# Pamela Smith
# Testimony to House re: S 206
# April 6, 2022

Thanks you for this opportunity to speak to the House Human Services Committee on behalf of S206. I was diagnosed with Younger Onset Alzheimer's at the age of 52, which simply means I was diagnosed prior to the age of 65. I am a graduate of Middlebury College and earned my Master's degree from the UVM School of Social Work. I spent my career working in mental health and human services. I live in Middlebury with my husband and 5 cats. I raised my children in Vermont and luckily for me, they have stayed.

The Odyssey of getting diagnosed:

I began telling my primary care provider, her nurses and her interns that I was having life-interfering memory loss beginning at age 50. I was misdiagnosed every 3 months for two years. The problem was menopause, or stress, or the anxiety which I had never previously experienced, or depression, or my insufficiently managed pain condition, poor sleep, or any combination of those. New medications were tried to address these problems but without any positive effect on my memory. Naturally, my symptoms continued to worsen. After I had a major meltdown at work another doctor agreed to see me as an emergency. He listened to the story and thus began my 6+ months journey to proper diagnosis. I had psychological and intelligence testing, neurologist visits, tons of bloodwork (good news-I don't have syphilis) and brain scans. I was grateful for the diagnosis when It finally came

Impact on me:

At the age of 52, it was apparent I could no longer work so I promptly retired. Apparently 6 months after the diagnosis is acknowledged, I began receiving disability checks. And 2 years after the first check. I will qualify for Medicare in October or November of 2022.

Immediately upon diagnosis, I redid my Advanced Directive, created a Power of Attorney so my daughter or son can make decisions for me, created my Will, consolidated my retirement accounts (none of which I will live long enough to collect on) and made funeral arrangements. I felt pressured to get all of my affairs in order while I was still considered, "competent".

Emotionally this diagnosis is devastating. It feels like each time I come to accept a loss, another one follows. Mourning loss is my constant. I had to cope with losing my memories and functional short-term memory. Losing my ability to handle my finances. Losing the career I loved. Losing my retirement dreams. I lost my ability to read books because I can no longer follow or retain a plot. I can't cook alone. I am losing the perception of my vision. So now I will lose my ability to drive even earlier than otherwise expected. If there is something I need to do or say, I have to do it immediately or else I forget. I was once a highly competent person and now that woman is fading away before my eyes. There are days that I literally feel myself slipping away. Memories dying. Losing time.

The importance of the thought, or conversation or experience is irrelevant to whether or not I will remember it. When I don't remember something particularly important to my 6 year old granddaughter, she puts her forehead to mine and taps it saying, "I hate that Alzheimer's.". And I think, "so do we all, honey." Then I apologize for forgetting and she reminds me it isn't my fault so I shouldn't feel bad.

Impact on family:

My daughter's name is Eryn. I believe you have a copy of her testimony to the Senate Committee. I would like to highlight a couple of her remarks as illustration of the impact my disease has on her as my primary caregiver. Eryn took care of my uncle for 9 years in her home. He had cognitive and physical disabilities from birth. I quote, "With my great-uncle, I had a team of support. I [had] money from the state to hire staff for about ten hours a week of respite.... I had doctors who were able to speak with each other, his case manager, his guardian, his staff, the pharmacy, myself, anyone I needed in order to have the continuum of care he needed and deserved. I was also able to get paid for caring for him. ...I have learned that this time in my life, when I was poor but paid, overworked but supported, was so much better than what my future held."

She goes on, "Now, as the primary caretaker for my mother, it does not matter how hard I work. It does not matter what agency I call, there are no services for her, let alone support for me.... So, after 9 years of needing to put my family's needs above [all else], I find myself back where I started and with even less.... Generation after generation of women have scraped through life with the bare minimum to provide better for their children. [Caregiving] is women's work, and therefore invisible and without value. So, my family will continue to [struggle financially] while they have to deal with the decline and inevitable loss of their grandmother, Mita. They have to watch their mother work hard for no pay, watch me mourn MY loss and theirs. This disease doesn't have boundaries. It lives in my mother, but it twists its web into all of us. Through sadness, struggle, loss of memories, loss of income, it imbeds itself into every aspect of our lives.... We are so sick of being sad all the time." End quote.

The hardest part for me is watching what this disease is doing to my family. Until my diagnosis I had never seen my husband cry. I am more a stressor to my daughter than a help. I worry about my son who has Non-Verbal Learning Disorder. He can't even tolerate talking about what's happening. And my mother is watching my decline instead of the other way around.

