



**Pennsylvania House Hearing on
Alzheimer's Disease and Related Disorders Office Infrastructure
June 3, 2024**

Thank you, Chairwoman Madden and Members of the House Aging and Older Adult Services Committee for convening this hearing on the Alzheimer's Disease and Related Disorders (ADRD) Office Infrastructure. I would also like to thank Sen. Kearney and Rep. O'Mara for their leadership in supporting constituents—like me—and for recognizing and seeking to address the Alzheimer's crisis in Pennsylvania.

My name is Jennifer Davis, and I am a volunteer advocate with the Alzheimer's Association and I am a former caregiver, from Media, Pennsylvania. I am also a nurse practitioner at the Hospital of the University of Pennsylvania, though I am testifying in my own capacity today, and I am not speaking on the behalf of Penn Medicine.

Let me first take you back to about 2007—this is when my mom, Linda, began showing signs of dementia. Predominantly, she had word finding difficulties. When she sought out medical advice, she was diagnosed with anxiety and depression. Then she began to have lapses in memory—there was no longer a delay in word recall. After struggles to locate a word once familiar to her, she would just omit the forgotten word.

In 2013, my mom was diagnosed with frontotemporal dementia, only to find out a few months later her formal diagnosis was that of vascular dementia. In 2015, she was additionally diagnosed with Alzheimer's, meaning she had mixed dementia.

I was by her side through the process of obtaining a diagnosis and determining a path forward. For more than five years I dedicated my life to providing care for my mother. Despite the obstacles we faced as her disease progressed, our love and joy far outweighed our struggles.

My mother died from Alzheimer's in 2022, but the disease also claimed my father's life. Growing up my mom always took care of everyone in our home. When the time came for her to be the recipient, my dad tried his hardest to meet the challenge. Caregiving in Alzheimer's and dementia is demanding for anyone. For my dad, with a half century living with an alcohol addiction and PTSD from his service in Vietnam, the task proved to be too difficult to overcome. He struggled to understand the disease and the true implications for their life. Ultimately, we had to remove my mom from their home. Alzheimer's was the catalyst for my father's decline and eventual death.

From that moment, I made the decision to devote myself to my mom's well-being. At first, I shared responsibilities with my one sister, later becoming the primary caregiver. Every moment outside of work was focused on my mom's ability to thrive despite the circumstances we were given. My mom and I sought out joy and laughter every day. We had many dance parties, often to Elvis, that brought sweat to our brows and a huge smile to our faces.

It was when she went to memory care that I came to realize how little verbal capabilities she had at that point. We were so in tune with each other, with me anticipating her every need, that I failed to notice our

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own evolution in communication. As a result, we had a deeper connection beyond the mother-daughter relationship.

In the years of navigating the ever changing world of Alzheimer's, there was also a fair share of tears, heartbreak and isolation. I don't regret, though, spending a single day with her as the center of my universe—caring for my mom was the greatest honor of my life.

Those last months which were to be her remaining time on this earth, I was stretched thin and exhausted. I didn't know how I was going to keep going. My days off were spent focused on her increasingly challenging care. I would visit her after my 13-hour shifts at the hospital because I couldn't trust that she would be cared for in a way I knew she deserved.

Then she passed away in August of 2022. The day-to-day needs suddenly vanished and my brain needed to be rewired in that recognition. I was confronted almost every moment with the reality that my mom, my best friend and soulmate, was no longer here. I am still dealing with physical ailments that stem from physically taxing caregiving. I feel lost without her—she was the only home I have ever known. And I didn't know the impact from those years as a caregiver would be felt so deeply and for so long.

With my mom's passing, I have been forced to face all that I experienced with both my parents during the progression of her Alzheimer's. I ache at the memories of all that my dad endured. I am angry that my mom was forced to slowly lose her function and autonomy. The role of caregiver was all-consuming and so pervasive affecting all aspects of my life—my career, my friendships, the possibility of starting my own family, and my physical and mental health.

The level of time and mental energy it took to coordinate my mom's care and navigate disparate systems was incredible, and I did this while maintaining a career as a nurse.

