

## Advocacy for Alzheimer's

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Over forty years ago a group of advocates came together to start what is now known as the Alzheimer's Association. They all came from different advocacy backgrounds but they had one thing in common: they were caring for loved ones with Alzheimer's and other dementias and they needed help. They needed answers from the medical community (a common phrase they shared was "diagnosis and adioses"), they wanted support and education for caregivers, research for treatment and a cure, and social insurance for long term care so that they no longer had to live in fear of bankruptcy.

The group was determined. They raised money, met with legislators, testified before Congress. The organization grew and eventually began providing support and educational programs in every state. They fought for research funding dedicated to Alzheimer's at the National Institutes of Health (NIH)<sup>1</sup> and since the passage of the National Alzheimer's Project Act (NAPA) in 2010 that funding has increased more than seven-fold. In 2021 the NIH will likely spend \$3.1 billion for Alzheimer's research.<sup>2</sup>

Because of the Alzheimer's Association we have seen progress in research funding and policy. Unfortunately, the progress isn't always felt at the doorsteps of American families living with the crisis of Alzheimer's. Karlawish<sup>1</sup> shares that in 1990 co-founder Hilda Pridgeon testified before Congress that Alzheimer's was a "national crisis" whose annual bill of \$80-90 billion...is paid for by families." She went on to say "(t)hey are afraid of what will happen to them if they get this disease. They are even more afraid of how their families will cope." Thirty-one years later, Alzheimer's costs the nation \$355 billion annually,<sup>3</sup> much of it still paid for by families. For most patients, definitive diagnostic tests are unavailable, prevention is limited to a healthy lifestyle, there remains no universal treatment, no cure, and families are still struggling to cope.

Families still need support. Many are juggling caregiving with jobs of their own, other family members needing care, and bills that just keep arriving. Many are juggling the stress of not knowing what to do or where to turn and subsequently developing their own health problems. When I didn't know where to turn, I called the Alzheimer's Association and then I became an advocate. There is a lot more ground to cover but when we join our voices together, we can facilitate change. It begins with telling our stories.

### What is Your Story?

My parents, Linda and Ron, dreamed of their retirement years. They planned to travel, bike, and spend time with the grandkids. My mother was a Radiologic Technologist and my father an engineer. Dad was never really sure *when* he would retire, but by the end of 2012, at the age of 61, his brain decided for him.

Dad was overwhelmed at work and began having difficulty concentrating. He couldn't keep things straight and something seemed off with his memory. By June, Dad developed anxiety, something that never afflicted him in the past. It was all too much and so, he retired. But this wasn't the happy moment my parents imagined. Dad's anxiety increased and he plummeted into depression. It was so unlike him that we determined he must be depressed about his retirement.

When Dad saw his primary care physician (PCP) in January 2014, he scored 29/30 on a cognitive test. In October he saw a psychiatrist and was diagnosed with clinical depression. Medication made things worse. By the end of 2014, Dad's cognitive score decreased and he saw a neurologist. She diagnosed him with mild cognitive impairment and recommended biofeedback for his anxiety. A few weeks later, the practice closed down and we were referred to a neuropsychiatrist at Hopkins. For weeks, no one returned our phone calls.

Meanwhile, Dad's PCP began researching neurological issues. It was probably dementia but maybe it was Lyme disease? By summer 2015, Dad was consumed with apathy. He no longer spent time on hobbies and was unable to help Mom around the house. Mom wasn't sleeping well. With every new doctor came a new medication. The transitions were nightmares. At no point did we feel like we had a handle on his disease or any idea how to manage it. The house and the illness became too much. My parents moved to Delaware to be closer to my family.

Once my parents settled in Delaware, I became part of the caregiving team. Dad's aphasia worsened and he struggled to take care of himself. He began to hallucinate. Dad started coming to my house when my mother had appointments or needed respite. Travel to Maryland for appointments consumed him with fear and anxiety but in Sussex County, the waitlist for new patients was too long, so the trips continued.

Dad was a participant in a study at Hopkins and it was finally confirmed: he had Alzheimer's. He wasn't going to get better. His grandchildren would never know his laughter or the way he could turn wood into furniture or inspire others to advocate for the environment. Mom feared that the costs of long term care could leave her with nothing. We avoided it as long as we could. Sleep continued to evade her.

We never connected with a social worker but through the Alzheimer's Association found a support group. A local friend referred us to the Gull House for daytime respite. We never once felt like we knew how to properly care for my father and none of his physicians offered care-planning. Then, in early 2018, Dad had a seizure, became a fall risk, and we had to move him to long term care. It was difficult. Even with our doubts, no one could care for him like we could. And he wanted to come home. He had one aide whom he connected with. She made sure he was bathed and fed. We will forever be grateful to her. We paid \$7,000 per month for his care. She earned \$10 an hour with no benefits.

