Meet the Winners of the AFA Teens for Alzheimer's Awareness College Scholarship Competition

Understanding Memory Health in Veterans

Sen. Susan Collins Discusses Advocacy and Funding for Alzheimer’s Research and Care
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”

FEATURES

PAGE 7
WASHINGTON UPDATE
Sen. Susan Collins discusses advocating for Alzheimer’s, the current state of funding for research and caregiver supports, and how people can get involved.

PAGE 9
GUEST COLUMN
Understanding Memory Health in Veterans

PAGE 14
SPECIAL TEENS SECTION
Teen caregivers share life lessons.

FRONT COVER
JANET A. COOK, “MY DISAPPEARING MOTHER”
To learn more about Janet, turn to page 2.

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IN EVERY ISSUE
1 A MESSAGE FROM OUR PRESIDENT AND CEO
2 HEART & SOUL
6 ASK AN AFA SOCIAL WORKER
23 GIVING CORNER
25 TO YOUR HEALTH

PUBLISHER
Alzheimer’s Foundation of America

EDITOR-IN-CHIEF
Amanda Secor

CREATIVE DIRECTOR
Laura De Silvio

CONTACT INFORMATION
Alzheimer’s Foundation of America
322 Eighth Ave., 7th floor
New York, NY 10001
National Toll-Free Helpline
866.232.8484
646.638.1546 fax
info@alzfdn.org and www.alzfdn.org

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Love and compassion are necessities, not luxuries. Without them, humanity cannot survive. – Dalai Lama

Truly, love and compassion are at the heart of this issue of AFA Care Quarterly. In the spotlight are three teens whose lives have been forever changed by Alzheimer’s disease. Their stories—shared as part of the Alzheimer’s Foundation of America’s (AFA) Teens for Alzheimer’s Awareness college scholarship competition—are heartfelt, poignant and inspiring. What’s more, their stories illustrate how teens’ lives increasingly are impacted by Alzheimer’s disease and the love, compassion and insight these young women demonstrated in the face of the disease. This year, AFA received 2,500 entries to the competition, and awarded $20,000 in scholarships to 16 students. I am delighted to share three of the winning essays—the two grand prizewinners and first runner-up—beginning on page 14.

On our cover is another example of love and compassion. The portrait, entitled “My Disappearing Mother,” was created by, Janet A. Cook, an artist and long-distance caregiver to her 88-year-old mother, who has mild Alzheimer’s disease and vascular dementia. On page 2, Cook discusses the experience of being a long-distance caregiver, and emotions that ring true for many in similar situations.

This issue’s guest column, penned by Richard E. Powers M.D., a member of AFA’s medical and scientific advisory board, examines the important topic of memory health in veterans. It is a topic not often discussed, but deserving of conversation, and underscores the need for love and compassion for the men and women who bravely served our country. The article begins on page 9.

Finally, it is no secret to you that love and compassion are essential to caregiving. From time to time, all caregivers need a spark of inspiration, a time-out, or just to talk with someone who “gets it.” As always, I encourage you to reach out to our team of compassionate, licensed social workers. Our national toll-free helpline (866-232-8484) is open Monday–Friday, from 9 a.m.–9 p.m. EDT and Saturdays, from 9 a.m.–1 p.m. EDT.

Have a wonderful summer and take good care,

Charles J. Fuschillo, Jr.
President & CEO
Alzheimer’s Foundation of America
When my mom announced recently that she had bought two new undergarments here, I was surprised. “I don’t know where they are,” she said. “Well, where do you think you are?” I asked. “At your house,” she replied. “So where do you live then?” I mentioned the area she grew up in. “No not there, somewhere else.” “OK where then?” She shrugged, “Just not here.”

It was then that I realized she had lost the last 30+ years of her life. She had no recollection of buying the house we now stood in. She bought it shortly after my dad died in 1981. “Did I buy it?” “Yes, you did.” “Well, I have been asleep since then,” was her reply—her favorite response to not remembering.

Home for my mother is just outside London, England. I live with my husband and work 3,000 some miles away in New York. It is not an easy commute, but I return four or more times a year. Fortunately, my brother David lives in the same house as my mother and works hard taking care of her. I wish I was closer and feel guilty that he has to shoulder most of the responsibilities, but I have responsibilities too, and it’s hard to take extended periods of time off from work. I do what I can.

My mother, now 88, was diagnosed with Alzheimer’s and vascular dementia after an MRI in 2012. Shortly thereafter, she was put on medication for memory loss; however, had to be taken off it for other health reasons. Since then, her memory has deteriorated and as I don’t live with her, it is all the more apparent when I visit.

From the beginning, my brother and I agreed that we would keep our mom at home as long as possible and that he would be her primary...
The U.K. government is very supportive of family caregivers and provides each of them with a small allowance, which pays for care and assistance. A district nurse and a health visitor for older people also came to the home to ensure it was properly equipped to help her remain safe.

Communicating long-distance with my mother has become increasingly difficult. We used to speak by phone, but her hearing loss is now so acute and her memory so bad, it is difficult to do so. I find myself oscillating between missing her and feeling guilty for not speaking to her more, and feeling frustrated when I do. I stay in touch via my brother.

In the past year, my mother has become more dependent on David, both night and day. At times, it is overwhelming for him. Wanting to help, I spoke with my mother’s general practitioner (GP) and mentioned how hard David worked. The GP and her care team devised a plan to give David some much-needed time off. Mum now goes to a daycare center twice a week, paid for by her allowance and sponsored by the local city. In addition to the day care center, a home care professional comes once a week to keep her company and provide a bit of exercise. I still wish I could do more, but I am relieved that my brother now gets regular respite.

