



Testimony on behalf of: **The Alzheimer's Association Ohio**
Proponent Testimony in support of: **Senate Bill 24**

House Aging and Long Term Care Committee

Chairman Steven Arndt, Vice Chairman Bill Reineke, and Ranking member Stephanie Howse

Testimony by Alzheimer's Association Advocate: **Jennifer Blough**

Supported by: Alzheimer's Association Director of State Public Policy **Trey Addison**

Good Morning. And Thank you, Chairman Steven Arndt, Vice Chairman Bill Reineke, and Ranking Member Stephanie Howse. We thank you, Senator Wilson and Senator Yuko for their leadership in sponsoring Senate Bill 24. We also would like to thank all the members of the Aging and Long Term Care Committee for your support for the millions of families in Ohio impacted by Alzheimer's and Dementia.

My name is Jennifer Blough and I am an advocate for the Alzheimer's Association. I am also a care partner to my husband, Rod, who is living with Young Onset Alzheimer's Disease and Lewy Body Dementia, a mixed-dementia diagnosis. I experienced first-hand the frustration, fear, fatigue and profound loss that comes with this disease, and I struggle with the emotional and financial impact of the disease on our family. I am not alone in this. Nearly **1 Million** residents of Ohio are facing this same or similar situation. Today, I advocate for all caregivers and the ones we love.

Senate Bill 24 is a necessity for us. We need experts in Dementia and Alzheimer's care to work together to ensure there is an infrastructure to help people living with the disease to lead purposeful, healthy and save lives. You see, an Alzheimer's or Dementia diagnosis is just the beginning of a new chapter. Life expectancy ranges from **4 to 8 years** after diagnosis. There is a lot of living yet to do in that time.

My husband was diagnosed 2 years ago, at the age of 58, but our journey into dementia started in the summer of 2014 when Rod, a Human Resources executive at a central Ohio manufacturer, collapsed at work and was knocked unconscious, suffering a concussion. Four months later, Rod collapsed at work again resulting in a second concussion.

After the second collapse and concussion, Rod was hospitalized for a week while specialists conducted tests looking for a cause. The tests were unremarkable. After his release, Rod continued to be seen by a neurologist and cardiologist to monitor his health and treat the severe headaches, memory loss, and difficulty processing information. Rod also started to see a psychiatrist to treat his depression and anxiety, and a neuropsychologist to test the impact of the concussions on his cognitive ability. Our effort and that of the doctors were focused on helping Rod recover from the concussion symptoms.

During this time, Rod struggled to return to work. Four-hour days were nearly impossible for him, let alone the 10-12 he used to work. He had difficulty responding to emails, remembering his colleagues' names, and following discussions during meetings.

After 5 months of gradually increasing his work hours, Rod had returned to a 40-hour work week. He still processed things much slower, and had difficulty remembering information, but he was able to contribute. We were grateful for his employer's flexibility while Rod tried to regain his cognitive abilities.

Finally, in May 2015, nine months after his first collapse, Rod had a bicycle accident in which he was knocked unconscious and suffered a third concussion. It was not evident from the people who found Rod at the side of the road, or to

the police, or to Rod, what happened that evening. It was clear that Rod had not been hit by a car, and the bicycle tracks showed a clear path leading into a utility pole. Rod's helmet was dented, and there was a mark on the pole. There were no witnesses and Rod has no recollection of the event.

This third and final concussion set Rod back further than before. It left him unable to work. Rod was placed on long term disability and shortly thereafter began to draw Social Security Disability benefits. His mood was best described as despondent, he found no joy in life, and he struggled with the loss of his professional identity.

By this time, Rod's doctors were all using the term dementia to describe Rod's loss of memory and thinking skills. The neuropsychologist suggested that Rod and I start to find support, specifically at the Alzheimer's Association. We immediately joined the local Young Onset support group, led by the Association, which was for people under the age of 65 with a dementia diagnosis. We attended our first meeting in spring 2017. Rod and I both realized in that first meeting that we were right where we should be – with people who understood the frustrations of memory loss and difficulty processing information. To this day, we continue to attend the monthly meeting for support, coping strategies, and friendship.

Around the same time, Rod's neurologist referred us to a Cognitive Neurologist who specialized in dementia. We were fortunate that a new doctor had joined the Ohio State Cognitive Neurology Department, so we did not have the long wait experienced by others. After more tests, specifically a PET scan and a lumbar puncture, Rod was diagnosed with Alzheimer's Disease in the summer of 2017. He was also presented with several physical issues, such as tremors in his hands, restless legs, a shuffling walk, and stiffness. He acted out his dreams while he was asleep, at times hitting me. By early 2018, Rod was also diagnosed with Lewy Body Dementia, or LBD. One of the attributes of LBD is the interference with the body's autonomic system – blood pressure for example. It is possible, that Rod's collapses were the early symptoms of Lewy Bodies, taking us full circle to the beginning of this journey.

I tell you this story in detail to illustrate the variety of symptoms Rod has experienced, and the time and effort it takes to get a diagnosis. While Rod's concussion history is not common, the length of time and difficulty in getting a diagnosis is a typical experience. There are not enough Cognitive Neurologists, and other trained medical staff, to diagnose and treat the number of people who are affected. Testing, especially PET scans for the brain, is often difficult to get approved by insurance. Symptoms can be elusive and easy to mis-diagnose. This is particularly true with Lewy Body Dementia. We were blessed with medical staff that knew to send us to the Alzheimer's Association. The early introduction to the Association's programs and resources helped Rod and I to accept the diagnosis. With the support of the Association, we have developed strategies to keep Rod independent and safe. As the disease progresses, we trust the Association will help us to adapt to the new limitations and needs.

Right now, I can honestly say that Rod and I are living well with the disease. I continue to be able to work to support our family and provide benefits for myself and our children. Our family is closer than ever, and we prioritize our time to be together. We know that Rod will get worse over time. At some point, he will not be able to stay on his own. I worry about how I will be able to work and keep him safe. I can't afford to not work. There are not enough facilities that offer day care for people living with dementia. A friend of mine is looking for a solution now for her husband and has found that the waiting lists are years long. Eventually, Rod will need assistance with every aspect of his life. I worry about the quality of care I will be able to find and afford. And I worry about my own health in managing the increasing stress of providing care.

It is this relentless fear and anxiety about our future that drives me to advocate. The system to diagnose, treat and care for those living with dementia must improve to reach more people earlier, and to provide support and resources to those who are living with the disease, particularly the middle and late stages. And, we need to find ways to professionally augment the care that is today provided by family members.

In Ohio, what we need is an Alzheimer's and Dementia State Plan outlined in Senate Bill 24. This task force should move quickly on legislation and administrative changes to how we address this debilitating disease. By bringing external stakeholders together we can identify opportunities to enhance dementia training, create public health education strategies on risk reduction, and develop a diverse and inclusive State Plan that works for the **220,000** Ohioan's living with Alzheimer's and the **1 million** Ohioan's that are directly impacted by the disease. As you may be aware the number is slated to increase over the next 5 years, and the cost burden of Alzheimer's and Dementia overtime will cripple the Medicaid budget. I ask for your support in passing this bill for me, and for all the people for whom I advocate for today.