
**Report to
The Vermont Legislature**

**Governor's Commission on Alzheimer's Disease and
Related Disorders 2019 Annual Report**

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

Submitted by: The Governor's Commission on Alzheimer's Disease
and Related Disorders

Report Date: January 15, 2020



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

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Recommendations for Legislative Action in 2019

PREVALENCE:

Over 13,000 Vermonters age 65 and older are living with Alzheimer's Disease. By 2025 this number is estimated to increase by 30.8% to 17,000. 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.

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 recommendations are critical to our success:

1. VERMONT NEEDS TO PASS A BILL TO ADDRESS THE CRITICAL HEALTH CARE

CONCERN THAT IS ALZHEIMER'S DISEASE: Once signed into law such a bill will help tens of thousands of Vermonters and their families who are living with Alzheimer's and Dementia gain access to statewide diagnosis, treatment, and supports; while ensuring Vermont's healthcare systems are better prepared to handle the most under-recognized threat to public health in the 21st century.

2. VERMONT NEEDS TO INCREASE SUPPORT FOR FAMILY CAREGIVERS WITH AN ADDITIONAL FUNDING FOR EVIDENCE-BASED ASSESSMENT AND TO EXPAND

SERVICES: Successful assessment and support of caregivers is essential to identify strategies and services to improve their ability to provide care.

3. VERMONT NEEDS TO SUPPORT "DEMENTIA FRIENDLY VERMONT" INITIATIVE

WITH FUNDING FOR DEDICATED STAFF: With assigned agency oversight, the [Dementia Friendly America](#) model will build a cross-sector community network to guide individuals with the disease, their families and caregivers from diagnosis to caregiver support, and provides supportive options that foster the ability of people living with dementia to remain in community and thrive in day to day living.

4. VERMONT NEEDS TO SUPPORT PUBLIC UNDERSTANDING OF ALZHEIMER'S & DEMENTIA WITH ADDITIONAL FUNDING TOWARD A PUBLIC HEALTH CAMPAIGN ON BRAIN HEALTH AND DEMENTIA AND FUNDING FOR DEDICATED STAFF:

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 educate across the lifespan and across sectors.



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Recommendations for Legislative Action in 2019 (continued)

1. INCREASE SUPPORT FOR FAMILY CAREGIVERS WITH ADDITIONAL \$100,000 FOR EVIDENCE-BASED ASSESSMENT AND SERVICES:

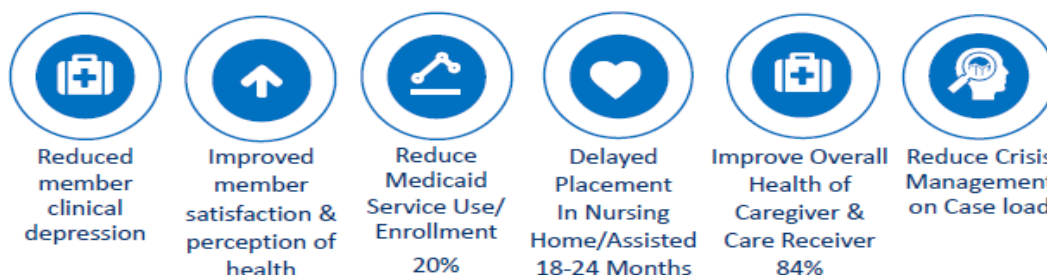
Funds to support this effort will expand the availability and improve the quality of the he following services

1. Psycho-social support and clinical counseling to reduce family caregiver stress.
2. Evidence-based education and skills training to support people living with dementia to remain at home.
3. Adult Day and in-home respite options to allow unpaid family caregivers to continue to work and take care of their own health needs.

The evidence-based [TCARE Assessment](#), a comprehensive system including software, assessment tools, decision algorithms, and a training and technical assistance program, is currently being piloted by the Northeast Kingdom Council on Aging. [In Washington State](#) where assessment, training and support have been effectively implemented using TCARE; family caregiver stress and burden is reduced up to 84%.

With the Legislative support of TCARE, Washington state has seen in 2 years, a delay in Nursing Home placement by 21 months; resulting in the reduction of Medicaid expenditures by \$20 million annually.

PROVEN OUTCOMES OF TCARE®



2. SUPPORT A “DEMENTIA FRIENDLY VERMONT” INITIATIVE WITH FUNDING FOR DEDICATED STAFF:

Dementia-friendly Communities is identified by the National Alzheimer's and



Dementia Resource Center as a key component in the framework for a dementia-capable workforce and Home and Community Based Service System. Using the data the Commission has already collected to determine readiness, strengths and gaps across the state, this initiative would be administered as a pilot program to prove its efficacy. It is critical that the State of Vermont ensure that all sectors of communities across Vermont are equipped to support people living with dementia and their caregivers.



