
**Report to
The Vermont Legislature**

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

For Fiscal Year 2017

**In accordance with 2015 Act 28, 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
Commission on Alzheimer's Disease and Related Disorders**

**Prepared by: Martha Richardson, Chair
Commission on Alzheimer's Disease and Related Disorders**

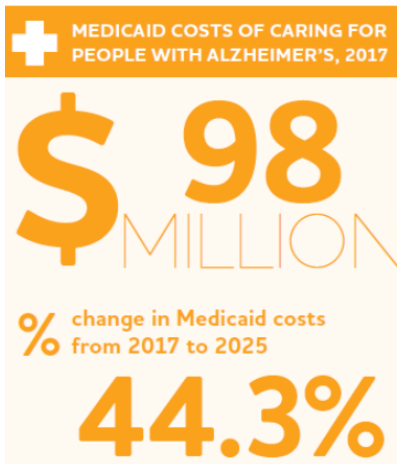
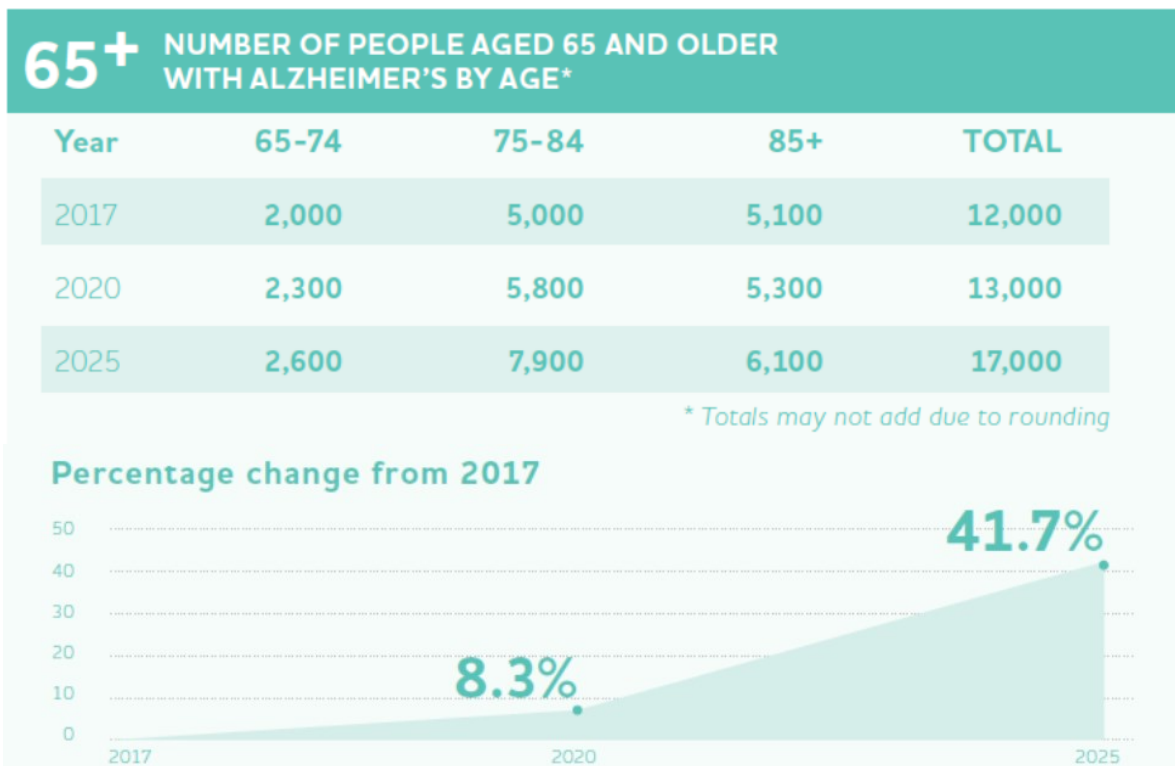
Report Date: December 21, 2017

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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 as of 2017. This is expected to increase 42% to 17,000 by 2025.



