

Good Morning

My name is Laura Murphy. I work for CVAA as the Dementia Respite Grant Coordinator and am the AAA representative for the Governor's Commission on Alzheimer's Disease and Related Disorders. I am also a long distance caregiver for a family member with mid-stage Alzheimer's.

Thank you for letting me speak on behalf of the Governor's Commission about the importance of supporting caregivers of people with dementia.

I could talk about Alzheimer's disease, and describe how this condition is robbing 11,000 Vermonters of their ability to live independently as they slowly lose the mental power to read a book, balance a checkbook, follow directions, process information to make a decision, drive a car, bathe, dress appropriately, make a simple meal, or even recognize a beloved spouse or child. In 10 years there will be 17,000 Vermonters living with Alzheimer's. Do you know how expensive it is to pay for care for this disease? The average per-person Medicaid spending for someone with Alzheimer's is 19 times greater than for someone without.

So, today, I want to talk with you about the unpaid family caregivers, the ones who are always there behind the scenes, trying to make best of an awful situation, balancing their own work/family obligations or medical issues with providing care and supervision for someone with Alzheimer's disease, sometimes for many long years. They do this so that their loved ones can remain at home as long as possible, avoiding or greatly postponing costly nursing home care.

These caregivers incrementally take over all of the life management duties including shopping, meal prep, laundry and housecleaning, outside chores, arranging for and transporting to medical and other appointments, managing medications, and providing supervision and emotional support to someone who is not aware that they need any help at all. They may do this at the expense of the time available for their spouses or children.

They are watchful for health issues their loved one may not be able to perceive or describe. They sleep fitfully, with one ear alert for late-night wandering. They patiently answer the same question over and over, trying to redirect when their loved one gets stuck in circular logic or perseverates on a single concern. They deal with misunderstandings, hurt feelings, temper tantrums, emotional or verbal abuse, physical acting out, or socially inappropriate or bizarre behaviors.

They do this with love, humor, patience, stoicism, sleeplessness, anxiety, depression, and heartbreak.

Our statewide Dementia Respite program, managed by the five Area Agencies on Aging via contract from DAIL, provides financial support to unpaid primary caregivers by reimbursing them for a wide variety of respite services as well as emotional support via telephone reassurance and referrals to other community resources and services.

Since early 1998, this unique program has allowed caregivers flexibility to get some of their needs met so that they can gain the strength to continue to care for their loved ones at home. Simple things like hiring substitute caregivers so they can finally get to work on time, play cribbage once a week, visit a doctor without worrying about mom wandering away from the waiting room, or have lunch with a friend and unburden themselves. Perhaps they try out adult day care. Maybe they find round-the-clock help while they deal with a family crisis, or get a chance to finally see that new grandchild in another state. Sometimes they just call a respite grant coordinator to talk and get new perspective.

Our 350-400 grantees each year tell us how grateful they are that someone is recognizing and honoring their needs and supporting them in their challenging caregiving role. But current funding (which has remained stable at \$250,000 for the last 12-14 years) now only pays for an average of 5-8 hours a month. How long could you do an endless 24/7 job with only a few hours' break a month?

On behalf Governor's Commission on Alzheimer's Disease and Related Disorders, I am respectfully requesting an increase to \$500,000 for this program. I know these are tough economic times but this is an important and unique program which can have substantial long term impact on avoiding or reducing nursing home placement and supports Vermont's long-standing practice of encouraging home and community based services. Caregiver burnout is real and has its own social and economic impact.

Thank you.

# Make Vermont a Dementia Capable State

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## Growing Public Health Crisis

Alzheimer's disease is a growing public health crisis, in Vermont and across the nation.