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Recommendations for Legislative Action in 2019 (continued)

3. SUPPORT PUBLIC UNDERSTANDING OF ALZHEIMER'S & DEMENTIA WITH \$150,000 TOWARD A PUBLIC HEALTH CAMPAIGN ON BRAIN HEALTH AND DEMENTIA AND FUNDING FOR DEDICATED STAFF: DAIL and VDH have built a collaborative relationship over the last two years focusing on efforts to address challenges of ADRD, but resources are limited. With the Healthy Brain Initiative as a guide, public messaging about brain health, maintaining cognitive reserve, and the early signs of cognitive decline and dementia is critical. With additional funding support, this work can achieve a bigger impact through more focused, sustainable initiatives.



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 remain relevant and critical today.

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

VERMONT STATISTICS:



NUMBER OF DEATHS FROM
ALZHEIMER'S DISEASE (2017)

370

Highest *Alzheimer's death rate in America*
176% *increase in Alzheimer's deaths since 2000*



HOSPICE
(2016)

480

of people in hospice
with a primary diagnosis
of dementia

17%

of people in hospice have a
primary diagnosis of dementia



HOSPITALS
(2015)

1,455

of emergency department
visits per 1,000 people
with dementia

18.8%

dementia patient
hospital readmission rate

65+ NUMBER OF PEOPLE AGED 65 AND
OLDER WITH ALZHEIMER'S BY AGE*

* Totals may not add due to rounding

Year	65-74	75-84	85+	TOTAL
2019	2,200	5,500	5,200	13,000
2025	2,600	7,900	6,100	17,000

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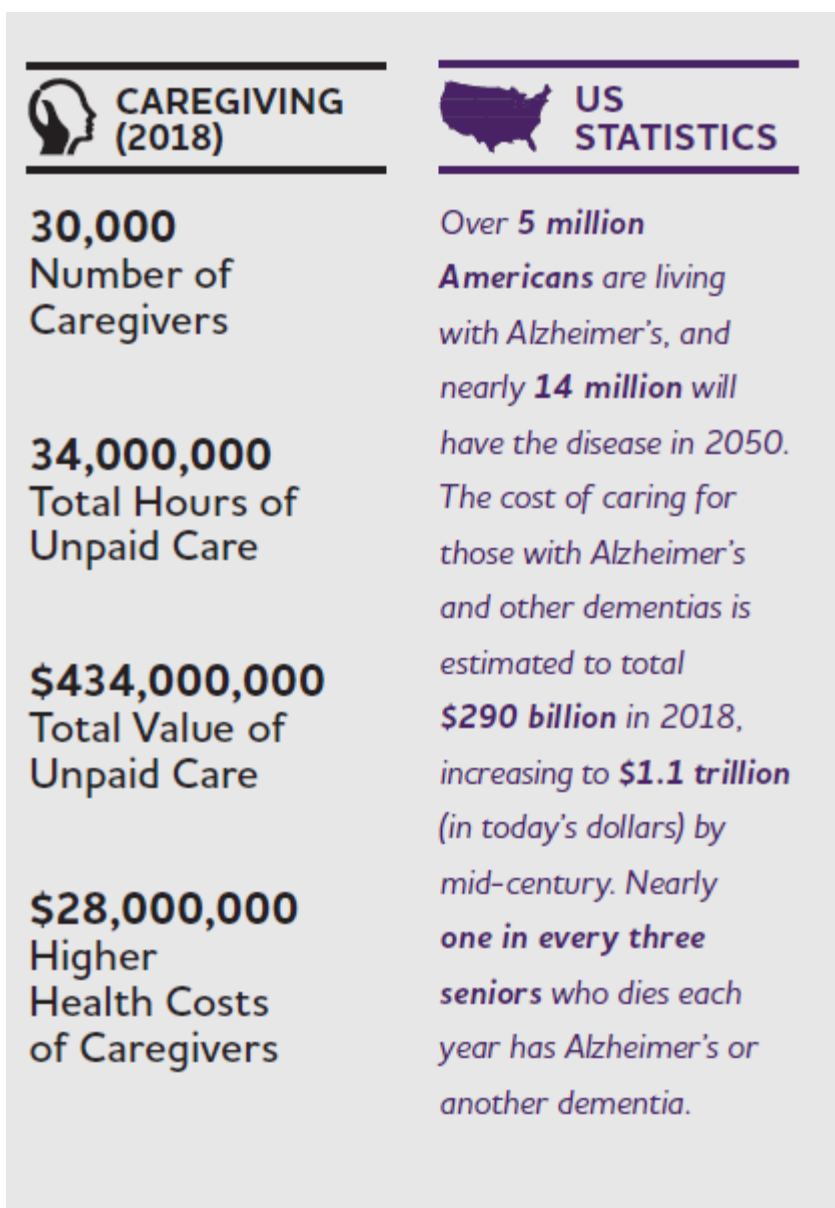
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Cost of Care in Vermont:

Medicare spent \$21,071 per capita on people with dementia in 2018.

Medicaid spent \$110 million on people with dementia in 2018.

Medicaid costs to care for people with dementia are expected to increase 31.7% by 2025.



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2019 Commission Findings & Activities



OUR CHARGE IN VERMONT: 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 2019:**

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.

