

My name is Meg Polyte and I'm the Policy Director for the Vermont Chapter of the Alzheimer's Association. Thank you for inviting me to share an overview of our work.

The Alzheimer's Association leads the way to end Alzheimer's and all other dementia — by accelerating global research, driving risk reduction and early detection, and maximizing quality care and support. Our vision is a world without Alzheimer's and all other dementia. The Vermont Chapter is one of 70 local chapters across the country.

We do this work on behalf of more than 6 million Americans, including over 13,000 Vermonters over the age of 65, living with Alzheimer's. This number doesn't reflect the whole picture as it does not count those under the age of 65 who have been diagnosed, nor those who do not have a diagnosis or have been misdiagnosed. The number of Vermonters with Alzheimer's is projected to rise by more than thirty percent to 17,000 in the next two years.

I also advocate for the 26,000 unpaid family caregivers here in Vermont. In 2021 these unpaid dementia caregivers provided 37 million hours of care with a value of more than \$758 million dollars. Over two-thirds of family caregivers are women and a substantial number are 'sandwich generation,' meaning they are caring for a parent and children at the same time. Compared with caregivers of people without dementia, twice as many caregivers of those with dementia indicate substantial emotional, financial and physical difficulties. Many are forced to reduce their hours at work and over 10% leave the workplace to fulfill caregiving responsibilities.

The costs of health care and long-term care for individuals living with Alzheimer's or other dementias are substantial, and dementia is one of the costliest conditions to society. In 2022, Alzheimer's and other dementias cost the nation \$321 billion, including \$206 billion in Medicare and Medicaid payments combined. In 2021, Vermont's per capita Medicare spending on people with dementia was \$24,091. Of the total lifetime cost of caring for someone with dementia, 70% is borne by families — either through out-of-pocket health and long-term care expenses or from the value of unpaid care.

One in three seniors dies with Alzheimer's or another dementia. It kills more than breast cancer and prostate cancer combined. And there is no cure.

I share all this to highlight the importance of programs and investments for Vermonters impacted by dementia and because I want you to know you are not alone. This is a national challenge and it will take work on the state and federal level to support those with dementia and their family caregivers. You can dig much deeper into Alzheimer's facts and figures at <https://www.alz.org/alzheimers-dementia/facts-figures> and I've attached the 2022 Vermont facts to my testimony. These will be updated to reflect the latest data in March.

So what does the Vermont Chapter actually do? We oversee development events, like our four Walks to End Alzheimer's, to raise funds that sustain the care, support and research efforts of the Alzheimer's Association. More importantly they ensure the

programs we offer here in Vermont are always free of charge. They also play an important role in building awareness and decreasing the stigma associated with dementia. Our Program Manager focuses on outreach and trains and supports our volunteers to ensure Vermonters have access to our free caregiver support groups and educational programs. On average, 80 Vermonters participate in these programs each month and that number is growing. We currently offer thirteen support groups and have three more starting soon.

And I, together with advocates, work on the state and federal level to implement policy and advocate for resources to support our constituents. An example of how our federal priorities impact our state work is the BOLD/CDC grant that I mentioned earlier. Last year one of our federal priorities was funding for these CDC grants, and I'm excited to report we were successful. In 2020, Vermont was one of the first recipients of this grant. We received \$249,000/year for three years to work on preparing to meet this growing crisis. One of the outcomes was the [2022-2025 Vermont Action Plan for Alzheimer's Disease, Related Dementias & Healthy Aging](#), the first Plan since 2008. In October I traveled with Ed DeMott, Program Manager for the Alzheimer's Disease & Healthy Aging Program in the Vermont Department of Health, to the first Annual State Dementia Coordinators Summit where we met with staff from 27 other states and municipalities and shared resources, knowledge, and outcomes. Based on what we have accomplished with our current BOLD grant and the feedback we have received, we feel confident we are strong contenders for the next round of BOLD funding. This time the amounts should be slightly larger and the grant will be in place for five years.

On the state level I work to connect legislators with their constituents and to support relevant legislation. Last year one way I built connections was by holding five "*We're ALZ in this Together: Destigmatizing Dementia*" community events. More than 175 Vermonters participated in these conversations. Four major themes came out of these conversations.