Not seeing my mother on a regular basis gives me more perspective on her condition. My brother is consumed by the day-to-day caregiving duties, so in some ways it is easier for me to assess the changes. When I return to England, I usually see her GP and discuss the results of her tests. At the beginning of this year, I got the ball rolling on required medical appointments, which can take weeks or months to arrange through her GP and the National Health Service.

It is easy to lament my mother’s memory loss, but I don’t dwell on it; I just try to enjoy our time together. My next trip is scheduled for August/September. I am looking forward to spending time with my mother and hope that David will be able to relax and take a vacation while I’m there.

“It is easy to lament my mother’s memory loss, but I don’t dwell on it; I just try to enjoy our time together.”
“Sudden outbursts of crying or laughing can be a sign of fine acting. But for people with Alzheimer’s, it could be PBA.”

—Danny Glover

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

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

‘PBA FACTS’ is a FREE kit that explains the facts and science behind this treatable neurologic condition.

For yours, call 1-800-810-3188 or go to pbafacts.com. Learn more and talk with your doctor.

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

*PRISM was a nationwide registry of adult patients with brain injuries or certain neurologic conditions, including 1799 who have Alzheimer's disease. PBA symptoms were defined as a Center for Neurologic Study Lability Scale (CNS-LS) score ≥13. This CNS-LS score may suggest PBA symptoms and merits further diagnostic assessment. Patients or caregivers completed the assessment. The CNS-LS has been validated in ALS and MS patient populations.
Dementia can bring about challenging care situations for both the individual living with the disease and the caregiver. It is not uncommon for caregivers to experience moments where their patience and abilities to provide are tested. For example, dementia can impact a person’s ability to understand and process information, thus requiring the caregiver to evaluate and modify their responses to accommodate the individual’s new norm. Often on AFA’s national toll-free helpline, I refer to this as a “limitless learning curve.”

Although difficult to acknowledge and accept, there may come a time when an individual living with dementia develops needs that go beyond what a primary caregiver can provide in the home. This may present another challenging situation for both the individual and the caregiver, because it may necessitate changes in their routine. For the individual living with dementia, it may mean becoming comfortable with additional and new support, and for the caregiver, it means being prepared to secure that support and accept outside help.

It sounds like, perhaps, you have come to a point in your caregiving journey in which you and your husband would benefit from more support. It is important to recognize that your health and wellbeing are just as important as his. Consider researching home health care agencies to offer in-home support for a few days or hours each week, or possibly enrolling your husband in an adult day program. Both options would deliver the care you and your husband both deserve. You would still be your husband’s primary caregiver, but you would also have an added layer of support that could allow you to have some respite and also to address and better manage your own health needs. For example, you could go to an appointment of your own, attend a support group or simply have a dedicated time to relax. At the same time, the day program could afford him the opportunity to have social engagement and care. As always, if you have additional questions or need further support, please call us at 866-232-8484.

**HAVE A QUESTION?** AFA’s licensed social workers are available Monday through Friday, from 9 a.m. to 9 p.m. EDT, and 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.*
First elected in 1996, Senator Susan Collins (R-Maine) has earned a national reputation as an effective legislator who works across party lines to seek consensus on our nation’s most important issues. She has had a long-standing interest in health care. As Senate co-chair of the Congressional Task Force on Alzheimer’s Disease, she has worked to increase funding for Alzheimer’s research and to strengthen support for family caregivers. AFA recently caught up with Sen. Collins, prior to Congress’ summer recess, to discuss her advocacy, the current state of funding for research and caregiver supports, and how people can get involved.

AFA Care Quarterly: You have been such a champion for Alzheimer’s disease. Do you have a personal connection to the disease?

Sen. Collins: Like many families who have experienced the pain of Alzheimer’s, I know there is no more helpless feeling than to watch the progression of this horrible disease. I lost my grandfather and two uncles to Alzheimer’s. It is an agonizing experience to greet a loved one, only to receive a blank stare in return. It is equally painful to witness the emotional, physical, and financial hardships suffered by family caregivers, who are often exhausted by endless days.

My commitment to combatting this devastating disease stems from my desire to help not only the more than 5 million Americans currently living with Alzheimer’s, but also their families and loved ones.

AFA Care Quarterly: Can you please share a bit about your chairmanship of the Senate Aging Committee and your leadership of the Bipartisan Congressional Task Force on Alzheimer’s Disease? What motivated you to get involved?

Sen. Collins: When President Reagan designated November as National Alzheimer’s Disease Awareness Month in 1983—a disease from which he would later suffer—fewer than 2 million Americans had Alzheimer’s. Today, based on projections, as many as 16 million Americans over the age of 65 will have Alzheimer’s by 2050. That means if we are to prevent this from being the defining disease of the next generation, we must dramatically increase our investment in research to identify better treatments, a means of prevention, and ultimately, even a cure.
More than a decade ago, I organized the Bipartisan Congressional Task Force on Alzheimer’s Disease to raise awareness, and generate support for greater research funding, for this disease. And I’m proud that, as Chairman of the Senate Special Committee on Aging and a senior member of the Senate Appropriations Committee, I was able to help lead the effort to successfully secure the largest increase in research funding in history.

**AFA Care Quarterly:** You’ve sponsored several pieces of legislation to support funding for Alzheimer’s research and supportive services for caregivers. Can you share your vision as to how the federal government can do more to help support people living with dementia and their family caregivers?

**Sen. Collins:** Quite simply, the federal government must do more because, in addition to the human suffering, the increasing number of people diagnosed with Alzheimer’s has dire implications for our federal budget. The U.S. currently spends more than $236 billion per year, including $160 billion in costs to Medicare and Medicaid, making Alzheimer’s our nation’s costliest disease.

There is promising research that holds hope for people with Alzheimer’s disease and their families. The research community is making great strides through clinical trials with new therapeutic targets. That is why I am so committed to continue working to provide adequate funding to advance this research.

