For the Love of My Wife –

Inspirational Thoughts for Caregivers

Plus:
Validation Techniques in a Real World
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MISSION: “TO PROVIDE OPTIMAL CARE AND SERVICES TO INDIVIDUALS LIVING WITH DEMENTIA—AND TO THEIR CAREGIVERS AND FAMILIES—THROUGH MEMBER ORGANIZATIONS DEDICATED TO IMPROVING QUALITY OF LIFE”

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“In every conceivable manner, the family is link to our past, bridge to our future.” —Alex Haley

Family is at the core of everything we do here at the Alzheimer’s Foundation of America (AFA). Since our founding, 15 years ago, AFA has been on a mission to educate and support families across the country whose lives are affected by dementia. We ask questions, we listen, and we aim to provide information and tools to help make navigating this caregiving journey just a little bit easier.

As we welcome spring, a time of holidays, gatherings and events celebrating family, I am pleased to present this family-focused issue of AFA Care Quarterly.

Our cover story, which begins on page 8, is an incredibly moving piece. One year after his wife Clare’s passing, guest columnist Allan Vann shares the inspirational thoughts that helped him cope during some of his toughest days as a caregiver, and even still today. His hope is that these words will help provide comfort and strength for spouses and family members in need.

On page 10, Alisa Tagg, president of the National Association of Activity Professionals, shares a simple technique that can help families better communicate with a loved one who has dementia. The Validation Technique® can help facilitate more quality conversations. Tagg presented on this topic at AFA’s Las Vegas Concepts in Care educational conference in March, and I thought the topic would truly resonate with you, the readers of “AFA Care Quarterly.”

Shifting gears, on page 17, Laurie Scherrer provides families and care partners alike vital insight into what individuals with dementia want us to know. Scherrer, who was diagnosed with young-onset Alzheimer’s disease and Frontotemporal Degeneration/Dementia (FTD) in 2013 now mentors newly-diagnosed individuals.

Finally, I am excited that so many of our readers continue to share personal stories of their families’ love and resilience in the face of Alzheimer’s disease. On page 3, Dr. Margaret J. Piel, a veterinarian from Chicago, Ill., introduces us to her dad, Stanley, who developed Alzheimer's disease in 2002, at the age of 83. Her tribute includes some of the challenges she faced and her abundant love for a wonderful man.

As you set about your spring routines, I encourage you to reminisce about the past, create new memories for the future and treasure all that our families give us.

Take good care,

Charles J. Fuschillo, Jr.
President & CEO
Alzheimer’s Foundation of America
I was chatting with a fellow caregiver as we left our loved ones off at the daycare facility. She asked me about my dad, commenting that he seemed so happy all the time. We both appreciated how precious that we can be with parents who have moderate to severe Alzheimer’s disease. Her mom also smiled a lot, despite myriad health issues including metastatic bone cancer, which had to be painful. We talked about how, as long-time caregivers, we have had to learn to “read” our loved ones for the nonverbal cues that something is wrong. She said that her mom gets crabby when the pain is acting up, or if she is hungry, or has to go to the bathroom. She said that she believed that her mom smiled through it all because their entire family had always been close, communicative, trusting. At her very core, her mom trusted those around her, whether or not she any longer understood that world. How much like an infant, we quipped. Or, for me as a veterinarian, like my nonverbal animal patients. It hurt when my dad stopped being able to reply to “I love you” or to respond to affection. Then I realized that he did……every time he smiled!

THE SMILE

by Margaret J Piel, D.V.M., Chicago, Ill.

I was chatting with a fellow caregiver as we left our loved ones off at the daycare facility. She asked me about my dad, commenting that he seemed so happy all the time. We both appreciated how precious that we can be with parents who have moderate to severe Alzheimer’s disease. Her mom also smiled a lot, despite myriad health issues including metastatic bone cancer, which had to be painful. We talked about how, as long-time caregivers, we have had to learn to “read” our loved ones for the nonverbal cues that something is wrong. She said that her mom gets crabby when the pain is acting up, or if she is hungry, or has to go to the bathroom. She said that she believed that her mom smiled through it all because their entire family had always been close, communicative, trusting. At her very core, her mom trusted those around her, whether or not she any longer understood that world. How much like an infant, we quipped. Or, for me as a veterinarian, like my nonverbal animal patients. It hurt when my dad stopped being able to reply to “I love you” or to respond to affection. Then I realized that he did……every time he smiled!

SLEEP

by Margaret J Piel, D.V.M., Chicago, Ill.

It’s 3:45 AM
I lie, tossing and turning,
unable to fall back to sleep.
He is 95 years old and they are discussing hospice care.
I try to imagine what it would be like.
Dad no longer under my care.
No food to grind up to prevent aspiration, no bed sheets to change with every accident;
to be able to sleep through the night uninterrupted.
The way it used to be before Alzheimer’s.
I am tired.
I am tired.
I am tired.
I love my Dad. Please don’t go.

