



Alzheimer's Association Ohio
Senate Health, Human Service, and Medicaid Committee
Chairman Dave Burke, Vice Chairman Stephen Huffman, and Ranking Member Nickie Antonio
Testimony by Ohio Advocate: **Pat Nauseda**

Good morning. And Thank you, Chairman Dave Burke, Vice Chair Stephen Huffman and Ranking Member Nickie Antonio. My name is Pat Nauseda, and I'm a volunteer and advocate for the Alzheimer's Association here in Ohio. I advocate because Alzheimer's has directly impacted my family. My mother was diagnosed with Alzheimer's disease and passed away a year ago this month. I know the enormous personal, emotional and financial impact that individuals and their families face with this, as yet, incurable disease.

My parents had lived in the Cleveland area since the early 1980s, and while visiting them in the fall of 2011, my Dad told me that a few weeks before, my Mom called him because she couldn't find her way home from the mall. My Dad had to direct her all the way home by phone even from the front entrance to their neighborhood. Her doctor diagnosed her with Mild Cognitive Impairment but didn't suggest to us that her memory loss would continue and didn't recommend we take her to a neurologist. We were given no information about the paths her condition could take. Early knowledge that this could lead to a diagnosis of dementia such as Alzheimer's would have helped us in our efforts to support my Mom.

In the beginning, she was able to function fairly well, writing things down on lists and asking my Dad when she couldn't remember things. But by Christmas 2014, when my parents came to visit us in Columbus, I could see how she had changed. She couldn't figure out how to do simple tasks like setting the table. That winter she started forgetting who my Dad was, her husband of over 60 years. She also often wanted to go home, not recognizing where she lived. I'd get phone calls in

the middle of the night from my Dad asking me to try to reassure her of who he was and that she was at home and safe. Like many people with Alzheimer's, my Mom also started to wander. If she woke up in the middle of the night, she'd often get up, get dressed and try to leave the house. We contacted the Alzheimer's Association for help, and they were able to give us suggestions on how to help calm her when she was agitated and how to put a hook at the top of the door that my Mom couldn't reach. She started to decline quickly, and we had trouble getting her to eat and sleep through the night, and she lived in a state of confusion. Then she became incontinent. While I was worried about my Mom, I was also worried about the physical and emotional toll on my Dad, her caregiver – he wasn't eating well, he was up at all hours of the night with Mom, and he was doing all the day to day tasks by himself that they used to do as a couple.

I began attending monthly meetings sponsored by the Alzheimer's Association for the children of people with the disease. Participants shared stories, offered suggestions and discussed resources for dealing with this disease. It was often a very emotional evening, but it was so helpful to learn how others were coping, and it helped me to prepare for the days ahead.

In August 2015, we moved my Mom to a Memory Care facility here in Columbus where she was able to receive the 24 hour a day care she needed. During this time she was hospitalized twice after falling. While she received excellent physical care, I was surprised that most of the medical staff didn't know how to interact with a patient with Alzheimer's. They would repeatedly ask her for her name and date of birth. When she didn't respond, they'd ask her again.

In 2017, after surgery for a broken femur, she was unable to learn how to walk again and was confined to a wheelchair. She also lost her ability to speak coherently – her words were all jumbled. When she died, I grieved, but the mother I knew and loved had been gone for some time, and I'd been grieving for her for several years. Alzheimer's not only robs a person of their memories, but it robs them of their identity.

Today, I speak on behalf of the Alzheimer's Association, Family Caregivers, and individuals with Alzheimer's and Dementia, and WE urge you to support and quickly pass Senate Bill 24. This legislation will help Ohio families, medical

professionals, service providers, and individuals with Alzheimer's and Dementia. By setting up a diverse task force of stakeholders, the goal of this critical group is to identify opportunities to enhance Dementia training, create education strategies on risk reduction, and develop an Alzheimer's State Plan that will help the nearly 220,000 Ohioans living with Alzheimer's and the 1 million Ohioans directly affected by Alzheimer's disease. Ohio is the only State without an Alzheimer's State Plan. We see this as an opportunity to learn from other states and create the best plan in the country.

Chairman Burke, the Alzheimer's Association thanks you for your leadership, and we also thank Senator Steve Wilson, and Senator Kenny Yuko for their leadership in introducing the bill.