- In 2019 the Commission chose the Dementia Friendly America Initiative as our focus. The commission acts as a cross-sector team that has collected data to identify the strengths and gaps in the current network of system and supports serving individuals with ADRD. Using the Dementia Friendly America model, the commission will create partnerships across the state to foster sector specific dementia friendly practices across their communities.
- Commission members provided information and resources to city leaders in St. Albans and Newport as part of a presentation on Dementia Friendly Communities at City Council meetings.
- Commission members hosted and participated in *Alzheimer's Awareness and Advocacy Day* at the State house on April 9 2019; members met with their senators and representatives to share stories and raise awareness.

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

- In 2018, the Commission made recommendations for Dementia Care Training regulations to Department of Licensing and Protection (DLP). As follow up, this year Commission Co-Chairs participated in a call with consultants contracted by DLP to provide stakeholder input on this effort.
- Commission members invited educators from UVM Memory Program to present on the development of a Caregiver Resource center and the 'CARERS' (Coaching, Advocacy, Respite, Education, Relationship, and Simulation) training program.
- Commission members participated in *Aging in Vermont: Exploring Solutions for Social Isolation* Conference by facilitating a session on 'Improving Social Connectedness for Individuals with ADRD and their caregivers', as well as a session on Memory Cafes.
- Commission members attended the Geriatrics Conference in 2019. Among the topics discussed was current telehealth practices , panel contributors discussed advantages and challenges at a Memory care residence where this service is being piloted.

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 (BRFSS) asked adults about cognitive decline. Commission members advocated alongside the Alzheimer's Association for inclusion of the cognitive decline module in the 2020 BRFSS.
- Commission members are participating in a working group to develop a "Hub and Spoke" model to support early detection and diagnosis across Vermont via a more trained and confident primary care workforce; with strong connections to community supports for both planning and services.

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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.

- UVM Center on Aging hosted a Gerontology Symposium: Navigating End of Life Care and Transitions. A caregiver learning track was offered that featured workshops on Grief and Bereavement, Hospice considerations for families living with Dementia, as well as a presentation for professionals on navigating complex decision making when there are agents & guardians involved.
- Commission members attended the Aging in Vermont Conference at Killington Grand Hotel . AD RD relevant presentation topics included: AD RD Respite Volunteer programs, Statewide Supports and social engagement initiatives for individuals with dementia are their caregivers, opportunities for social engagement and support through Memory Cafes.
- The Tailored Caregiver Assessment and Referral (TCARE) tool is being piloted by the Northeast Kingdom Council on Aging. The TCARE protocol is designed to tailor services to the unique needs of each caregiver, thereby reducing depression and burden (i.e., objective, relationship, and stress burdens) associated with caregiving. TCARE provides a consistent, objective, and reliable screening and assessment process that identifies at-risk caregivers and allows care managers to target resources to those most in need and determine whether support and services are making a measurable difference to caregivers. The Commission will follow the progress of the pilot to advocate for its expansion statewide.

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Commission Membership

NAME (alphabetical by last name)	REPRESENTATION
Mohamed Basha	Registered Nurse
Mark Boutwell	Area Agencies on Aging
Senator Randy Brock	State Senate
Alecia Demario	Nursing Home Administrator
Molly Dugan	SASH- Support Services at Home
Grace Gilbert -Davis	Alzheimer's Association
Glenn Jarrett	Legal profession
Paula Johnson	Family Caregivers
Pastor Jeff Kelley	Clergy
Dr. Alexandra Messerli	Physicians
Representative Dan Noyes	State Legislature
Janet Nunziata	UVM Center on Aging
Roberta Rood	Mental health provider
Angela Smith-Dieng	Dept. of Disabilities, Aging, and Independent Living
Andrea Stauffenecker	Adult Day Provider
Rhonda Williams	Vermont Department of Health
Appointment Pending	Residential Care
Appointment Pending	Social Workers
Appointment Pending	Business community
Appointment Pending	Home Health

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References

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2. [Caregiver Statistics: Work and Caregiving](https://www.caregiver.org/caregiver-statistics-demographics), <https://www.caregiver.org/caregiver-statistics-demographics>
3. [Tailored Caregiver Assessment and Referral® \(TCARE®\)](https://acl.gov/sites/default/files/programs/2017-03/Tailored_Caregiver_Assessment_and_Referral_ISR_08_20-2014.pdf) https://acl.gov/sites/default/files/programs/2017-03/Tailored_Caregiver_Assessment_and_Referral_ISR_08_20-2014.pdf
4. [2014 Impact of using TCARE in Washington State](https://www.tailoredcare.com/solutions/medicaid/) <https://www.tailoredcare.com/solutions/medicaid/>
5. [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.
6. [UVM Memory Program](https://www.uvmhealth.org/medcenter/pages/departments-and-programs/memory-program.aspx) and [CARERS Program](https://www.mountsinai.on.ca/care/psych/patient-programs/geriatric-psychiatry/dementia-support/caregivers-and-family-members-caring-for-someone-dementia/carers/reitman-centre-carers-program)
<https://www.uvmhealth.org/medcenter/pages/departments-and-programs/memory-program.aspx>
<https://www.mountsinai.on.ca/care/psych/patient-programs/geriatric-psychiatry/dementia-support/caregivers-and-family-members-caring-for-someone-dementia/carers/reitman-centre-carers-program>