**AFA Care Quarterly:** What can family and professional caregivers of people with Alzheimer’s do to help further the mission of increasing funding for Alzheimer’s research and caregiver supports?

**Sen. Collins:** The family and professional caregivers of people with Alzheimer’s already make great personal and financial sacrifices to ensure that their loved ones have the care they need. We need to do all we can to support them.

I’m pleased that the Senate has passed bipartisan legislation that I introduced, along with Sen. Tammy Baldwin (D-Wis.), to require the Department of Health and Human Services to develop a national strategy to recognize and support our more than 40 million family caregivers. Our legislation is called the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act. I urge each and every one of you to contact your representative in the House and ask them to pass this important legislation.

By supporting our family caregivers, we can assist more people with Alzheimer’s to live at home, where they want to be, helping to delay or prevent costlier institutional care, and unnecessary hospitalizations.
More than 22 million living American men and women or about 7 percent of the population have served our nation in the armed forces. About 10 percent of veterans are women, and this number will increase in the next decade. The U.S. Department of Veterans Affairs, commonly referred to as the VA, was established at the end of the civil war to fulfill President Lincoln’s promise: “to care for him who shall have borne the battle, and for his widow and his orphan.” The system now consists of 1,700 clinics and hospitals across America. Published data suggests that over a half million veterans are living with dementia.

Seven million Americans served during Vietnam and more than two million in Operations Enduring Freedom and Iraqi Freedom (OEF/OIF). In contrast, fewer than one million World War II veterans remain with us. The 18-year-old draftee who fought in Vietnam in 1968, and the 40-year-old sergeant who fought in Operation Desert Storm in 1991, are now over 65 years of age. The Vietnam-era veterans are the single largest group of future VA care recipients, as the aging World War II and Korean conflict veterans have died in greater numbers during the last decade. Most American veterans are over age 55 which is beginning of the at-risk age group for developing dementia. Almost half of all OEF/OIF service members will have more than one deployment overseas and almost half are parents worried about fighting a war and assuring the welfare of their children at home. The intense tempo of today’s military service may exceed the stresses of service members in previous wars.

The majority of veterans who serve in combat theatres return from war and resume their previous lives with few difficulties. VA data shows that they are more likely to achieve success in their professional civilian lives than those who did not serve. Some veterans return with a mixture of physical and mental health injuries that may impact their lives for years or decades.

Understanding Memory Health in Veterans
By Richard E. Powers, M.D.
America’s veterans have unique life experiences and personal attributes that may both provide protection from, and risk for, dementia. Military service requires certain baseline physical and mental abilities that separate those who qualify for service from the general population. Most veterans remain physically active and socially connected after discharge. In addition, military service emphasizes learning and supports preventive healthcare. These features are thought to be memory-protective.

For example, about 400,000 American female veterans are over the age of 65 and this group exhibits many protective factors for memory function such as higher educational or professional achievement and higher lifetime intellectual achievement than women who did not serve. However, recent studies suggest that older female veterans had a more aggressive intellectual decline when memory problems developed as compared to women who are not veterans. Combat duties may carry burdens that increase long-term risk factors for dementia, including post-traumatic stress disorder (PTSD), depression, traumatic brain injury (TBI), long-term treatment with benzodiazepine medications, and exposure to environmental hazards.

Current studies suggest that our nation’s aging veterans may have a small, but increased, lifetime risk for developing dementia in later life. Memory and concentration complaints are not limited to older veterans. Some young veterans returning from war may also exhibit problems with concentration, memory and attention that first may be noticed by the veteran’s family. These difficulties may mislead the family to believe that the veteran is not attentive or engaged with family life. In fact, these individuals may have PTSD, depression or be suffering the consequences of TBI—all of which can mimic symptoms of dementia.

Post-Traumatic Stress Disorder (PTSD)

PTSD is a stress-induced mental illness that produces intense anxiety with hypervigilance as well as nightmares, flashbacks and negative alterations of mood or cognition. Flashbacks may include re-experiencing traumatic events such as car wrecks or explosions. Individuals affected by PTSD often seem distant and preoccupied with possible threats to their family or themselves. PTSD is common in combat veterans and probably impacts about 15 percent of returning combatants. PTSD is also common in the civilian world for first responders and individuals who have survived a near catastrophic event, such as a car accident, physical violence or natural disaster, like an earthquake. PTSD can cause problems with working memory, concentration and a wide range of other intellectual functions; however, these symptoms are different from dementia.

In a young soldier with PTSD, its symptoms may manifest as difficulties with school or work-related
learning, and he may worry that he has some kind of memory disorder, like dementia. If untreated, these symptoms can often persist through life. Older Vietnam veterans may worry that their lifetime of poor concentration is a sign they will develop dementia, especially if they have a family history of Alzheimer’s disease or witness friends develop the illness.

Many veterans who have PTSD also develop sleep apnea, which further worsens memory and concentration. Sleep apnea includes periods of slow breathing or breathing cessation, during sleep, causing the veteran to awaken to the point where his sleep is disturbed. Veterans will not remember the awakenings but they will report that they are fatigued in the morning and often describe a “foggy concentration.” Proper diagnosis of sleep disorders is important because specific treatments, like using a continuous positive air pressure (CPAP) machine, may improve symptoms and quality of life.

Some older veterans—about one in 10—will experience PTSD symptoms later in life and this delayed onset can cause alarm as the individual develops nightmares, anxiety and memory problems. Delayed symptoms often occur after retirement from work. Some individuals with both PTSD and dementia may have worsening of the PTSD symptoms as they lose their coping skills. Caregivers of these individuals may report greater challenges with the veteran’s behavior and feel a greater sense of caregiver burden than other caregivers. Non-verbal patients with PTSD and dementia cannot explain their symptoms and may exhibit agitation or restiveness. Caregivers can take steps to reduce noise, avoid approaching the individual from behind, and refrain from exposing the individual to environmental cues like scenes of combat or violence on television.

