How Alzheimer’s Affected My Life

Meet the winners of AFA’s Teen Scholarship Essay Contest

Loving Care
Caregivers’ Stories from the Heart

Kyra Carbone, grand prize winner in the Alzheimer’s Foundation of America’s Teen Scholarship Essay Competition, with her father.
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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WE WANT TO HEAR FROM YOU!
Send your questions, feedback and comments to info@alzfdn.org.

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“The most important thing in the world is family and love.” – John Wooden

Coach Wooden was right when he uttered those words; family and love are the most important things. It’s especially true for those living with Alzheimer’s disease, who depend greatly on both as resources to get the care they need. Love is what drives spouses, children, parents and siblings from all walks of life to become caregivers for their family member without any formal training. Love is what drives professionals to give everything they have to care for a patient.

Family and love are also what led to AFA’s founding 15 years ago. Our Board Chairman, Bert Brodsky, started this organization 15 years ago because of his love for his mother, who had Alzheimer’s disease, and for those who were caring for a family member as he did. From our programs, services and educational training, it’s at the heart of everything we do here, which is also why it’s the focus of this issue.

Our cover story, which begins on page 10, highlights four teenagers who detailed their experiences with Alzheimer’s disease for AFA’s annual Scholarship Essay contest. From helping a family member through their battle with this disease to providing care to strangers in their time of need, each one is incredibly moving and powerful.

Joe and Peggy Jester share their story about their daughter, Kathy Sanford, who was diagnosed with early on-set Alzheimer’s disease at age 56, and their experiences as caregivers.

Included in this issue is a discussion with actor David Haydn-Jones about his experiences watching his grandmother battle Alzheimer’s when he was growing up as a young boy, and how watching his grandfather, mother and aunts care for her taught him the true meaning of unconditional love. Out of love for others, David is graciously creating his own fundraising program to help support AFA’s services.

We’re so grateful to each of them for sharing their stories and experiences. If you have a story you’d like to share with us for possible publication in a future issue of AFA’s Care Quarterly, please send it to our office at 322 Eighth Avenue, 7th Floor, New York, NY 10001, call us at 866-232-8484 or email me at cfuschillo@alzfdn.org. We’d love to hear it.

Hoping your summer has been an enjoyable one surrounded by family, friends and loved ones.

Take good care,

Charles J. Fuschillo, Jr.
President & CEO
Alzheimer’s Foundation of America
ANSWER: It’s important to recognize that each case of Alzheimer’s disease is unique, just like the individuals who are living with it. That said, there is some general information that may give you a sense of what to expect. When an individual enters the final stage of Alzheimer’s disease, they can experience both physical and mental decline. The individual may lose the ability to speak, comprehend the speech of others, and respond to their environment. There can also be a decline in physical abilities, such as walking, eating, swallowing, and making eye contact, and an ability to perform activities of daily living, including dressing and bathing. In addition, individuals in this stage may become incontinent. Many individuals in this stage cannot be left alone and require round-the-clock care.

Dignity and quality of life are essential for a person in the end stages of Alzheimer’s disease. You may wish to speak to your mother’s physician about current treatment options and care. Additionally, since your mother is in the last stages of this illness you and your family may want to consider whether hospice services are appropriate for her.

The main goals of hospice are to keep an individual as comfortable as possible to preserve a person’s dignity during the dying process. A doctor must certify that a person has a medical reason to be eligible for hospice services. When a person is receiving hospice care, curative treatments are stopped and no extraordinary measures are taken to prolong life (e.g., artificial respiration or feeding). Individuals in hospice have access to a hospice nurse, social worker, clergy person and volunteers to help support them through the process.

If your mother put advance directives in place that indicate her end of life wishes, I would suggest consulting those documents for guidance. If she did not put her wishes in writing, it would be important for your family to come together to revisit conversations that may have taken place and to discuss what she might have elected for herself, if she was able to do so. However, if she designated a specific medical power of attorney or health care proxy, the decision would, ultimately, be up to that individual.
To learn more about hospice services and to identify local providers please visit the National Hospice and Palliative Care Organization (NHPCO) at www.nhpco.org.

A final thought for you: take time to focus on your own needs as a care partner and daughter. This can be a very difficult time emotionally, and there is help to process all that you might be feeling. Take advantage of local support groups to connect with other people in your area who might be experiencing similar situations. You may also wish to contact AFA’s national toll-free helpline to speak to a licensed social worker for guidance and assistance. We are always here for you and your family.

**QUESTION:** I am a new caregiver and my friend told me to call AFA’s helpline. Can you let me know how it could help?

**ANSWER:** Our national toll-free helpline is a free service that gives people across the country access to compassionate, licensed social workers. We understand that some people might feel apprehensive calling, and that’s OK! Our team is experienced and trained to help ease those anxieties and start the process of learning and healing. There is no such thing as a “silly” question. We encourage people to ask whatever they like and will spend as much time as each individual needs.

