

**Testimony in Support of S.302 for Senate Health and Welfare on Feb.
20, 2024**

I am Mary Claire Carroll, a resident of Richmond, and I am testifying in support of S.302 An act relating to public health outreach programs regarding dementia risk. I'm here to speak to section A of the bill, the importance of educating medical providers.

My older sister was diagnosed with Alzheimer's in January 2020. As upsetting as the diagnosis was, what was more upsetting to her partner and I, was the length of time it took to receive a definitive diagnosis. My sister lived in New York City, she had great medical care from NYU Medical Center, 2 blocks from her home, but it took her partner and I a couple of years to convince her PCP that they should refer her to a Alzheimer's/ Dementia Specialist for assessment. In her late 70's, my sister, a journalist, and a teacher, with a vibrant personality, had begun to show signs of confusion and memory loss. Her partner and I saw the changes, but my sister hid her decline so well no one but family members saw it.

Because her primary doctor did not immediately notice the cognitive changes, he questioned our desire for some sort of cognitive assessment. Without the assessment my sister was not eligible and could not access programs that might have helped her. And her partner could not access programs for respite care or support.

Finally, after nearly 2 years of her partner badgering her physicians, we had an appointment at the Barlow Center, NYU's Dementia and Alzheimer's Center. She was given some cognitive tests, and then scheduled for further testing. The early tests confirmed our fears that

something was wrong. Almost immediately she was signed up for a program to help her learn coping and communication skills. She was also signed up for a physical therapy and exercise programs, and nutrition programs. Her partner suddenly had access to lots of information and support, including one on one counseling that he still uses today.

Almost a year after her diagnosis my sister ended up in a long term care facility in our home town in the Adirondacks thanks to a broken hip and COVID. I can't help but think that had she been diagnosed even a year earlier she would have had a better quality of life and more time receiving the supports she needed.

My experience with my sister made me realize how important early detection and early supports are for someone diagnosed with Alzheimer's or dementia and their caregivers. What a difference it would have made if her health care providers had some sort of testing protocol or information that would have provided early clues to her cognitive decline. My sister's experience in NY is not different from the experiences I hear from many in Vermont. I believe if health care professionals had the tools and information and clearly understood the harm being done by postponing diagnosis they would be better equipped to detect dementia.

I would also like to speak to section A (iii) the importance of Medicare or other annual visits to screen for Alzheimer's and dementia.

I must admit that I had assumed that during my Medicare annual exam that there would be questions or simple testing that would give my providers and myself a base line from which I could base my own care decisions. I am a sister of an Alzheimer patient, and the daughter of someone diagnosed with Dementia 30 years ago, my

Dad. Certainly I am a candidate for early testing. I was surprised. My PA checked in and asked questions about other diseases in my family history but didn't even acknowledge dementia. Except in a discussion of how my sister was doing. I only realized this oversight as I reflected on the visit and I also realized how important it is for me to know my brain is functioning as it should be. This was a missed opportunity for me, my family, and for the state because we know waiting until there is a crisis is the most costly and challenging time to address a medical need.

I know changing wording won't make all systems operate perfectly, but I strongly believe focusing attention on educating and preparing medical professionals to better diagnose and support those with dementia is important. Vermont has done a great job educating our community and health providers about the benefits of early detection in so many diseases. I am happy that the passage of S.302 would increase public understanding and perhaps take away the stigma of the disease.

While dementia is not a normal part of aging, risk does rise with age. Thank you for taking up this bill and helping Vermont build a better framework to address Alzheimer's and all other dementias.

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