build consensus among family members and to align with one another for the betterment of a loved one’s care.

**PLANNING AND FOLLOW-UP:**

Planning, coordination and follow-up are key to family meeting success. Here are some tips to help things flow smoothly:

- Include the individual with Alzheimer’s disease if he or she is able to communicate preferences and has the ability to understand issues being discussed.
- Determine all who are, or will, be part of the caregiving team (family, friend, professional) and make sure everyone is included in the meeting.
- If family members are in different geographical areas, consider having the meeting via Skype, phone or video conference.
- Set start and end times for the meeting and create an agenda ahead of time; encourage all family members to contribute ideas to the agenda.
- To help keep meetings on track, limit topics to one or two.
- Try to hold meetings regularly, and as needed, when there is change in your loved one’s condition or care plan.
- After each meeting, send a summary of decisions and agreements to all participants; Be sure to clearly define the responsibilities for each family member.
- Create a family calendar, including medical appointments and activities, and each individual’s responsibilities and commitments.
- Consider using an outside facilitator, such as a social worker, clergy member or other professional to help guide the conversation and ensure everyone is heard.

**OTHER STRATEGIES FOR SUCCESS:**

- Be prepared—bring information, such as doctor’s notes and legal documents, to the meeting.
- Assign roles—for example, choose one person as the speaker and one as record keeper.
- Keep opinions out of the mix; stick to the facts of your loved one’s care, such as a change in his or her physical abilities.
- Use personal examples to illustrate points (e.g., “I have been present when mom has been up all night”).
- If a family member is feeling angered or stressed, take a break to process these emotions.
- Create a culture of respect and acceptance.
- Acknowledge each member’s strengths and try not to be judgmental of their limitations.
- Collaboration and compromise are key: be mindful that there is no “right” way of being a care partner—we do things our way; others do it their way.
- Not all issues regarding caregiving and decision-making will be ‘solved’ to your expectations; sometimes it is important to accept a solution that is “in the ballpark.”

**HERE ARE SOME TIPS AND STRATEGIES TO HELP PLAN A PRODUCTIVE FAMILY MEETING:**

- **Getting the Most Out of A Family Meeting**
- **Other Strategies for Success**
- **Set Goals**
- **Planning and Follow-Up:**
- **Include the individual with Alzheimer’s disease if he or she is able to communicate preferences and has the ability to understand issues being discussed.**
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A SMALL STRETCH OF THE IMAGINATION

From American Acrostics
Volume 2: American Ingenuity, © Cynthia Morris. All rights reserved.

INSTRUCTIONS: Fill in the words based on the clues, then transfer the letters to the grid. Work back and forth between the grid and the clue list. When complete, the grid will contain a quote, reading across. The first letters of the clue words, reading down, will spell out the author’s name and the title of the book the quote is taken from.

Cynthia (Cyn) Morris has worked as a writer and editor for 35 years—including 10 years as an award-winning science writer for the University of California, Irvine. She has published several nonfiction books—one of which is currently in development as a TV series—and written thousands of news and feature articles on topics ranging from camel farming in the desert to negative wormholes in outer space.

A lifelong cruciverbalist, Cyn has been solving acrostic puzzles since she was 8 years old, and constructing them since 2005. Her puzzle series include CynAcrostics™, American Acrostics™, and AnimaCrostics™. More information about all three series can be found at www.acrosticsbycyn.com.