ABOUT MARGARET

My dad was diagnosed with Alzheimer’s disease following a severe fall in 2002, but had begun showing signs of the illness following my mother’s passing the year before. I was adamant that he be able to live for as long as possible in his home of more than 50 years. I moved in with him and became his permanent caregiver, while maintaining a full-time job. As his illness progressed, the level of care he required intensified and so we transitioned from an adult day center to home health aides to hospice. I NEVER regret having taken on this duty. We became very close as a result, and it’s the least I could have done for a wonderful man and father. He died at home in his bed, after a brief illness, in 2014.
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- nausea and vomiting
- difficulty passing urine
- seizures
- worsening of lung problems in people with asthma or other lung disease

The most common side effects of memantine HCl include: headache, diarrhea, and dizziness.

The most common side effects of donepezil HCl include: diarrhea, not wanting to eat (anorexia), and bruising.

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NAMZARIC is a prescription medicine used to treat patients with moderate to severe Alzheimer’s disease. NAMZARIC contains 2 medicines, memantine hydrochloride (HCl), an NMDA receptor antagonist, and donepezil HCl, an acetylcholinesterase inhibitor. NAMZARIC is for people who are taking donepezil HCl 10 mg.

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- asthma or lung problems
- seizures
- stomach ulcers
- liver, kidney, or bladder problems
- surgical, dental, or other medical procedures scheduled and anesthesia may be used

Tell your doctor about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements.

What are the possible side effects of NAMZARIC?
NAMZARIC may cause serious side effects, including:

- muscle problems if you need anesthesia
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Call your doctor for medical advice about side effects. You may report side effects to the FDA at 1-800-FDA-1088.

How should I take NAMZARIC?
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- If you do not open and sprinkle NAMZARIC capsules on applesauce, the NAMZARIC capsules must be swallowed whole. Do not divide, chew, or crush NAMZARIC capsules
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- You should not breast-feed during treatment with NAMZARIC
- Tell your healthcare provider if you are pregnant or planning to become pregnant

Need more information?
The risk information provided here is not complete. It summarizes the most important information about NAMZARIC. If you would like more information, talk to your doctor.

For the FDA approved product labeling or for more information go to NAMZARIC.com or call 1-800-678-1605.

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QUESTION: My best friend is starting to have a hard time reading menus and responding to the waitress, remembering to write down important dates, and asks the same question two to three times in 10 minutes. Should I be concerned?

ANSWER: Your friend is very fortunate to have someone like you, who is thinking about them while making these observations. It definitely sounds like you’re noticing some changes in your friend’s cognition. The main question to consider: is what I’m observing related to Alzheimer’s disease, normal aging, or something else? At times changes in one’s biology, i.e.: new medications, lack of sleep, poor diet, vitamin deficiencies, etc. can cause changes in thinking, memory, and cognition. Your friend may also have a lot on their mind or may be dealing with other emotional factors. It’s important to take into account the various changes that your friend may be experiencing in their life when considering what might cause these changes you’re noticing.

It’s normal to be concerned when you observe someone close to you acting different from what you’re used to. Would it be possible to sit down with your friend and have an honest conversation? They likely will best respond if approach the situation in a non-confrontational manner, using only objective observations without adding any kind of judgment or assumption. For instance, you could ask if there’s something on their mind because you have noticed that they have been asking the same questions in a short period of time and they seem distracted. You may find out that your friend is aware of these changes and will open up to you about their concerns. You may also want to speak to someone else who is close to your friend and would be able to have this conversation or see if that person is also observing the same changes if you feel you are not comfortable with having this conversation.

If you notice that these changes are affecting your friend’s safety, you may need to take a more direct approach. For example, could you encourage your friend to speak to their primary care physician? Having a medical professional involved may help to uncover if there are any biological causes or provide another viewpoint to your observations.

By doing so, you will enhance their ability to have a conversation and empower them to take their own action if they feel they can be honest without judgment.
**QUESTION:** My mother is 81 years old and living with dementia and may be getting worse. She seems very confused and is calling me 15-20 times a day and does not remember the conversations. What do I do?

**ANSWER:** Dementia does cause changes in one's short-term memory. It sounds like your mother maintains the capability to connect with you independently; however she is unable to recall that she has already spoken with you for the day.

Although it can be difficult to not answer each phone call, it is important to recognize alternative ways to help your mother and you feel reassured and supported. It may be beneficial to begin with exploring how your mother spends her day. With a more active day, she may not be as inclined to call as much, because she is engaged and interested in another pleasurable activity or option. Adult day programs, senior centers, friendly visiting programs and other companion services are all opportunities to assist in redirecting your mother’s focus from calling repetitively to something more enjoyable for her. With these consistent calls, your mother may be feeling anxious or unsure, and so having **someone** or **something** for her to engage with/in may be beneficial for her as well as for you. I will add that in considering services for your mother, this new need and her personality, think especially about what type of support would be most suitable for her.

