

Caregiving in Vermont

Profiles of individuals caring for family members with Alzheimer's disease or a related dementia



Eighteen percent of Vermont adults report providing regular care or assistance to a friend or family member with a health problem or disability. **One in four caregivers in Vermont care for someone with Alzheimer’s disease, dementia, or a related neurocognitive disorder.** Caregivers of people with dementia and related disorders may face unique stressors that impact their physical and mental wellbeing.

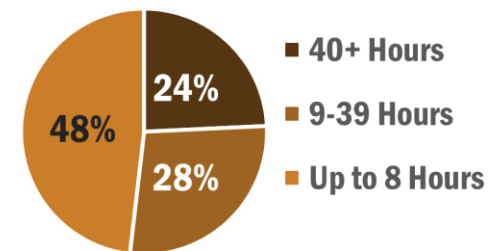
The Vermont Department of Health’s Alzheimer’s Disease and Healthy Aging Program collected stories from four individuals who provide care for family members living with Alzheimer’s disease or a related dementia. Caregivers were identified by the Health Department, the Alzheimer’s Association Vermont Chapter, and the University of Vermont Health Network’s Dementia Family Caregivers Center. Caregivers were asked to share their stories reflecting particularly on access to support, care coordination, mental and physical health impacts, and self-care.

Their stories illustrate the challenges and joys facing Vermonters caring for an individual with dementia. The goals of sharing these stories are to:

- Raise public awareness about the challenges facing caregivers.
- Educate and inform the Health Department and partners.
- Educate and inform legislators and other community leaders about the unmet needs of family caregivers.

One in four caregivers spends 40 or more hours per week on caregiving responsibilities.

Average number of hours per week spent on dementia-related caregiving



What is lived experience?

Lived experience means knowledge based on someone’s situation, perspective, personal identity, and history, beyond their professional or educational experience. People with lived experience have insights that can inform and improve systems, research, policies, practices, and programs.

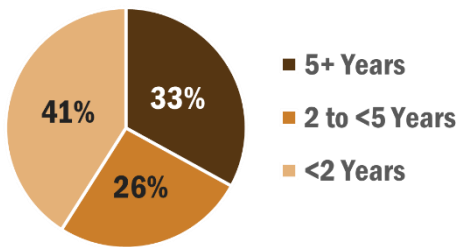


Thea cares for her mom, Abbie, who was diagnosed with Alzheimer's in 2018. **Abbie moved in with Thea and her family** at the onset of the COVID-19 pandemic. Thea is compensated by [Choices for Care](#) for her caregiver role; however only for 18 hours a week at a rate that is not a livable family wage.

Thea had to abandon her career as an artisanal stone mason. This has had a devastating financial impact.

One in three dementia caregivers has been a caregiver for 5 years or longer.

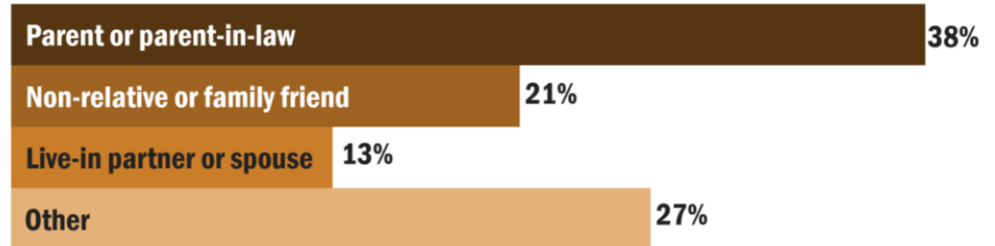
Prevalence of length of time spent as a dementia caregiver



(Act 39) for people in Abbie's condition. Currently, Act 39 contains requirements that an individual with advanced dementia would not be able to meet.

Nearly 40% of dementia caregivers are caring for a parent or parent-in-law.

Prevalence of types of relationships to care-receiving person



A long-term care placement for Abbie is unlikely because she was deemed combative and a flight risk by the local adult day care and Thea was asked not to bring her back. Thea was advised to "expose mom to pneumonia, then to bring her to the Emergency Room when symptoms arose and use this as the entry point into long-term care."

Though she tries to be diligent about self-care, Thea is worn down and often feels as if she falls short in providing care for her mother. Thea maintains that **she and most caregivers are unaware of certain tools that may benefit them.** She also wishes that Vermont would establish another law or expand the [Medical Aid in Dying Act](#)

"I'm mad at the disease, mad at her [Abbie], mad at myself, mad at everything!"



Time and Again, built by Thea Alvin with the help of student and staff volunteers, on the campus of St. Michael's College

Charles, 84, cares for his wife Stephanie who was diagnosed with Alzheimer's disease in the fall of 2020. Stephanie, now 81, had a long, distinguished career in academia.