In addition to PTSD, many returning veterans develop depression as a consequence of combat service. Although this condition is less-recognized than PTSD, if untreated, it can create significant difficulties for the veteran. Individuals with depression also may complain of intellectual problems such as poor concentration or memory. Depression and PTSD often occur together and both can be successfully treated with psychological care and antidepressant medications that help increase brain chemicals, such as serotonin or norepinephrine.

Brain imaging studies in patients with PTSD show reduction of brain volume in the hippocampus, which is the brain region that is damaged early in Alzheimer’s disease and mild cognitive impairment (MCI). The hippocampus is the brain’s “save button” and hippocampal malfunction can reduce our ability to retain new information without erasing old information stored elsewhere. Persons with PTSD do not develop the brain pathology of Alzheimer’s disease—plaques or neurofibrillary tangles—unless they also have dementia. The human hippocampus contains a high density of stress-related steroid receptors as well as an abundance of serotonin and norepinephrine. Excess stress hormone secretion, as seen in PTSD, may impact this brain region and contribute to memory complaints. Likewise, the reduction of brain serotonin and norepinephrine that causes depression may contribute to memory complaints that are common to depressed individuals. Other brain regions, such as the frontal lobe, which manages emotions, may be altered in both PTSD and depression. New research reports that aging individuals with chronic PTSD may be at greater risk for developing dementia. Older persons with PTSD have greater risks for complications of heart disease and diabetes—recognized risk factors for dementia—as well as several other age-related disorders.

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In the past, many older individuals with depression or PTSD were treated with anti-anxiety medications called benzodiazepines, such as alprazolam or diazepam. Chronic use of these medications has now been associated with greater risk for developing dementia. Selective serotonin reuptake inhibitors, on the other hand, are the current recommended medications for depression or PTSD and are not associated with an increased risk for dementia.

**Traumatic Brain Injury (TBI)**

Many persons who served in Vietnam or the Gulf Wars experienced head trauma, often referred to as traumatic brain injury or TBI. Though the number of Vietnam veterans who experienced TBI is unknown, we do know that mild TBI occurred in some 300,000 OEF/OIF service members. Vietnam veterans did not receive the systematic evaluation and treatment of mild TBI as today’s soldiers do. Falls, blows and explosive devices, such as land mines, incoming artillery rounds or improvised explosive devices (IEDs), can all cause TBIs. TBI, of any severity, may worsen the risk for depression and PTSD. In addition, brain trauma is a known risk factor for dementia.

Risk factors for dementia following TBI include older age, carrying the APOE4 gene, and more severe and more numerous TBIs. More than half of OEF/OIF veterans with TBI have multiple blast episodes. Individuals with severe TBI may experience immediate loss of intellectual function following the injury, though the chronic damage from repeated trauma may not become apparent until decades later, usually after age 65. The individual’s increased risk of developing dementia following head trauma is quite small; however, repeated traumas such as that experienced by boxers or professional football players will increase this risk.

Veterans are often exposed to unique environmental hazards during military service. Agent Orange, a chemical defoliant used widely in Vietnam may be a risk for Parkinson’s disease, but its relationship with dementia is unclear. Gulf War veterans were exposed to a range of toxic substances in the combat environment. About one quarter of Americans who served in Operations Desert Shield or Storm, in 1991, complain of chronic health problems and difficulties with memory. The impact of Gulf War Illness on the risk for dementia in later life is unknown.

When it comes to treatment, some older veterans may report a reluctance to seek care from the VA, due to problems that occurred 30 or 40 years ago. And recent news stories about VA shortcomings can reinforce that perception. The VA is divided into three organizations, one that delivers health care; one that manages benefits, such as disability determinations; and one that manages the care of deceased veterans. Today’s VA provides some of the best medical care in our nation, in particular, to older individuals who have complex needs and reside at home. What’s more, VA healthcare professionals have an unique understanding of the military experience.

Frequently, the public confuses problems in the VA benefits system or its procedures with the quality of its health care services. All veterans should be encouraged to determine if they are eligible for VA healthcare services and consider utilizing them. At time of military discharge, each Veteran should have received a DD–214 form that details their service (duplicates may be requested). Most VA hospitals have the medical and psychiatric resources to provide integrated care to an older Vietnam veteran living with PTSD, dementia and multiple medical problems through services such as outpatient care, telemedicine or home-based primary care teams. In addition,
every VA hospital should offer specialized medical, mental health and rehabilitative services to all veterans who have PTSD, TBI or other injuries that occurred during service to their nation.

In conclusion, published data suggests that aging combat veterans may have more risk factors for dementia in later life than those who did not serve in the armed forces. The risk profile includes PTSD, depression, medications used to treat PTSD, TBI, and environmental hazards associated with military service. However, the increased risk is small and most combat veterans live their entire life with intact intellectual function.

By the year 2020, the VA system may struggle with a surging number of Vietnam veterans as these Americans age and develop dementia. Many Vietnam veterans came home, in the 1960s, to a country that ignored their sacrifice and devotion to our nation. The aging of our nation’s Vietnam veterans provides Americans with a last opportunity in the 21st century to express our gratitude to a group of men and women, who may not have received the thanks they had earned, by providing them with the services that they deserve in the last years of their lives.

Dr. Powers is a psychiatrist and neuropathologist, and a member of the AFA’s medical and scientific advisory board. He previously practiced in the VA Health Care system as a geriatric psychiatrist and the director of a PTSD clinical team. He served in the U.S. Army from 1977 to 1980, and currently practices in the University of Alabama Memory Disorders Clinic in Birmingham, Ala.