Mom visited Dad nearly every day. He continued to fall, and stopped eating. The facility was going to recommend we move him but instead, hospice was called in. On May 6, we lost my father for the last time. He was 66. An autopsy confirmed he had high-level Alzheimer's disease and neocortical Lewy body disease.

## **Beatrice's Story**

Around the same time that my father began struggling with work, so did Traci's mother Beatrice. Beatrice was in her early sixties. She was a fashionista who fiercely loved her family, a kind and generous woman. A longtime cashier, Beatrice began forgetting things she said and passwords for the computer. This was all secondary to headaches she suffered from due to meningiomas. Beatrice was a young 64, but realized it was time to retire. A few months later, Beatrice was diagnosed with mild cognitive impairment. Beatrice saw her PCP and a neurologist. She tried some medication. No one told them that Beatrice had dementia, but Traci's research led her to

believe her mom had vascular dementia. No one else in the family had experienced it so Traci didn't really know where to begin.

"It's hard" she said. "You don't know what's coming at you."

One day Beatrice fell at home and hit her head. It was time to move to a one-story home. Losing her house was difficult. Traci's brother helped care for their mother when he wasn't working but mostly, Beatrice spent time at Traci's house and with aides in her home. She was high functioning but couldn't be alone.

"Do you think my mother has dementia?" Traci once asked the neurologist. The answer: "Yes."

After a hospital stay, their family was connected with a social worker who recommended a local day break program at the Modern Maturity Center. There was a caregiver resource center that Traci found helpful. The next few years were dedicated to Beatrice's care. Traci managed her schedule, her aides, her meals, and made sure she was not alone. Medicaid allowed limited hours for the aides, so Traci was grateful to be a stay at home mother and able to juggle it all. But she had health issues of her own, a young daughter, and a husband. It was a lot for one person. Traci was particularly grateful to the aides who went the extra mile for her mom but challenged by those who did not provide quality care.

Eventually, it got to be too much for Traci's family. Traci longed to be the daughter again and not just the caregiver. Her mother's personality had changed and she was having hallucinations. Their social worker agreed that it was time to move Beatrice to long term care. She started in an unrestricted area but was soon moved to memory care. The entire transition was difficult for both Traci and Beatrice. Her mother just wanted to be home.

In March of 2020, Traci was invited in to see her mother before the lockdown was to begin. Beatrice was talking, eating, drinking. After 68 days of isolation, Beatrice became unresponsive. She was admitted to the hospital and soon Traci received a phone call.

"There's been a setback. Your mom has COVID-19."

Traci was asked to sign a DNR. Like so many relatives of long term care facility residents, Traci lost her mother to COVID-19. Beatrice was only 72.

When Traci began this journey, she had no idea how it would impact her and her family.

"I was there for them physically but mentally, I wasn't." She felt isolated. "The disease had a destructive impact." Alzheimer's takes a relentless toll on caregivers. During the pandemic and when Traci lost her mom, she wasn't sure, for a time, who she was. For eight years she was her mother's caregiver and advocate. Who would she be now?

## **Kent's Story**

Nancy's husband Kent was a brilliant biophysicist. He was a researcher who had many patents and a calm demeanor. They moved to Delaware in 2010, and in 2016 Nancy knew something was off. Kent was 68 and struggling to manage finances. His handwriting was different. A friend convinced him to be tested at Hopkins and he was diagnosed with mild cognitive impairment. The following year he was exhibiting Parkinsonian symptoms. He received an MRI, spinal tap, and CAT Scan. Eventually he was diagnosed with Alzheimer's.

Kent the researcher got to work. He read everything he could about the disease. He was determined to find a way out but Kent's research led him to the truth: there is no cure. The idea that he couldn't find the answer was devastating.

"This is going to get really bad. I trust whatever you decide," he said. To his daughter he said, "You'll need to take care of your mom when I'm gone."

Kent's behavior quickly changed. He became frustrated and violent. He couldn't handle losing himself and he likely had frontal temporal dementia. His calm demeanor disappeared. They had a social worker through the neurology department at Hopkins who suggested Nancy join a support group. Nancy was uncomfortable joining for the first time so a friend went with her. Now Nancy does the same for others.

As things got worse, Nancy found adult day care, but once Kent flipped a table in anger he wasn't allowed back. Then Kent decided he wanted to go on a cruise. Against her better judgement, Nancy took him in June 2018. She wanted him to be happy. He walked onto the cruise ship but being out of his familiar environment was rough. He left in a wheelchair.

At home, the anger got worse and Nancy felt it was time for long term care. Her children came to visit and agreed; Nancy could not care for him alone. In November, Kent entered his first long term care facility. He lasted ten days. He was admitted to the local hospital in an effort to find a medication that would calm him down. He was restrained. Nothing helped. Kent was returned to long term care and then sent to a psychiatric hospital in Philadelphia that specialized in geriatrics. Still, nothing worked. Nancy was lost. She couldn't care for him and no facility in Delaware would admit him. What was she supposed to do?

