

Governor's Commission on Alzheimer's Disease and Related Disorders 2020 Annual Report ~ January 15, 2021

Recommendations for Legislative Action in 2021

OVERVIEW

Over 13,000 Vermonters 65 and older are living with Alzheimer's disease. By 2025, this number is estimated to increase by 30.8% to 17,000. Vermont is in the top five oldest states (by median age), with one in three Vermonters expected to be 60 or older by 2030, and the number of those over 80 expected to double. Vermonters are living longer but experiencing more chronic and complex health conditions, Alzheimer's and dementia being foremost among them. (See Page 5 for statistical graphics.)

This crucial public health issue needs a coordinated and comprehensive response. The State is setting long-term goals and securing additional federal funding. For example, in September, Vermont was one of 14 states selected for new BOLD grants through the Centers for Disease Control and Prevention (CDC) to build capacity for addressing Alzheimer's and brain health as a public health initiative. The three-year grant will strengthen infrastructure through partnership engagement and planning, input from [caregivers](#) and Vermonters impacted by dementia, surveillance, and workforce training for increasing knowledge, screening and diagnosis.

Covid-19 has amplified the challenges in an already stressed system, exacerbating a dire need for caregivers at all levels and having severe, disproportionate effects on the health, wellbeing and security of Vermonters with dementia, their families and caregivers. Alzheimer's patients have been isolated, often cut off from family, supports and programs, such as adult day centers, that in normal times keep them stimulated and connected to community. Programs such as adult day centers also provide respite for overburdened caregivers, whose long-term separation from family members has caused significant stress and worry. Also stressing caregivers are additional household responsibilities, the risk of household Covid-19 infections, a decline in their own wellness, and financial instability.

Much work is already underway to overcome this isolation and barriers to service via technology, but more financial support is needed to build expertise and deliver it to vulnerable Vermonters in all parts of the state.

The 2020 Vermont Action Plan for Aging Well, included in the 2020 Older Vermonters Act, will provide strategies and cultivate partnerships to promote aging with health, choice and dignity to establish and maintain an age-friendly state for all Vermonters. Its creation will bring together a wide variety of stakeholders, including older Vermonters, adults with disabilities, and their families; local government officials, health care and other service providers, employers, community groups, foundations, researchers and others. The plan will include:

- A review of Medicaid reimbursement rates paid to home- and community-based service providers.
- Performance measures that address the needs of individuals with Alzheimer's, including memory care services and housing, and access to early diagnosis.

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To address this pervasive health issue, the Governor's Commission on Alzheimer's Disease and Related Dementias (ADRD) is recommending a focus on education and funding in three areas:

- Collaboration
- Technology
- Infrastructure

1. COLLABORATION TO INCREASE SCREENING, DIAGNOSIS AND CARE

VERMONT MUST ADDRESS THE CRITICAL HEALTH CARE, ECONOMIC AND SOCIETAL CONCERNS PRESENTED BY ALZHEIMER'S DISEASE: People and families experiencing ADRD are often overwhelmed, struggling financially and charting their own course. Essential lines of communication and collaboration must be established so that families, health professionals, social workers, community organizations and researchers can learn from each other about dementia's unique course, share best practices for patients and their support teams, use appropriate medications, and develop new solutions for the many challenges ADRD presents. Only a system of formalized collaborative support for those impacted by ADRD will provide the comprehensive wrap-around services needed to address this public health issue. The Enhancing the Care and Health of Older Adults Living with Dementia (ECHO-D) project that many Commission members participated in throughout 2019 and 2020 is evidence of the success of such a model. Members have been involved in planning for a Vermont-specific ECHO project on Dementia Screening, Diagnosis and Care starting in the summer of 2021.

State resources are necessary for the Commission to support this and future trainings for a successful interdisciplinary approach.