Among the most common questions from caregivers of newly diagnosed individuals are referrals to community resources and supportive counseling, as well as where to find support groups or respite services, such as home-care and adult day programs.

Other individuals may reach out because they are feeling overwhelmed by their caregiving role and they want to talk with someone outside their circle of family and friends, who can lend an objective and professional perspective on the situation. Still others may want to learn how to help a loved one get diagnosed.

Our national toll-free helpline provides a place for callers to feel supported, think through different situations, and search different options. And because some people may not be comfortable to speaking on the phone, AFA’s social workers also offer support via live online chats, email and Skype.

Think of the helpline as an added care partner in your journey.

**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.
Caring for your child is the first and foremost priority for any parent.

Peggy and Joe Jester of Canal Winchester, Ohio are no different. But they became caregivers of their child in a different sense in 2009, when their daughter, Kathy Sanford, was diagnosed with early on-set Alzheimer’s disease.

“Nothing could prepare us for this,” said Mr. & Mrs. Jester. “But our first reaction was to do everything possible to help our child. So we educated ourselves about the disease as best we could, put one foot in front of the other and moved forward.”

Kathy had always been a very smart and active person. She received two degrees from Ohio State University. Professionally, she spent a decade working in banking as a bank officer and another 13 years in the insurance industry. She spoke publicly at conferences as an expert in her field.

But warning signs started appearing that led Kathy and her parents to think that something just wasn’t right. What began as forgetfulness started to progress further. Memory lapses occurred with increasing frequency. When she transferred to a new department at work, she had difficulty remembering her training and procedures. Tasks and activities which normally came second nature to her started presenting great difficulty.

“The progression was gradual over a period of years; there was no singular moment that set off alarm bells, but it became apparent that something was clearly wrong,” Mr. & Mrs. Jester said.

Concerned about what was going on, Kathy sought medical help. After being examined by several different healthcare professionals, Kathy received her diagnosis. She was just 56 years old. Following her diagnosis, Kathy continued to live on her own, aiding her memory by using post-it notes and writing reminders to herself. But things got worse and the medications prescribed to her in order to slow the disease’s effects were not working.
That’s what led Kathy to sign up for an experimental procedure in 2012 through the Ohio State Neurology Department. The technique, called deep brain stimulation (DBS), utilizes pacemakers implanted on each side of the brain to help improve memory and communication. Like the way cardiac pacemakers work in the heart, the brain pacemaker uses electricity to stimulate portions of the brain.

DBS had been used to help block tremors in Parkinson’s disease patients, but had never before been tried to stave off the effects of Alzheimer’s. According to Ohio State University, Kathy was the first person in the United States to undergo this procedure for Alzheimer’s disease.

“It was experimental and of course we were concerned, but we felt, as did Kathy, that the alternative was doing nothing and watching her continue to deteriorate. That was not an option,” stated Mr. & Mrs. Jester.

The brain pacemaker helped slow the progression of the disease but didn’t ultimately stop it. Her cognitive abilities still continued to deteriorate. Kathy’s parents continued to care for her; Peggy managed all of Kathy’s medications. Joe handled her finances and took her to all of her medical appointments at Ohio State.

This past January, the type of care Kathy required reached a level that could not be sustained in a home setting. Kathy moved to a memory care facility designed by Dr. Douglas Scharre, one of the neurologists who worked with her at the Ohio State Neurology Department. Mr. & Mrs. Jester continue to visit their daughter constantly.

Helping Kathy through her progression has been difficult for the Jesters, but it’s a journey to which they are totally committed and unwavering.

“Seeing how this illness changes your child and watching them succumb to it is painful. It’s a long battle and you can’t take anything personally, no matter what the person says or does. In a way, you feel completely helpless, but you’re not. You never stop helping or caring.”

For family caregivers who are going through a similar experience with a loved one, Mr. & Mrs. Jester offered the following advice:

“Go with the flow, do everything you can and most importantly, keep loving your loved one. Hold their hand, put your arms around them and tell them you love them.”
5 Questions with David Haydn-Jones

Of all the stories actor David Haydn-Jones has told in his career, one of the earliest left a lasting impact on him. His grandmother, Annette Elizabeth White (née Crocker), began showing signs of dementia in her mid-50s, when the names of her three daughters began eluding her. As he watched his grandmother’s illness progress—and her devoted husband and daughters’ painstaking care for her, Haydn-Jones learned the meaning of unconditional love.

Recently, Haydn-Jones reached out to the Alzheimer’s Foundation of America (AFA) wanting to contribute to the cause. He is donating profits from the sales of his <3=LOVE shirt to AFA. The shirt will be sold through WWW.REPRESENT.COM and promoted on David’s social media channels (https://twitter.com/davidhaydnjones and instagram.com/davidhaydnjones).

AFA Care Quarterly: David, first, thank you again for choosing AFA as the beneficiary of your fundraising efforts. How did you come to choose us?