An additional idea is to change your outgoing voicemail greeting so it personally addresses her, as well as offer a notepad that she can keep by the phone for her to mark that she spoke with you already; however this suggestion may not be a long-term approach to meeting your mother’s needs. This situation can be complex in that you may feel strange or guilty not answering when your mother calls; however we understand that in this situation her short term memory is impacted, and she is, unfortunately, unable to recall speaking with you, even if the conversation occurred a few moments ago.

It also may be helpful to make an appointment with your mother’s primary care physician to rule out any other factors, especially if this change has come on suddenly. Medical conditions and medication side effects can cause significant changes.

The progression of this disease often warrants that we, as care partners, continually modify and adapt our approach for offering support. I encourage you to consider exploring different opportunities that can help provide your mother reassurance and fulfillment.

As always, please reach out to AFA’s helpline to speak with any of our licensed social workers to discuss this or any other concern you may have.

**HAVE A QUESTION?**

Please feel free to call AFA’s national toll-free helpline at 866-232-8484 if you have additional questions or need further support, information, clarification or referrals to local resources.
There were several inspirational thoughts that kept me afloat during my darkest days as a caregiver, and some of these thoughts were extremely helpful as I dealt with the sadness, grief, and tremendous feelings of loss that I experienced for many months after Clare had passed. I present them here in the hope that one or more may also be helpful to you.

For many months I kept singing along to two Katy Perry songs—“Roar” and “By the Grace of God.” On my worst days I sang them aloud, over and over and over again, shouting more than singing, both at home and in my car. In “Roar,” Perry sings about having “the eye of the tiger, a fighter,” and that she is “a champion.” I wanted to feel like a champion. I wanted to feel in control of my life again, and to feel that I was going to come back from my despair and depression.

In “By the Grace of God,” Perry sings about how, after a love break-up, she finds herself lying on her bathroom floor. She sings, “I picked myself back up, I knew I had to stay, I put one foot in front of the other, I looked in the mirror and decided to stay.” She also sings that “the truth was like swallowing sand,” a fairly good description of how I felt on some days knowing that I was losing Clare more and more each day and soon would be widowed … and how I felt after I had to face the reality, upon her passing, that she was now gone forever. Sadly, the only certainty with Alzheimer’s is that death is inevitable … there are no Alzheimer’s survivors.

There were many other phrases in “By the Grace of God” that I related to … lines such as “running on empty, so out of gas” and “found I wasn’t so tough.” But that song also had the line, “I am not giving up.” Louder and louder, over and over again, I would shout out that song … and it helped me. A lot.

Something else that helped me a lot was re-reading the “Serenity Prayer.” I keep it posted in my home office … “God grant me the serenity to accept the things I cannot change, the courage to change the things I can, and the wisdom to know the difference.” These words reminded me that I had to accept the reality that Clare was dying and there was absolutely nothing I could do to change that reality. All I could do was make sure that Clare was receiving the best care possible and was as happy as possible.
Those same words were just as valuable after I lost Clare ... I had to accept that she was gone from my life, but also accept the reality that I needed to move on with my new life as a widower.

I also knew I had to accept the fact that I now had to make some important decisions in my life and not dwell on what might have been or could have been. I had to focus on what I needed to do in order to give myself the best opportunity to live a reasonably happy and healthy life as a widower.

I also came across some very wise words from Swiss psychiatrist Elisabeth Kubler-Ross, who wrote this about grief: “The reality is that you will grieve forever. You will not ‘get over’ the loss of a loved one; you will learn to live with it. You will heal and you will rebuild yourself around the loss you have suffered. You will be whole again but you will never be the same. Nor should you be the same nor would you want to.”

And that brings me to the last inspirational thought I want to share, words that led to my “Aha” moment. I no longer remember where I read these words or who wrote them, but the author said that when you lose a loved one, instead of looking back with sadness at your loss you should think instead about how fortunate you were to have had your loved one in your life for all of those years.

When I read those words, I literally looked at a picture of Clare and cried ... but I also smiled, recognizing how incredibly lucky I was to have been with Clare for all those years, and how instead of mourning her loss each day I should feel incredibly happy and lucky that I shared 51 years with her. I know that I will grieve forever, but each month, I am making progress in learning how to live with that grief.

These inspirational thoughts continue to keep me going even now. I sincerely hope that one or more of these thoughts may also bring solace to others. A caregiver watching a loved one die of a degenerative disease such as Alzheimer’s ... a disease that is without any hope of “remission” or “survival” ... cannot avoid deep emotional pain and anticipatory grief. An Alzheimer’s widow or widower may find that pain and grief remaining for a long time after the death of a loved one.

But, if one can find some comfort in the words of others, the path to moving on with one’s life during and after caring for a loved one with Alzheimer’s may be somewhat easier. I know it was that way for me.

Editor’s Note: Allan Vann began writing as a means for helping to cope with the changes in his life after his wife Clare was diagnosed with young-onset Alzheimer’s disease. Throughout his caregiving journey, Allan contributed several articles to AFA Care Quarterly—tackling everything from adapting travel routines so that they were enjoyable and safe for his wife, making the transition from home to a residential care setting, and coping with feelings of loss that this devastating illness brings, even while the individual with the disease is still alive. This article, written one year after Clare’s passing, is his last article written specifically for family caregivers of people with Alzheimer’s disease.

