



ONLINE TRAINING for FAMILY CAREGIVERS

PROBLEM

An estimated 120,000 Wisconsin residents aged 65 and older have Alzheimer's, a number projected to grow to 130,000 by 2025. The cost to Medicaid alone for Wisconsinites 65 and over with dementia was \$777 million in 2020 and is projected to increase to \$924 million in 2025. The majority of care for people living with Alzheimer's and all dementia occurs at home rather than in a care facility or institution. In 2020, an estimated 196,000 family members spent 204 million hours caring for people with dementia in Wisconsin, equating to \$3.4 billion of unpaid care.

Family caregivers of people with dementia experience the highest rates of stress of any groups of caregivers. They balance caring for the person living with dementia with their own responsibilities at work and at home. Because of family caregiving, people with dementia can stay at home for longer than otherwise might be possible. Providing this assistance can be rewarding but also quite challenging for the caregiver to sustain. The role can be isolating, and caregivers often struggle to find supportive resources and to learn how best to care for someone with dementia. Long-term caregivers may feel stretched beyond their ability to cope.

In the Wisconsin Department of Health Services (DHS), public health and aging services leaders understood that problems accessing needed support negatively affected Wisconsin families'

ability to provide care. They wanted to find a way to support unpaid family caregivers to ensure that individuals with dementia could remain in the comfort of their own home for longer, including helping the caregivers to take control of their own health. DHS also wanted to honor both paid and unpaid caregivers and ensure that the state has enough caregivers for Wisconsin's aging population.

SOLUTION

In 2014, DHS published the *Wisconsin State Dementia Care System Redesign* — an update of its state plan for dementia — which proposed ways to make Wisconsin more dementia-capable and to identify priorities and focus areas. One strategy created by the plan was to expand the Dementia Care Specialist program that supports people with dementia and their caregivers in order to ensure the highest quality of life possible while living at home.

In 2014, the Wisconsin DHS Department of Public Health, Bureau of Aging and Disability Resources — which houses the Dementia Care Specialist program — received a grant from the Administration for Community Living. The Bureau used the funding to create a program for family caregivers to learn how best to respond to the behavioral symptoms that come with dementia. The Bureau partnered with the University of Wisconsin (UW) Oshkosh Center

for Community Development and Training, which had existing training for medical care staff, first responders and professional caregivers. To start, UW Oshkosh and the Bureau conducted focus groups with family caregivers about which topics are most important to them as caregivers. The new online training module was carefully designed for family caregivers and features two hours' worth of content. To make it as easy as possible for family caregivers to use the training, UW Oshkosh segmented the content into shorter clips that responded to the top challenges identified by caregivers.

The training provides a basic introduction to dementia and describes strategies family caregivers can use to address behavioral symptoms of dementia. For instance, some videos focus on addressing and redirecting agitation. The training module also includes information about how caregivers can monitor and maintain their own health while caregiving. Viewers can watch demonstrations of many of the strategies discussed.

INITIAL OUTCOMES

The online training has been viewed approximately 1,000 times since its development. The training asks participants to take a voluntary post-viewing survey to track responses and outcomes. While the feedback so far has been limited, it trends positively. A second grant — based on the success of this initial program — is enabling DHS to translate the training into Spanish, make culturally appropriate adaptations to the content, and rerecord all videos in Spanish.

KEY POINTS

- » Nationally, nearly 75% of Alzheimer's and dementia caregivers are somewhat or very concerned about maintaining their own health since becoming a caregiver.
- » Over 1 in 3 dementia caregivers in the United States say their health has gotten worse due to their care responsibilities. More than a quarter of dementia caregivers delay or do not do things they should to maintain their own health.

LESSONS LEARNED

- » To minimize costs, the staff person leading the project played one of the roles herself and recorded the voiceover narration for the videos.
- » The actors were recruited from the UW medical school's standardized patient program where actors portray patients experiencing a variety of medical conditions for medical students to practice diagnosing. This ensured that the actors already had familiarity with this kind of acting and were able to appropriately apply that experience to dementia.
- » The internal review and approval process took considerable time — over a year — so ensuring the process is outlined and leadership agrees to it is essential.
- » Input from family caregivers was critical. The initial focus groups helped shape the content development and allowed the Bureau to incorporate existing training materials that had been previously developed.



For more information on the public health response to Alzheimer's, visit alz.org/publichealth