David Haydn-Jones: When I was researching Alzheimer’s organizations, I was impressed by AFA’s four-star Charity Navigator rating, and the fact that more than 85 percent of the money AFA raises is put directly into programs and services. Education and services to help people living with the illness and their families are critical.

AFA CQ: In addition to lapses with names, did your grandmother exhibit any other symptoms consistent with Alzheimer’s disease?

DH-J: One of the scariest symptoms of my Nana’s illness was wandering. When she started showing signs, it was back in the 1980s before cell phones, GPS tracking and the technology available today. Literally, if she would wander out, the family would set out into the woods around her home to look for her.
One instance that sticks out in my mind was a trip to the West Edmonton Mall, which was formerly the largest mall in North America. The place was huge. We literally turned our heads and Nana was gone. Can you imagine trying to find someone with Alzheimer’s in a giant mall, with tons of people, and also what it must have been like for her?

AFA CQ: That must have been scary and stressful for all of you. How did your family support your grandmother during this time?

DH-J: My Grandad, Stuart Hanson White was a World War II veteran and seven years Nana’s junior. He retired early, at the age of 62, because my grandmother needed full-time care. I was still very young at the time, so didn’t fully understand what was happening, but knew Nana was different. My Grandad was completely devoted to her. He would still take her out to dinner, getting her dressed in her Sunday best. As she got to the later stages of the disease, he would bring a full apron with them to the restaurant, and help her eat. One time my mom looked and saw she was eating her napkin. My Grandad gently helped her, and another patron commented to him, “You’re doing God’s work.” It was really something to see the magnitude of his love for her despite the circumstances.

AFA CQ: Did your family have any outside support in coping with the illness or caring for your grandmother?

DH-J: We were fortunate enough that she was in one of the first fully funded studies in 1982, at Duke University, under Dr. Albert Heyman. Just being able to get her into the study was a real boost to the family. Following her death, at the age of 75 in 1986, an autopsy at Duke confirmed the Alzheimer’s plaques that had altered the later years of her life.

AFA CQ: Are there any other memories of your grandmother that you’d like to share?

DH-J: There were definitely moments of lucidity, even as the disease was progressing. When she would read to me—I was probably about five or six years old at the time—it was like everything would come back. Even though she was not good with names at that point, and I could tell that she was becoming more fearful of everything, she was herself when she was reading. She was a very well-educated woman – she had attended Simmons College in Boston, Mass. during The Great Depression and received a degree as a professional librarian—and it was great to see that shining through. Another example was the Christmas before she died—December 1985—she received a Rachmaninoff tape, and when my aunt played it—it was one of her last moments of lucidity and was truly amazing how the music sparked something in her.

David Haydn-Jones has been a professional working actor on stage and screen for the last 15 years. He is currently best known for his recurring role on the hit TV show “Supernatural,” and his holiday movies on the Hallmark Channel.
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 fundraising.alzfdn.org to register the event and create a fundraising page that you can share.
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 AFA. In lieu of gifts, ask friends to make a donation to AFA in honor of your special day.

**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.

For more information, visit fundraising.alzfdn.org or call AFA at 866-232-8484
I was 7 years old when my father was diagnosed with having Early-Onset Alzheimer’s Disease. At the time I didn’t really know what that meant. I only knew that my father was changing and life was not going to be the same.

My mother explained it to me by saying dad might forget things that he normally wouldn’t forget, like Dory from Finding Nemo. Just like Dory, he may repeat himself and not remember what we talked about. There would be many “Dory moments” to come. Just like the famous Disney fish, my dad enjoyed life and relished the company of friends and family. Even if he didn’t always remember who you were or where you were going. Dory and my Dad had a lot in common.

Before all of this started, my father, simply put, had been my hero. He and I had our own private club, and we went on many adventures that included only the two of us. Special adventures where we went to exotic restaurants, like doughnut shops, where we ate chocolate covered doughnuts for breakfast. Or we went to the local Chinese restaurant for my favorite dinner of pot stickers and dim sum. We would spend hours talking and discussing the world’s most important issues. Like how I had done on the spelling test or what we were doing in Brownies.

Dad loved going on walks. This is a fact that any who knew him held to be true. Any time there was a free second, he was quick to suggest “Does anyone want to go on a walk?” It didn’t matter where we were or what time of day it was. I’ve never met anyone else with the same enthusiasm for wandering aimlessly that the two of us have. I guess it’s just one of those father and daughter things.

I vividly remember taking day trips into the city to go to museums. There we would see dinosaur skeletons and tar pits and imagine what the dinosaurs were thinking. We could make up some pretty wild stuff. Afterward we would play on the swings and slides outside the museum. I remember going into the gift shop and my Dad saying I could pick out one of the toy dinosaurs to take home. I picked the biggest one I could find and my Dad didn’t blink an eye as he pulled the cash from his pocket. I still have it today and it always makes me smile.

