

Testimony of Phyllis Gallagher
Hearing on "The Arc of Alzheimer's: From Preventing Cognitive Decline in
Americans to Assuring Quality Care for those Living with the Disease"

Special Committee on Aging
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Thank you Chairman Collins, Ranking Member Casey and members of the Committee for the opportunity to testify today on the toll of Alzheimer's and other dementias. As a caregiver for my husband John, I hope my story will shed some light on the reality of this cruel disease.

My husband John and I have been happily married since 1993 -- and I do mean happily. John is the nicest, kindest man. We had fun together. Prior to his diagnosis, John was healthy as a horse. He was 6'2" and 260 pounds and went to the gym every day. He ate well, though he is a good Irishman and did enjoy a beer here or there. John worked in the Pennsylvania State Capitol in a job he enjoyed. He was social and was living a full life.

After his father passed away in 2008, I started to notice that John was having a harder time finding his words. As we would later learn, this was the start of our journey with Alzheimer's. John was only 49 years old at the time.

We started with our primary care doctor, who thought John might be suffering from a stroke, or depression and anxiety following his father's death. When John did not get better, we went back to the primary care doctor 6 months later, which was then followed by a visit to a local neurologist. We had no new answers, and months went by as John continued to struggle with his speech and was showing more erratic behaviors. He wasn't himself, he behaved irrationally. John was physically healthy -- it was his brain that wasn't.

After months and months of unanswered questions and new combinations of medications to address the symptoms, John started seeing a psychiatrist. The psychiatrist was the first one to suggest that these symptoms could be

memory-related. I tried to get John in to see a specialist at several facilities in Pennsylvania but each place had a 6-month wait. The Memory and Alzheimer's Treatment Center at Johns Hopkins only had a 3-month wait to see someone, so that's where we went. If there were more trained specialists in this field, we might not have had to wait so long or travel as far to see someone.

After our 3-month wait, John and I made the first of what would be many drives from our home in Frackville, Pennsylvania, to Baltimore, Maryland, for John to have a full neurological work-up at Johns Hopkins. The team at Hopkins wanted to use a PET scan as part of their diagnostic process, but unfortunately, it was not covered by our insurance. After a wave of testing, John was officially diagnosed with Alzheimer's disease.

John retired from his job in March 2012, and we decided to do what we could to help the next person going through this disease. It was extremely important to both of us that we not be complacent--we had to do something. We got involved with our local Alzheimer's Association chapter and walked together in the Walk to End Alzheimer's. John participated in several research projects at Hopkins and in one of them was finally able to get that PET scan. He also decided that he wanted to donate his brain to research after he dies. As John put it, "They might not be able to help me, but what if my girls get it?"

We also decided to live our lives fully while John still could. We went to Ireland for the big "bucket list" trip. We went out a lot with friends. If he wanted to go to lunch at the same place every day, we did. We made regular trips to New York to see his daughter. I did anything to make him happy in the course of this, and we had as much fun as we could.

That does not mean we did not face our share of challenges. As time went on, John always needed supervision. If I needed to take a shower, I would have a neighbor come over to watch him. I would do things around the house at night while he was sleeping. The first time you have to help your spouse in the bathroom is traumatic. People don't tell you about that.

Because of his age, John was not eligible for many programs available to people with Alzheimer's. Many of these programs are only for people over

the age of 60. Or they are aimed at people with physical disabilities; I could get help if he'd lost a limb, but not because he has dementia. If you can't find someone to help you, you're stuck. I was able to get John into an adult day program 2-3 afternoons per week. What a relief that was -- I could go grocery shopping or run other errands without worrying about John.

The difficulty that came with communication was a surprise. When he couldn't find his words or had trouble speaking, we had to communicate through what I came to call the "Charades of the Gallaghers." We had as much fun as we could in such dire circumstances.

After John's diagnosis, we talked a lot about what he wanted as the disease progressed. We talked about the likelihood of John needing to be in a nursing home one day and planned his funeral. I remortgaged our house, hoping to care for him at home as long as I could. We renovated our first floor to include a full bath and laundry room to make the home handicap accessible to anticipate his future needs.

Today, John is now in a nursing home. Medicaid helps to cover the cost, but I still pay \$1,850 out of pocket each month. That means that I don't go out unless a friend can pay for me. I work with a limited grocery budget, and I rarely can afford to go to the movies. I participate in activities that don't cost money so that the resources I do have can go to my husband's care.

When someone has Alzheimer's, it's not just the person who gets sick -- it's the whole family. This disease takes a toll on a community of people. Without our friends, family and neighbors, I would not have been able to care for John.

John and I believe that you can't just sit around go "boo-hoo." You have to do something. That's why I wanted to be here today and why I participated in the Alzheimer's Association Advocacy Forum for the first time this year.

This week, I joined 1,300 advocates from across the country to make a difference here in Washington. We are here to speak on behalf of the 5.5 million Americans living with Alzheimer's today, to advocate for their care, and to fight for more research funding. Alzheimer's is a fatal disease with no means to prevent, cure or even slow its progression. Investing in research is

the only way to change that.

Alzheimer's research is currently funded at \$991 million annually, but the scientists at the National Institutes of Health (NIH) say they need more to make progress toward ending this disease. Researchers at the NIH asked for an additional \$414 million for Fiscal Year 2018. As a caregiver and advocate, I am respectfully asking Congress to fulfill that request.

Today, John is 58 and in the end stages of Alzheimer's. This disease has ravaged our family, but that doesn't mean we have given up hope. Something positive has to come out of this. It's inspiring to be here on Capitol Hill for the first time with so many others just like me. We all are counting on you to take action so we can, once and for all, end Alzheimer's.