2. TECHNOLOGY TO INCREASE MEDICAL AND SOCIAL SUPPORTS

VERMONT NEEDS TO INCREASE SUPPORT FOR FAMILY CAREGIVERS WITH IMPROVED COMMUNICATION AND ACCESS TO TECHNOLOGY: When human resources are limited, either by supply or geography, technology can serve a critical role in connecting those with ADRD, their families and caregivers. Covid-19 has increased the need for these supports and made clear current deficiencies, especially as it has limited in-person interactions and forced the closing of specific community resources. The cost of personal technology, such as electronic tablets, and training in how to use it – particularly for those who have cognitive issues – is often out of reach. Community-based organizations such as Home Health, SASH affordable housing providers and Area Agencies on Aging have begun working with clients to facilitate the transition to virtual platforms for medical appointments, prevention programs and social connection. These efforts require additional money to make technology accessible to homebound clients and those lacking the economic wherewithal to obtain it themselves. Training and technical assistance for clients and caregivers can ensure successful virtual connections, but this, too, requires financial support.

Community organizations require funding for additional capacity to build and deliver this expertise.



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Recommendations for Legislative Action in 2021 (continued)

3. INFRASTRUCTURE TO BUILD A DEMENTIA AND AGE FRIENDLY VERMONT

VERMONT NEEDS TO SUPPORT THE “DEMENTIA FRIENDLY VERMONT” INITIATIVE WITH FUNDING FOR DEDICATED STAFF: The State of Vermont must ensure that all sectors of communities across Vermont are equipped to support people living with dementia and their caregivers. National and state data indicate that as many as half of families with a loved one receiving a dementia diagnosis receive little or no information about the disease or support for its impact on them, and this deficiency is wide-ranging. To facilitate access to the broad scope of existing programs and services in Vermont, the Commission recommends creation of a Dementia Resource Center as a key component in the framework for a dementia-capable workforce and Home and Community Based Service System in the state's infrastructure to address dementia through a trained and capable workforce and HCBS system.. Using data already collected to determine strengths, gaps and readiness across the state, a pilot program would be run to demonstrate its efficacy. With assigned agency oversight, the [Dementia Friendly America](#) model will build a cross-sector community network equipped to guide individuals with the disease, their families and caregivers from diagnosis through advanced disease stage. With a full-time coordinator, the network will:

- Provide resources that foster the ability of people living with dementia to remain in their community and thrive in day-to-day living.
- Provide resources to caregivers and family members for making decisions and accessing education, respite, mental health and financial support.
- Coordinate efforts with the Department of Aging and Independent Living (DAIL) and Department of Health on an Age-Friendly state designation making communities desirable for Vermonters of all ages.

