
Report to

The Vermont Legislature

**Annual Report of the
Commission on Alzheimer's Disease
And Related Disorders**

For Fiscal Year 2016

In accordance with Act 28 (2015), an Act related to the membership of the
Commission on Alzheimer's Disease and Related Disorders

Submitted To: Senate Committee on Health and Welfare
House Committee on Human Services

Submitted By: Martha Richardson, Chair
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VERMONT

AGENCY OF HUMAN SERVICES

Department of Disabilities, Aging and Independent Living

Governor's Commission on Alzheimer's Disease and Related Disorders

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Overview: The State of Alzheimer's and Dementia in Vermont

Prevalence: Over 5 million Americans, including over 12,000 Vermonters, are living with Alzheimer's. This is expected to increase 42% to 17,000 by 2025.

Mortality: Alzheimer's is the 5th leading cause of death in Vermont, and Vermont has the 4th highest Alzheimer's death rate in America. Although deaths from other major causes (heart disease, cancer, etc.) have decreased over the last decade, deaths from Alzheimer's have increased 71%.

Caregivers: In 2015, 30,000 Vermonters provided unpaid caregiving to people living with Alzheimer's and dementia, totaling 34 million hours at a value of \$417 million. But caregiving comes at a high price, with caregivers' physical and psychological health suffering and many struggling financially to pay for basic needs.

Cost: Not only does the disease burden families financially, but the entire nation pays the bill. The total cost of healthcare, long-term care and hospice for Alzheimer's in 2016 was estimated to be \$236 billion nationwide. By 2050, it will cost more than \$1 trillion. In Vermont alone, the Medicaid costs of caring for people with Alzheimer's in 2016 was \$96 million.

Our Charge in Vermont: Vermont is the second oldest state in the nation (by median age), with one in three Vermonters expected to be over 60 by 2030 and those over 80 expected to double. People are living longer but with more chronic and complex health conditions, Alzheimer's and dementia being foremost among them. Vermont currently lacks the capacity to adequately support the growing number of individuals with Alzheimer's or dementia and their families. We must work to raise awareness, strengthen our workforce, and engage our decision makers if we are to be prepared to fight this disease now and into the future. The Governor's Commission on Alzheimer's Disease and Related Disorders is proud to play a role in this critical effort.

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2016 Commission Activities & Findings

In 2016, the Commission and its members continued to focus efforts in three main areas of work:

- 1. Early Detection and Diagnosis**
- 2. Public Awareness, Education/Training, and Advocacy**
- 3. Enhancing Caregiver Support**

Below are a few highlight's of this year's efforts.

Early Detection and Diagnosis: For years Alzheimer's and dementia have been viewed as diseases of the elderly and rarely addressed until chronic symptoms begin to affect activities of daily life. However, research continues to emphasize the importance of early intervention for the effective development of disease modifying therapies.

- The Commission worked to strengthen connections with primary care offices to increase screenings and referrals. An educational article was submitted to physicians via the Vermont Medical Society's e-newsletter.
- The Vermont Department of Health worked with Commission members to include information about Alzheimer's in its Smoking & Brain Health initiative and implemented the Cognitive Impairment Module as part of the 2016 Behavioral Risk Factor Surveillance Survey, a telephone survey conducted annually among adults 18 and older.
- Commission members provided information to the primary care audience at the BluePrint for Health conference and the Geriatrics Conference.

Advocacy, Public Awareness, Education/Training: Despite rising concern regarding the increasing prevalence of ADRD and the growing healthcare costs associated with the disease, significant stigma and misunderstanding still exists. It is critical that our state develop the knowledge and understanding needed to address the needs of those impacted today and in the future.

- Commission members hosted and participated in Alzheimer's Awareness and Advocacy Day at the Statehouse on March 30, 2016, and members met with their senators and representatives to share their stories and raise awareness.

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- DAIL Commissioner Monica Hutt asked the Commission to identify best practices from across the country. Recognizing the lack of specific dementia-related training for long-term care professionals in Vermont, the Commission began by reviewing statutes from various states and met with leaders in the Division of Licensing and Protection to explore opportunities to improve dementia specific training in Vermont.

