

Dear Senate Health and Welfare Committee Members,

I am Pamela Smith. I have Younger-Onset Alzheimer's. In other words, I was diagnosed before the age of 65. I was 52.

My diagnostic experience: I began telling my PCP, her nursing staff, and her interns at every visit that I was having memory issues by age 50, after noticing problems for about 6 months. I was concurrently having severe anxiety and mild depression. In hindsight, these mental health issues were clearly consequent to, and not the cause of, my memory problems.

But my PCP did not hear me. My symptoms were explained away as menopause, or anxiety and depression, too much stress, or because my chronic pain condition was making it hard to concentrate. Family members saw I was having problems and had their own theories as to the cause. I admitted to my supervisor that I was having memory problems. She proposed that it was because the job was stressful. Someone in my support group recently noted: "With 'regular' onset Alzheimer's everyone is trying to convince you there is a problem whereas with Younger-Onset, you are trying to convince everyone else there is a problem."

What finally worked for diagnosis: I was at work one day struggling to complete some paperwork. I had spent 4 hours writing a note that should have taken me less than 20 minutes. I called my PCP in tears. My provider wasn't available but a colleague agreed to see me the next morning. He ran lots of blood tests. All normal. Then sent me to the memory clinic for an evaluation. I discovered that my IQ had dropped 40 points. The odd thing was that each medical provider kept telling me that the next medical provider would go over the results with me. The first neurologist diagnosed mild dementia. Then the brain scans began. No tumor. Finally got in with the UVM Memory Clinic neurologist. At the end of my appointment when a definitive diagnosis still hadn't been stated, I asked him directly if I had Alzheimer's and he said yes and seemed surprised no one had told me yet. It just felt like no one wanted to give me the bad news. But I needed the specific diagnosis in order to apply for "Compassionate Allowance" Social Security Disability. And for my sanity.

What does it feel like to have Alzheimer's: Alzheimer's is a process of letting go, mourning, and acceptance. I ended my career. I had to let go of all of my "retirement" dreams. I won't write the books I planned. I won't get to see the big milestones in my grandchildren's lives. I let go of reading. Of following the plots to new movies or tv shows. Of using the stove when I'm alone. Soon I will stop driving. I often feel like I have ADHD (which I don't) because I bounce from one task to another. If I think something is important I have to act immediately before I forget it. Some days I actually feel myself slipping. Memories dying. Losing time. I sit and think of nothing.

I am anxious nearly all the time because I never know what I will remember and know that most everything I am living I will forget. The importance of a topic has no relevance to whether or not I will remember it.

My world is now blurry despite wearing glasses because the issue isn't my eyes, it's my perception of what I see that is out of focus. When I found out about my vision I cried in the ophthalmologist's office asking what else Alzheimer's would take from me. Knowing that the answer is everything. I am better now at living in the moment, enjoying the moment. But I also get overwhelmed, impatient and even angry. There are good days and bad, just as they say. But I can speak for myself and for others who can't articulate their experience. We feel that we are drowning nearly every day and pulling our loved ones down with us. I still have some work to do on acceptance.

Some days I feel great. I am content with the losses and accept who I am and where this is going. I know I have Alzheimer's and not that I am Alzheimer's.

Impact on my family: I feel like a burden to my family. I see them hurting and struggling because of me. I know there is no way to get better. I will only get worse, much worse, and each step will cause them more pain. I worry for them. I had never seen my husband cry before the diagnosis. Now it is a regular occurrence. I worry for my son who has Asperger's Syndrome and still needs my assistance regularly. And I worry about all the strain I am putting on my daughter who has to function as my case manager, negotiating systems she sometimes doesn't know. I will never qualify for Medicaid because my husband has to work to support his children. My daughter feels she can't work because she never knows when I will need her, for what, and for how long on any given day. And there is no system in place that can pay her because she is a family caregiver. My daughter has power of attorney, including finances, for everyday things. I am lucky that I can still be home alone, but eventually that won't be the case. I will need someone to feed me and to make sure I don't get lost wandering into the woods during winter.

My 6 year old granddaughter climbs up on my lap, puts her face to my face and taps me on the forehead to say, "I don't like that Alzheimer's" when I forget something that was important to her.