If you would Like Dr. Vann to respond to questions or comments about this article, please email him at acvann@optonline.net. You can learn more about his journey with Alzheimer’s at www.allansvann.blogspot.com.
As caregivers working with clients or loved ones who are living with symptoms of dementia it can become difficult to engage in quality conversation. It’s easy to become frustrated when a loved one is unable to answer day to day questions such as: “What day is it?” “What did you eat for breakfast?” or when we respond: “No, you can no longer drive.” “No, dad passed away.”

We must change our way of thinking, so we can provide better quality of life for—not only our loved ones—but also for ourselves.

In this article, I would like to share a technique that can help facilitate more quality conversations with your loved one. In the late 1970s, a social worker by the name of Naomi Feil developed Validation Therapy as a response to her dissatisfaction with traditional methods of working with persons living with dementia. This method challenged the traditional method of reality, orienting someone every time that they stated something “wrong.” But really, who is the one to determine what is right and wrong?

Validation Therapy was developed through clinical practice with residents living in memory care facilities, and is based on a developmental theory that in old age, when one is no longer able to communicate effectively, this technique assists in improving the individual’s quality of life.

Validation is accepting the values, beliefs and reality of the person living with dementia—even if it has no basis to your reality. Carl Jung said: “Feelings that are expressed, and then acknowledged and validated by a trusted listener, will become less intense. When ignored or denied, feelings, gain strength. The cat ignored becomes the tiger.”

The goals of Validation are simple: restore self-worth, reduce stress, justify living, work toward resolving unfinished conflicts from the past, reduce the need for chemical and physical restraints, increase verbal and non-verbal communication, prevent withdrawal inward, and improve gait and physical well-being.
Here is an example of using validation:

Dad: “I have to find my car keys.”
Child: “Your car keys...” (the child doesn’t tell him he doesn’t have a car and hasn’t driven for years)
Dad: “Yes, I need to get home – lots of work to do, you know!”
Child: “You are busy today?” (the child doesn’t tell him he really has nothing to do)
Dad: “Yes. I am busy every day!”
Child: “You like being busy.” (the child is redirecting the conversation at this point)
Dad. “I didn’t say I liked it. I just have to work – like most of the rest of the world, you know!” (Dad seems to be getting a little frustrated but has not mentioned the keys)
Child: “I know all about work, Dad. I do some of that myself. In fact, I am getting ready to fix some lunch for us. Care to join me?”
Dad: “Lunch, huh? What are you having?”

As you see with this scenario, the conversation has shifted and now both parties are able to move into another one. There was no lying involved. The child didn’t say things such as, “the car is in the shop,” “you can’t drive today,” or “your keys are missing.” This conversation allowed for the dad to vent and the child to engage. The point is to agree with what they want and to steer them to do something else along the way without them realizing they are being redirected. True, this doesn’t always work but it will allow for a non-confrontational approach when conversing with our loved ones. Think about it this way, when somebody tells you that you are wrong, how do you feel?

In using the technique of Validation, it is important to recognize these 10 principles:

1. All people are unique and must be treated as individuals.
2. All people are valuable, no matter how disoriented they are.
3. There is a reason behind the behavior of disoriented people.
4. Behavior in old age is not merely a function of anatomical changes in the brain, but reflects a combination of physical, social, and psychological changes that take place over the lifespan.
5. Older people cannot be forced to change their behaviors. Behaviors can be changed only if the person wants to change them.
6. Older people must be accepted nonjudgmentally.
7. There are particular “life tasks” associated with each stage of life. Failure to complete a task at the appropriate stage of life may lead to psychological problems.
8. When more recent memory fails, older adults try to restore balance to their lives by retrieving earlier memories. When eyesight fails, they use the mind’s eye to see. When hearing goes, they listen to sounds from the past.
9. Painful feelings that are expressed, acknowledged, and validated by a trusted listener will diminish. Painful feelings that are ignored or suppressed will gain strength.
10. Empathy builds trust, reduces anxiety, and restores dignity.
The techniques are simple. They require the capacity to accept and empathize with persons living with memory loss. Naomi Feil stated, “There is a reason behind the behavior.” Our responsibility is to assist the person through the process.

When we apply the Validation Techniques method, there are 14 simple skills that we can develop that will help us put aside our own judgments and expectations of behavior, and learn to be sensitive to the logic behind the disorientation. This can help significantly reduce the anxiety of the disoriented individual.

1. **Centering:** The caregiver must focus on his breathing, in order to expel as much anger and frustration as possible. By releasing those emotions, the caregiver can open up to the feelings of the person. This is critical to being able to listen empathetically to another person.

2. **Use non-threatening, factual words to build trust.** People in resolution (going through conflict) do not want to understand their feelings. They are not interested in understanding why they behave the way they do. They retreat when confronted with their feelings. The caregiver should focus on factual questions—who, what, where, and how. Caregivers should avoid asking why, as this can cause even more anger and frustration.