As a nurse practitioner I work in an Emergency Department observation unit. A major component of my role, in addition to addressing the acute presenting medical issue, is to consider the patient's discharge needs, and to assist in the coordination of services or resources for the patient and their caregiver.

Even with the knowledge and experience I had amassed after 15 years as a registered nurse/certified registered nurse practitioner in a healthcare setting—a background many others do not have—I often felt like I was fighting to keep my head above water trying to manage my mom's care and navigate the disjointed systems currently in place in Pennsylvania. I was left to my own devices, to do my own tedious research, to locate resources through several different entities, and to figure out how to piece them together.

I benefited from my nursing background as it enabled me to create care plans, identify modifications and equipment needed to address the constant cognitive and physical changes. I had a level of understanding of the questions to ask and the possible needs of my mom.

We also had the finances to support my mom's needs. We were fortunate that my dad had the foresight to plan financially for the future, including provisions to account for my mom's needs. Even still, I had to use money I had earmarked for my savings and retirement. We were able to cover the out of pocket costs of a

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day program and later memory care in a long-term care facility—services many across the state may not be able to afford. But the obstacles we faced required ingenuity and money to ease their burden.

But what I am left thinking about is the time—the time I spent researching, calling, coordinating, and managing the unnecessarily segmented aspects of her care and support. This ultimately meant less time with my mom, less time fulfilling my favorite role—being her daughter.

The logistical challenges and burden that fell to me forced me to carve time from my career, from my own down time—as scarce as that already was—and it forced me to take time away from making memories with my mom. What I find most ironic, is that caregivers often have to source help from others, just so they can devote time to researching and sourcing even more other help and support for their loved one.

This vicious cycle, and the negative impacts on caregivers' health and wellbeing will only continue if Pennsylvania does not take action to better support residents through the implantation of the Alzheimer's Disease and Related Disorders Office Infrastructure.

When we look at the nearly 7 million Americans currently living with Alzheimer's and the 11 million providing unpaid care nationwide, it is clear that Alzheimer's is a public health crisis.

In Pennsylvania, it's well reported that there are more than 282,000 people aged 65 and older living with Alzheimer's, and another 465,000 individuals caring for their loved ones. But what I can tell you—from my own personal experience and from hearing the experiences of others across the State—the numbers and the impact of caregiving exceeds these statistics.

As my story demonstrates, Alzheimer's and dementia impacted every aspect of my life. And that same far-reaching impact continues for every person living with the disease and their caregivers—the impact reaches every corner of the Commonwealth, every county, district, and neighborhood.

When the numbers are so staggering, and the true impact of this disease runs so deeply in our communities, we simply cannot afford another minute of delay.

As I prepared for this moment, and for the work I would do this year as a volunteer advocate with the Alzheimer's Association, I thought about the time I could have had with my mom, if the state plan that had been developed a decade ago had been funded and adequately implemented.

I think about the minutes I spent on the phone or the computer piecing together the care and support my mom needed, and I am left with a deep sense of sadness and disappointment that our state government had not done more, earlier to support Pennsylvania's like my mom and me. I know my mother is no longer on this earth, but it is with her in my mind and in my heart that I have chosen to continue my devotion to this cause. To be a voice for those without, and to tell my story in the hopes that it will affect change.

There are so many others like me—who came before, and who I know will come after—and they deserve support. They deserve to have a state government that works collaboratively and cohesively—as we have seen other states do successfully—to implement public health strategies to combat this crisis.

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As someone who works in a large, matrixed organization, I understand there are challenges and obstacles that can get in the way of progress. But when the cost of these obstacles is the health and well-being of Pennsylvania residents, and when we see the progress being made in the field, we have to do more to support each other here at home.

I can tell you, first hand, by committing to action, and implementing the ADRD Office Infrastructure, you will be making a tangible difference in the lives of countless individuals affected by this devastating disease in Pennsylvania.

Thank you Chairwomen Madden, and thank you to all of the Members of the House Aging and Older Adult Services Committee. I appreciate the invitation to speak as well as your time and consideration.

Respectfully,

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