Case Management: I had to be my first case manager. I made numerous calls to multiple state agencies trying to get help. Each agency told me to call another one and why they couldn't help me themselves. Eventually I figured out there is no real case management for people with Alzheimer's, especially for Younger Onset, as I was defining case management from my work experience. I said to someone during this process that I couldn't believe that the person with Alzheimer's was who had to figure out how to get help. Through this process I learned that I had to pay out of pocket for anything I needed. And that the expectation is that family members figure all this out--without any training or compensation for their time. Elderly Services in Middlebury was helpful in giving a concise description of case management for Alzheimer's--basically someone who will help fill out forms for benefits, for a significant fee or with Medicaid.

For years I was a case manager for adults with intellectual disabilities. I need one of those--comprehensive case management that will help with whatever comes up including budgeting, filling out forms, attending appointments to ensure follow-up, making sure my meds are right, getting any extra help that I need. We rightly have recognized that a person who is born with an

intellectual disability needs a comprehensive case manager. Now we need to recognize that a person who acquires an intellectual disability through Alzheimer's or another form of dementia needs a comprehensive case manager.

People with Alzheimer's need:

- All medical providers to be trained to look for the signs of dementia and know how to initiate the diagnostic process. And they really need to listen to their patients.
- Counselors who are trained and experienced with Alzheimer's to help us and our families navigate the emotional impact
- Cross training of state and private non-profit support providers so that a person calling for help can get accurate information about services regardless of which place they call first. And coordination between all the state and non-profit agencies that help people with Alzheimer's.
- Someone to educate the patient and their family members about how to adapt to each change in functioning
- Comprehensive case management available to everyone diagnosed with dementia. I don't yet qualify for Medicare through Disability, and Medicare doesn't cover case management anyway.
- Someone to help making decisions through power of attorney or guardianship and to protect us from financial exploitation
- In-home direct assistance for cooking, managing the household, completing tasks, and eventually personal care
- Transportation to appointments, basic needs, and socialization opportunities, and
- Support for family caregiver's including training and payment for services rendered.
- All services need to be free or reasonably affordable. Most of us with Alzheimer's don't qualify for Medicaid. At least not until our disease nearly bankrupts us.

Thank you for listening to my story and caring about those of us living with Alzheimer's—patients, caregivers, medical providers, family members and the community at large.

And thank you for listening to my daughter's story as well.

I am available to talk further with anyone who wishes via email or zoom. Feel free to share my story with anyone who is interested. Advocacy is now my life's work and I want to make the most of it.

Pamela Smith of East Middlebury, Vermont

Testimony of Eryn McElhaney Smith
VT S206

Re: Alzheimer's Care

Hello,

Allow me to start off by thanking this committee for the opportunity to speak about my experience as a caregiver and daughter of a person with Alzheimer's. My name is Eryn McElhaney Smith of Ripton, Vermont. I am a 30-year-old mother of two. For the last 9 years, until his death in May, I was the caretaker for my great-uncle, who had cognitive and physical disabilities from birth. Through the last year of his life, and since, I have also been the primary caretaker for my mother, Pamela. These two experiences have had some stark differences, as well as some unsettling similarities.

With my great-uncle, Kirk, I had a team of support. While I lived with him in the home, I was able to use money from the state to hire about ten hours a week staff to help, to provide him with amazing opportunities out of the house, that I was unable to offer as a young single mother. I had doctors who were able to speak with each other, his case managers, 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. And while I have much to say about the need for better paid home providers, and a respite budget that actually makes our lives manageable, 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.

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. The only trainings available to me on caring for my mother seem to be through the Alzheimer's Association. So, after 9 years of needing to put my family's needs above my career, above my ability to earn money, above my dreams for myself, I find myself back where I started and with even less. My family has been struggling for generations. Generation after generation of women have scraped through life with the bare minimum to provide better for their children. And I had thought and hoped that our decades of work had finally resulted in a life where I was going to be able to escape the cycle. But generational poverty continues to be a stronger force than all our education and hard work. This is women's work, and therefore invisible and without value. So, I will continue to be on food stamps, qualify for TANF, struggle to pay for my kids to go to a week or two of summer camp, say no to reasonable requests because I can't afford them. All 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. That is why my family is here, living this impromptu extended tropical vacation. Because we are so sick of being sad all the time. We don't have much time together anymore. But we can go on an adventure, be warm, and have a tiny bit of fun amongst the crushing weight of the inevitable.

Thank you for your time.