My most vivid memory and our most frequent activity was spending time on the beach together. We lived across the street from the ocean and we would walk for miles up and down the seashore picking up seashells, making sandcastles, and talking about the creatures of
the sea. Our family dog would swim out to meet
the human surfers and would bodysurf into the
shore with the waves. These are the precious
memories I choose to keep. These are the ones
that keep me in touch with who my father really
was and how much he truly loved me.

But these are not the only memories I have of
my father. There other memories that are much
less fun. Seeing him struggle with everyday
life was hard. Watching him struggle to find a
word or a try to remember something he once
knew. My father evolved into a pale facsimile
of who he had been. One minute he was doing
something with purpose and in the next minute,
he couldn’t remember what it was he was doing.
These are the memories that hurt and cause me
to reflect on my father’s life before Alzheimer’s.

I know that my Dad was smart. He had a PhD in
law, and for a number of years had his own legal
practice. He was a self-taught engineer and he
owned and ran an aerospace company. He just
loved the work he was doing and it showed. To
me the saddest part of the disease was that all
of the things he worked so hard to accomplish
were slowly taken away by something he had
no control over: a simple little disease called
Alzheimer’s. Unfortunately, it’s anything but
simple.

There are a large number of misunderstandings
surrounding Alzheimer’s. Most often I come
across people who are confused by the fact
that my father had Alzheimer’s in his 50s. There
is a big misconception that Alzheimer’s is a
disease that just affects old people. According
to the Alzheimer’s Association, over 200,000
people in the United States have Early-Onset
Alzheimer’s. In my family there are two people
who have it. My cousin Leon’s wife was also
affected when she was in her mid-50’s. What are
the odds that my little family would have two
completely unrelated people that were both
affected? Apparently the odds are higher than
one would think.

My father was lucky enough to respond
exceptionally well to his medications. Before
treatment, my dad had trouble with all sorts of
daily tasks like putting a key in a lock, tying his
shoes, and he couldn’t figure out how to use a
spoon to feed himself. The medications
they prescribed allowed him to regain a lot
of his abilities. And he did quite well for quite
a while and was even able to return to work.
The medications were good but eventually the
positive effects of the medications started to
decrease and his memory declined once again.

As his abilities were declining, I had to learn
some new skills. I now had to do things that I
never thought I would need to do, like holding
his hand in crowd so he wouldn’t get lost, or
being the one that had to look for cars while
we walked across the street, or helping him to
put his jacket on when we went outside. Now,
our roles were reversed. I was happy to help
him even though it was strange to see my dad,
someone who I looked up to, not being able to
do daily tasks by himself.
When the disease progressed to the point that dad could no longer take care of himself, my older sister Robyn took on a lot of responsibility. She managed his finances and found him a place to live where he could be properly supervised. We would go and visit him and take him to dinner. We would seek out restaurants that served his favorite food. Which was pretty much anything Italian and dripping in red sauce. He died at the young age of 59. When we received the call that he had died, it was a shock. I had not known that his condition had drastically changed and that he was having seizures. My brother called and said things weren’t looking good. Within hours he was gone.

So, you might be wondering what exactly I’ve learned from this experience. For one thing I know how fragile and precious life can be, and just how quickly it can change. For me, understanding that has been a gift. Some kids might take their parents for granted. I know differently, and I let my family know that I love them and appreciate them being there. The other positive outcome of this ordeal would be my deep interest in medical science. Because I watched my father struggle with Alzheimer’s and my mother battle cancer, I developed a fascination with watching the medical professionals decide what kind of treatment was the appropriate course. Since then I have poured over research in the subject in hopes of having a better understanding. Today I’m looking to study biochemistry and biotechnology in the hopes of applying it to medicine. Who knows? Maybe one day, I’ll even be able to do some good for the other 200,000 people with Early-Onset Alzheimer’s Disease.

Kyra Carbone, 18, earned the grand prize in AFA’s 2017 Teen Scholarship Essay Contest. A resident of Stoughton, Wisconsin, Kyra plans to study biochemistry and biotechnology at Madison College.
Two weeks into my job I was called into my boss’ office. I knew from the look on her face that she was not happy with me. As I stepped into the office I tried to figure out what I had done wrong. She got right to the point. “You need to stop spending time with the senile residents. They won’t remember who you are tomorrow. They won’t even remember a conversation from five minutes ago.” I asked if it was okay to spend just a little bit of time with them but she cut me off and reprimanded “Do not put your time into patients with Alzheimer’s. Do I make myself clear?” My face flushed red and I felt extremely conflicted. Do I go against my own values and conform to a belief system that ignores the rights of the disadvantaged? Or do I stand by my conviction that no one should be denied the joy of human connection and risk getting fired? At first I really tried to be a good employee and I stopped myself from interacting with the “forbidden” residents. One resident in particular, Salvatore, made this very difficult. I watched Sal wander the halls

I work at a senior citizen residency. The mental health capacities of the residents vary vastly; some are still able to read novels while others are lost in worlds of their own. As an activity leader, it is my duty to entertain the residents and bring smiles to their faces. I love being around these sweet elderly souls and learning about their lives. There are a number of residents who have about a billion great stories to tell and no problem sharing them, while others have a harder time communicating their memories. I try to give a little extra time to the ones who seem to be alone most of the day. It’s hard to watch these residents sit alone at dinner and have no one to talk to all day. After the first day of seeing this, I decided that I could not allow them to disappear because of something that was out of their control. I promised myself that I would get to know these disregarded elders, which proved to be more looked down upon than expected.

