

Senate Health & Welfare Committee

Alzheimer's Awareness Day – April 6, 2023

Testimony – Barbara Edelman, Family Member, Alzheimer's Association, Vermont Chapter

Good morning. Thank you for this opportunity.

My name is Barbara Edelman and, as you heard, I'm Darryll's "care partner". Darryll is still in the early stage of the disease, so the demands on me currently are relatively light. But I know things will gradually get much more difficult, and I'm doing everything I can to be ready for the challenges ahead. Unlike many people in my situation, I have the time and flexibility to do so. I currently attend two monthly caregiver support groups, am about to join an 8-session weekly support group and will participate in an intensive caregiver training program through the UVM Medical Center in the fall -- all to help me prepare for what's inevitably down the road.

No one can tell me how long that road is or exactly what it will look like. All I know for sure is that, at some point, the road will get very rough and stay rough for the rest of the journey, which could last several years.

To care for Darryll and keep myself safe and healthy, I will need help. This might mean respite care to fill in for me, or a safe, socially engaging place for Darryll to go during the day. At some point, I'll likely need some home nursing support. And eventually we will need hospice support. How I will find, coordinate, and pay for all of this – while also caregiving – is mindboggling!

The wide variance in how Alzheimer's manifests makes creating a system of care extremely challenging and *that* is why Vermont needs a State Dementia Coordinator to focus on the latest – and constantly evolving – training, treatments, research, state and federal program requirements, and funding opportunities to close the gaps for us... and to identify appropriate, cost-effective solutions to what is a *growing* challenge for our state, given that we have the *third highest median age* of any state in the nation. *Please* support this critical position in the FY24 budget on behalf of the more than 26,000 unpaid family caregivers like me in Vermont.

Thank you.