



Caring for Caregivers S.242 Dementia Respite Grant/Dementia-Friendly Community Programming

The Vermont chapter of the Alzheimer's Association, the Vermont Aging Network Consortium, and the Vermont Association of Adult Day Services support legislation to significantly increase support for Vermont's unpaid dementia caregivers through the Dementia Respite Grant (DRG).

Investing in respite care and dementia-capable programs is a proven, cost-effective prevention strategy that reduces long-term Medicaid expenditures while improving health outcomes for both caregivers and those living with dementia.

The DRG has been level funded at \$250,000 since 2003, and in FY'27 we are requesting the following:

- An additional \$500,000 in General Funds for the DRG for a total of \$750,000
- A cap increase from \$2,000 to \$3,000 per qualifying caregiver.
- \$100,000 in General Funds for a pilot to expand dementia-capable programming in Washington and Rutland

By increasing the DRG to \$750,000 and raising the award cap to \$3,000 we believe we can provide respite to 250 Vermont families.

About DRG

The DRG provides funding to families who do not yet qualify for Choices for Care and make less than 300% FPL. It is funded by the General Fund. Of the current \$250,000, the state holds \$50,000 to support TCare licenses and the remainder is distributed to the 5 Area Agencies on Aging (AAA) based on the population of their regions. Funds can be used for respite or other items that will help the unpaid caregiver reduce their burden, while ensuring the safety and wellbeing of the person with dementia.

- In 2025, 123 families received respite funding.
- In 2024, Vermont's 20,000 unpaid dementia caregivers provided 29 million hours of care valued at \$773 million.
- 61.5% of Vermont's unpaid dementia caregivers live with one or more chronic conditions, and more than 35% report depression.

Dementia Capable Community Program Pilot

The one-time appropriation of \$100,000 will be allocated to pilot dementia-capable programming in Rutland and Washington Counties—areas that lost Adult Day Programs during the pandemic. The goal of this pilot program, with trained staff and volunteers, is to ensure caregivers and those with dementia have access to vital social engagement opportunities, which have been proven to improve health outcomes and will reduce caregiver stress.

Vermont Caregivers Need Respite!

A sampling of testimonials collected from unpaid dementia caregivers in Vermont

Taking care of my husband who had Alzheimer's was the most challenging and heartbreaking thing I have ever faced. There are so many uncertainties. Taking the new role as caretaker rather than wife was tricky. While there is some help the bottom line is you. I chose to keep my husband at home where he was most happy, but it is difficult taking care of home and another being. Hopefully there will continue to be more knowledge about this disease and more help to individuals who are caretakers of them. *Sheryl, Addison County*

I am a caregiver to my husband of thirty-odd years. I believe this job as caregiver to my husband is my first priority. My goal is to simplify my life as caregiving takes up more and more of my time. With two other caregivers, I run a monthly Alzheimer's support group. What strikes me is that our regular members seem to be faring well. **It's the ones who are unable to make our meetings that truly need respite.** Ironic? Pathetic is more like it. That they are unable to even get out for a monthly support group! *Janet, Caledonia County*

I had a successful career in leading business strategy and product development when I realized my wife's early onset Alzheimer's required more care. I work hard to provide a caring and loving environment at home, but I have to admit that 24/7 care is taxing and tiring. **The opportunity for respite is important for both the physical and mental health of both of us.** *Rich, Washington County*

I cared for my mom for around 7 years at home. One of the hardest parts was the lack of any social interactions for people with dementia. **The toll on the caregiver of 24 hours of care a day is emotionally traumatic in itself, it's a brutal experience for the caregiver.** It's 24 hours a day keeping someone safe and being literally next to them the whole time for years. After my mother died, I saw a therapist because my mental health was just in such a bad place not from grief but from being in crisis mode for years. *Deborah, Grand Isle County*

I have basically given up my life to keep my mom in her home. I am unable to get away for a vacation. I work from home while taking care of her so I am basically working two jobs at once. My family has suffered as well because I'm not able to be with them as much. *Joanne, Franklin County*

I helped care for my father who had Lewy Body dementia for almost a decade - which means our whole family lived with the disease. We did our best to find the moments of joy, but the pressure on everyone's health was immense. **There was no shortage of sympathy, but that's not enough to sustain families.** *Emily, Chittenden County*

I'm a care partner for my husband Jeremy. The constancy of caregiving is overwhelming; respite helps to alleviate that constancy. Anxiety is one of the symptoms that Jeremy has and if I'm not around for even just a few hours is a lot for him. **Caregivers desperately need respite, the number of people I know who are caregivers is phenomenal and most of us work with tiny budgets and fixed incomes.** I have dropped out of the painting class that I was a part of because it was just too much. *Sue, Windham County*

I was my mother's full-time caregiver until her death in 2022. During the years I cared for my mother I did not have a paying job. I passed up social invitations, job opportunities, and missed out on career advancements and wage increases. Caregiving is both a sacrifice and a privilege. **Having respite for caregivers is imperative!** It helps the health and well-being of the caregiver, which allows them to provide the care their loved ones deserve. *Carmen, Windsor County*

I have been my mother's caregiver since 2022. My husband also has dementia. Taking care of two people you love with dementia can be quite a challenge. I'm the chef, maid, money manager, and chauffeur. It's a very demanding, tiring, challenging job that I would not wish on my best friend or daughters. Respite is very much needed in this household. I would love to spend more time with hubby, but most of all I need respite for myself. **So many days of just wanting to cry, shout at the walls, and run away. Caregiving is very challenging.** *Deborah, Rutland County*