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The opinions expressed in this article are the author’s and do not reflect the views of the Veteran’s Administration or any other organization.
A TEENS PERSPECTIVE

Daddy’s Girl
by Tania Bridges

Age 10 - Daddy diagnosed with Dementia.
Age 11 - Daddy's Dementia had progressed to Alzheimer’s disease.
He no longer knew who I was.
Age 14 - Daddy passed away.

When he was first diagnosed, I had difficulty understanding what was actually happening. The only explanation Mom could give was, “he will slowly start to forget everything.” I was completely lost. How does a 10-year-old comprehend that every single memory she shares with her father, the most important man in her life, will no longer be remembered? His memory of her and the sweetness of their time would
It all happened so fast. Overnight. It seems that I woke up one day, and he was no longer able to feed himself, walk or talk. What was once a robust 6’2, 180-pound tennis guru had become a small individual, confined to a wheelchair, absent of life. The look in his eyes was as blank as a sheet of paper. Mentally, he was absent. I quickly understood that he had no idea who I was, but I often wondered if he had any recollection of my identity. I felt quite helpless. There was nothing I could do, nothing I could say, no prayer that I could pray to make it go away. Yet, I was expected to be “okay” with what was happening with him and “understand.” But I couldn’t. I was 13 years old.

I was entering high school. I had just joined the basketball team. All the while, Daddy was dying. I wanted to share with my friends, but I couldn’t. It was too much for me to process. I had my own questions, and I did not have the desire to answer their questions. I knew they would be supportive, but I just could not bring myself to answer questions that I, myself, didn’t have answers to. Was it hereditary? How do you accept having a disease that is incurable? What was his first thought when being diagnosed? When he was informed of his diagnosis, did he ever look at me and get sad because he knew that one day he would not be able to share in life with me? There were, and still remain, so many unanswered questions.

One day, while in the family room, we were playing pool and he said, “Be right back. I have to use the bathroom.” Daddy reached the top of the stairs, turned, looked at me, and said, “Wait... what was I about to do again?” It was then, in that moment, that I knew it was true. Mom was right. Memory could be erased just like the sand pixels when shaking an Etch-A-Sketch.

But couldn’t. I was 13 years old.

I don’t recall the day Daddy died. I did not attend the funeral service. I don’t quite know why, but I suppose it was for the best. My father died a slow, painful, unwarranted death. Part of me was relieved when he finally transitioned, because although it all happened within a short amount of time, the end of his life was no indication of who he was, what he believed,
Alzheimer’s is a very real disease. It is often overlooked and seen as an “old person’s disease.” It is often misconstrued and misinterpreted. The disease affects everyone in ways that are unimaginable, and as a child, my father confined to a wheelchair absent of life, is not the picture most favored. The little girl that I was did not have a professional to help me process this “new normal.” My family and I discovered that there were many support groups for spouses and for their adult children, but there were not many resources for adolescents whose parents struggle with this disease.

It is because of this absence in my community that I desire to start a nonprofit organization for adolescent children whose parents are suffering from Dementia/Alzheimer’s. I want my organization to provide mentorship, counseling, and create a safe, fun and loving environment for children who are journeying the road of my reality. I desire that my organization is considered a “vacation from their reality.”

“I want my organization to provide mentorship, counseling, and create a safe, fun and loving environment for children who are journeying the road of my reality.”

My father’s rapid decline and eventual death motivates me in ways that I rarely discuss. The innocence that I once had was lost by no fault of my own. The average issues of a 12-year-old, such as who said what about whom, boy crushes, going to the local hangout after school and sharing Hot Cheetos and Slushies with friends, stewing over potential dates for the Homecoming dance, and searching for the best dress for the winter formal were not a priority of mine. Yet, while my innocence was shattered, Daddy’s death taught me that my youth remained. I had to live life differently. I had to learn how to have fun in spite of my pain. I had to move forward, progress, and make the best lemonade out of this crappy bag of lemons. In the name and memory of my father, I found a new sense of strength, wisdom, and faith.

I woke up one morning, and as I passed his picture on the nightstand, I realized that the drama between friends at school, the mistakes made during basketball practice, the latest videos on SnapChat or the worst photos uploaded to Facebook were not “end-of-the-world” moments. Each moment was one to be enjoyed, lessons were to be learned, wisdom was to be shared, and love was to be expressed. My father seized each day, and I learned that I owed it to him, to me, and to all those whose lives I would impact in my future to seize each day and savor every moment. Daddy’s last days...
taught me that time is borrowed and will expire without notice or consequence.

The passing of my father has not only strengthened me, but it has strengthened my entire family. My mother, two sisters, and I depend on each other in a way that we never have before. We communicate, share perspectives, and love on one another a lot more than we ever have.

We share values of truth that are real, we understand the true measure of time, and we interact with one another in a way that if Daddy were still here, we might easily take for granted. We engage in greater acts of community service—together—because my father’s sickness taught us that everyone—regardless of race, socio-economic status, or privilege—is battling and fighting their way through life in some form or fashion. We have a much stronger desire to serve others, and we choose to serve together.

I want to accomplish as much as I can with the time that I am given on Earth. I work hard to excel academically, as well as in any acts of service and my extracurricular activities. I work hard to create positive memories for myself and others. My desire is to attend college, achieve success, and serve youth by way of my future foundation. These aspirations are my mission. Why? Because I realize, perhaps more than others, that life is short—and sometimes, memories are even shorter. Thanks Daddy!

Tania Bridges, 18, of Moreno Valley, Calif., is one of two grand prize winners in the 2016 Alzheimer’s Foundation of America Teens for Alzheimer’s Awareness college scholarship competition. This column is the essay she wrote for the competition. Bridges’ father, Tyrone Bridges, was diagnosed with Alzheimer’s disease around age 50. This fall, Bridges will attend Howard University, where she will major in business management.
When I was 16 years old, I decided to apply for a job as a dietary aide at an Alzheimer’s special care center. As I began to work and get to know the residents, I decided that I wanted to give more to the community than just a few meals. So, the day I turned 17, I enrolled in a class to receive my certification to be a nursing aide. I completed my clinical in an intensive dementia care unit, where I was exposed to the true tragedy of the disease.