WE SANG, WE FLEW

By Mary Chasen

I work at a senior citizen residency. The mental health capacities of the residents vary vastly; some are still able to read novels while others are lost in worlds of their own. As an activity leader, it is my duty to entertain the residents and bring smiles to their faces. I love being around these sweet elderly souls and learning about their lives. There are a number of residents who have about a billion great stories to tell and no problem sharing them, while others have a harder time communicating their memories. I try to give a little extra time to the ones who seem to be alone most of the day. It’s hard to watch these residents sit alone at dinner and have no one to talk to all day. After the first day of seeing this, I decided that I could not allow them to disappear because of something that was out of their control. I promised myself that I would get to know these disregarded elders, which proved to be more looked down upon than expected.
of the one story building, getting increasingly agitated as he was ignored when asking “How do I get upstairs to my wife and kids? They are on the second floor of the house and I cannot find the stairs.” I felt a strong sense of empathy for his confusion and I could not help but respond to his question. “There’s no second floor Sal.” He nodded his head and five minutes later he asked the same question. And five minutes later I answered as I walked him back to his room. In that moment I decided to let my boss’ words become my challenge. Maybe the residents with dementia will not remember who I am tomorrow but I will remember how I treated them today. I set off on a mission to make every resident feel like he or she mattered. Because to me they all did.

My quest began. I snuck into Salvatore’s room one day to chat with him. He was very unaware of who I was or what was going on around him as per usual. I knew Salvatore was Italian, for he had a thick accent. I’m Italian and I study the language in school, so I tried speaking to him in Italian. I asked him if he had seen one of my all time favorite movies “La Vita Bella”. His only response was “I don’t know”. I asked him again expecting the same confused response, however this time he broke out into a song. The main lyrics of the song were “La Vita Bella”, so maybe he thought I was talking about a song. I was in awe of this feeble man’s booming voice. I cheered and clapped for him when he finished, and this was the first time I saw Sal smile. I then played every classic Italian song I could find on my phone, and sang along with him. Sal loved to sing! I did this with him each day, of course in secret so I would not get in trouble, and our favorite song became “Volare, Cantare”. This means “to fly, to sing”. Every time we finished that song I would tell him my name and remind him that he was my very good friend. Weeks passed and one day I got the courage to ask Sal if he knew my name. I knew in reality it would be impossible since he did not even recognize his own children. I asked anyway. I approached Sal and tilted his chin so we could be eye to eye. I said “Sal do you know me?” He looked into my eyes. There was a pause. “You Mary right? And you my friend?” I truly thought I was hallucinating. My eyes filled with tears as I exclaimed “Yes Sal, I am Mary and I am your friend.” That was one of the best moments of my life.

After my experience with Salvatore in the senior residency, I came to value the idea of helping other residents celebrate their memories and the stories of their lives, despite how unrealistic it could seem.

One activity that often helped the residents to calm down and open up was coloring. I noticed the peaceful feeling that would fill the activities room when the residents were coloring and making art. As an artist, I know art and emotional consciousness go hand in hand. Because of the vibrancy I felt from the residents when they told their stories, the idea came to me to create a personalized coloring book for them. I took a specific memory from each one of them, and turned it into a page that they could color in. I sketched outlines of cultural icons they spoke of from their era, images from old song lyrics they enjoyed, and important historical events they lived through and felt connected to. I then copied each
of the pages and compiled one collective coloring book for each of the residents incorporating all the sketches of the memories that they shared with me. Veteran Bob, who suffers from dementia, smiled at me as he colored the famous image of the soldier kissing the woman in Times Square at the end of World War II, and said, “That’s me and Gayle!”, referring to his wife. Rosemary started singing “music music music” as she colored the nickelodeon. Robert talked excitedly about Coney Island as he colored in the boardwalk while Tony fondly reminisced about his old home as he colored the New Rochelle city skyline. As we colored together, I started to realize that we are all looking for connection in one way or another, and sometimes the simple act of listening to those who are disregarded because of age or ability can open a door that may have seemed locked.

I have developed a true appreciation for the value of listening with my heart through my experiences with people who suffer from Alzheimer’s. I have come to understand that there is a need to pay attention to those who have no voice; those who are kept separate or are deemed useless by society. All people, regardless of mental capacity, have a story to tell and a desire to be heard. It is impossible to release the locked memories without the key of connection.

