

**Remarks to the Aging & Older Adult Services Committee
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Josie Romatowski
131 Ashmont Drive
Butler PA 16002

Thank you for giving me the opportunity to speak to you this morning. I also would like to thank you for coming together today to tackle the looming problems being brought on by Alzheimer's disease.

My name is Josie Romatowski and I am married to Alan Romatowski who spoke earlier.

Three years ago, when Alan was undergoing tests to determine the cause of his difficulties, I was afraid he had a brain tumor. When we were told it was Alzheimer's, I was blindsided. He was only 55 years old and flew jets, how could he have Alzheimer's? Wasn't that an elderly person's disease? I had the feeling of standing on the very edge of a volcano, and now I was falling into its very depths. With the diagnosis, came the burden of trying to find out all I could about the disease and figure out what I needed to do next, but I did not know where to turn... let alone where to begin. The doctor had given us a brochure about Alzheimer's. It had a phone number and I called. It belonged to the Alzheimer's Association. Thus began our journey of living with Alzheimer's.

Alan has early-onset Alzheimer's. Early-onset is Alzheimer's disease that affects people under the age of 65. It is said to account for only 10% of Alzheimer's diagnoses, but that translates to over 640,000 people in the United States, the youngest on record being 17 years old. Even though the symptoms and outcome are the same, it is a different disease than the one that affects those in their 70's, 80's and 90's. Early-onset presents a unique set of challenges, as the disease strikes people in the prime of their lives. We are still working, raising families, and trying to save for retirement.

We have three children. Two are in college... our daughter is going to Slippery Rock University, majoring in elementary education (she wants to open a day care/preschool) and a son is at Penn State studying chemical engineering. Our youngest son, who just got his learner's permit, is 16. The

diagnosis, and prognosis, has been hard on the children, especially our younger son, who sees his dad's decline on a daily basis. He sees the changes and no longer has the dad he once did. My older son has told me he needs to find a well-paying job upon his graduation, because, he said, he knows he will have to help us financially. That is not something a mom wants to hear.

A few years before the diagnosis, Alan had taken a severe pay cut and, as he stated earlier, lost his pension when USAirways went into bankruptcy. We refinanced the house and cut back in many areas. I started a business to try to rebuild a retirement savings. Then we got the diagnosis and our world was turned upside down. Financially, every day is a struggle. We are living on about a quarter of what we used to. The recession has taken a toll on my business, and I am contemplating closing it and trying to find employment elsewhere. But Alan's disease is progressing, and I know it will not be long before I will need to stay home and care for him full-time. From what I have learned, the funds to pay for private care, for those in the latter stages of Alzheimer's, usually come from retirement savings. That will not be an option for us, nor for the many others who are being diagnosed at younger ages.

We are one of the lucky ones. We still have medical benefits and are able to collect disability. Even with our prescription drug plan, Alan's medicines cost over \$300 a month, which is a lot to us ...but there are many who aren't as fortunate. Even so, when I think about the future and the situation I will be faced with, I don't know what I am going to do. Many of the social support programs that are in place to help those in need, don't provide assistance for those under the age of 65. Once again, I am having the feeling of not knowing where to turn or what to do.

Alan's and my family all live out-of-state. When they call and ask how things are going, I say, "We're fine. Everything is going well." even though it is not. I don't want to burden them, for there really isn't anything they can do. But I am not going to sit here before you and tell you the same thing. Everything is not fine.

Our local Alzheimer's Association began an early-onset support group and at the last meeting, I asked them what they wanted me to let you know. They want you to know that those of us living with early-onset Alzheimer's and related dementias are in a unique group. We are dealing with unique

problems, and we are finding ourselves between a rock and a hard place. We still are raising children, trying to send them to college, trying to figure out how to support our families while taking care of spouses who need 24 hour a day care, and trying to figure out how we, the caregivers, are going to support ourselves when we reach retirement age . . . all this without the help of social services, because we are under the age of 65. It feels impossible.

I am hoping there is something you can do for those of us trying our hardest to do the best we can, faced with this disease, and all the problems that come with it. The number of people in Pennsylvania being diagnosed with Alzheimer's is only going to grow, and with that, the numbers of early-onset diagnoses. Without some type of plan in place, all the associated problems will only escalate. It is a frightening scenario.

When Alan was being tested to find the cause of his impairment, I was so afraid he had a brain tumor. I wish, now, it *had* been a brain tumor. With cancer, there are treatments, and perhaps surgery. There is hope... people survive. With Alzheimer's disease that hope does not now exist. Perhaps someday, with funding, the many people studying this disease will find a cure, or at least find a way to arrest it. Until then, those of us who are able must do what we can to educate, to advocate, and to support those who are working so hard to make a difference.

I would like to add one further point. I don't know where Alan and I would be right now, were it not for the help of the Alzheimer's Association. They were there when I called, when I didn't know where to turn. They sent me literature, free of charge, when I needed answers to my questions. They guided me to support groups, and then started an early-onset support group when we couldn't find one that addressed early-onset concerns. It was their phone number that started our path to *living with* Alzheimer's rather than dying from it.

Thank you.