Finally, Nancy found a small group home in Maryland. If Kent came with a full-time aide, he could live there. He lasted three weeks. The stress was unrelenting. And then a nurse practitioner referred them to another group home. It was a small, family-like environment. The staff was consistent. They got to know Kent, learned how to react to his anger in a way that deescalated him. They got to know his family. They prepared food the residents wanted and provided private rooms and bathrooms. It cost no more than a larger facility at \$8,000 per month.

Then, in 2020, COVID-19 found its way into the home. Kent contracted the virus. Nancy and their children sat outside Kent's window offering the comfort of their presence. Kent passed away. Alzheimer's doesn't end any other way.

## **Delaware: Facts and Figures**

According to the Alzheimer's Association, there are over 19,000 Delawareans 65 and older with Alzheimer's. Over 46,000 family caregivers provide \$1.1 billion in unpaid care. It costs the state \$253 million in Medicaid spending. Our hospitals see 1,578 emergency department visits per 1,000 people with dementia.<sup>4</sup> There *are* programs and services available in Delaware but most caregivers will tell you, "I had no idea they existed." And in Sussex County, where one quarter of the population is 65 and older, we have a physician shortage. Statewide, there is a shortage of cognitive neurologists and geriatric psychiatrists.

## **A Path Forward**

Reflecting on the stories I've shared, I see three areas for growth. First, we need more clinicians who can take on new patients, properly diagnose the disease, and provide care planning services.

Kent and Beatrice had social workers to help them, but effective care planning should be in coordination with a physician's office. Medicare billing code 99483<sup>5</sup> covers care planning services but many physicians don't use it. I believe that if we had had a social worker or a care plan we would have had a better handle on my father's care.

Second, a massive training effort is needed. Clinicians must be trained to diagnose, treat, and manage care. Massachusetts requires such training. Medical professionals in emergency departments and psychiatric wards need training to care for individuals with dementia without restraints and harmful medications. Employees at long term care facilities need training on a *regular basis* to provide quality care to residents. Simply knowing how to speak to a person with dementia can be the difference between a hospital admission and a quick de-escalation. Training for caregivers is readily available but difficult to find. A doctor's office, library, and grocery store are all places families are likely to frequent and are all potential sites of training.

Third, something needs to give with long term care. We need options like the group home Nancy found in Maryland. Families should not have to cross state lines for care or live in fear of bankruptcy. Long term care costs \$7,000 to \$15,000 per month in Delaware. Unskilled home care costs \$22-\$25 per hour. But families cannot provide all of the care alone. The wealthy can find a way to pay for it. Those with Medicaid often have coverage for some of it. It can be a financial crisis for families in the middle.

One final note specific to Sussex County: With a growing aging population, more services are needed. Families are forced to commute for doctor's appointments. There is no memory care practice, no geriatric psychiatric facility, and for some rural families, no transportation. Fortunately, in Delaware, one positive result from the pandemic is that Telehealth services are now permanently available.

## **Be an Advocate**

Advocacy can be described as the act of using your experience to raise awareness and influence change. Anyone can be an advocate for families living with Alzheimer's: caregivers, persons with the disease, medical professionals, public health officials. There are three main components to advocacy: share your story, share the facts of the disease, and make an ask. You can share your story on social media, with legislators and medical professionals through phone calls, emails and meetings, even in a letter to the editor of your local newspaper. If there is a hearing before our state legislature, attend, and if you're comfortable, speak. If you want to advocate as part of a group, contact our local Alzheimer's Association.

## **Call to Action**

Alzheimer's is the most expensive disease in America. It often goes undiagnosed, prevention remains limited to a healthy lifestyle, and we still can't universally treat it or cure it. We *have* made progress in the past 40 years. Support and education for caregivers is available but not yet in a way that means caregivers are coping well. Research is well-funded but there is still a lot of ground to cover. Families continue to watch their loved ones deteriorate into a shell of themselves and are desperate for help.

Delaware is a small but mighty state. It's time for public health officials, the medical community, policy makers, and advocates to come together to forge a path forward for families to live with dementia without fear of financial ruin and lack of resources, to provide care planning to families

and training to professionals serving those with Alzheimer's, and to always have a place available to care for someone who can no longer be cared for at home. When we work together, families can get through this disease with a little less trauma and a lot more support. And perhaps our engineers, cashiers, biophysicists, mothers, fathers, spouses, grandparents can hold on to a little more dignity in a disease that, for now, has no happy ending.

## Acknowledgements

The interviewees, Traci and Nancy, were interviewed by me for this article and have given me permission to include their stories. Last names have not been used to protect their privacy.

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