- It is the sixth leading cause of death in the United States and affects **11,000 Vermonters**.
- The average per-person Medicaid spending for seniors with Alzheimer's is 19 times more than for seniors without Alzheimer's and there are nearly **30,000 family caregivers** in Vermont providing **34 million hours of unpaid care** for their loved ones living with Alzheimer's disease, valued at more than **\$400 million**.
- **By the year 2025**, 17,000 Vermonters will be living with Alzheimer's disease, **an increase of 55%**.
- According to the **2013 Cognitive Module of the Behavioral Risk Factor Surveillance System (BRFSS)**, 9% of adults aged 18 and older are experiencing increased confusion or memory loss that is getting worse. Of those aged 45 and older reporting memory issues, 26% had to give up household activities/chores and 30% say their cognitive problems interfered with their ability to work, volunteer, or engage in social activities.
- A study released by the *New England Journal of Medicine* reports that **Alzheimer's disease is now the most expensive disease in America**, surpassing both cancer and heart disease, and the costs are expected to skyrocket.
- It is the only cause of death among the top 10 in America without a way to prevent it, cure it or even slow its progression.

## WHAT Can State Officials Do?

Work with the Governor's Commission on Alzheimer's Disease and Related Disorders to Implement the *Vermont State Plan on Dementia* to:

- 1.) Enhance early detection and diagnosis efforts in Vermont.**
  - Integrate specific practice protocol in Blueprint for Health for early detection screening and diagnosis of dementia as well as referral to community resources and supports.
- 2.) Allocate \$500,000 to support the Dementia Respite program.**
  - This allocation will provide grants to families to help them pay for respite care and create a coordinated system of support that connects Vermonters with the community resources and services they need to navigate all stages of the disease.
  - Caregiving for a person with memory loss can be stressful and take a toll on the caregiver's own health. Dementia Respite Grants can be used for a range of services that give family caregivers a break from their caregiving responsibilities.
- 3.) Request that the Cognitive and Caregiver modules be used in the 2016 Behavioral Risk Factor Surveillance System (BRFSS).**
  - Continuous surveillance through the **Cognitive** and **Caregiver** modules of the **Behavioral Risk Factor Surveillance System (BRFSS)** collects **essential public health information**.
  - Vermont has not yet used the Caregiver module. Use of both modules will provide valuable data on the burden of cognitive decline among adults as well as the impact of caregiving for someone with dementia (or other conditions) on caregivers' health and wellbeing.

# Support the Implementation of Vermont's State Alzheimer's Disease Plan

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

The Vermont Legislature established the Governor's Commission on Alzheimer's Disease and Related Disorders in 1991. Since its inception, the Commission has provided leadership on a number of public policy matters specific to the needs and concerns of people affected by Alzheimer's Disease or a related dementia (ADRD). The Commission is composed of sixteen members including the Commissioner of Disabilities, Aging and Independent Living or a designee, one senator chosen by the committee on committees of the senate, one representative chosen by the speaker of the house, and thirteen members appointed by the Governor. The members appointed by the Governor serve for terms of three years and represent the following groups: Physicians, social workers, nursing home managers, the clergy, adult day providers, the business community, registered nurses, residential care home operators, family care providers, the home health agency, the legal profession, mental health service providers and the Alzheimer's Association. The Commission's mission is threefold: 1) to identify key public policy issues related to ADRD, 2) to educate the public and private sectors regarding these matters and 3) to make policy recommendations in support of developing programs and services essential to providing accessible and appropriate services to people with dementia illnesses and to their families and other care partners.

### The Commission published Vermont's State Plan on Dementia in 2009 with the following GOALS:

1. Vermonters are adequately informed regarding dementia.
2. A strong quality improvement system exists to support the ongoing enhancement of dementia care.
3. Vermonters are active stakeholders in the system of dementia care.
4. All Vermonters with dementia have equitable access to the continuum of dementia care.
5. Vermont has an adequate workforce to support the needs of persons with dementia and their families.
6. All Vermonters have access to credible expert opinion, latest scientific findings and the most promising new therapies for the prevention and treatment of dementia.
7. Vermont policies, regulations and laws promote improved access, quality and efficiency of the dementia care system.

**To download a copy of the Vermont State Plan on Dementia, visit [alz.org/stateplans](http://alz.org/stateplans).**

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