

Kristine Johnson

Alzheimer's Testimony for Appropriations Hearing February 11, 2016

Good evening Members of the Committee,

At the young age of 52, my father, Nathan Johnson Jr., was diagnosed with Younger-Onset Alzheimer's. This diagnosis was a devastating and inconceivable one at the time. My family was unaware of Alzheimer's striking people who were as young as my father. We didn't know that Younger-Onset, those who have a diagnosis of Alzheimer's or another type of progressive dementia at the age of 65 years old or younger, was not as uncommon as one might think.

One of the challenges we faced as a family was that my father was not of retirement age, so he wasn't eligible to receive his pension. He didn't serve in the military, so there were no Veteran's programs we could turn to. He was a Lineman for North East Utilities, a hard worker with longevity; however my parents didn't have the savings in the bank that could sustain all of his care needs. He paid into a long-term care insurance policy for years, but its benefits did not cover assistance for Respite services. Because of my father's young age, he did not qualify for the few programs in the community that could have been of some assistance.

One day, the Respite Program was explained to us by the Alzheimer's Association in the Eastern Region of CT. We were introduced to Joan Marshall from Senior Resources who explained the program and helped us fill out the necessary paperwork. The relief this program provided for my family cannot be adequately put into words. My father was able to attend an Adult Day Program and as his disease and limitations progressed, we were able to get some Homecare assistance in place. Our desire was to keep my father home and provide the best care we could for him. He was a loving, involved father and husband, he provided for his family and helped people in his community. He deserved the best we could give him, we just needed a little help. I worked full time and my mother was in need of a double knee replacement that she put off so she could care for my dad. The Respite program allotted for that help.

The Respite program allows families like mine to increase their care-team to provide for the ever changing and growing needs that comes with a progressive dementia. It allows caregivers to have the support they need, to help reduce their stress, strain on their health and increase their knowledge of the disease as they learn from others who have become part of their care-team. As I have learned through firsthand experience and from countless families and doctors since, caregivers often forsake their own health and mental well-being to attempt to provide care with very little help. As I have since relayed to families, if something happens to you as the caregiver, what will happen to your loved one you are caring for. Caregivers need Respite. I often use the analogy of the instructions Flight Attendants give during their safety chat. Put the oxygen mask on yourself first, before you put it on the person next to you. Caregivers need support to be able to support the ones they are committed to caring for.

The Respite Program helped us to increase our Care-team. It helped us to not only successfully keep my father home, but was a source of social engagement for him and helped to reduce an overwhelming experience of isolation for my father and my family as a whole.

This program is not fluff. It's not a babysitting service. It's not a "nice thing to do". This program is a necessity. This program helps to keep individuals with a progressive, fatal disease, in their homes until end of life or delaying the time in which they might enter long term-care.

My father's sparkling brown eyes closed in the wee hours of the morning for the last time 5 years after his diagnosis at the age of 57. The Respite Program was a saving grace for my family. The program helped to keep him home. The funds of the program did not cover all of his homecare expenses, but it was a start and helped to get my family as a whole, the support we needed. We are familiar with the old proverb "it takes a village to raise a child". I say it takes a village to successfully care for someone with Alzheimer's or a progressive dementia. The Respite program helps to get that village in place.

Sincerely,

Kristine Johnson, proud daughter of Nathan Johnson Jr.