

United States Senate Special Committee on Aging

The Fight Against Alzheimer's Disease: Are We on Track to a Treatment by 2025?

Testimony of Kim Stemley

March 25, 2015

Good afternoon Chairman Collins, Ranking Member McCaskill and members of the Committee. On behalf of caregivers for individuals living with Alzheimer's disease and other dementias, thank you for the opportunity to testify before you today.

Alzheimer's is a devastating, progressive and ultimately fatal disease. More than 5 million Americans are currently living with Alzheimer's disease or another dementia. These men and women living with Alzheimer's are your friends, your neighbors, some may even be your family members. They are business leaders, school teachers, store clerks, and construction workers. They are both Republican and Democrat. My beloved mother, Dorothy Stemley is one of them.

I am honored to be here today to share our story and discuss issues facing people with Alzheimer's and their caregivers. I find the more vocal I am about how this disease has impacted my family, the more I hear from other people who have gone through or are going through similar situations. Today, my mother is living in a skilled nursing facility in Missouri. I am confident that she is receiving care that is appropriate for her and that she is in the right setting. However, getting to this point was a challenge, and there are many families out there who never get the care and support they desperately need to face this terrible disease.

For several years, my mother and I were in denial about the changes in her behavior. I did a great job rationalizing unusual incidents, and she did an even better job hiding others. But all the rationalizing and denial came to an abrupt halt the morning I received a call from a stranger telling me my mother was in the middle of Martin Luther King Drive in St. Louis, alone and confused. She had slept all night in her car on the side of the street. She must have become lost and scared. My mother was a long way from home, and that day marked the beginning of our journey with Alzheimer's.

I knew then that the world we had always known was no longer. At the age of 30, I was thrown into a world that was completely foreign to me, a world of Alzheimer's disease. Her diagnosis was the result of three different evaluations. Neurologists performed a number of blood and cognitive tests on my mother, ultimately concluding that it was, in fact, Alzheimer's disease. So there I was, 30 years old, an only child caring for my single mother who had Alzheimer's. I felt completely lost. We did not receive much information from her doctors about the disease, or much advice on what we should do next. A friend of mine recommended looking into resources online. Through that research, I found the Alzheimer's Association, which was the first time light began to shine through the darkness. I was able to learn more about the disease, what the diagnosis meant for both myself and my mother, as well as what our next steps should be in considering options for her care. I also learned how to cope with all the emotions I was feeling throughout the whole process. The physical and emotional impact of caring for someone with Alzheimer's disease costs the nation dearly. Caregivers for people with dementia report higher rates of depression and stress as a result of their caregiving responsibilities. The chronic stress of caregiving is associated with physiological changes that could increase the risk of developing chronic conditions. This was especially true for me. The stress of being a caregiver was only compounded by the stress I faced at work. I would wake up in the middle of the night with back spasms, and my back pain was severe enough that my own doctor recommended I make lifestyle changes to maintain my own health. I now work out three times a week and have been eating a healthier diet. However, the emotional part of it continues to be difficult for me- when I see my mother now, it still feels like day one, every single time.

At the time she was diagnosed, my mother had been living by herself. She had exhibited other warning signs that raised concerns about her safety. For example, my mother started a fire in her condo, and although no one was hurt, I knew that it was time to consider other living arrangements for her. After working through various options, we moved her into a seniors' independent living apartment, which provided her with the security, hospitality, and social outlet that she needed. Not only did my mother adjust to her new living environment, she thrived in it. She lived on her own for another four years, until she took another step down with the disease. Her memory loss had progressed to the point where additional care and attention were needed. This next step was my own personal nightmare coming true: moving my mother to a skilled nursing facility, where she currently lives today.

Since becoming an advocate for my mother, I hear from friends and strangers alike who are just as lost as I used to be, and that is one thing we have to change. When people are diagnosed with Alzheimer's disease, they need to have the opportunity to learn about the disease as well as their options for treatment and support. Based on my experience, I know I am not the only one who has had difficulty getting help after learning about an Alzheimer's diagnosis. Getting this help for caregivers is especially important because caring for an individual with Alzheimer's can have a negative effect on employment, and as a result, financial security. More than half of Alzheimer's and dementia caregivers who are employed full or part time report that their caregiving responsibilities cause them to go in late to work, leave work early, or take time off.

Throughout this experience I have also learned that there are gaps in our health system when it comes to dealing with Alzheimer's. Far too many physicians are not familiar with how to properly advise patients and their caregivers after an Alzheimer's diagnosis. It took a friend's advice -- not my mother's health care provider -- and finding the Alzheimer's Association for us to get even basic information about what to expect from this disease. No one should have to feel as lost as I felt back then. Though Alzheimer's disease cannot be prevented, cured, or even slowed, I have learned that there are many things that can be done to improve a family's ability to cope with the disease, especially immediately following a diagnosis.

Getting this help is not always easy. This is why the HOPE for Alzheimer's Act, which was reintroduced this week with strong bipartisan support is critically needed. The HOPE Act would help ensure that families like mine who are facing an Alzheimer's diagnosis are provided with care planning services to help guide their next steps. Care planning services, including information about the disease, what the diagnosis means for the family, and what steps should be taken to keep a loved one safe and healthy for as long as possible, are critical to getting a family on track after an Alzheimer's diagnosis. Eventually, I found the resources that empowered me to manage my mother's condition while also managing both my own health as well as my career. If we had had access to this type of benefit at the time of my mother's diagnosis, I am certain that I would have felt much less alone in this fight. Until a cure is found, we must support the family, caregivers, and people with the disease immediately after diagnosis. We need care which is exactly what the HOPE Act would provide.

Through my work as an advocate, I have also had the opportunity to speak to many researchers about the current progress that has been made toward the development of a cure for Alzheimer's. I continue to be disheartened because I realize that although there has been a lot of progress, we still have a long road to walk. When I see the progress that has been made in other areas as the result of a strong federal investment in research, I think of the opportunity that exists for scientists to develop a truly groundbreaking treatment for Alzheimer's disease, one that could spare millions of families the same heartache I feel every time I see my mother. Alzheimer's disease is one of the worst out there. We need to increase funding for Alzheimer's disease research. I implore you and all your congressional colleagues to work to provide additional funding for Alzheimer's disease research. A breakthrough would allow future generations to avoid the journey that I, my mother, and more than 5 million Americans living with Alzheimer's and their families are currently facing. Research is the only way we can truly create a world without Alzheimer's.

Conclusion

Thank you again for the opportunity to testify today. I appreciate the steadfast support of the Committee and its focus on improving the lives of those affected by Alzheimer's disease. Alzheimer's disease not only impacts the diagnosed person, but also the lives of their loved ones. I ask Congress to address the current gaps in federal funding for Alzheimer's research in accordance with the goals and principles of the *National Plan to Address Alzheimer's Disease*. We must make this investment now if we ever hope to see a world without Alzheimer's. I also ask that you pass the HOPE for Alzheimer's Act this Congress, as it would provide much-needed comprehensive care planning to patients, families, and caregivers following a diagnosis. Thank you.