3. **Rephrasing:** People in resolution often find comfort in hearing their own words spoken by someone else. To rephrase, the caregiver repeats the gist of what the person has said, using the same words.

4. **Using polarity:** Polarity involves asking the person to think about the most extreme example of his complaint. By thinking about the worst case, the person being validated expresses his feelings more fully, thereby finding some relief.

5. **Imagining the opposite:** This leads to the recollection of a familiar solution to the problem, providing the older person trust.

6. **Reminiscing:** Exploring the past can re-establish familiar coping methods that the disoriented person can tap to survive present-day losses.

7. **Maintaining genuine, close eye contact:** An older person in time confusion and repetitive motion feels loved and secure when a caregiver shows affection through close eye contact. The caregiver becomes a nurturing parent, and the person feels safe, anxiety is reduced, and he sometimes becomes aware of present day reality.
8. **Using ambiguity:** Time-confused people often use words that have no meaning to others. They also frequently communicate nonverbally, in ways that are difficult to understand. By using ambiguity, caregivers can often communicate with the time-confused even if they don’t understand what is being said. Here’s an example: When a person with dementia says they want to go home, even though they are already in their home, using ambiguity can help redirect the conversation. “You have a lovely home, don’t you?” “You take good care of your home. You are a good person.”

9. **Using a clear, low, loving tone of voice:** Harsh tones cause disoriented people to become angry or to withdraw. High, soft tones are difficult for many older people to hear. It is important to speak in a clear, low nurturing tone of voice. This can trigger love and reduces stress.

10. **Observing and matching the person’s motions and emotions (mirroring):** People in time confusion and repetitive motion often express their emotions with inhibition. To communicate, it is important to take stock of their physical characteristics and the ways in which they move. The caregiver should observe their eyes, facial muscles, breathing, changes in color, chin, lower lip, hands, stomach, position in the chair, position of the feet, and the general tone of their muscles to match these postures.

11. **Linking behavior with the unmet human need, such as using the toilet, hunger, thirst or pain:** Most people need to be loved and nurtured, to be active and engaged, and to express their deep emotions to someone who listens with empathy.

12. **Identifying and using the preferred sense:** Discover which sense the person prefers and listen carefully to their needs. The first sense a person reveals is the person’s preferred sense. For example: a person is looking out the window and asks: “Can you see the horses?” The caregiver looks out the window and there are a bunch of cars. It is noted that the person is using the mind’s eye—his preferred sense is vision.

13. **Touching:** Before employing this technique, it is critical that caregivers understand whether the individual likes to be touched. If so, some positive touch techniques to try are using the finger tips on the cheek, back of head, or earlobe, rubbing the shoulders or back, and cupped fingers on the back of the neck. If the individual is receptive to touch, these techniques can provide reassurance.

14. **Using music:** When words have gone, familiar, early-learned melodies return. People in repetitive motion will often say a few words after singing a familiar song. Music energizes people who are time confused as well.
Alisa Tagg, BA ACC/EDU AC-BC CADDCT CDP is a certified activity consultant who has worked in the health care industry since 1995. She teaches the MEPAP education course to new activity professionals as well as providing in-services and training. Tagg writes for and teaches the HCC course with R.O.S. Therapy Systems. She holds a bachelor’s degree in Psychology from the University of Nevada, Las Vegas, a provider’s Certificate of Completion specializing in Aging with the Nevada Geriatric Education Center, and is a Certified Alzheimer’s Disease and Dementia Care Trainer and Certified Dementia Practitioner with the National Certification Council for Dementia Practitioners. She also serves as president of the National Association of Activity Professionals, and speaks on local, state and national levels on various topics relating to family caregiver services, the health care industry, and the activity profession. She recently presented a workshop, entitled “Validation Techniques in the Real World,” at AFA’s Concepts in Care educational conference in Las Vegas.

In validation, the person’s feelings are accepted. The caregiver acknowledges the feelings, sometimes mirrors them, and encourages free expression. The feelings are not discouraged, criticized, forced, or analyzed. Even though the person living with dementia is experiencing feelings about a long past event, they are seen as true, meaningful, and current. This can help improve the quality of life of both the individual with dementia and the caregiver.

For more information about Validation techniques, visit the Validation Institute at vfvalidation.org.

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SENIOR HELPERS IS A PROUD SPONSOR OF THE AFA
January marked a political sea change in Washington with both a new Administration and new Congress vowing to quickly dismantle the previous Administration’s health care reform measures, cut budgets and reform the tax code.

While Republican majorities in both the House and Senate, and a Republican in the White House, put the GOP in the driver’s seat regarding overall policy direction, fighting Alzheimer’s disease is a bipartisan issue and the Alzheimer’s Foundation of America (AFA) is fortunate to have strong and influential champions on both sides of the Congressional aisle.

