



Minnesota - North Dakota Chapter

Testimony
House Bill 1433
Human Services
Rep Matthew Ruby, Chair
January 22, 2025

Good morning Chairman Ruby 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 House Bill 1433. Alzheimer's and dementia touch our lives as caregivers, loved ones, friends, family, and in our professional lives. Alzheimer's disease has been a part of my life for as long as I remember. I spent years afraid of my great grandma because I didn't meet her until after Alzheimer's disease left her nonverbal. But how can you explain dementia to a six-year old?

Off and on through high school and after college, I spent a number of years working in long term care facilities. I grew to understand how special it is to connect with someone living with Alzheimer's or another dementia. It became a privilege to be the person who could bring a smile to someone's face, make the one meal they would eat, or understand their communication when language became more difficult. And then my grandma was diagnosed with dementia. 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 secure memory care facility and finally moving to a skilled nursing facility. When I say things have changed in our understanding of Alzheimer's disease and related dementias in those nearly thirty years, it is an understatement.

This morning I would like to take a few moments to do a bit of level setting and provide you all with the new way we understand and talk about Alzheimer's disease and related dementias. It seems silly to ask, but what is dementia? We hear and use the term frequently enough but it isn't always used in the same way. So when we talk about dementia, it is an umbrella term for the collection of symptoms related to cognitive decline. These symptoms can be cognitive, behavioral, and psychological. There are a lot of diseases that cause the symptoms of dementia, Alzheimer's is the most common cause of dementia at around 60-80% of the diagnoses. But there are others such as vascular dementia, Lewy body, and even diseases like Huntington's and Parkinson's can cause dementia. It is important to note that not everyone with cognitive decline has dementia. Some causes of cognitive decline are even reversible.

There are still no cures for Alzheimer's disease or related dementias, but there are now two FDA approved treatments for Alzheimer's disease that alter the actual biology of the disease when Alzheimer's is in the early stages. Which leads to another change, we used to only talk about

dementia when people were diagnosed in the late stages. As though a person went from being perfectly healthy to having advanced dementia overnight. We now understand that there is a continuum for Alzheimer's and dementia which changes our ability to respond. The earliest stage of memory loss or loss of other cognitive ability that could develop into dementia is called Mild Cognitive Impairment. This is the stage where Alzheimer's treatments are the most effective.

But we also now know something that has bothered me ever since I learned it; the biological changes in our brains can start up to twenty years prior to showing any symptoms. And at this point you are probably wondering what any of this has to do with House Bill 1433 so I'll tell you. One of the most important things we have learned about Alzheimer's disease and related dementias is that there are things we can do to reduce our risk, slow the progression of mild cognitive impairment, and possibly even prevent ourselves from developing dementia.

Alzheimer's disease and related dementias come in as the fifth leading cause of death in North Dakota, yet there is no public health program in Health and Human Services to address lifestyle interventions for risk reduction and prevention. This is why we chose to put specific activities into the dementia response program to be overseen by a State Dementia Coordinator as each activity can be considered to fit into the purpose of public health; protecting and improving the health of people and their communities.

First, implementation and maintaining an updated Alzheimer's and Dementia State Plan. The most recent state plan was released three years ago. The plan was considered robust and shared with other states as an example of what a well-designed plan looks like. Unfortunately, there was no person or agency tasked with implementing the plan and it has spent three years sitting on the shelf. The state plan was heavily influenced by the Healthy Brain Initiative Road Map which was recently updated, meaning the state plan that was held up as an example has been left behind.

Second, the collection and dissemination of Alzheimer's disease and related dementia data is an integral piece of a comprehensive dementia response program. The most recent data on cognitive decline, caregiver needs, and diagnoses is necessary to both plan for future resources and evaluate the impacts of risk reduction efforts.

Third, we need to start talking about Alzheimer's disease and related dementia. Not only among professionals and in committee hearings, but every day. How many of you joke about memory loss when you misplace your keys or can't find a word even though it is right on the tip of your tongue? How many of you make those jokes to cover up the fear that you are really losing your memory? We need to stop acting like talking about Alzheimer's will mark us as the next person who will get it and start having conversations in the open about what it is like for people living with the disease and their caregivers. We are living in an era of treatment, the generation of hope. It is time to reduce the stigma of dementia and start addressing the lifestyle interventions that reduce our risk for developing dementia. The fear of Alzheimer's and dementia can be fought by learning about the disease and how to keep our brains healthy.

I have included with my testimony a few different infographics for you with statistics on the current prevalence of risk factors in North Dakota, the 2024 statistics for Alzheimer's and caregiving, and ten healthy habits for your brain that you can adopt.

Please give House Bill 1433 a do pass recommendation, let's send the message that brain health is a priority for all North Dakotans.

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