



Center for
Rural Health
The University of North Dakota
School of Medicine & Health Sciences

alzheimer's association
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Policy Brief

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Dementia Care Services project: Supporting Caregivers in North Dakota

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Bonnie's story

The diagnosis of Alzheimer's wasn't as shocking to hear as the word "severe." I had noticed signs and symptoms, but was still overwhelmed to hear a man give my mother a life sentence after spending forty minutes with her.

With Mom suffering from untreated depression most of her life, she has been a difficult person to get close to. I believed if she really wanted to be a different person, she would change and we could have a normal relationship. Even though Mom is still physically here, I grieved over the loss of the relationship I now knew we could never have.

Jodi Keller, Regional Care Consultant, helped me see things differently. I could choose to grieve over what would never be, or I could redefine our relationship. Her specific advice: "Make the most of the time you have left." Even though that put finality on Mom's condition, it changed my perspective. In the beginning I struggled to control my frustrations, but with Jodi's help I've learned a whole new level of patience. With this newly defined fortitude, our relationship is changing for the better. I will cherish the memories we are now creating. Ironically, these are the memories Alzheimer's disease will steal from Mom.

Jodi helped me separate the facts from fiction about Alzheimer's disease. She is knowledgeable about the stages of the disease, including a realistic picture of what is yet to come. Jodi is supportive of my approach to caring for Mom, but has also taught me some effective ways to ask family members for help without being overbearing. This has taught me another level of patience. I have to understand each sibling will have to redefine their relationship with Mom in their own time.

My perspective continues to change regarding Mom's care. Instead of keeping track of her medicine and worrying about what to make her for supper, I can focus on what her mind chooses to focus on. Jodi has been a true provider of encouragement and hope. She's told me several times, "Yes, this is difficult, but you are doing a great job. What you do really does make a difference to your Mom."

How Bonnie benefited from the Dementia Care Service project

- **True support.** *Jodi has the experience of talking to many people in my shoes. She shares those experiences so I can learn how to become a better caregiver. No medical staff, family member, or Web site can provide the insight one caregiver can give to another.*

“ Jodi [from the Dementia Care Services project] helped me separate the facts from fiction about Alzheimer’s disease. She is knowledgeable about the stages of the disease, including a realistic picture of what is yet to come. ”

- **Knowledge about the disease.** A reliable source of information was explained in terms ‘simple caregivers’ can understand. I didn’t have to question where the information came from to accept it as truth, in contrast to mixed messages found by surfing the Web.
- **A sounding board.** When faced with a life-altering disease, having someone who really listens is what keeps me from being overwhelmed. This disease robs your family of ‘life as you know it’ and many of the thoughts and emotions that come with this can make you feel crazy.

Alzheimer’s disease and dementia

Every 70 seconds someone in America develops Alzheimer’s disease. By 2050, it will be every 33 seconds.¹ Alzheimer’s disease is the most common type of dementia, a syndrome that can be caused by a number of disorders that affect memory, thinking, behavior and the ability to perform everyday activities.²

- In 2000, there were 16,000 North Dakotans aged 65 and older with Alzheimer’s disease
 - In 2010, there will be 18,000
 - In 2025, there will be 20,000³

People with Alzheimer’s disease and other dementias are high users of health care, long-term care and hospice. Total annual costs to all payers for the care of people with Alzheimer’s disease and other dementias will increase from \$172 billion in 2010 to \$1.08 trillion in 2050, which does not include the value of unpaid care provided by families and others, estimated to be \$144 billion in 2009.

The challenge of providing care

As Bonnie’s story shows, providing care to a person with dementia poses special challenges. As a result, many family and other unpaid caregivers experience high levels of emotional stress and depression. Caregiving also has a negative impact on the health, employment, income and financial security for affected families.¹

Almost 11 million Americans provide unpaid care for a person with Alzheimer’s disease or another dementia.

- In 2009, caregivers provided 12.5 billion hours of unpaid care. At \$11.50 per hour, this is a contribution of nearly \$144 billion¹
- In 2009, 19,741 North Dakota caregivers spent about 22.1 million hours of unpaid care. The economic value of this care is estimated at \$255 million¹

North Dakota’s Dementia Care Service project

In 2009, the North Dakota Legislature passed the Dementia Care Services bill (House Bill 1043) to provide resources, assistance, and support for the people of North Dakota. The Aging Services Division of the North Dakota Department of Human Services awarded the Alzheimer’s Association of MN/ND the contract to do this work. The

Alzheimer’s Association of MN/ND is working with the Center for Rural Health to analyze and evaluate the program.