In addition, President Trump has firsthand knowledge of the disease as his father had Alzheimer’s. On the campaign trail, he indicated his support in making the fight against Alzheimer’s a national priority. This should be reinforced by his close advisor, Newt Gingrich, who was a strong proponent of investment in the National Institutes of Health (NIH) for an Alzheimer’s cure when he served as Speaker of the House.

Health Care Reform

Despite efforts from both the Administration and House Republican leadership, plans to replace the Affordable Care Act (ACA) (aka Obamacare) are now stalled in Congress. While AFA has not taken any position on a replacement bill, it has emphasized to Congress that several provisions of the ACA have a positive impact for those living with dementia and should be retained. Such provisions include:

- the Medicare annual wellness exam, which includes cognitive screening;
- protection for pre-existing conditions;
- incentives for clinical training in geriatrics;
- the Centers for Medicare and Medicaid Innovation (CMMI);

- Medicare-Medicaid Coordination - Integrated Care Resource Center;
- Patient-Centered Outcomes Research Institute (PCORI) funding for dementia research; and
- Medicaid expansion.

AFA will continue to monitor Congressional efforts to replace the ACA and will weigh-in on issues impacting people living with dementia and their family caregivers as negotiations move forward.

2017 Federal Budget

Last year, Congress failed to pass a budget for Fiscal Year 2017 (FY’17) which started on October 1, 2016, and instead, passed a continuing resolution (CR) extending current (FY’16) funding levels through April 28, 2017.

The FY’17 budget; however, has good news for the Alzheimer’s community. The House Appropriations Committee approved a $350 million increase for Alzheimer’s in FY’17; the Senate Appropriations Committee’s budget increased spending by $400 million.

AFA continues to call on Congress to pass the FY’17 budget and proposed increases for Alzheimer’s disease research. In a statement, AFA’s president and chief executive officer Charles J. Fuschillo Jr., praised the members of the Senate Appropriations Committee saying that, “Increased dollars will enable Alzheimer’s research partners to continue and expand much needed efforts in finding a cure ... however, much more needs to be invested if we are to achieve the goal of the National Alzheimer’s Plan—to find a cure or meaningful treatment for this devastating illness by 2025.”
2018 Federal Budget

In March, the Administration released a “skinny” budget for FY’18 which includes deep cuts in non-defense discretionary (NDD) spending, including an 18 percent reduction to NIH, the major funder of Alzheimer’s disease research. In addition, Older Americans’ Act programs like specialized dementia caregiver training, Meals on Wheels and respite care, will be targets for deep cuts.

AFA is working with other dementia and aging advocates to urge the lifting of sequestration of NDD programs. AFA has also weighed in with both President Trump and Office of Management and Budget Director Mulvany renewing the call for funding Alzheimer’s disease research at $2 billion per year. In a letter, Charles J. Fuschillo, Jr., AFA’s president and CEO, wrote, “We need to ensure there is proper investment in promising research today that will get us to a cure tomorrow.” In addition, AFA is calling for an increase of $40 million for Alzheimer’s disease long term care services and supports, as well as $5 million to funding the Missing Alzheimer’s Disease Patient Program which provides grants to help find and safely return people with dementia who wander.

Senate Aging Hearing on Alzheimer’s Disease

The Senate Aging Committee, chaired by Sen. Susan Collins (R-Maine) held a hearing titled, “The Arc of Alzheimer’s: From Preventing Cognitive Decline in Americans to Assuring Quality Care for Those Living with the Disease.” The hearing focused on the full spectrum of Alzheimer’s disease, from prevention research focusing on clinical factors and lifestyle modifications, to assuring quality care for those living with Alzheimer’s disease and other dementias. It also highlighted the human and economic toll of Alzheimer’s disease.

Expert witnesses testified on the need to increase resources for a cure, and how healthy aging—including a healthy diet, frequent exercise and cognitive stimulation—can help prevent or delay cognitive decline.

In written testimony submitted for inclusion in the hearing record, AFA discussed the increasing incidence of the disease, its costs and that there is currently no cure of modifying treatment to stop Alzheimer’s. AFA also stressed the importance of memory screenings, and being proactive about brain health. Early and accurate diagnosis of Alzheimer’s disease can empower and enhance quality of life for the person living with Alzheimer’s and their family caregivers. AFA’s testimony points out that early detection makes it possible for family members to establish caregiver networks, address financial and legal matters, express end-of-life wishes, and take advantage of caregiver training and support services.

Other legislation supported by AFA in the 115th Congress includes:

- **S. Res. 49** - A resolution, introduced by Sens. Susan Collins (R-Maine) and Amy Klobuchar (D-Minn.). The resolution calls on the Senate to make curing Alzheimer’s disease by 2025 a national priority and to commit $2 billion for Alzheimer’s disease research at the National Institutes of Health.

- **S. 445** - the Home Health Care Planning Improvement Act of 2017 - introduced by Sens. Susan Collins (R-Maine) and Ben Cardin (D-Md.) would expand Independence at Home (IAH) demonstration project (1866E of the Medicare Act) that provides home-based primary medical care to Medicare beneficiaries with severe chronic illnesses, including Alzheimer’s disease.