I met residents who couldn’t sleep at night because they didn’t know where their parents were, and why they were left at “this place.” I met others who would pace back and forth through the locked down hallway as if they had some purpose, or a meeting they had to attend. I met a few that wouldn’t even talk to me at first, lying in bed all day pretending either I didn’t exist, or they didn’t exist. Some patients would not get up in the morning, refusing care, and stay there all day and all night until they decided that taking a few steps out of bed was worth it. Overall, the unit was small, sad, and quiet.

When I finished my clinical, I realized that being a caregiver was going to take a lot more than...
just giving basic physical needs to the patients. I would be capable of making a difference in the remaining time of someone’s life. As I finished my class and moved on to the care center, I took a personal interest in my residents, and I also became very familiar with the disease itself.

Alzheimer’s encroaches on one’s most precious memories, such as the name of your grandchild, or the knowledge that one’s husband has passed away. Then, it steals one’s personality, as a state of confusion grasps and molds it into something of bitterness and sadness. Many of my residents experience depression and anger, justifiably so. Not only is the person robbed of their memory but the ability to do everyday tasks and basic functions is lost as well. This is perhaps the most tolling on the resident. Yes, I’m talking about the lady who is always cold, but can’t figure out how to put her arms through the sleeves of her warmest sweater. Or the patient who tries to speak and communicate with you, but words are seldom formed and nothing comes from her mouth but incomprehensible parts of speech. The worst part about that is that she doesn’t even realize that I can’t understand her, so it’s unimaginable to understand how she feels when no one answers her questions. Another example might be about a movement we take for granted, such as walking. Many higher level patients may forget that they are incapable of walking, and they fall, often causing serious or even fatal injuries. I have discovered in my journey working with people with this disease that Alzheimer’s strips away everything that is important mentally and physically. It strips people of their independence. It takes away all that one holds close to their heart. No more walks in the park with your husband. No more going out to dinner with your kids to hear about their job and their kids. No more reading your favorite book. No more writing to your best friend who is in another care center. No more of so many things that you used to do.

In the midst of all of this struggle and pain however, I believe that light can shine through the cracks of even the darkest room. This is where my job rises in importance. Yes, I do believe that Alzheimer’s disease is very tragic, but what many do not understand is that even in a place filled with disease, depression and confusion; I have never felt a larger presence of life, hope, and love.

When I talk about life, hope and love, I’m talking about the kind of life I see as a resident laughs and sings along to an old Frank Sinatra Christmas tune. Or the type of hope I see them experience as their grandchild reaches for their fragile, worn hands during a visit. And finally, I’m talking about the love that is shared between a resident and caregiver when I hug and comfort a woman who just remembered that her husband passed away years ago. As I attended the funeral of one of my patients, I learned that he was a decorated soldier, and a loving husband and grandfather to many beautiful children. I also learned that he loved cars and barbecuing. Although I hadn’t known anything about his background before, I knew that he was a kind, wonderful man, with Alzheimer’s disease and without. Alzheimer’s disease can strip away as much of a person as it wants, but it can never strip away the human instinct to laugh, smile, comfort, cry, and most
importantly, to love. So as I sneak an extra cookie to the “grumpy old man” who sits and sleeps for most of the day, as I blast loud music while dancing and giggling with the lady who refuses to get out of bed half the time, and as I say “goodnight, I love you!” to the mournful woman who always wants to see her parents again, I, as their caregiver, begin to feel like part of their loving circle of family.

In my job, I spend a great deal of time with the residents. I am the friend that tells them that they are important, and that so many people care about them. I am the friend that makes sure that they feel safe and loved. And some of the time, I am the friend that says “Goodnight, I love you very much,” as I sit with them through their last night and their final breath.

Alzheimer’s disease is complex and full of loose ends that are currently trying to be tied together by doctors and scientists. A cure is hopefully in our future. However, finding a cure is not the only thing that is important with this disease. As a primary caregiver for so many people with Alzheimer’s disease, I feel like it is crucial that I share what I personally think is something just as important: just because patients with this disease forget, does not mean they can ever be forgotten. With this disease or not, these people are still full of life! They have so much to give to us, and I have seen miracles happen. I have seen people recover from hospice when no one thought they would. I have seen a lady who hasn’t spoken in years say full sentences. And I have seen people who are on their death-bed smile and laugh one more time with their families or with us caregivers. Those special moments I have shared with my residents are some of the most special I have spent with anyone. As Karl Menninger once said, “Love cures people—both the ones who give it and the ones who receive it.” As I go on to college to pursue my pre-med degree in neuroscience, I do it in memory of the ones I have lost, and in acknowledgment of those in the care center who have changed my life forever.

*All names and room numbers have been adjusted to protect the privacy of the residents.

Nearly five years ago I was introduced to a completely new way of living my daily life. Before my freshman year of high school began, my grandmother, then newly diagnosed with Alzheimer’s, moved into my house to live the remainder of her life and disease with my family and me. It was the beginning of a new experience for my family, and one that we are still learning and growing from today.

My grandmother, Joyce Bowden, has always been a dominant aspect of my life. When I was younger, she lived less than five minutes from my house. I remember my sisters and I spending almost every weekend with her. We baked cookies, played games like Dominoes and Skip-O, and performed concerts for her on her keyboard and karaoke machine. My grandma’s house was where I learned to ride a bike and buried my first dog. Throughout my childhood, she grew to become my closest friend.

