



Minnesota - North Dakota Chapter

**Testimony
Senate Bill 2140
Human Services
Sen Judy Lee, Chair
January 14, 2025**

Good morning Chair Lee and members of the committee. My name is Melanie Gaebe and I am the North Dakota Public Policy Director for the Minnesota-North Dakota Chapter of the Alzheimer's Association. I am here to provide testimony in support of SB 2140. Alzheimer's and dementia touch our lives as caregivers, loved ones, friends, and family. I usually ask those in the room to raise their hand if they have been touched by this disease. However, in my time with the Alzheimer's Association, I have learned that the majority of the people we come into contact with on a daily basis would raise their hands. My family is no different.

This past Christmas, was the sixth anniversary of my grandma passing away with Alzheimer's dementia. Prior to that, she spent sixteen years in care facilities moving from basic care to a locked memory care facility and finally moving to a skilled nursing facility. All of this to say, we started navigating the Alzheimer's journey with grandma before the Dementia Care Services program existed. The original language authorizing the Dementia Care Services program was passed in the 2009 session. Through the 15 year partnership between the State and the Alzheimer's Association, we have provided a lifeline for thousands of North Dakota families facing the unknown of living with or caring for someone with memory loss. The Dementia Care Services Program has also provided dementia education for tens of thousands of community members and professionals across the state.

North Dakota Century Code 50-06-33 has not changed in the time since it was written. What has changed in those years, is our understanding of Alzheimer's and dementia. When grandma was diagnosed, there were no biomarker tests, there were no scans; grandma had a paper exam that tested her cognitive abilities. Grandma drew a clock face with all of the numbers clustered in the bottom right and thought it was correct. At that time, her doctor diagnosed her with dementia because that is all the more accurate a diagnosis he could provide. Alzheimer's could only be confirmed with an autopsy. Now, we have the ability to accurately diagnose Alzheimer's disease through a combination of the standard cognitive exams, biomarker testing, and amyloid PET scans. We even have treatments that alter the underlying biology of Alzheimer's disease. All of this led us to believe it is time to update the language in 50-06-33 to reflect what we now understand about the continuum of the disease.

This understanding is the reason we propose removing the definition of dementia and replacing it with a definition of who our clients are. We now know that Alzheimer's disease exists on a continuum. Previously, we didn't really talk about Alzheimer's disease until it had progressed into the mid- to late stages. Now, we recognize the stages of disease progression and have even learned that biological changes are occurring in our brains up to twenty years before showing symptoms of cognitive decline.

We have also changed how we talk about dementia. Alzheimer's and dementia are no longer seen as interchangeable terms. This is because dementia isn't a disease, but a cluster of symptoms related to cognitive decline that are caused by diseases like Alzheimer's, Huntington's, Lewy bodies, and many others. It helps to think of it in the same way as cancer. When someone tells us they have been diagnosed with cancer, the first question we have is "what kind"; and that is the way we think about and talk about dementia now.

The changes proposed to NDCC 50-06-33 are technical updates and don't alter the purpose or goals of the existing Dementia Care Services Program. The changes are simply to bring the authorizing language into alignment with what has changed through research and ensure we continue providing services to the North Dakotans who need to know they aren't navigating Alzheimer's disease and related dementias alone.

Thank you for your time, I'm happy to take questions.