COST: In Vermont alone, the Medicaid costs of caring for people with Alzheimer's in 2017 was \$98 million and is projected to increase by 44% to \$141 million by 2025.

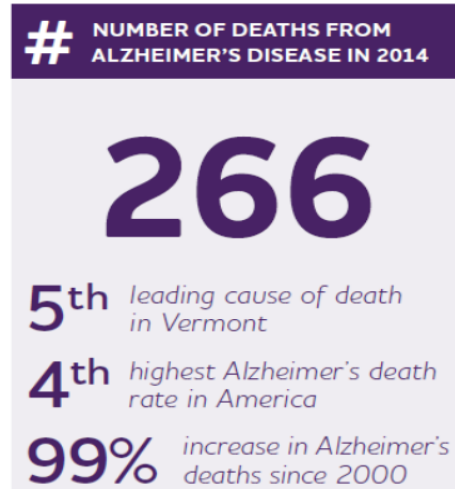
The total cost of healthcare, long-term care and hospice for Alzheimer's in 2017 was estimated to be \$259 billion nationwide.



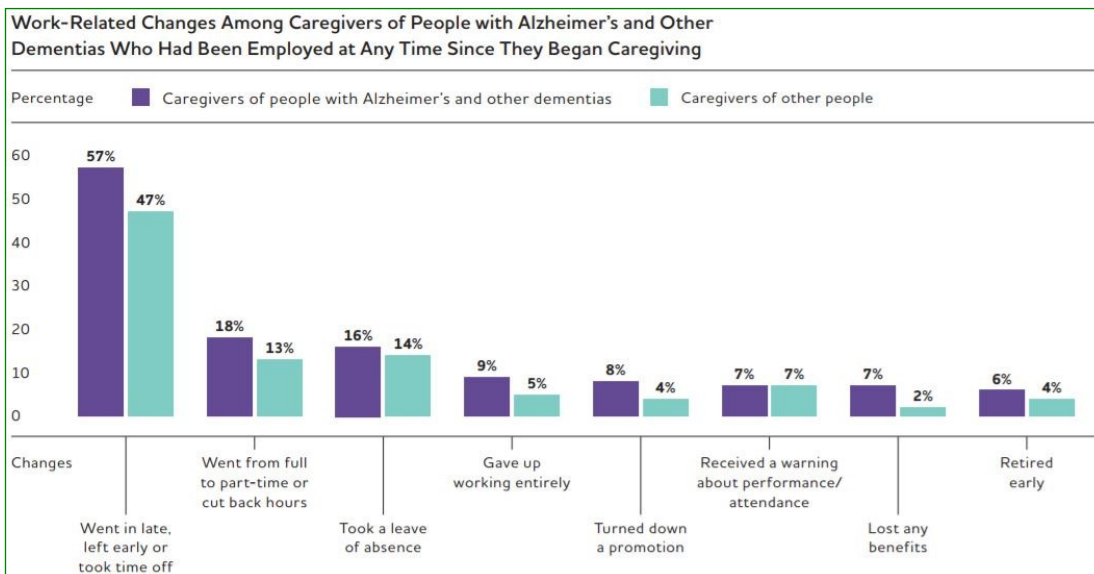
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MORTALITY: Alzheimer's is the 5th leading cause of death in Vermont, and Vermont has the 4th highest Alzheimer's death rate in America. Although deaths from other major causes (heart disease, cancer, etc.) have decreased over the last decade, deaths from Alzheimer's have increased 99% since 2000.



CAREGIVERS: In 2016, approximately 30,000 Vermonters provided unpaid caregiving to people living with Alzheimer's and dementia, totaling 34 million hours at a value of \$430 million. But caregiving comes at a high price, with caregivers' physical and psychological health suffering and many struggling financially to pay for basic needs. Caregivers suffer loss of wages, health insurance and other job benefits, retirement savings or investment, and Social Security benefits. 10 million caregivers aged 50+ who care for their parents lose an estimated \$3 trillion in wages, pensions, retirement funds, and benefits, impacting the entire workforce.