I remain inspired to watch out for the overlooked solutions that seem too easy and to create safe spaces where authentic communication is based in mutual respect, gratitude and sincere interest.

Because of my experiences with Alzheimer’s, I now know my life’s work will be touched by a brushstroke of humility for I have come to understand the blessings of the ability to remember and capacity to interact. If we all took the time to radically listen, to hear the messages held in the eyes, I believe we would come to see that we are more alike than different.

In defying my boss’ orders I discovered a world beyond the veil of dementia. Just because one door closes in the mind does not mean another is not waiting to be opened. When Sal started singing in his native language I saw the sparkle in his eyes and I knew I had to follow him. Not only did we sing, but we also flew.

Mary Chasen, 18, of Babylon, New York, won first runner-up in the AFA 2017 Teen Scholarship Essay Contest. Mary will attend the University of Vermont this fall and major in environmental studies.
The summer before my junior year of high school I began my first job at a nursing home serving food and keeping the residents entertained. I expected this to be a job, a way to make money. What I did not expect was what it would teach me about love.

Before I began working with people with Alzheimer’s and dementia diagnoses, I knew very little about its effects. I knew that older people are at risk and that their memory is affected. My uncle had dementia and was put in a home, but I was too young and too removed from his life to understand the devastating effects it had on him as well as his wife. He went from calling me Sally-Mae as a joke to seriously not knowing my name.

On my first day as an Alzheimer’s Certified Activities Aide, I put in a movie and sat next to a man who seemed very kind. I told him small tidbits about myself, and that I was nervous because it was my first day on the job. He reassured me that I would do great and told me about himself. The conversation was superficial but it went well. He asked me what my name was for a second time, so I told. It did not strike me as strange until the third time, and countless times following. After I had the same conversation with him three times in the half hour, I realized that I was not fully aware of the vast extent of Alzheimer’s.

Slowly but surely I connected with each one of the residents. Getting to know a person with dementia is challenging because a lot of who they are comes from their past experiences, experiences that they may not recall. Family of the residents would fill me in on their lives in the best way they could. I was told about what they enjoyed doing, where they traveled, what they did for a job. On a good day, the residents and I would strike a conversation about their past. I cherish the days that I got to connect with the residents on a more personal level. A usually quiet man told me all about cars and his fifty year employment with General Electric. A man and his wife told me about the years they spent driving an RV cross country, sparked by the Map of America puzzle we were doing together. Another man began to tell me about war, but stopped himself because he found it too horrific to put on another person’s shoulders. I felt like I was chipping away at the story of their lives; hearing their experiences made me appreciate the life I have and have left to live, the love I have left to give.

One of the most profound stories involves a couple that were not allowed to be together, although they were in the same nursing home. She was constantly caring for him at the risk of her own safety, making it dangerous to live together. The couple, both in their nineties, were eventually able to stay together. Once they were reunited, they did not leave each other’s side. They made sure to go to time their days so that they would always be together, from the moment they woke up to the time they went to bed. My fondest memory of the two was when I told them that I had to move her to her own side of the table for dinner so he asked to leave her there because anywhere not next to him was too far. He was constantly struck by her beauty, seventy years later. “Isn’t she the most beautiful woman you’ve ever seen?” was uttered daily. The genuinity of the statement lingers in my mind. Even though neither of them could remember much, they remembered that they loved each other and that they never wanted to be apart. Their love was always there, but it was jumbled by Alzheimer’s. So much had been taken from the two of them, but it left their love for each other unscathed.
I entered their room to her freshly made bed and a black suit laying on his bed for the funeral. He was sitting in a chair, staring at the bed of his late wife. The day after she passed we sat together as he recounted the decades since he met her, the best parts of his life. He told me about how he proposed at eighteen before he went off to war, her favorite flowers and how she was the best thing that ever happened to him. Her death brought him clarity in a world of haze.

The pain of his loss ignited his memory and connected the puzzle, the puzzle of their everlasting love story. They have been together through war and peace, love and loss, and sickness and health. They taught me, a seventeen year old girl, what love is and what love should be. They taught me that being together is what matters, that loving each other through everything and not giving up on each other is what matters in this life.

Love is sitting and eating lunch with your mom on your lunch break, making sure your dad’s coffee is hot and sneaking him extra pie, and calling your sister from across the country because you do not want her think she’s forgotten. It is going to your spouse’s nursing home with the knowledge that they do not know who you are so you can eat lunch together. Love is sitting for hours with your mom, telling her about your day while knowing that she cannot answer you. Love is willingly feeding your spouse their meals when just months ago they played checkers, and always won. Love is sitting in the same room, everyday, all day, just to make sure that your spouse knows they are loved and not forgotten. Love is not giving up on love.

Love is having to make the decision to put your family member in a home because it is in their best interest, not the easiest way out. It is taking care of your husband until you cannot anymore, until you begin to need help yourself.