The project provides care consultations which can consist of assessments of needs, identifying issues and concerns, identifying available resources,

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developing a plan of care, referrals, providing support and education about dementia, and follow-up.

The project’s goal is to inform people with dementia and their caregivers about dementia care issues which, in turn, may

lead to decreased depression, increased family support, delays in nursing home placement, and reductions in redundant use of health services. The project began in January 2010 and will continue through June 30, 2011.

To what extent has the Dementia Care Services program been used?

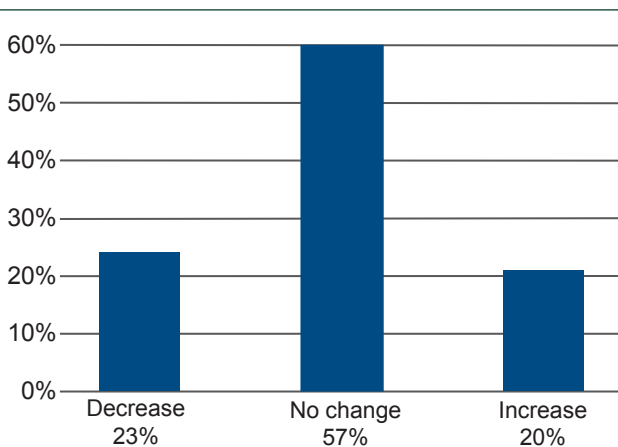
- From January through September 2010, 554 contacts were made to the Dementia Care Services project by 292 caregivers of 224 persons with dementia
- The Alzheimer’s Association provided service delivery in every region of North Dakota
- 25% of services provided was to caregivers living in small or isolated rural areas

Who are the caregivers and persons with dementia the project has helped?

- Caregivers who used the project services were mostly female (80%) ranging in age from 28 to 89 years, with an average age of 64.1
- The caregiver was often (40%) an adult child of the person with dementia
- Ages of the person with dementia ranged from 48 to 98 years, with an average age of 78.7
- One in six persons with dementia was a military veteran
- The majority (54%) of persons with dementia were living in their home
- Among persons with dementia, 45% lived in rural counties of North Dakota
- Three-quarters of persons with dementia had a dementia-related diagnosis, and 17.5% reported having another disease in addition to having dementia

What has been the project’s effect on caregiving in North Dakota?

Figure 1



As shown in Figure 1, caregivers who had one or more in-person visits with Dementia Care Services staff had the following changes in their intention to place their person with dementia in a nursing home.

The Figure includes only those caregivers who have had an in-person visit with project staff, change in placement likelihood is for the time period after initial encounter with project staff.

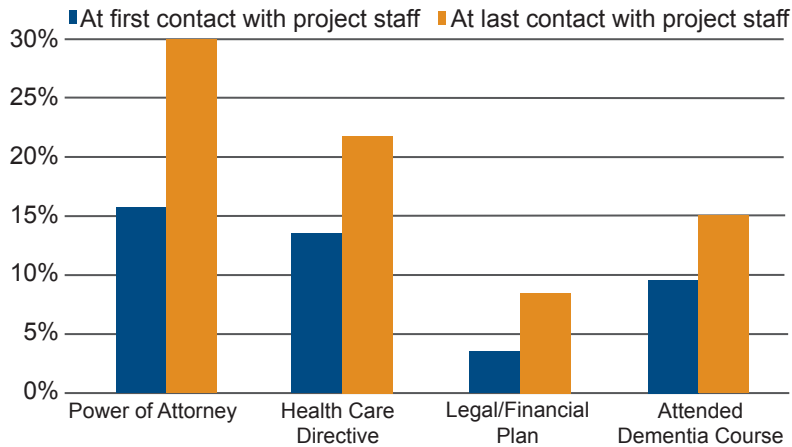
Figure 2

Figure 2 shows that caregivers who had multiple contacts with project staff and services showed increases in completing important dementia care-related action steps.

Conclusion

Preliminary results indicate the Dementia Care Services project is having positive impacts on the lives of persons with dementia and their caregivers, including enhanced support for caregivers and reduced intention for placement of persons with dementia in nursing homes.

As Alzheimer's disease is becoming more common, it is important to bolster efforts for finding a cure, develop new pharmaceutical treatments, and provide meaningful support to caregivers of persons with dementia through both the administration of proven, effective programs and the development of new and innovative approaches.

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