

Maine: Improving Dementia Care through the Savvy Caregiver Program

The Maine Department of Health and Human Services' (DHHS) Office of Aging and Disability Services collaborates with statewide interdisciplinary partners to improve the care of people with Alzheimer's disease and other dementias and provide training for their caregivers.

Overview

Dementia is a disabling set of symptoms that results in declining mental abilities, thinking, remembering, and reasoning, impairing a person's daily functioning.¹ As the condition progresses, the person is in need of greater supervision, more assistance with activities of daily living, and eventually help with palliative and end-of-life care. People with Alzheimer's disease, the most common cause of dementia, live with the condition for four to eight years on average, with some living as long as 20 years.² The disease's long duration and degenerative nature place significant strain on family members and friends who act as caregivers.

In 2012, Maine ranked second among states in the greatest percentage of people aged 65 or older. The impact of caring for the aging population, including those with dementia, rests heavily on family members and friends. Seven out of 10 people with Alzheimer's disease and other dementias live at home in Maine.³ The number of people with Alzheimer's disease in Maine is expected to nearly double from an estimated 26,000 in 2010 to nearly 50,000 by 2030, which will have a major impact on the state's social systems, community resources, and long-term care and healthcare systems.⁴

The increasing number of people with dementia and the subsequent cost of care will place an alarming economic burden on families and social systems. The monetary value of the dementia care in the United States provided by caregivers in 2010 was between \$157 billion and \$215 billion.⁵ For this reason, Maine is invested in effectively training home- and community-based caregivers to promote safe at-home living for as long as possible.

In response to a lack of community-based programs aimed at improving outcomes for family caregivers and people with dementia, Emory University Professor and Associate Dean for Research Director of Graduate Studies, Kenneth Hepburn, and University of Texas School of Nursing at Houston Professor, Emerita Sharon Ostwald, developed [Savvy Caregiver](#), a 12-hour, self-contained dementia caregiver training program. Savvy Caregiver was designed so that organizations can offer and implement the evidence-based psycho-educational program without program initiators' direct involvement.

Evidence supporting Savvy Caregiver's value has been documented through several studies, demonstrating success in improving caregiver knowledge, confidence, and mastery of skills. These skills include self-care, understanding and managing the caregiver's own feelings, decision-making, and navigating family issues. The program has shown positive results even when adapted in different settings, such as rural and urban, and when the training length varies slightly.^{6,7} With these results, it does not appear that modifying the program format in setting and/or length sacrifices desired outcomes. The Maine DHHS Office of Aging and Disability Services is responsible for delivering services to promote independence for older adults with cognitive impairment through evidence-based prevention programs and community-based services. These services are funded by the Administration

for Community Living/Administration on Aging under the Alzheimer's Disease Supportive Services Program (ADSSP).

Steps Taken

Since the late 1990's, Maine has recognized the important role that family caregivers play in supporting relatives to stay at home, particularly family caregivers of persons living with dementia. Once the Savvy Caregiver program became recognized as an evidence-based program to support family caregivers, Maine's Office of Aging and Disability Services pursued the opportunity to implement it in Maine. The Maine Savvy Caregiver program has evolved since 2008 from two three-year grants into the implementation, evaluation, and sustainability of a caregiver trainer program in two parts. Part I is an evidence-based psycho-education curriculum for caregivers of those living with dementia in the community. The focus is on increasing caregiver knowledge, skills, and emotional health, while reducing negative reactions to behavioral symptoms, improving emotional tolerance, increasing caregiver situational control, and increasing access to support services. The key teachings in these areas are to take action to adjust approach and environment through establishing routines, setting boundaries, better understanding dementia, and providing directive instruction with limitations. A group of six to 10 caregivers meet over six two-hour sessions with a certified trainer and other community health programs.

In response to requests for further training, the Maine Savvy Caregiver Program Part II was developed as an advanced psycho-education curriculum for family caregivers who have already completed Part I and who continue to assist a person with dementia living in the community. A trained facilitator conducts this advanced course over four two-hour sessions with six to 10 caregivers, with a heightened focus on solving current problems, making difficult decisions, planning for future challenges, and ongoing care of self. As of April 2014, the U.S. Administration for Community Living funds the program.

At Maine's five Area Agencies on Aging—not-for-profit entities established under the Federal Older Americans Act to create a system of elder support services—a team of associate- and master-level certified trainers is embedded in the [Family Caregiver Support Program](#) staff, trained in both parts I and II. Caregivers are identified through a variety of marketing strategies, including advertisements in newspapers and TV/radio outlets and through other service providers. Maine DHHS also partners with primary care physician practices statewide to deliver information, training brochures, and DVDs.

In 2013, Maine began expanding the program's reach and emphasis by offering the Savvy Caregiver curriculum to caregivers of individuals with intellectual and developmental disabilities (IDD). This targeted outreach initiative was in response to strategies reflected in the Office of Aging and Disability Services' [State Plan on Aging](#) (FY 2012-2016) and the [State Plan for Alzheimer's Disease and Related Dementias in Maine](#). In the State Plan for Alzheimer's and Related Dementias in Maine, one recommendation is to "design a broad-based dementia and brain health public information campaign that includes grass-roots initiatives which address services to underserved populations."