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OUR CHARGE IN VERMONT: Alzheimer's is a public health issue that needs a coordinated and comprehensive response. 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 do more to educate around prevention, expand and strengthen our workforce, and engage our decision makers if we are to be prepared to meet the needs of Vermonters now and into the future. The Governor's Commission on Alzheimer's Disease and Related Disorders (ADRD) is proud to play a role in this critical effort. **We focus on 1) increasing awareness of the disease, with a focus on early detection, 2) advocacy for resources and training of providers across the continuum of care, and 3) supporting the growing number of family caregivers. Below are highlights of the Commission's work in 2017:**

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.

- After reviewing statutes from various states and meeting with leaders in the Division of Licensing and Protection and Vermont Health Care Association to explore opportunities to improve dementia specific training in Vermont, the Commission hosted a meeting of 30 stakeholders, including administrators of Long-term Care Facilities, dementia care practitioners, dementia training educators, advocates and family caregivers to identify current dementia training taking place in the state, key successes and challenges in the field, and important areas for improvement to the dementia training standards in current state regulations. Participants overwhelmingly agreed that increasing and enhancing dementia training statewide would improve quality of care.

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ADVOCACY, PUBLIC AWARENESS, EDUCATION/TRAINING (CONTINUED):

- Commission members hosted and participated in Alzheimer's Awareness and Advocacy Day at the Statehouse on April 6, 2017, and members met with Lieutenant Governor Zuckerman as well as their senators and representatives to share their stories and raise awareness.
- Commission members provided information, resources and stories to the Burlington Free Press for a [Brain Awareness Month Special Section](#) during the month of June.

PREVENTION, 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 to allow families the time to plan and prepare for future needs.

- The 2016 Behavioral Risk Factor Surveillance Survey asked adults about cognitive decline. 10% of adults age 45 or older reported experiencing worsening confusion and memory loss in the last year. Of those who reported cognitive decline, less than half (46%) reported that they or someone else had discussed this with a health care professional.
- Commission members met with Vermont Department of Health Commissioner Dr. Mark Levine and Vermont Department of Disabilities, Aging and Independent Living Commissioner Monica Hutt to advocate for an Alzheimer's Action Plan led by the Department of Health and the Department of Disabilities, Aging and Independent Living. The Departments agreed and have begun development of a plan that will include Grand Rounds education on dementia, including its links to chronic disease, such as vascular risk factors, increased media focus on Healthy Brain Month, and workforce development/training for those interacting with people with dementia. VDH and DAIL will use [The Healthy Brain Initiative: A National Public Health Road Map to Maintaining Cognitive Health](#), developed by the CDC, as a guiding tool.
- Commission members provided information to the primary care audience at the Blueprint for Health conference and the Geriatrics Conference.

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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.

- In 2016, the Commission worked with Dr. Kelly Melekis to develop a statewide survey of caregivers of people with ADRD. Dr. Melekis presented the resulting report, "[Caring for Caregivers in Vermont](#)," to the Commission in July, 2017, which included a focus on: 1) increasing affordability of dementia care, 2) increasing and coordinating access to services and supports for caregivers, and 3) providing more skills training to caregivers, both paid and unpaid, around dementia care.
- Commission members submitted editorial articles published in six Vermont publications to raise awareness about November as National Family Caregiver Month, the results of the caregiver survey, and the supports available to family caregivers in Vermont (Ex: [Caring for Caregivers](#), Times Argus, 11/14).
- Commission members are also taking steps in their individual organizations to address caregiver support. For example, the 2018 Gerontology Symposium will include a special track for family caregivers, *Caregiving for Persons with Dementia: Families and Professionals Working Together*.