1. We heard over and over about the **lack of coordination of services**. Alzheimer's is a complex disease that changes over a period of up to 20 years. Physicians, community partners, paid and unpaid caregivers, patients, and those from the faith community all shared challenges of finding resources and navigating systems.
2. **We must grow our workforce**, including direct care workers. We heard from Vermonters who have been approved for care, but those on Medicaid and with acute needs are prioritized, leaving no support for people with dementia. At Allen Brook Memory Care in Williston, the only affordable memory care community in the state, there are over 100 on a waitlist for one of their 14 homes. In November, Dr. Stephen Leffler, president of the University of Vermont Medical Center, told VPR "Every single day, we have 50 to 70 beds taken by people who don't need hospital care, but can't leave the hospital." ([Source](#)) This is costing us millions of dollars, adding significant stress to nursing staff, and hospitals are a

challenging location for a person with dementia. Hundreds of nursing home and long term care beds are offline because there are not staff to cover them.

3. **Lack of services and supports for those in the middle class**, even when they are willing to pay. Too many of our services are only accessible to those on Medicaid or Medicare. This system is forcing families to choose between falling into poverty to gain access to services and trying to figure out how to manage a very complex disease on their own. A participant at our event in Brattleboro shared his desire to send his wife, with very advanced Alzheimer's, to the Adult Day. It would cost him around \$200/day or \$1,000 a week for her to have the care she needs and deserves, but it would leave him with no funds for the rest of his life. There is a lot of talk about childcare; caring for elders is also bankrupting families and keeping Vermonters from the workforce.
4. **Equity for those with Younger Onset Alzheimer's**. This would ensure those diagnosed before the age of 65 have access to all the services and supports afforded Vermonters over 65. Some services are already available through the Older Americans Act, but we need to expand access and we must find a way to count them so we know what including them will mean for our systems of care.

These issues are complex and they will not be solved by one organization or one committee. Vermonters with Alzheimer's and other dementias are older Vermonters and they need services in all sectors. We have heard of their challenges with transportation, food security, internet access and more. As part of our work to address these issues, staff of the Vermont Chapter of the Alzheimer's Association participate in many committees, projects and working groups and, when possible, we bring those with lived experience to share their ideas directly.

Last year we worked with you to pass S.206/Act 113. As a result:

- The new State Plan on Alzheimer's, which I mentioned earlier, was attached as an amendment to the State Plan on Aging when it was released on October 1, 2022. Having these plans tied together is extremely useful.
- The Governor's Commission on ADRD, which I Chair, was very involved in creating the new State plan on Alzheimer's, and we have representatives from all sectors now appointed. To aid us in our work, we have invited four advocates with lived experience to participate in our meetings in 2023. Our Annual Report and 2023 legislative priorities are [online](#). In September 2022 we appointed three members to lead our work developing a Professional Educational Opportunities Report, which we will share with you in January 2024.
- Our Program Manager and I are currently collaborating with the Department of Public Safety to identify appropriate dementia training and annual refreshers to add to their training requirements. We will be providing that training to them by the end of this year. Their work establishing a system for older Vermonters who wander will be enhanced by this deeper understanding of how to recognize the signs and communicate with those who have dementia.

- The Department of Health and Department of Disabilities Aging and Independent Living (DAIL) have started to compile resources for patients, families, caregivers and healthcare providers as required by Act 133. Last year they testified about limitations on state websites. While progress has been made, the information is extremely difficult to navigate and causes frustration because it is not searchable by keyword or region. You can view this work at <https://www.healthvermont.gov/wellness/brain-health>.

In order to meet the Department of Disabilities, Aging and Independent Living's mission of making Vermont the best state in which to grow old or to live with a disability – with dignity, respect, and independence, we need a State Dementia Coordinator. This session we are working with Representative Noyes and others to introduce a bill to create that position. This position is vital to our success and will aid us in implementing, reporting on, and updating the State Plan on Alzheimer's; identifying and applying for grant opportunities to expand the scope of services while reducing state costs; establishing and maintaining relationships with the many agencies and organizations working in this sector; and most importantly allow Vermonters with Alzheimer's and other dementias and their family caregivers access to the tools and support they deserve.

I'm happy to answer questions and I look forward to working with you this legislative session.