

Kristine Johnson

Alzheimer's Respite Care Testimony for Appropriations Hearing 3.4.11

Good evening Senator Toni Harp and Rep. Toni Walker and Members of the Committee,

Please allow me to introduce myself. My name is Kristine Johnson, proud daughter of the late Nathan Johnson Jr. My beloved father passed away six months ago on August 26, 2010 from Alzheimer's disease at the age of 57. He was diagnosed with Early onset Alzheimer's when he was a mere 52 years old.

The picture I want you to envision this evening is of a 52 year old healthy husband, father and grandfather being given the heart wrenching news that he has Alzheimer's. My father was a Lineman for North East Utilities. He was strong, healthy and active. The news of this diagnosis changed our lives forever. Alzheimer's not only afflicts the person it attacks, but the family as a whole.

Alzheimer's at 52 years old is unheard of, or so I thought. The prognosis of Early Onset Alzheimer's is more prevalent than we could have ever imagined. In Connecticut there are over 3,000 cases. As the case with my dad, it's often misdiagnosed which can unfortunately lead to a loss of valuable time; time that our loved ones could have been receiving treatment and support services. One thing that my family and I learned throughout this exhausting and emotional experience is that "It takes a Village to care for an Alzheimer's patient". I know the village scenario is typically used when talking about raising children, but it couldn't be more true for our situation.

Janice Padsada, a reporter from The Hartford Courant wrote a touching and informative article about my dad and the struggles we faced as a family, with his diagnosis of Early Onset Alzheimer's. We encountered road blocks with the health insurance through his job as they were not willing to pay for certain treatments that were recommended by professionals. We encountered roadblocks for my dad not being eligible for certain local services because of his age. There are a number of local programs that provide services and support to Alzheimer's patients and families, but those services are only available to the senior population. My dear father didn't belong to the "senior" population at any point throughout the time of his decline. He was not at the "normal" or "typical" Alzheimer's age. We found that a number of local support programs to hospitals were not equipped to care for or provide services to Early onset patients. In sum, for folks who are younger, who are not Medicare eligible, finding home care, family support can be even more complicated.

Alzheimer's disease is like no other. It is a debilitating condition that turns our afflicted loved ones into shells of their former selves as it drains and strains care takers. Early onset is a faster, more fierce track of the perils of what you would expect from Alzheimer's. The phases and stages of this disease can be intense, ever-changing and overwhelming. Especially when you are dealing with a fit person in their 50's who still has some strength in their body, yet the disease is ravaging their mind.

Alzheimer's Respite Care Program in partnership with The Alzheimer's Association needs to be available to help coordinate **those villages** of support for

countless other families. We need them. Our loved ones, neighbors and co-workers need them. One day you or your families might need them.