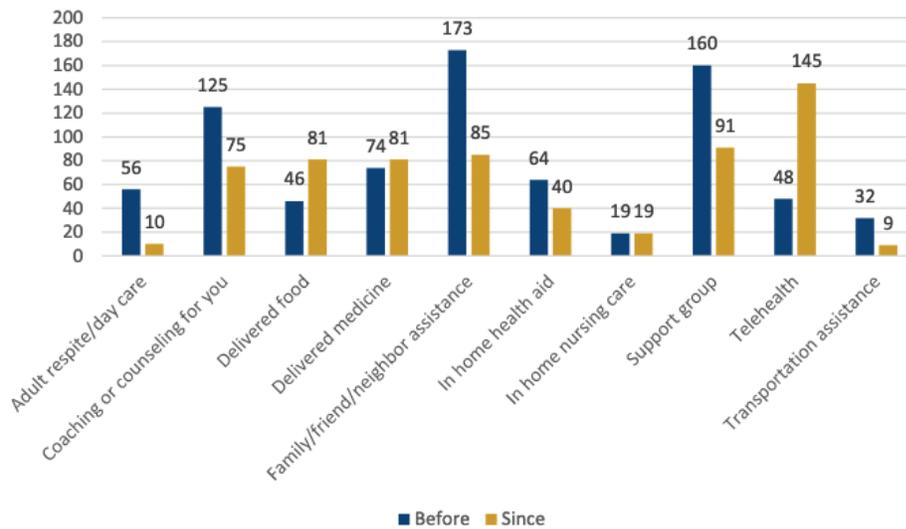


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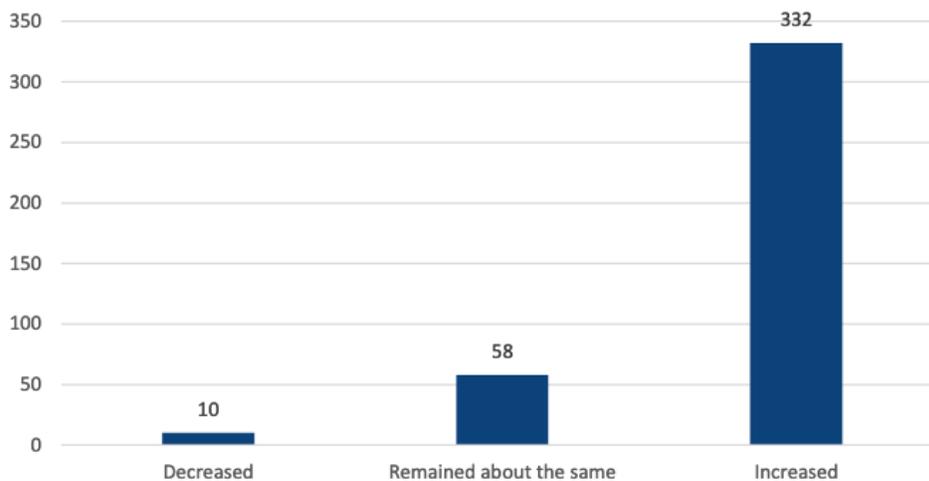
Recommendations for Legislative Action in 2021 (continued)

Finally, the Commission requests that the Legislature hold a briefing on Dementia: [Past Progress](#), Current Challenges and Future Needs. This will allow the Commission to share data and highlight our priorities, the potential of the Older Vermonters Act and the resources needed to build capacity across the state among impacted populations.

Caregiver support received before and since the Covid-19 outbreak



Change in stress associated with caregiving (n=400)



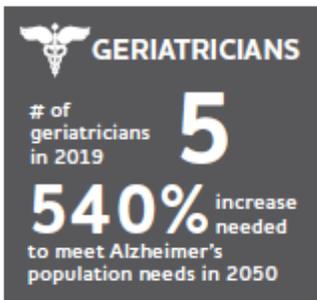
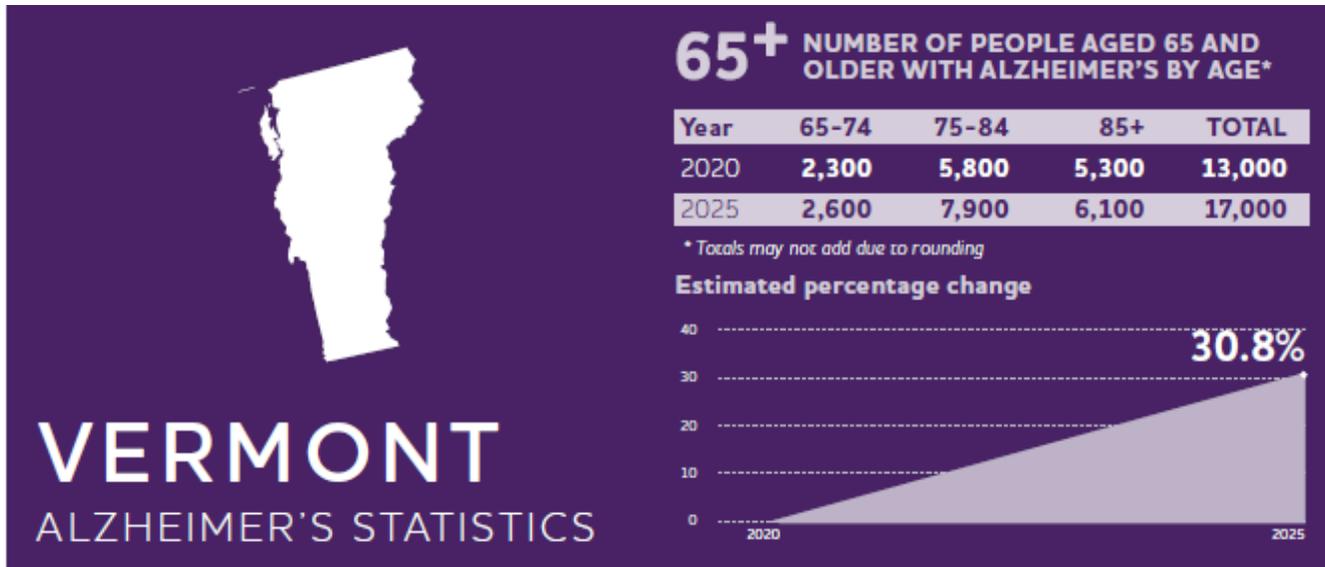
Rosalynn Carter Institute for Caregiving, October 2020 Survey



