Testimony House Bill 1012 – Amber Moen, Devils Lake, North Dakota Senate Appropriations Committee Senator Ray Holmberg, Chairman March 11, 2021



Mister Chair and members of the committee, my name is Amber Moen, and I am from Devils Lake, North Dakota. I was a caregiver for 7 years for my mother who had Early Onset Alzheimer's.

My mother's name is Susan. Growing up, she was just your average mom. She somehow found the perfect balance of parent and friend, being just strict enough but always there for you if you needed someone. She ran an in-home daycare for 17 years while also raising my younger sister and myself. She was creative and artistic, often working on beautiful cross stitching's that she would donate and were always a high-priced item at our Catholic School fundraisers. She had so many wonderful qualities about her, her laugh was infectious, and her strong Catholic faith guided her through the most difficult times in her life.

In 2008, we celebrated her 50th birthday, I had turned 21 and my sister graduated from high school. It was also that year that she confided in me that something wasn't quite right. She was losing her speech. It started gradually but was getting noticeably worse. Her handwriting and the ability to do simple math was also declining. As a business owner and caregiver for small children she was genuinely concerned. It was this phone call that would begin our 2-year journey of trying to figure out what was going on.

By the time 2010 came, she could hardly speak. We had tried everything. We were referred to Mayo Clinic in Rochester. After 2 weeklong stays and 1 follow up visit, we received the diagnosis of Early Onset Alzheimer's Disease. She was 52 years old.

After that, we went home. We didn't know what to do next. My parents were divorced and with my sister and I both trying to find our own paths in life, my mother was living alone trying to process this unbelievable information. She started on medication that would help to slow the progression, but she would never get any of her speech back eventually losing it completely.

In 2011, her disease progressed to the point where she had to close her daycare and stop driving. Realizing she needed more help I decided to move back to Devils Lake to become her primary caregiver. Even though it had been a year since we received her diagnosis, we were still in a sort of limbo. I was trying to figure everything out basically on my own and had no idea where to start. Then one day I heard of an education series being held at the college by the Dementia Care Services Program. It was at this time that I met my care consultant, Ashley who would change things for our family tremendously.

It was Ashley who was finally able to give me some sort of direction. She provided resources on everything from general information about the disease to certain programs that she knew my mom could qualify for. More importantly, she was the support that I needed as a caregiver. She did not live in Devils Lake but was always willing to find time to meet. Through the Dementia Care Services Program, I was able to become a better caregiver which in turn gave my mother a better quality of life.

This is why the Alzheimer's Association is asking you to increase funding, so that more families like mine can receive these critical services. So, we are asking today to increase funding for the Dementia Care Services Program to \$1,332,000.

As for my mother, it was decided in 2017 that it would be best to move her into a Memory Care Unit. On January 11, 2018, my mother passed away, 3 days later, I gave birth to my daughter, Finley Sue, who would have been my mother's first grandchild. It is now for my children that I continue to advocate and fight to end this terrible disease.

Thank you so much for taking the time to hear my story today. Please let me know if you have any questions.