- **S. 464** - Independence at Home Act of 2017 – sponsored by Sen. Ed Markey (D-Mass.) the bill would provide for a permanent Independence at Home (IAH) medical practice program under the Medicare program. IAH is a person-centered interdisciplinary medical and social services team that provides health care 24/7 where the person resides.

- **S. 693/H.R. 1676** - Palliative Care and Hospice Education and Training Act (PCHETA) – introduced in the Senate by Sens. Tammy Baldwin (D-Wis.) and Shelley Moore Capito (R-W. Va.) and by Rep. Elliot Engel (D-N.Y.) in the House. This bill would strengthen training for physicians and other members of the palliative care team, boost palliative care research and provide incentives to practice and study palliative and hospice care, and will ensure that there are the necessary number of trained, specialized health providers to provide this high quality care.

What Can You Do?

Knowledge is power, and AFA will continue to provide updates as we move forward our policy agenda in this new political environment. Remember, all politics is local, and your voice adds weight and urgency to our message. Contact your representatives and encourage them to support funding for Alzheimer’s research and caregiver supports. Only by working together, and tirelessly, can we effectuate the type of change needed to impact the trajectory of this disease and its impact on American families.
THROUGH MY EYES:
10 THINGS PEOPLE WITH DEMENTIA WANT CARE PARTNERS TO KNOW

By Laurie Scherrer

In August 2013, at the age of 55, I was diagnosed with early-onset Alzheimer’s disease, and Frontotemporal Degeneration/Dementia (FTD). Through my website and other networks, I share many of the triumphs, challenges and strategies that have become a part of this journey.

Generally, more than half of the comments and questions I receive are from care partners. I am often touched by the number of care partners who thank me for expressing what their loved one can’t always tell them.

HERE ARE THE TOP 10 POINTS I WOULD LIKE CARE PARTNERS, FRIENDS, FAMILY, NEIGHBORS, THE COMMUNITY, AND ANYONE INTERACTING WITH PEOPLE WITH DEMENTIA TO KNOW:

1. **Although we may not always tell you or act it – we still love you and we do appreciate all you do.** We just don’t always know how to tell you.

2. **Maintain as much of a routine as possible (especially in the morning and evening).** Make a list of routine tasks in the order they are done (e.g., scrub teeth, get washed, get dressed, etc.) and check them off as completed. A routine can help to establish an automatic reaction and reduces some of the “think work” required during periods of confusion.

3. **Identify things that cause agitation.** Many times, something triggers dementia symptoms causing the person with dementia (PWD) to “act out” or get confused. It is important to take time to observe what the surroundings and events were prior to the agitation and try to identify what may have caused it. For example: Was there a lot of noise? Did someone have an argument? Were their surroundings changed?
Embrace and encourage our abilities—rather than focusing on our inabilities. Like a set of lights on a Christmas tree, parts of our brain flicker on and off. There are moments of lucidity and moments of confusion. Tasks may be easy one day and difficult the next. Build on the strengths we can accomplish in the moment.

Engage us in activities. The more we sit idle, the more we fall into our shell. As with anyone, our brains need to be stimulated and challenged. In advanced stages, this may be as simple as sorting buttons into the same color. Include laughter and fun in every day.

Challenge us to stay as independent as possible. The more you do for us, the more you enable our dependence. There will be moments when we can’t do things for ourselves, but with some guidance, often, we can figure it out. The clothes may not be folded right, but praise the effort.

Maintain social activity as much as possible. This is important for care partners, as well as for the person living with dementia. Video chats, forums and mentor programs are wonderful ways to learn best practices for dealing with dementia symptoms. There are a variety of resources for social engagement available online, as well as through organizations like the Alzheimer’s Foundation of America and its members.

Interact the same as you did prior to the diagnosis. Although dementia may rob many of our abilities and memories, it does not take away feelings or intelligence. Even when a person is “living” in their past they are still living as an adult—not as a child—and should be treated as such.

Communicate visually as well as audibly and slow down your speech just a tad. Look at the person when speaking and encourage them to look at you. Dementia slows processing time, being able to see and hear helps clarify the communication. Using video chats rather than the telephone, writing down tasks, and even asking restaurants for a written list of specials are all ways to increase visual communication.

Understand that dementia does not make a person hearing impaired; in some cases, their hearing becomes stronger. Speak with the person directly rather than speaking about them. If you need to have a conversation about the person, do so when you are well out of hearing range.

Learn more about Laurie and follow her blog at www.dementiadaze.com
Ingredients:

• 2 eggs plus 2 egg whites, lightly beaten
• 1/4 cup ground golden flaxseed
• 1/2 cup part-skim ricotta cheese
• 3/4 teaspoon baking powder
• 1/4 teaspoon salt
• 1 teaspoon stevia powder or 2 Tablespoons maple syrup (optional)
• Nonstick cooking spray, olive oil

Method:

• In a large bowl, combine all ingredients and stir well. If the batter is too thick, add water. If it’s too loose, add more ground flaxseed.
• Heat a large nonstick skillet on medium-high heat and spray with cooking spray.
• Pour one-quarter of the batter into skillet to make a pancake. Cook until golden on both sides, about 2 minutes per side. Repeat to make three more pancakes.