In addition to generational poverty, we have generational Alzheimer's. Both my grandfathers died from Alzheimer's so my children have had a preview of what to expect. I am certain my mother has Alzheimer's but as a fiercely independent woman, she refuses to pursue diagnosis. And of course, I am terrified I have passed this on to my children. Thus far, I am the only one with Younger-Onset Alzheimer's.

Difficulty negotiating the system of care:

Firstly, there is no "System of Care." A system of care implies that there are at least several services available, that there is a treatment plan to ensure services received matches what the patient wants, and that there is some kind of case manager who helps ensure all services are well coordinated and there is accountability built in. There is no such thing for those of us with Alzheimer's and other dementias. Instead, we have to be our own case manager, calling numerous community and state-based agencies to craft a patchwork of limited services. I found each agency did not know what other agencies do and who they will serve. People with Alzheimer's are stuck finding our own help. I suspect this makes us vulnerable to scams. I was told a family member usually provides this help. Eryn had also been making calls with no greater success. I do not believe the average Vermonter knows how to negotiate all that is needed. Ultimately, we learned that the kind of case management I was looking for doesn't exist for my population. I am able to purchase only 3 hours per week of direct care in-home support because of staff shortages despite the determination that 5 to 10 hours per week was appropriate. After all state and non-profit agencies didn't work out, I looked into private providers for care management and learned this costs $125/hour. This charge is also accrued for travel time and the closest provider was an hour away. This Isn't functional.

What is needed (In no specific order):

- **Accessibility and Affordability:** All legislation and services must include coverage for those of us with Younger-Onset Alzheimer's. Services must be available regardless of age and insurance status. For many of us, especially with Younger-Onset, we will never qualify for Medicaid because our spouses are also younger and have to work. Private pay should be charged at the same rate or less than the Medicaid reimbursement rate, at least for any provider that accepts Medicaid. Remember, private insurance does not cover most care like case management and cooking/housekeeping services.
- **Training for early detection:** Medical providers, by which I mean nurses, PAs, APRNs, doctors, social workers, and therapists need additional training in early detection of Alzheimer's and that must specifically include Younger-Onset.

- **Comprehensive Case Management:** Nearly everyone with Alzheimer's needs comprehensive case management akin to what is available to adults with intellectual disabilities. So, if an individual who is born with intellectual disability is in need of comprehensive case management, why isn't it equally acknowledged that those of us who acquire a cognitive disability also needs this service. Agencies designated to serve older Vermonters must be required to serve those of us with Younger-Onset. If we are to get this old people disease, we need to get old people help.
- **1 Place to call for help:** There must be one place that individuals with Alzheimer's and their families call for help to learn what we qualify for, what it costs, what are the logistics for private pay, whether there is currently an opening and the array of services offered. And every agency should also know to direct us to that central person. Hopefully, that person can also advocate for us when an agency that should provide a service denies us that service.
- **In Home and Community-Based Services:** Nearly all of us with Alzheimer's is diagnosed while still living in our homes. So, we all need home and community-based services and we need that at all care levels, from 3 hours per week of in-home assistance up to 24/7 personal care. Individuals with Alzheimer's and our families should have the option to decide how much in home care we need and whether or not we want to enter an assisted living or nursing home facility. A facility should not be forced upon us because our families are not getting adequate support or payment for services rendered. Choices for Care is only available to people with Medicaid and is typically only available in other people's home. Lastly please remember, caring for us disproportionately falls to our daughters and granddaughters, forcing them out of the workforce and into unpaid physically and mentally challenging work.
- **There must be more training for direct care workers** about how to support someone who is in decline including such topics as self-care, de-escalation techniques, respect for a person's as their behaviors become increasingly challenging, the laws and regulations about what constitutes abuse, neglect and exploitation, and how to efficiently perform personal care. These trainings must be made available free of charge to family caregivers since they are not getting paid and may be living in poverty themselves. A couple hours on zoom by the Alzheimer's Association, while being a good starting point, is not sufficient for what caregivers face.

Thank you so much for listening to my testimony. My first year after diagnosis I told almost no one outside of my family. I felt ashamed. But I didn't ask for this disease. I don't deserve this disease. Nobody does. I decided it was time to tell everyone about my invisible condition. Hiding it was too exhausting. I wrote a letter to the editor and posted on Facebook. I became determined to have no one else suffer from the isolation we all seem to feel upon diagnosis. I look for any opportunity to tell my story. It gives me hope and brings me joy that this

Committee cares enough to listen to us today and take action on a bill that would have a direct positive impact on my life.

I am open to answering any questions now. I am also willing to answer questions that may occur to you later. And lastly, I am eager to speak with any other groups that may benefit from my experience. My contact information is below.

Gratefully,
Pamela Smith, former LICSW
450 East Main St
Middlebury, VT 05753
pamsmith66@hotmail.com