Testimony of Katelyn Montanez
Taking Aim at Alzheimer’s: Frontline Perspectives and Caregiver Challenges

Special Committee on Aging
United States Senate

May 20, 2021

Chairman Casey, Ranking Member Scott, and members of this Committee, thank you for the opportunity to testify before the Committee about my experiences as a caregiver for my father. My hope is that, in sharing my story, others who are impacted by this disease will feel less alone. I am a social worker and an advocate for my father and for the millions of Americans who have family or loved ones living with Alzheimer’s and other dementia. I’m here today to share my personal experience as a caregiver for my father, Luis, who was diagnosed with younger-onset Alzheimer’s at age 54.

More than 6 million Americans are living with Alzheimer’s – my father’s story represents only one set of unique challenges which individuals and caregivers live with every day. My hope is that my testimony effectively conveys my father’s story, and underscores the importance of what this hearing is based around – expanding the support of daily and long-term care needs of people with dementia, which includes the support of their caregivers.

Like many other individuals, Alzheimer’s disease can be traced hereditarily in my family. My grandmother passed away from Alzheimer’s at age 62. My father’s sister passed away last year from the disease, and currently, another aunt of mine is living with the disease, requiring her to reside in a nursing home.

My father began showing symptoms of Alzheimer’s in his early 50s, but he wasn’t formally diagnosed until 2015 at the age of 54. After he began displaying symptoms my family was familiar with, my parents visited a few providers to see if they could figure out his neurological and other health issues. Each doctor my father visited didn’t recognize the signs of younger-onset Alzheimer's. Prior to his diagnosis, it became my mother’s responsibility to attempt to understand how to navigate resources that could be available to my family. My dad was unable to earn a living for his family and just stayed home, confused and disoriented. He had been a custodian at a local school and now we were faced with a difficult new reality as a family. My mom and I were both working full time and we were unable to provide the 24-hour supervision he needed. The delay in diagnosis and fragmented care he received, left us feeling frustrated, alone, and unable to access much-needed supports and services. It was an incredibly challenging time for us. At first, when he was assessed for home- and community-based services, he wasn’t eligible because he could still do many things on his own - but that was only on good days. On bad days, he wasn’t able to do anything.

I am a social worker, I know the system well, and I had to fight to get him the services he needed. Unfortunately, it took cutting through many layers of red tape, hundreds of pages of paperwork, and most distressing of all, nearly five years to receive the care and support services he needed.

While the emotional toll of younger-onset Alzheimer's is something which I have channeled into advocating for individuals like my father, there are significant costs for individuals living with their disease and their families. This placed a large financial responsibility on both my mother and I as his caregivers and now the financial support for our family. Of the total lifetime cost of caring for someone with dementia, 70 percent is borne by families — either through out-of-pocket health and long-term care expenses, or from the value of unpaid care. I am part of that statistic - I ended up leaving my first year of graduate school to come home in order to help with his care.

Last fall, we were fortunate enough to finally get him Medicaid home and community-based services through the waiver program in Pennsylvania. A medical social worker helped us through the application process and with the numerous assessments and paperwork that had to be done. But it shouldn't be this hard for people to receive services they need.

My father has been receiving home- and community-based services now for about seven months. I know this Committee's hearing today is focused on the importance of these services, and I cannot tell you how thankful I am that we have been able to have access to them. We recently had to move my dad to my sister's house because my mom was no longer able to take care of him. The transition was difficult because he understands what is happening.

The services he's receiving give him an aide for 3 hours per day and meals on wheels. When he was living with my mom, the aides would help clean the house, help my dad with breakfast, and even take him on short car rides. Now that he's living with my sister, the aides take him on walks and sometimes even bring along my sister's dogs. The aides also come in the evening to give my sister a chance to run errands and have a break. But we've also run into some issues: right now my sister hasn't been able to find an aide for my dad because of the high burnout and turnover rates.