Serve with sliced seasonal fruit and pure maple syrup or with part-skim ricotta cheese and jam.

For passed hors d’oeuvres or to make bite-size pancakes, divide the batter into eight servings and cook as instructed.

Nutritional Information: Per pancake (79 grams) without added sweetener: 113 calories, 6.9 grams fat, 245 milligrams sodium, 4.3 grams carbohydrates, 2 grams dietary fiber, 9.6 grams protein.

Recipe and photo by Layne Lieberman, M.S., R.D., C.D.N., culinary nutritionist and award-winning author of “Beyond the Mediterranean Diet: European Secrets of the Super-Healthy.” For more information and recipes, visit www.WorldRD.com
FIT TO BE TIED

From American Acrostics
Volume 5: Puzzling Holidays and Celebrations
(forthcoming),

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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 fun and timely quotation, 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 quotation is taken from.

<table>
<thead>
<tr>
<th>Clues</th>
<th>Words</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. Frasier and his dad, Martin, shared an apartment here on “Frasier” (2 wds.)</td>
<td>86 132 85 183 231 74 64 78 156 193</td>
</tr>
<tr>
<td>B. “No duty is more ___ than that of returning thanks.” (James Allen)</td>
<td>68 206 121 182 96 198</td>
</tr>
<tr>
<td>C. Kid's drawing toy (3 wds.)</td>
<td>187 124 87 42 13 153 61 201 27 128 81</td>
</tr>
<tr>
<td>D. Duty</td>
<td>233 73 227 118 62</td>
</tr>
<tr>
<td>E. 1939 Oscar winner McDaniel</td>
<td>56 148 80 154 170 140</td>
</tr>
<tr>
<td>F. Was a figure of speech?</td>
<td>16 175 228 82 166 48</td>
</tr>
<tr>
<td>G. He played TV dad Steven Keaton on “Family Ties” (2 wds.)</td>
<td>200 91 115 214 148 76 66 222 117</td>
</tr>
<tr>
<td>H. Celebrated</td>
<td>136 173 160 223 28 147 67</td>
</tr>
<tr>
<td>I. He played TV dad Eric Camden on “7th Heaven” (2 wds.)</td>
<td>177 7 23 135 214 148 76 66 222 117</td>
</tr>
<tr>
<td>J. It’s bad to lie under this</td>
<td>76 138 70 22</td>
</tr>
<tr>
<td>K. John Chancellor was one of the anchors of this evening staple (2 wds., with “NBC”)</td>
<td>32 76 77 145 103 150 48 66 213 1 114</td>
</tr>
<tr>
<td>L. Baseball stats</td>
<td>90 76 204 11</td>
</tr>
<tr>
<td>M. Ripley’s rare find</td>
<td>83 180 33 217 193 38</td>
</tr>
<tr>
<td>O. Rubbed the wrong way</td>
<td>129 88 209 144 8 194 105 139 231 131</td>
</tr>
<tr>
<td>P. Bob Saget played this TV dad from 1987-1995 (2 wds.)</td>
<td>181 31 43</td>
</tr>
<tr>
<td>Q. Scout’s dad (2 wds.)</td>
<td>226 186 71 65 157 47 211 57 141</td>
</tr>
<tr>
<td>R. “Tomorrow hopes we have learned something from ___.” (John Wayne)</td>
<td>229 173 207 128 220 93 153 171 55 159 54</td>
</tr>
<tr>
<td>S. “Hitch your wagon to a ___.” (Ralph Waldo Emerson)</td>
<td>3 130 30 185 60 34 125 18 106 179</td>
</tr>
<tr>
<td>T. Had a hankering for</td>
<td>173 100</td>
</tr>
<tr>
<td>U. Original title of “The Danny Thomas Show” (4 wds.)</td>
<td>14 8 189 55 55 102 195 219 164</td>
</tr>
<tr>
<td>V. Lorne Greene played this iconic TV dad from 1959-1973 (2 wds.)</td>
<td>25 36 234 10</td>
</tr>
<tr>
<td>W. Ref’s call, in football</td>
<td>171 235 95 188 196 238 182</td>
</tr>
<tr>
<td>X. Fit to be tied</td>
<td>112 184 122 120 149 53 187 5 39 143</td>
</tr>
<tr>
<td>Y. Family member who raises cane? (2 wds.)</td>
<td>44 176 191 5 121 72</td>
</tr>
</tbody>
</table>

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To their advantage, retailers wasted no time in jumping the holiday egetable Farmer’s Day greeting cards, and mothers appeared on the masculine gift’s necktie industry. When Mother’s Day did for the necktie industry, it wasn’t a secret Washington.
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This program is approved by the National Association of Social Workers – Provider #886446769