Love is sitting in the activities room, talking to a seventeen year old girl about your life together and how hard it is to see your husband slowly forget who you are. Marriage is “in sickness and in health” and an Alzheimer’s diagnosis is a true test of the vows people make when they are young and healthy. It is not when it is most convenient, but when it is hard, it is being there for the person you love when they need you most.

The man I sat next to on my very first day did not ever get a visitor, and he was not the only one. I saw people live out their lives by themselves without anybody familiar to comfort them when they were scared. Residents would yell and scream, asking why their family put them there or ask where they were and when they got to leave. Knowing that these people had nobody who cared enough to come visit or call is what made me love my job. I was able to be that person for so many people. I could come into work and greet them as if I had known them my entire life. I would talk to them for hours about nothing and make sure that they were not forgotten. That is what I want to do with my life. I want to make sure that people know that they are not forgotten, that they are special, and that somebody loves them. So many people are so concerned with material possessions, but the only stories I ever heard were love stories. I was never told about the fancy cars or big houses because sitting at the home, nearing the end of their lives, all the residents cared about was who they loved and who loved them. The memories outweighed the things, and that is what is important. I truly believe that while so much of who these people are is being ripped away from them, the love they feel is always there.

Love may not always be present. It is broken into pieces like a puzzle, but when the puzzle pieces connect, nothing is more beautiful. Through thick and thin, love is what matters.

Julia House, 18, was named second runner-up in the AFA 2017 Teen Scholarship Essay Contest. Julia lives in Blackstone, Massachusetts and will be entering a Physician’s Assistant program at Hofstra University this fall.
It was the first time my sister and I were getting the chance to visit our Nana after her diagnosis of dementia. I was only ten years old, but my mom had tried to prepare me for the possibility that she would not recognize me. I entered her hospital room filled with fear and trepidation because my grandma on my dad’s side had died just a year earlier; I did not want to lose this Nana too. During my visit, several doctors and nurses stopped in and for the most part, my grandma appeared to be her same jovial self. She told crazy jokes and even hit on a few of the male doctors. The only thing that was different was she continued to introduce me as her daughter instead of her granddaughter. As I was leaving, I told her that I was her granddaughter. Surprisingly, she chuckled and motioned for me to come close. My Nana whispered in my ear, “I know exactly who you are, but do you think I want these hot, young fellas to think I am old enough to have a granddaughter?” I left the hospital hopeful that dementia would not change the relationship between my grandma and me, but I could not have been more wrong.

The next three years brought about a rapid deterioration of Nana’s memory and overall health; doctors identified my grandma’s dementia more specifically as Alzheimer’s. I found myself making up excuses to avoid going to my grandparents’ house because it saddened me that she could not engage in a conversation without asking my name a half dozen times. What had happened to my Nana? Would she ever return or would I be left to reflect on days past with no hope of creating new, meaningful memories?

One Saturday afternoon, my dad had gone to Nana’s house to replace their kitchen sink. He was nearly done when he slid out from underneath the sink to find my grandma standing above him, armed with a bat, ready to strike like Ken Griffey Jr. with bases loaded. My dad is Mexican, but does not speak any Spanish, so communicating with my Panamanian grandmother was tricky. Something caused dad to find the words, “Soy tú hijo, Manuel.” This stopped Nana in her tracks and immediately she realized my dad was her son-in-law. Incidents like this were happening all too frequently and my parents began to worry that my grandma might become so confused and irritated that she resorted to violence with my sister and me.

In middle school, I began to do research on dementia; I was looking for a way to strengthen my bond with my Nana. I read studies that indicated that food and music could spark brilliant recollections of the past. I was a bit skeptical, but eager to see if grandma could be transported by music. I found her old Julio Iglesias vinyl albums and played them on the record player that I located in the garage. Before long, she was up and swaying to the rhythmic blends and singing in Spanish. It was magical! As I observed the dramatic change in my Nana, I considered other ways to ignite her memories. I began asking each of my uncles and my aunt what they remember about Nana from their childhood. All of them recanted stories of their time in Panama as young children with their mom and the tremendous adventures burned deeply in their minds. That got me thinking that perhaps I should travel to Panama and experience the culture, food, and atmosphere myself.

My family had vacationed in Mexico several times, so we were familiar with that part of our heritage, but we had never visited Panama. At my request, my parents agreed to arrange for a summer vacation in Panama City, Panama. From the moment we arrived in the airport, I sought to memorialize everything through pictures and videos. I created an itinerary for the trip, which included exploring Colón, my grandma’s hometown. We went to the jungle, took a boat tour through the Panama Canal, ate all sorts of local cuisine, and traversed the Bridge of Americas. In my research of Panama, I learned that the Bridge of Americas was built in 1962, just a few years before my Nana came to the United States. It was the connection between the North and South American land masses. As I stood on the bridge looking out over the Panama Canal, the beauty of the place my grandma once called home mesmerized me. In that moment, I felt more connected to her than ever before, and it was not just a blood connection, it was a heart connection. The remainder of the trip, I spent sampling foods like plantains, coconut rice with chickpeas, and peanut butter...
chicken molé. The flight home was bitter sweet, I reflected fondly on all I had seen and experienced, but I realized my grandma would never get the opportunity to return to the country she loved so much.

