My name is Lisa Pratt, In 2018 I lost my mother to Alzheimer's Disease. Less than two years later I lost my father to Lewy Body Dementia. It's hard to summarize the impact of caring for them over the course of many years in just a few minutes, but I'm going to try. When my mother was first diagnosed with Alzheimer's Disease, my father had over $400,000 in his retirement account and they lived independently in their own home with no assistance from others. While my mother was able to remain in their home until she passed, it required my brother and his wife to move in to take care of her. Both had full time jobs of their own, so we also had to hire in-home caregivers and used Adult Day services to supplement. I took over all the finances and coordination of care, which was almost a full time job in itself, all while working and raising a child. Eventually we put my mom on hospice care, which provided us with amazing medical care, but still no care giving services. After my Mom passed, my Dad declined significantly. Unfortunately his needs far surpassed our ability to care for him in the home and we had to place him in a dementia care facility where he lived out the last 16 months of his life. We used hospice care services to help care for him as well. By the time my father passed, there was approximately $30,000 left in his retirement account and he was getting very close to running out of funds to pay for the dementia care facility he was living in. It took the resources of my entire family, in-home caregivers, adult day programs, hospice care, a dementia care facility, and my father's entire life savings to care for my parents through their battles with dementia. It also took a huge toll on my entire family that we are still trying to recover from today. But, without affordable care options to help care for them, we had no choice but to step up and do it ourselves. Finding the resources we needed wasn't easy. We eventually contacted AgeWell VT and one of the things they recommended was an Estate Planner. We were fortunate enough to find one that was very knowledgeable about the resources available and worked with us to plan our finances and care options given the resources we had. Eventually that led to more helpful contacts in other organizations and over time we were able to coordinate the care we needed to help us in our situation. We were lucky to have the financial resources and family members who could help, but not everyone is so fortunate to have those things. We should be doing more to care for those with dementia and not putting so much of the burden on them or their loved ones to figure it out for themselves.

Thank you for inviting me to this, I enjoyed listening. I had to drop at 10:30 for work.

I had so many other comments to make along the way. Here are some of them.

1. Choices for Care is a great program, but is very hard to qualify for. It is intended for those with very little financial resources. Our Estate Planner helped us move our finances around in such a way that my mom would qualify, but he is very, very familiar with the rules and without him we would have never even thought there was a chance she would qualify. Without that program we would not have had money for my dad to pay for his dementia care facility. That being said, the problem with that program is that so few people qualify for it or even try to be on it. I'm curious to know what the percentage of people in VT with dementia who are on this program actually is. I'm guessing it's low. Then there is the group of people who have the financial means to pay for the care themselves, which I also presume is a low percentage of the

overall dementia patients in Vermont. This leaves a large percentage of dementia patients with no resources still and there is no good option for assistance for this group.

2. I'm very appreciative of the work that is being done to better educate providers. I am personally concerned about the future of my own health and find conversations that I have with my providers to be similar to what Pam was describing. Another area to consider is education around hospice care. I'm finding that providers are unaware of just how early on someone with dementia can actually qualify for that program. I've had to educate a few friends who have had to push hard with their PCPs to get them to put in the order for hospice evaluation. Due to their persistence, their parents were able to get on that program early and found it to be just as helpful as I did. My mom was on hospice for 18 months and my dad for 16 months.