Dementia-related services and programs are typically geared towards the general population with little acknowledgment of dementia's impact on individuals with IDD, particularly Down syndrome. Many families are the primary lifetime caregivers for adults with an IDD, so they face new challenges when

dementias occur and they need considerable support, such as effective education and training in management and care of dementia. Maine DHHS co-sponsored a statewide conference on IDD and dementia in May 2013 that brought together nationally recognized speakers and was attended by 250 professional caregivers. As a result of the conference, the Maine Development Disabilities Council has undertaken a statewide needs assessment of services for individuals with IDD and dementia. The final report from this project will be completed in mid-July 2014 and will contain recommendations for addressing barriers and gaps in services to individuals with IDD and dementia. The conference has directly resulted in increased discussion statewide of the unmet needs of these individuals, as well as raising awareness of the need for increased collaboration between the aging network and development disability network. Maine DHHS Office of Aging and Disability Services has a representative seat on the Maine Developmental Disabilities Council.

Results

Savvy Caregiver has been largely successful in Maine, expanding across the state and welcomed with a positive response from caregivers who are gaining improved skill sets.

Reach:

- From March 2009-2014, 196 Savvy Caregiver Part I trainings were delivered to 1,481 family caregivers supporting a person with dementia living at home in the community. Of those participants, 43 percent of the caregivers have been providing care for their person at home for three or more years.
- Since August 2011, a total of 184 caregivers have taken the Savvy Caregiver Part II course. Of those participants, 53 percent of caregivers have been caring for their person at home three or more years.
- Caregivers from all of Maine's 16 counties have participated in Savvy Caregiver Part I, with 56 percent of these family caregivers living in rural communities.

Effectiveness:

- Pre- and post-test data on Savvy Caregiver Part I indicate statistically significant improvement in caregivers' sense of personal gain derived from increased confidence within their caregiving situation and enhanced sense of self-efficacy in their ability to respond to disruptive behavior within five months of the program. They experienced a reduction in depressive symptoms and negative reactions to the behavior of the person for whom they are providing care. These outcomes were sustained at 12 months.
- Outcomes at five-months post-Savvy Caregiver Program Part II suggest that course participants experience improved competence in caregiving skills even as the person for whom they are providing care moves into more challenging stages of dementia, personal gain in their relationship with said person and in the caregiver role, improved confidence to respond to disruptive behavior, reduced symptoms of depression, and improved mood.
- Since introducing the Savvy Caregiver program in Maine, there has been an overwhelmingly positive response from participants. Ninety-nine percent of caregivers reported through their evaluations that they would recommend this program to others.

Lessons Learned

The project resulted in a number of lessons learned, for example, to maintain fidelity of project trainers and to explore alternative delivery methods.

- To ensure adherence to the evidence-based program, have an independent contractor monitor project trainers.
- Savvy Caregiver Part II should be scheduled about five months after Part I and in the same geographical location. Statewide agencies often report that recruitment for Part II is labor intensive, and timing of the training does not work caregiver schedules as respite is more challenging given the disease's progression. This is especially problematic in rural areas where there are only small clusters of Part II participants from which to draw.
- Alternative delivery methods should be explored as substitutions for face-to-face encounters because caregivers are often challenged with leaving the person for whom they are providing care, particularly as the disease progresses. In addition to online delivery, the project should be considered for translation to prevent language barriers. In parts of Maine, there are significant French-speaking populations.

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¹ U.S. Department of Health and Human Services. Office of Disease Prevention and Health Promotion. Healthy People 2020. Washington, DC. Available at <http://healthypeople.gov/2020/topicsobjectives2020/overview.aspx?topicid=7>. Accessed 7-15-2014.

² Alzheimer's Association. "2012 Alzheimer's Disease Facts and Figures." *Alzheimer's & Dementia*, Vol. 8, Issue 2; p. 25. Available at: https://www.alz.org/downloads/facts_figures_2012.pdf. Accessed 4-9-2014.

³ University of Southern Maine Muskie School of Public Service, Maine Department of Health and Human Services Office of Elderly Services. "Caring for People with Alzheimer's Disease or Dementia in Maine." Available at: http://www.maine.gov/dhhs/oads/aging/alz/alzheimer/alzheimers_brief.pdf. Accessed 3-31-2014.

⁴ University of Southern Maine Muskie School of Public Service, Maine Department of Health and Human Services Office of Aging and Disability Services. "Dementia in Maine: Characteristics, Care, and Cost Across Settings." Available at: <http://www.maine.gov/dhhs/oads/policy/documents/FINALDementiaChartBook20132014-01-14.docx>. Accessed 7-15-2014.

⁵ Hurd MD, Martorell P, Delavande A, Mullen KJ, Langa KM. 2013. "Monetary costs of dementia in the United States." *New England Journal of Medicine*, 368, 1326-34. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/23550670>. Accessed 7-15-2014.

⁶ Scharf L, Bell PA, Smith SA. 2006. "Number of training sessions does not change program effectiveness: Evaluation of formats of one, two, or three sessions for the Alzheimer's Savvy Caregiver Training Program." *Dementia: The International Journal of Social Research and Practice*, 5, 559-569. Available at: <http://dem.sagepub.com/content/5/4/559.short>. Accessed 3-14-2014.

⁷ Smith SA, Bell PA. "Examining the effectiveness of the Savvy Caregiver Program among rural Colorado residents." *Rural and Remote Health* 5 (online) 2005: 466. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/16162076>. Accessed 3-17-2014.