Even before she was diagnosed, my grandmother played an enormous role in shaping me to be the person I am today. As I grew older, she became my confidant and source of wisdom when I was going through a rough time. She was always there for me when I needed her and was the person I trusted most. This bond that we shared, however, made the change even more drastic the day my parents brought my grandmother’s belongings to our house and moved her into my sister’s old bedroom.

The first year of my grandmother living with us was very hard for me. I went through a phase of denial where I did not want to accept the idea that I was going to have to watch the day-by-day progression of my grandma losing her mobility and memory to this disease. Instead of taking advantage of being with her every day while she was still herself, I chose to turn my anger at the disease on her and ignored her completely. I refused to take any part in helping my parents take care of her and rarely spoke to her. It was not until the following year, when her condition had worsened to the point that she could no longer recall who I was, that I realized my error. I had made the mistake of not being there for her as she had been for me every day of my life. To this day, I still consider how I handled the situation at the beginning to be one of the greatest regrets of my life.

Although I regret what I have done, I am also aware of the fact that the process of accepting her illness and admitting my mistakes allowed me to develop as a person. Once I came to terms with my wrongdoings of that first year, I completely changed my perspective and behavior towards her disease. I took responsibility for my actions and used the experience as a way to learn how to handle difficult situations in a more mature manner. I also developed a greater appreciation for the time I have been allotted with my grandma, and strive to take advantage of every moment I now have with her. In the years following my initial reaction, I have dedicated myself to participate as much as possible in my family’s efforts to make her as healthy, happy and comfortable as possible while she suffers from this awful disease.

Becoming active in taking care of my grandma has influenced my life greatly. I have witnessed my grandma gradually forget how to do basic everyday tasks that we often take for granted like walking, driving, eating, bathing, and even using the restroom. My family and I have had to learn how to do all of these tasks for her, not only because without us she would be unable to function, but also because if the roles were reversed, she would do the same for us. My grandmother, a once independent and strong-willed woman, now depends on me to do things for her like feed and dress her. Her dependency on me has forced me to grow above the maturity level of what is typically expected of someone my age. Because of Alzheimer’s disease, I have had to learn the responsibilities of taking care of someone else before I have even had the chance to begin taking care of myself.

It has been five years since my grandmother has moved in with us and by now she has lost nearly all recollection of who I am. She can no longer look at...
me and put a name to my face. Every day when I get home from work or school she asks me “Where am I?” or “Who are you?” I look forward to the rare, brief moments where she is almost certain I am even related to her. It has truly been a heartbreaking process to see my best friend change into someone who views me as a stranger. Despite all of this, I know her unconditional love for me is still there, even if she cannot always express it. This phase of my life has helped me learn to be grateful and appreciate what I have and might have otherwise taken for granted.

One incident, in particular, has had a great impact on my life. It was a beautiful day one afternoon and my family and neighbors decided to enjoy the weather by having lunch together outside. I was alone in the house with my grandma, preparing her meal before taking her outside to join the rest of our family. As she sat in her wheelchair waiting for me to finish her sandwich, she began to get agitated that she was not outside with everyone else. Although I was speaking to her the entire time, attempting to console her, I failed to see that she had begun to try and lift herself out of her wheelchair. In a split second, she went crashing to the floor and I heard the crack of her head on our floor. I saw my grandma’s split open head and my world went into slow motion as I called for help. Everyone rushed in and I will never forget how they handled the situation. The different families, who lived on my street, found their own way to aid in the situation. Some left to grab as many medical supplies as they could from their house, while others offered transportation to the nearest hospital. One woman in particular held onto my dazed grandmother’s hand and began conversing with her to keep her from panicking. I have never felt closer or more touched by my community than when coping with them through this horrific incident.

The financial strain of this process has also caused me to realize the diligence of my family. Due to the increasing amount of attention required by my grandmother’s worsening condition, my mom had to quit her job in order to stay home to ensure my grandmother’s well being. This has caused my family of six to now live on the single Houston Firefighter’s income from my father. He now takes on as many overtime opportunities as he possibly can and works hard to keep our family functioning. My other sisters and I have had to also pick up jobs while in school and learn how to manage our money more responsibly in order to help support our family. My extended family has also contributed greatly by providing food, financial support, and their time so that my family and I can continue participating in activities like high school softball, choir, National Honor Society, Key Club, and FFA. I have developed a strong sense of pride in my family and their willingness to help with my grandma affected by Alzheimer’s disease.

Despite the sorrows my family and I have endured from taking care of my grandma, I would not deny taking on the job again if given the choice. Love is often about give and take. Just as my grandma once continuously provided me with love and support during my struggles, I now strive to return the same love and support to her throughout this phase of her life.

By being given the honor to care for her, she has continued to have a profound influence on my life and the development of my character. I have learned the responsibilities of having someone depend on me and have realized how to be grateful for the little things in life. Although the illness has caused many struggles, Alzheimer’s disease has also allowed me to grow closer to my family and community. I do not regret my family taking on the task of caring for my grandma, and instead I have allowed myself to relish and grow in the experience that I am still living through today.

Sarah Bowden, 18, of Tomball, Texas, is the first runner-up in the 2016 AFA Teens for Alzheimer’s Awareness college scholarship competition. She offers this advice to teens caring for a loved one with Alzheimer’s disease: “Cherish every possible moment. Don’t take a single moment for granted even if your loved one is having a bad day. Give it your all!” Bowden will attend Texas A&M University, and major in business administration.

Editor’s Note: Additional runners-up essays are posted at www.youngleadersofafa.org
THE POWER OF GIVING

TIPS FOR COMMUNITY FUNDRAISING

The power of giving—your time, money and energy—is extraordinary. At the Alzheimer’s Foundation of America, we rely on generous support from the community to increase awareness of Alzheimer’s disease and to help fulfill our promise of educating and supporting individuals and families living with Alzheimer’s disease and related illnesses.