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

VERMONT STATISTICS:

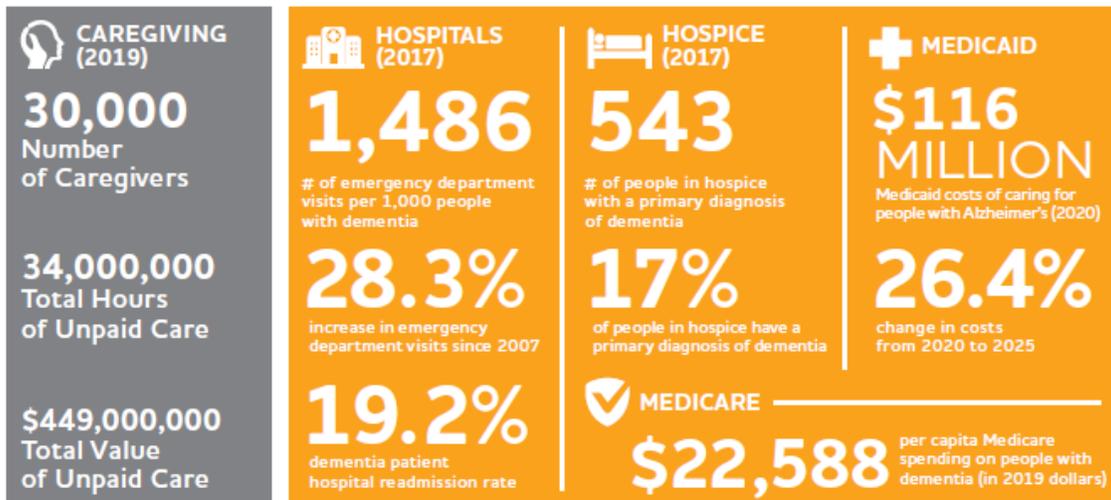


Cost of Care in Vermont:

Medicare spent \$22,588 per capita on people with dementia in 2019.

Medicaid spent \$116 million on people with dementia in 2019 .

Medicaid costs to care for people with dementia are expected to increase 26.4% by 2025.



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Commission Membership 2020

NAME (alphabetical by last name)	REPRESENTATION
Mohamed Basha	Registered Nurses
Mark Boutwell	Area Agencies on Aging
Senator Randy Brock	State Senate
Susan Brooks	Business Community
Alecia Demario	Nursing Home Administrators
Grace Gilbert-Davis	Alzheimer's Association
Molly Dugan	SASH Support Services at Home
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
Stephanie Parker	Residential Care
Roberta Rood	Mental Health Providers
Pamela Smith	Social Workers
Angela Smith-Dieng	Dept. of Disabilities, Aging, and Independent Living
Andrea Stauffenecker	Adult Day Providers
Deborah Wesley	Home Health Providers
Rhonda Williams	Vermont Department of Health

Seeking Applications for: Clergy & Social Worker for 2021

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References

1. [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
2. [Caregiver Statistics: Work and Caregiving](https://www.caregiver.org/caregiver-statistics-demographics), <https://www.caregiver.org/caregiver-statistics-demographics>
3. [Dementia Friendly America](https://www.dfamerica.org/) <https://www.dfamerica.org/>
4. [Tri State Learning Collaborative Project ECHO-D](https://agefriendly.community/project-echo-d/) <https://agefriendly.community/project-echo-d/>
5. [Rosalynn Carter Institute Caregiver Survey, October 2020](https://www.rosalynncarter.org/wp-content/uploads/2020/10/Caregivers-in-Crisis-Report-October-2020-10-22-20.pdf) <https://www.rosalynncarter.org/wp-content/uploads/2020/10/Caregivers-in-Crisis-Report-October-2020-10-22-20.pdf>