

## **Testimony for Alzheimer's Day April 6, 2023**

Thank you everyone for donning my flowers to indicate your personal relationship to Alzheimer's and other dementias. As you can see, I now wear 5. The 2 purples represent my grandfathers who died from Alzheimer's. One yellow represents that I was a caregiver to my uncle who developed dementia. Another yellow represents that my mother is living with me and has mild dementia. And lastly, I wear blue as I am personally living with Alzheimer's, in my case, Younger-Onset.

My name is Pamela Smith and I was diagnosed with Alzheimer's at the age of 53. In Vermont, 13,000 people are counted as having Alzheimer's. This number doesn't include me, because I am under the age of 65, nor my mother because she can't afford the diagnostic process. Nationally, it is estimated that about 6% of people develop Alzheimer's prior to the age of 65. But we are uncounted, because there is no easy mechanism to count us. And I have learned from personal experience that uncounted often leads to unserved. But I need all the same services as an older person with dementia needs.

I have also discovered that Vermont lacks a coordinated system of care for people with dementia. Families have to locate the limited help available. For many, then they need to figure out how to pay for it. I am faced with 4 primary barriers. I am under the age of 60 or 65 thus disqualifying me for some assistance programs. I am in the middle class so I will never qualify for Medicaid. My family members have to work full time so I don't have them to serve as caregiver or case manager. And lastly, when I try to pay for the help I need, agencies don't have staff. Every time I try to figure out whether I do qualify for some assistance, the rules are so difficult that I can't figure out the process or remember the rules on my own, so I give up.

I am doing all I can to help by using my professional experience as a social worker in the "before times" and my "lived experience" with Alzheimer's now. I am an advocate for the Alzheimer's Association. I have joined the Governor's Commission on Alzheimer's Disease and Related Disorders, the Older Vermonters Caucus and the Home and Community-Based Services Work Group. This work can positively impact those of us with Alzheimer's if there is effective coordination of a dementia support system

which I hope includes full equity for all struggling with Alzheimer's and other Dementias.

We need a Statewide Dementia Coordinator to pull together the variety of services into a system, to assess effectiveness, and to count people like me. Please fully fund the Statewide Dementia Coordinator position.

Thank you for taking the time to hear my story. And I'd like to add how wonderful it is to see this garden of care in purples, yellows, blues and oranges.