In the weeks after my trip, I pondered how I could bring Panama to my Nana. Fortunately, her eightieth birthday was just around the corner and the entire family had decided it was the perfect time to plan a reunion focused on Nana. I got busy putting together a scrapbook of mementos from Panama along with pictures that I had taken while there. Additionally, I bought several books that showed Panama then and now. My mom resurrected recipes for all of the foods Nana used to cook when she was growing up. I was a bit nervous that my plan to conjure up memories and emotions in my grandma could backfire, but our relationship had become almost nonexistent; it was worth a try.

August 27th was a swelteringly hot day, but worthy of celebration to commemorate this milestone in my grandma’s life. While I fully understand that there is no known cure for dementia, I was hopeful that my Nana would react favorably to the foods and pictures I gathered from my Panamanian experience.

Everyone was outside enjoying the barbeque and unusually hot weather, but my grandma was inside, so I decided to approach her with a plate of food and the books I had purchased and created for her. She was clearly in a state of confusion as she stared at me. I offered her a few plantains and she slowly nibbled on one, and within minutes, she was grabbing for more and gobbling them down as quickly as she could. I told her we had made her favorites, coconut rice with chickpeas and peanut butter chicken molé. Her disorientation and irritation had subsided and before long, she offered me a seat next to her on the sofa. This was my opportunity to show her the scrapbook I had made from my trip. As she flipped through the book, a twinkle in her eye appeared that I had not seen in years. Nana began talking about her childhood as she recognized different places in the books. The family heard her talking and giggling, so one by one they entered the house as she reminisced and told stories of growing up in Cólon. Tears streamed down their faces as they listened; it was as though Nana had been transported back fifty years and the images she painted were as vivid as if it all happened yesterday. When she got to a picture of the Bridge of Americas, she suddenly stopped. After several minutes, she turned to all of us and said, “This is where my heart is,” and she pointed to the exact spot where I was standing at the time the picture was taken and without missing a beat, she looked at me and said, “Your heart is there too.” It was in that moment that I knew dementia had not taken the love that my Nana and I shared and that our hearts would be forever intertwined. I felt closer to her that day than in the days prior to dementia entering our lives.

I realized that Alzheimer’s could not take my grandma, or our memories together, away from me. I am no longer fearful about spending time with her, I simply accept that some days are better than others, but each day is a blessing. Our relationship did change; it was strengthened because my eyes and heart were opened. Nana and I now have our special, nostalgic dates where we eat many Panamanian foods and flip through our scrapbooks while listening to Julio Iglesias. The Bridge of Americas ultimately helped build the Bridge of Hearts for my Nana and me, a bond that cannot be broken.

Damita Gomez, 17, was named second-runner up in AFA’s 2017 Teen Scholarship Essay Contest. Damita lives in Lakewood, Washington and will be pursuing a degree in biomedical engineering at the University of Washington-Seattle.
TO YOUR HEALTH

If hovering over a hot stovetop is not your idea of fun, this no-cook pea soup is for you! Preparation is a snap – just a few ingredients and no cooking. The soup is protein-packed, light and healthy, vegetarian, and gluten-free.

THE POWER OF PEAS:
• High in protein (4 grams per half-cup serving)
• A source of iron, zinc and vitamin K
• Low in sodium
• High in thiamin, vitamin A, vitamin C, vitamin B6 and dietary fiber
• Low on the glycemic index (beneficial for people with diabetes)
• Low-fat and heart-healthy
• Cholesterol free and high in soluble fiber, which helps to lower cholesterol
• Ecological and sustainable

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

No-Cook Pea Soup

SERVES 4 AS AN APPETIZER OR 3 AS A MAIN DISH

INGREDIENTS (choose organic when available)
2 cups frozen peas, thawed
2 cups low-sodium vegetable broth
2 tablespoons fresh mint, coarsely chopped
4 tablespoons nonfat plain Greek yogurt
Sea salt and freshly ground pepper to taste

METHOD:
• Place all ingredients except yogurt in a blender or food processor and process until smooth.
• Check to make sure the peas at the bottom of the blender bowl are pureed.
• Serve with a dollop of yogurt, if desired, or skip to make it vegan.

This soup can be served hot, cold or at room temperature.

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.
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The Alzheimer’s Foundation of America (AFA) believes that when Alzheimer’s disease or a related illness enters someone’s life, they should have access to professionals who are specifically-trained in dementia care. That is why when you call AFA’s national toll-free helpline, you will speak with a dementia care-trained licensed social worker, who will provide answers to your questions, offer caregiving tips and strategies, and provide referrals to services and support in your area. If someone in your life is living with Alzheimer’s disease or a related illness, call AFA today. We are here as your partner in care.

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