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Recommendations for Legislative Action in 2018

The ADRD Commission recognizes the inherent challenge in this work. These are complicated diseases and require a coordinated, multi-pronged approach and a public-private partnership to address effectively. As a state, Vermont must have long-term goals and plans that include collaboration at all phases and levels. While working on the long-term vision of a world without Alzheimer's, the ADRD Commission believes that the following short-term recommendations are critical to our success:

1. SUPPORT PUBLIC UNDERSTANDING OF ALZHEIMER'S & DEMENTIA WITH \$100,000 TOWARD A

PUBLIC HEALTH CAMPAIGN ON BRAIN HEALTH AND DEMENTIA: With a growing body of research showing the importance of physical activity, mental stimulation, and social activity in building a cognitive reserve, as well as the critical need for early detection and diagnosis, now is the time to be educating across the lifespan and across sectors (medical, social, business) to impact the future.

2. INCREASE DEMENTIA TRAINING HOURS AND COMPETENCIES FOR STAFF IN LONG TERM CARE

FACILITIES: Develop statewide standards for dementia care training for the healthcare and caregiving workforce in acute and long-term care settings (institutional, residential, and home based). We specifically recommend increasing the dementia training hours and competency requirements in nursing home and residential care home regulations as the starting point, building out additional training for other settings from there.

3. INCREASE SUPPORT FOR FAMILY CAREGIVERS WITH AN ADDITIONAL \$100,000 FOR

TRAINING AND RESPITE: Increase funding to support family caregivers through caregiver trainings, psycho-social support and dementia respite grants, all of which help reduce caregiver stress, improve caregiving skills, and support people living with dementia to remain at home. Provide incentives to businesses who institute caregiver-friendly workplace policies such as in-house training/counseling services, flexible hours, teleworking, and family leave policies that include caring for relatives with dementia.

4. PROTECT MEDICAID, which helps thousands of Vermonters living with dementia pay for long-term care.

In addition to the recommendations above, the Commission encourages the legislature to revisit the recommendations in the [2008 Vermont State Plan on Dementia](#). While the scope of the challenge has increased over the last decade, and some good progress has been made, many of the recommendations still apply and have become more critical today.



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Commission Membership

NAME (alphabetical by last name)	REPRESENTATION
Mohamed Basha	Registered Nurse
Mark Boutwell (appt. pending)	Area Agencies on Aging
Molly Dugan	SASH
Ellen Gagner	Family Caregivers
Walter Gundel	Physicians
Glenn Jarrett	Legal profession
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
Joyce Touchette	Residential Care
Rhonda Williams	VDH
Current Vacancies:	
Nursing Home Administrator	In process of seeking applications
Adult Day Provider	In process of seeking applications

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References

1. [2017 Vermont Alzheimer's Statistics](https://alz.org/documents_custom/facts_2017/statesheet_vermont.pdf?type=interior_map&facts=undefined&facts=facts) (https://alz.org/documents_custom/facts_2017/statesheet_vermont.pdf?type=interior_map&facts=undefined&facts=facts).
2. [Caregiver Statistics: Work and Caregiving](https://www.caregiver.org/caregiver-statistics-work-and-caregiving), Family Caregiver Alliance, 2016 (https://www.caregiver.org/caregiver-statistics-work-and-caregiving).
3. [A Statewide Survey: Caring for Caregivers in Vermont](http://asd.vermont.gov/sites/asd/files/documents/2017%20Caregiver%20Survey%20Report%20-%20Kelly%20Melekis.pdf) (http://asd.vermont.gov/sites/asd/files/documents/2017%20Caregiver%20Survey%20Report%20-%20Kelly%20Melekis.pdf), July, 2017.
4. [Burlington Free Press Brain Awareness Month Special Section](https://www.ifoldsflip.com/i/832872-brain-awareness-month-2017), (https://www.ifoldsflip.com/i/832872-brain-awareness-month-2017) June 2017.
5. [The Healthy Brain Initiative: A National Public Health Road Map to Maintaining Cognitive Health](https://www.cdc.gov/aging/healthybrain/roadmap.htm) (https://www.cdc.gov/aging/healthybrain/roadmap.htm), 2013.
6. [Vermont State Plan on Dementia](https://www.alz.org/national/documents/Vermont_State_Plan.pdf) (https://www.alz.org/national/documents/Vermont_State_Plan.pdf), 2008.