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North Dakota Dementia Care Services Program

A love story for the ages that has become a family affair

Agnes and Matt Fettig have a love story for the ages. The couple raised their nine children in Bismarck, ND, and their love is one that endures in sickness and in health.

When they each received a diagnosis of Alzheimer's disease within three weeks of one another in December of 2020, all they asked was that they be able to stay together.



Finding care and support resources
At the time, the family did not know where to turn. Their children sought the resources of the Alzheimer's
Association to help guide them through next steps. All nine children participated in virtual, no-cost care consultations with a professional Alzheimer's staff member who guided the family with information about the



disease, and next steps for housing, legal and financial considerations. These sessions brought together the siblings in Zoom meetings from nine locations across the country.

Daughter Danette said, "The Association helped to ground us, help us think logically, and to put in place a plan for our parents to stay together." Son David said these meetings helped to get all of the siblings on the same page about next steps and to learn about "the deep web of resources in North Dakota with people eager to help us." Daughter Diane reported "When I couldn't be there as a caregiver in person, the Association helped me with ways to be a caregiver from afar." And, son Doug shared, "What I found most helpful was that we were not alone."

From diagnosis to legacy

Last year, Agnes and Matt celebrated their 65th wedding anniversary — together. They now live safely in a senior living community in Bismarck. Danette reports that her parents are proud of their long marriage and have not forgotten they are together.

"They hold hands and are still very much in love. It is even more powerful, when you consider what they are going through."

Before their diagnosis, Matt and Agnes were always active volunteers in the community, instilling in their children a sense of giving back to the community and those who needed help. It's no surprise that a few of the Fettig family members have made the Alzheimer's Association a bigger part of their lives after receiving services from the organization. Daughter Denise is now working as a community programs volunteer with families experiencing dementia and Alzheimer's. And, more than a year ago, Danette joined the program staff as the chapter's grant manager. "These are the blessings that come out of my parent's difficult diagnosis", Danette says.

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North Dakota Dementia Care Services Program

The Alzheimer's Association has served North Dakota residents through the Dementia Care Services Program (DCSP) since 2010 to improve disease management and increase family support to people living with dementia and their caregivers. Services include:







Care Consultation

Individuals with memory loss, family members, or concerned professionals meet with Alzheimer's Association Care Consultants. Consultants provide a customized road map including information about the diseases, care plans, resources for housing, financial and legal planning, referrals to community resources and support for caregivers. Meetings generally take place via phone, at the individual's home or at their preferred location.

Physician Outreach

Health care setting outreach informs medical staff in clinics, hospitals and public health agencies about the importance of Alzheimer's early detection and diagnosis, as well as how to make referrals for family education and support.

Education - General Public & Professional Development

Community outreach offers education on dementia-related topics, such as understanding memory loss, brain health, partnering with one's doctor, and understanding communication. Classes are available for the general public, professionals, care partners, medical professionals, and law enforcement.

Participant Responses

"I would love to attend another session to build on the knowledge learned today. Today I have a greater empathy for dementia than I did yesterday."

- RN attending a training

"I always refer to our Care Consultant as "Our Angel." All nine of us were lifted by her sincere show of support for our situation. Her followup demonstrates the extraordinary significance of our North Dakota staff." - Care Consultation Client "The program and information provided to me helped me better understand my mother's [...] behavior. I was able to comfort her and assure her everything was okay. It also gave me the confidence in relating and relaying this information with my siblings"

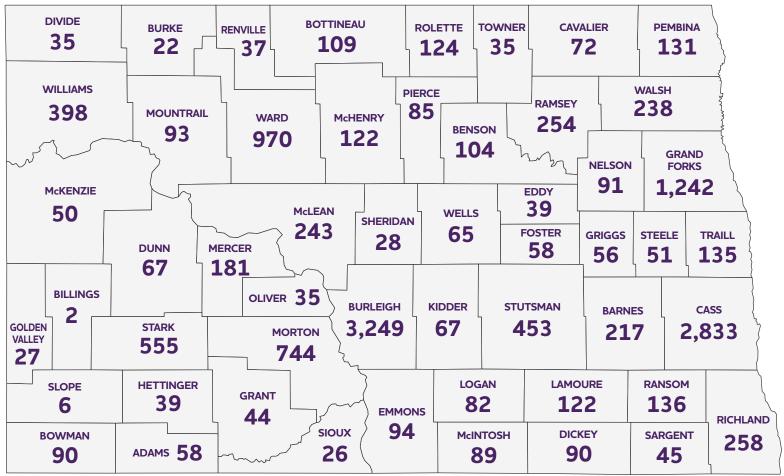
- Care Consultation Client

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The Alzheimer's Association has supported the families of 3,829 people living with dementia, including providing 14,258 care consultations for 7,835 caregivers.





Data collected by the Alzheimer's association for the Dementia Care Services Program contrat January 1, 2010 through October, 2022.

We have provided no-cost services to **61,740** people across the state, increasing awareness of community resources, understanding the disease process, and improving the quality of care of people living with dementia in North Dakota.

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North Dakota Dementia Care Services Program

What is the value of the Dementia Care Services Program?

Recent research has demonstrated that two types of programs have potential for reducing avoidable health care and premature nursing home placement. One is the DCSP's caregiver support programs, and the other focuses on the care delivery team. Studies indicate that resources assisting caregivers have promise for reducing unnecessary emergency department visits and hospitalizations, and reducing transitions to residential care for individuals with Alzheimer's disease and other dementias.



An evaluation from the Center for Rural Health at the University of North Dakota School of Medicine and Health Sciences found:



- Over a 42-month program period, the legislature appropriated an investment of \$2.2 million for the contract and has estimated results of long-term care cost saving of \$39.2 million, such as those incurred through hospital or emergency related services and delays in placing a person with dementia in long-term care facilities.
- Caregivers who were more engaged in DCSP activities had greater hospital and rural ambulance cost savings compared to caregivers who were not.
- Caregivers who participated were more likely to complete important dementia care-related tasks like establishing a power of attorney and instituting health care directives.
- Caregivers who received DCSP services were twice as likely to either delay nursing home placement or decrease their likelihood of placement. The total cost avoided was \$3,007,147 (based on 46 people who indicated an increase in the amount of time to place a person with the disease in an institution).

Additional Services Provided Outside of the North Dakota Care Services Program





24/7 Helpline (800.272.3900)

Staffed in 200 languages, this resource serves people with memory loss, their caregivers, healthcare professionals and the public by providing information and referrals to local community programs and services; dementia-related education; crisis assistance; and emotional support.

Support Groups

Many support groups are held each month in various North Dakota locations and are led by trained volunteer facilitators to provide support, assistance, and encouragement to individuals and their care partners impacted by dementia.



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