

## Vermont Chapter

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 speak to the value and importance of S.51, An act relating to the Vermont unpaid caregiver tax credit.

I want to begin by sharing some information specifically related to caring for a family member with dementia. I know this bill is for anyone providing unpaid care, but I believe the majority of people who qualify will be providing care to a family member with Alzheimer's or another dementia. After, I will share some specific thoughts on S.51 as it passed the Senate.

According to the Vermont Department of Health, "one in four caregivers in Vermont care for someone with Alzheimer's disease, dementia, or a related neurocognitive disorder." In 2020, Vermont had 12,800 people over the age of 65 diagnosed with Alzheimer's. We know Vermont's over 65 population has grown and that number has too. It also doesn't capture Vermonters with other dementia, those who are mis or undiagnosed or those who are under 65 with a diagnosis.

Last year 20,000 Vermonters provided 29 million hours of unpaid care to loved ones with dementia. The value of this care was \$773,000,000.

Caregivers for those living with Alzheimer's or another dementia play an essential role in maintaining the quality of life for their loved ones and helping them live independently in their homes and communities. Compared with caregivers of people without dementia, caregivers of those with dementia indicate more substantial emotional, financial, and physical difficulties, and face time-intensive demands – on average spending 27 hours more care per month than caregivers of people without dementia. The amount of time required for caregiving increases as dementia progresses; one study showed that people with dementia required 151 hours of caregiving per month at the outset of dementia and this increased to 283 hours per month eight years later. One in four Vermont dementia caregivers spend 40 or more hours a week on dementia-related caregiving.

Dementia causes a prolonged and devastating toll on caregivers. One in three dementia caregivers have been so for five years or longer. As dementia progresses caregiving duties may be needed 24 hours a day. The additional demands of caring for someone with dementia impact a caregiver's ability to work. While six in ten caregivers were employed last year, 57% had to go in late or leave early to meet caregiving demands. Eighteen percent went from full to part-time and nine percent gave up work to fulfill caregiving responsibilities.

Caregivers for a person with dementia also have higher out of pocket expenses than those caring for someone without dementia. For example, the average annual out of pocket expenses for someone caring for a loved one without dementia is \$6,887 versus for \$12,388 caring for someone with dementia.

As a result of this financial strain, many families significantly cut back on savings contributions and other spending. Nationally, 41% of dementia caregivers have a household income of \$50,000 or less. Nearly 40% of caregivers reported the food they purchased often ran out before they could afford more and 30% shared they had to eat less due to care costs.

The total lifetime cost of care for one person living with dementia is estimated at almost \$400,000 (in 2023 dollars). Of this, 70 percent is borne by families — either through out-of-pocket health and long-term care expenses or from the value of unpaid care.

I understand this bill is for all caregivers, but the financial impact of caregiving is often felt more acutely by women. Approximately two-thirds of caregivers are women; more specifically, over one-third of dementia caregivers are daughters. Approximately one-quarter of dementia caregivers are 'sandwich generation' caregivers, meaning they care not only for an aging parent but also for at least one child.

Alzheimer's disease takes a devastating toll on caregivers, but the majority of Vermonters with dementia report they want to remain in their home or community. Any support we can provide to support this is beneficial not only to families dealing with dementia but to our entire long term care system which is stretched very thin. S.51 is a tangible way to provide much needed recognition to unpaid caregivers and slightly alleviate the overwhelming financial burden.

I listened to your walk through of S.51 last week and I'd like to respond to some of the specific pieces of the bill you discussed.

There was some discussion about who would be eligible to receive this credit. I was under the impression this credit was targeted to those who were providing unpaid care for an adult family member. You may want to consider making that change to the bill by changing the word 'individual' to 'adult' in the provisions. (P.2, line 18)

I wanted to clarify that the national Credit for Caregiving bill has been re-introduced and is one of the Alzheimer's Association's federal priorities. That bill proposes an up to \$5000 nonrefundable federal tax credit for eligible family caregivers.

I hope my testimony has provided some clarity on what caring for a loved one with dementia entails. I know the bill requires the person receiving care to need assistance with activities of daily living (ADL's) Sometimes those do not accurately reflect the urgent need or amount of time required by a family caregiver. If one of the goals of this legislation is to recognize and provide some compensation for the large number of hours an unpaid caregiver is requiring, I would suggest (2) on P.2, line 20 to 'needs assistance with activities of daily living (ADL) or instrumental activities of daily living (IADL)'. For clarity and to remove redundancy I would suggest removing 'home health care, or assistance remaining safe at home' from that section.

You had a short discussion on the actual impact of a \$1000 tax credit. At Alzheimer's Awareness Day last week, one family caregiver stood up and said, "Am I correct this bill would provide a \$1000 credit if I attest to providing 1,040 hours of care?" We had a robust conversation about what \$1000 would mean to many of the caregivers in the room. We also talked about the very valuable impact of having unpaid care being widely recognized. We agreed this credit is meaningful and would be incredibly helpful.

Finally, I would like to address the projected \$6 million cost of this bill. I understand that is a very significant amount of money, but I urge you to remember the statistic I shared with you at the beginning of my testimony. In 2023, Vermonters provided 29 million hours of unpaid care to loved ones with dementia with a value of \$773,000,000. I urge you to recognize this work and the sacrifices they are making and to advance this \$1000 refundable tax credit.

## Alzheimer's 2024 Vermont Statistics

## The Impact of Alzheimer's on the Workplace

Caregiving in Vermont: Profiles of individuals caring for family members with Alzheimer's disease or a related dementia, VT Department of Health