With someone living with Alzheimer's or dementia, consistency of care, including who is providing the care, is essential. Unfortunately, burnout and turnover are very common with home health aides. Being an aide is hard work with little pay. Aides should be paid more for the work they do and have better access to dementia education and training for their workers. If aides received proper training to work with individuals living with Alzheimer's and dementia, they would have the tools they need to help redirect, would understand common behavioral issues, and it could lead to more successful interactions. People living with Alzheimer's have good days and bad days and having better trained aides who get paid higher wages would bring more consistency for my dad, and a better quality of life for him and our family.

Congress has continued to keep Alzheimer's and dementia top of mind when working on important issues like home- and community-based services. Chairman Casey, I'm grateful for your leadership on this important and deeply personal issue. I am a passionate advocate for my dad and for others living with Alzheimer's and other dementia. It's important to me that people living with Alzheimer's - including those who are younger than 60 - are able to receive the care and support they need. Strengthening these services is not only essential, it will help people like my father live with family members for as long as possible before having to receive care in a nursing home setting. I want to start my own non-profit to help families like mine to have better access to available services to help the person they love remain at home longer.

After my dad's diagnosis, it felt like a struggle to get the information we now know we needed. The fragmented, improperly managed care he received only added to our struggle. It would have been and would continue to be incredibly beneficial to my family if we had more comprehensive care for my dad. As you've heard from my testimony, caring for an individual with Alzheimer's or another dementia poses unique challenges. Thankfully, dementia care management can ease these challenges, improve the quality of care, and reduce costs. Unfortunately, dementia care management programs have not developed within the current Medicare fee-for-service system. Legislation like the bipartisan Comprehensive Care for Alzheimer's Act (S. 1125 / H.R. 2517) would ask the Center for Medicare and Medicaid Innovation to test a different payment structure for dementia care management. It aims to reach diverse populations, rural areas, and medically underserved communities so everyone has an opportunity for more comprehensive care. This bill has the potential to streamline today's complicated health care maze for people living with dementia and their caregivers – making this easier will provide a better quality of life for individuals like my father.

I am Puerto Rican, and unfortunately that means I am at greater risk of developing the disease. Hispanic Americans are one and one-half times more likely to develop Alzheimer's disease but we are historically underrepresented in Alzheimer's and other dementia clinical trials. In fact, in 2018, across all clinical drug trials - not just Alzheimer's - Hispanic Americans represented only 1 percent and Black Americans represented only 5 percent of trial participants, despite representing 18 percent and 13 percent of the population, respectively. The best available evidence suggests that this trend is similar in Alzheimer's research.The underrepresentation of these populations, as well as Asian and Native Americans, not only hinders the ability of researchers to understand these health disparities, it also restricts their knowledge of how an approved drug or diagnostic may affect the population most likely to need the therapy. Senators Ben Ray Lujan and Collins introduced the bipartisan Equity in Neuroscience and Alzheimer's Clinical Trials (ENACT) Act (H.R. 3085 / S. 1548), to increase the participation of underrepresented populations in Alzheimer's and other dementia clinical trials by expanding education and outreach to these populations, encouraging the diversity of clinical trial staff and reducing participation burden. I ask the Committee and other members of Congress to support this bill to ensure current and future research includes increased numbers of Blacks, Hispanics, Asian and Native Americans in clinical trials to ensure everyone, including my family, benefits from advances in Alzheimer's science.

Throughout the past few days, I've virtually joined the Alzheimer's Impact Movement and the Alzheimer's Association, along with over 2,100 advocates from across the country to make a difference in our nation's capital. I am here as a daughter, niece, and granddaughter of Alzheimer's. We all are and we will continue to be a voice for people who have lost theirs. Congress must ensure all communities have access to high-quality, culturally-appropriate services and supports. Additionally, I respectfully ask you to increase access to home and community-based services for individuals living with Alzheimer's and dementia including individuals living with younger-onset Alzheimer's disease or other dementia. Please continue to make Alzheimer's research a priority and to work together to pass critical legislation like the Comprehensive Care for Alzheimer's Act (S. 1125/H.R. 2517) and the Equity in Neuroscience and Alzheimer's Clinical Trials (ENACT) Act (S. 1548/H.R. 3085) to help other families like mine receive the support and services we all need and deserve. Thank you for inviting me to speak, listening to my story, and for all you have done. Please continue to join us in the fight to end Alzheimer's for generations to come.