Enhancing Caregiver Support: National and state information indicates that as many as half of families receiving a dementia diagnosis receive little or no information or support for addressing the disease and its impact on the person and their family. The Commission is working to combat this trend.

- The Commission urged the five Area Agencies on Aging, who provide caregiver support and training, to develop regional resource lists for caregiver support. These lists now exist for each region and are shared with any family who comes to the agencies for support.
- The Commission promoted the state dementia respite grants, designed to provide support for caregivers to care for their own health. DAIL administers the grants and the five Area Agencies on Aging work with the families to distribute the funding appropriately. In State Fiscal Year 2016, 245 families received respite grants totaling \$250,000. 90% of caregivers statewide reported that the grant helped improve their health and ability to continue caring for their family member.
- The Commission's 2015 proposal for a statewide assessment of caregiver needs was implemented as a survey conducted by UVM professor Kelly Melekis, MSW, PhD. The survey was conducted until December 1, 2016, so final results are not yet available. The Commission expects results will provide the information necessary to better identify what are currently viewed as viable and accessible resources and what are the gaps and needs of caregivers in our communities.

Moving Ahead: The Commission hopes to build on these activities and findings in 2017. With results from the survey, expanded relationships across departments and divisions, and enhanced advocacy, Commission members will forge ahead with the goal of increased detection, resources, and support. Additionally, with CMS's recent decision to implement dementia assessments and care planning as a reimbursable service in 2017, the Commission will work to educate the medical community and increase connections between healthcare and home and community based services for people with Alzheimer's and dementia.

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Recommendations for Legislative Action in 2017

Identify Needs: Institute a formal statewide needs assessment of those living with Alzheimer's or dementia, their families, and the care networks supporting them, to better understand the unique needs of our state given the growth of the aging population and growing prevalence of these diseases.

Invest in Understanding: Invest in a public education campaign to increase awareness of individuals, families, and the health care community with the goal of increasing early detection and diagnosis.

Increase Screenings & Referrals: Support universal utilization of Alzheimer's/dementia screening by primary care practitioners for patients 65 and older and increased referrals and collaborations with community service agencies for additional support.

Enhance Training: Develop statewide standards for dementia care training for the healthcare and caregiving workforce in all acute and long-term care settings (institutional, residential, and home based).

Encourage Caring: Provide encouragement and incentives to businesses who institute caregiver friendly workplace policies, such as flexible hours, paid caregiver leave, and teleworking.

Honor Families: Increase funding to support family caregivers through dementia respite grants, caregiver trainings, and caregiver counseling.

These recommendations are a starting point, but fighting Alzheimer's and dementia is a marathon effort and must have long-term goals and plans that includes collaboration at all phases and levels. In addition to the recommendations above, the Commission encourages the legislature to revisit the recommendations within the 2008 Vermont State Plan on Dementia. While the scope of the challenge has increased over the last eight years, and some good progress has been made, many of the plan's recommendations still apply and have perhaps become more urgent today.

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Commission Membership

NAME (alphabetical by last name)	REPRESENTATION
Mark Boutwell (appt. pending)	Area Agencies on Aging
Molly Dugan	SASH
Mary Fredette	Adult Day
Ellen Gagner	Family Caregivers
Walter Gundel	Physicians
Glenn Jarrett	Legal profession
Bianka LeGrand (appt. pending)	Residential Care
Constance Moser	Clergy
Janet Nunziata	UVM Center on Aging
Nancy Oakes (appt. pending)	Social Workers
Diane Olechna (appt. pending)	Home Health
Martha Richardson, Chair	Alzheimer's Association
Roberta Rood	Mental health provider
Linda Seaver (appt. pending)	Business community
Angela Smith-Dieng	DAIL
Rhonda Williams	VDH
Current Vacancies:	
Registered Nurse	In process of reviewing applications
Nursing Home Administrator	In process of seeking applications

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References

1. 2016 Vermont Alzheimer's Statistics, www.alz.org/facts.
2. "Smoking and Brain Health," Vermont Department of Health, 2014. http://healthvermont.gov/prevent/tobacco/documents/smoking_brainhealth_fs.pdf.
3. Vermont State Plan on Dementia, 2008. <http://www.ddas.vermont.gov/ddas-publications/publications-dementia/publications-dementia-documents/state-plan-dementia-exec-summary>.