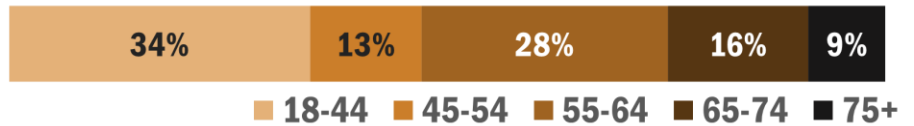
Charles has had a **difficult time arranging access to primary care and vital services for Stephanie.**

Stephanie began seeing a psychiatric neurologist at their regional medical center. However, the doctor retired soon after and has yet to be replaced. Charles is finding it difficult to get in-home care, credentialed or not. **There are few other options, and no adult day options are available in their area.** Half of Vermont counties do not have any adult day centers.

Travel for the couple is also increasingly difficult. A recent trip to see friends proved challenging for Charles because Burlington International Airport has no signage indicating where travelers can find a wheelchair or other amenities to make navigating airports easier and more comfortable. **He is concerned about the future and how to find the best care for Stephanie.**

Nine percent (9%) of dementia caregivers are 75 years or older and 53% are older than 54 years old.

Prevalence of age groups of dementia caregivers in Vermont



The COVID-19 pandemic severely impacted Vermont's Adult Day Centers. All 17 centers were closed during the pandemic. Only 11 have been able to reopen.

"The system is not equipped to deal with the full range of needs people with dementia and their families experience."



Linda's father, Mike, began experiencing symptoms of dementia when he was in his late 60s. After Mike's wife died in 2021, his two daughters and son-in-law began taking turns spending the night with Mike, who lives two hours away.

Neither Linda nor her sister have been able to properly grieve their mother because of the **intensity of care and coordination of care for their dad.**

Linda has to prepare herself each time she heads to Mike's house, often crying and bracing herself emotionally to be able to care for him. Trauma from adverse childhood experiences (ACES) have had deep effects on Linda. Mike himself had endured ACES too. Linda emphasizes that **there should be more mental health support for caregivers.**



[Choices for Care](#) covers an aid for only three hours per day. Neighbors report that Mike walks beyond his neighborhood and has been seen walking on a busy main road.

Mike's physical and financial decline have not been matched by the services available. **The financial and emotional stress of caregiving are big factors** in Linda's life. Her dad's financial situation doesn't allow him to cover his monthly expenses now that his savings are depleted.

Caregiving can add stress to one's physical and mental health, yet 27% of dementia caregivers did not have a routine doctors visit in the past year.



“Sometimes you just fall into the caregiving role, which can be emotionally charged because you may be taking care of someone [a parent] who did not really care for you.”

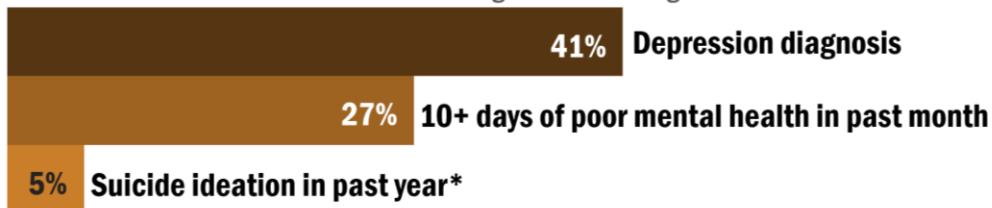
Adrien is the principal caregiver for her mother Michelle, age 57. Michelle is not able to work anymore but she had been a therapist, public guardian, and mother of two. Adrien's responsibilities in caring for her mother began when **her mom could no longer manage her own finances** and she was becoming very forgetful.

“Caregiving takes up so much emotional space and doesn't allow you to grieve for your loved one fading away.”

Michelle was diagnosed with early-onset Alzheimer's disease at the start of the COVID-19 pandemic. Early- or young-onset dementia is relatively rare and health professionals may have little experience detecting the symptoms in a younger person. Symptoms might be attributed to other factors such as stress, anxiety disorders or menopause.

Dementia caregivers may face mental health challenges.

Prevalence of mental health outcomes among dementia caregivers



*calculated among all caregivers due to small sample sizes

Adrien was unable to **work full-time**; the demands of caring for her family and the financial stress of having to cut back her work schedule was overwhelming.

Adrien has a chronic condition herself and **being a caregiver makes it harder to take care of her own healthcare needs**. The mental health impacts have been enormous. Adrien has been experiencing suicidal ideation and is now in mental health counseling. As a result, Michelle is terrified of asking her daughter for help despite her increased need for help.

Three out of four (71%) caregivers identify as female.



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