Community fundraisers are a fun and easy way to enlist family, friends, and the community to support our cause. From bake sales to dance-a-thons, birthdays and special occasions, fun runs or concerts, the goal is to have fun and raise money together for a cause that is close to your heart.

Here’s how it works:

**TIP 1**

*Pick a Fundraiser.* Do what you love! Think of an activity or event that you enjoy and determine what is required to turn it into a fundraiser.

**TIP 2**

*Tell us about your plans.* We want to hear what you are doing and can help spread the word and provide educational materials and goodies to give your participants. Visit [http://www.alzfdn.org/ContributetoAFA/yourownfundraiser.html](http://www.alzfdn.org/ContributetoAFA/yourownfundraiser.html) to register the event and create a fundraising page that you can share.
Goals are important! Set a specific goal. Not sure where to start? If you are holding a “Laps for Alzheimer’s” fundraiser at your local pool, consider a goal of $5 for each lap you swim. Commit to a specific, minimum number of laps to set your goal. For example, if you plan to swim at least 200 laps during the event, set a goal of $1,000.

Make a plan. Create a budget and be sure to consider any costs involved with the event before getting started. Next, recruit friends, coworkers, and family, secure a date, and find a venue (if needed). Cover all bases to make sure the event is a success.

Be social! Share the fundraiser and why you are hosting it on Facebook. Tweet it out so friends and family can make donations. Keep everyone informed of your progress and how they can help. Send weekly updates on your training or preparations.

Thank, thank, and thank again! Be sure to thank the people who supported you, encouraged you, and inspired you to make a difference. Showering friends with thanks is a great way to make them feel good about their support and contribution.

Here are just a few examples of events inspired by imaginative donors like you:

- **“Donate Your Change” Coin Cans**: Sign up for our change can program. Place the can in your office or business and collect money for AFA.

- **Dance Marathon or a Fun Run**: Charge a registration fee and encourage participants to get sponsors.

- **Sports Tournament**: Form a team—dodgeball, kickball, softball, etc.—and recruit other teams to join. Charge a registration fee to enter the tournament and encourage participants to get sponsors.

- **Hold a Street or Neighborhood Garage Sale**: Rally the neighborhood to join you and make the garage sale THE place to go to get a great deal for a great cause!

- **Celebrate with AFA**: Celebrate birthdays, anniversaries, weddings or other special occasions with the AFA. In lieu of gifts, ask friends to make a donation to the AFA in honor of your special day.

For more information or to receive a copy of our Community Fundraising Kit, contact Tracy Cramer, director of development at tcramer@alzfdn.org or 866-232-8484.
TO YOUR HEALTH

THREE CHEERS FOR CHERRIES
Summer is the (short) season of the cherry. In Europe, the largest cherry crops are produced in Poland, Italy and Spain. In the United States, 70 percent of the cherries come from Washington, Oregon, Idaho, and Utah, and are available May through August. This recipe is inspired by the flavors of sun-kissed Southern Italy.

ITALIAN CHERRY AND RICOTTA CHEESE MUFFINS

MAKES 8 MUFFINS

INGREDIENTS:
1/2-cup part-skim ricotta cheese
1 large egg
1/2-cup low-fat buttermilk
2 teaspoons vanilla extract
2 teaspoons fresh lemon juice
2 Tablespoons unsweetened applesauce
1-cup whole-wheat flour
1/3-cup raw sugar
1-teaspoon baking powder
1/2-teaspoon baking soda
1/8-teaspoon salt
1 cup fresh cherries, pitted and cut in half or
1 cup frozen cherries, pitted and thawed

METHOD:
• Place rack in middle of oven. Preheat oven to 350°. Spray an 8-muffin tin with non-stick cooking spray and set aside.
• In a medium bowl, whisk the ricotta cheese with the egg, beating well. Mix in the buttermilk, vanilla extract, lemon juice, and applesauce until well combined. Set aside.
• In a large bowl, whisk the flour, sugar, baking powder, baking soda and salt. Add the ricotta mixture to the flour mixture. Stir just until combined and then fold in the chopped cherries. Do not over-mix or the muffins’ texture will be hard.
• Evenly scoop batter into muffin cups.
• Place in oven and bake about 25 minutes or until golden brown. Remove from oven and allow to cool.

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

DID YOU KNOW?
• Sour cherries are lower in calories and higher in vitamin C and beta-carotene than sweet cherries. Sour cherries are normally cooked with sugar and used for pies, preserves, and relishes.
• If purchased in good condition and stored in the refrigerator, cherries should last up to a week. They can also be frozen. To freeze, rinse and thoroughly drain cherries, spreading them out in a single layer on a cookie sheet and placing in the freezer overnight. Once the cherries are frozen, transfer them to a heavy plastic bag. The frozen fruit may be kept up to a year.
• One cup of sweet cherries has less than 90 calories and contains 3 grams of fiber, which can aid in digestion and help lower cholesterol and blood sugar. One cup also contains 16 percent of the recommended daily value (RDV) of vitamin C. One cup of sweet cherries also contains 260 mg of potassium, which is important for muscle, heart, kidney, and nerve cell function. In addition, anthocyanins in sweet cherries give the fruit its red color and may help promote heart and brain health.

AFA’s Concepts in Care Educational Conferences Across the Nation!

Chicago, Illinois
September 15, 2016 - Intercontinental Hotel - Miracle Mile

Washington, D.C.
September 29, 2016 - The Whittemore House

Long Island, New York
October 26, 2016 - Melville Marriott Hotel

West Palm Beach, Florida
November 11, 2016 - Hilton West Palm Beach

To find out more information about AFA’s Concepts in Care Conferences call Josie Di Chiara, AFA’s Senior Vice President at 866-232-8484 or jdichiara@algfdn.org