<table>
<thead>
<tr>
<th>Clues</th>
<th>Words</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. This idiom can mean to eat something or to hide something (2 wds.)</td>
<td>135 117 103 87 30 41 83 10</td>
</tr>
<tr>
<td>B. “Never ____ on the glory of the morning nor the smiles of your mother-in-law.” (Japanese proverb)</td>
<td>65 93 140 108</td>
</tr>
<tr>
<td>C. Sally Ride or Eileen Collins, for example</td>
<td>37 107 90 116 133 28 143 123 9</td>
</tr>
<tr>
<td>D. This stereoscope was originally intended for all ages but is now primarily a kids’ toy (2 wds., hyph.)</td>
<td>16 127 95 76 38 47 84 110 120 42</td>
</tr>
<tr>
<td>E. Ovoid (2 wds., hyph.)</td>
<td>49 61 44 123 77 12 98 131 26</td>
</tr>
<tr>
<td>F. Boisterous</td>
<td>121 101 11 92 35</td>
</tr>
<tr>
<td>G. Like spandex</td>
<td>1 8 73 68 46 24 60 145</td>
</tr>
<tr>
<td>H. “____ is the ability to fully experience life.” (Henry David Thoreau)</td>
<td>102 17 22 67 142 45</td>
</tr>
<tr>
<td>I. Something you shouldn’t lie under</td>
<td>91 85 126 80</td>
</tr>
<tr>
<td>J. Stop lying</td>
<td>56 52 105 20</td>
</tr>
<tr>
<td>K. Expand, in a way</td>
<td>96 78 15 51 128 136 64 109</td>
</tr>
<tr>
<td>L. Easily reshaped</td>
<td>89 129 75 113 2 32 35</td>
</tr>
<tr>
<td>M. “Happiness is not something ready made. It comes from your ____ actions.” (Dalai Lama)</td>
<td>97 57 63</td>
</tr>
<tr>
<td>N. “Son of ____,” 1963 Disney flick</td>
<td>132 69 7 118 34 88 144</td>
</tr>
<tr>
<td>O. In a lackadaisical manner</td>
<td>141 27 3 33</td>
</tr>
<tr>
<td>P. Armstrong or Diamond</td>
<td>53 39 139 4</td>
</tr>
<tr>
<td>Q. Feasible</td>
<td>94 74 99 119 31 27</td>
</tr>
<tr>
<td>R. Flexibility</td>
<td>137 100 66 86 130 43 23 114 59 5</td>
</tr>
<tr>
<td>S. Paper for papers</td>
<td>18 70 82 122 6 134 14 48 29</td>
</tr>
<tr>
<td>T. “Science never solves a problem without creating ____ more.” (George Bernard Shaw)</td>
<td>106 112 79</td>
</tr>
<tr>
<td>U. Pair in “People,” perhaps</td>
<td>58 19 62 138</td>
</tr>
<tr>
<td>V. “I paint ____ as I think them, not as I see them.” (Pablo Picasso)</td>
<td>104 124 36 54 115 72 40</td>
</tr>
<tr>
<td>W. “We are all experts in our own little ____.” (Alex Trebek)</td>
<td>50 25 71 111 81 13</td>
</tr>
</tbody>
</table>
A Small Stretch of the Imagination

W. ___ __

U. ___ __

Q. ___ __

D. ___ __

2: American Ingenuity, © Cynthia ___ __

“...as I think them,

problem without creating ____. 

Paper for papers ___ __

Armstrong or Diamond ___ __

your ____ actions.” (Dalai ___ __

“Happiness is not something ___ __

Easily reshaped ___ __

Thoreau)

Like spandex ___ __

example ___ __

something (2 wds.) ___ __

This idiom can mean to eat ___ __

104 ___ __

106 ___ __

137 ___ __

102 ___ __

121 ___ __

135 ___ __

Silly Putty was invented accidentally by James Wright, an engineer ___ __

Rubber substitute for the military... when he was asked to develop a low-cost ___ __

A. Tuck away, B. Rely, C. Astronaut, D. View-Master, E. Egg-shaped, F. Rowdy, G. Stretchy, H. Wealth, I. Oath,

J. New, K. Elasacity, L. Rubbery, M. Bond, N. Tacky, O. Nitty, P. Adhesive, Q. Subject, R. Inclines

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SOLUTION

A Small Stretch of the Imagination

W. J. Travers (ed.) World of Invention

Silly Putty was invented accidentally by James Wright, an engineer

with General Electric... when he was asked to develop a low-cost

rubber substitute for the military...
AFA Springtime Tip:

Gardening is a therapeutic activity that can be adapted to many different skill levels. Whether planting seeds in a pot or weeding and watering, gardening offers many ways to engage your loved one.