

Testimony of Lauren Kovach

Senate Finance Subcommittee on Health Care Hearing Alzheimer's Awareness: Barriers to Diagnosis, Treatment and Care Coordination November 20, 2019

Good afternoon, Chairman Toomey, Ranking Member Stabenow, and distinguished Members of the Committee. Thank you very much for the opportunity to share my personal story on the impact Alzheimer's has had on my family. My name is Lauren Kovach and I'm here today to share my story as a caregiver and an advocate with the Alzheimer's Association and Alzheimer's Impact Movement. Twenty years ago, my life took an unexpected turn when my grandmother, Helen Tannas, was diagnosed with Alzheimer's at the age of 82.

Alzheimer's is a progressive brain disorder that damages and eventually destroys brain cells, leading to a loss of memory, thinking, and other brain functions. Ultimately, Alzheimer's is fatal. We have yet to celebrate the first survivor of this devastating disease.

My grandmother lived to take care of her family - we're Macedonian, that's what we do. Growing up, my mom, brother, and I lived four houses down the street from my grandmother and since my mom was a single, working mom, we were always over at grandma's. My grandmother helped my brother and me with our homework, she cooked dinner for us, and was the center of countless family celebrations. As a child, my grandmother was a daily part of my life. I never imagined life without her down the street.

I was 21 years old and in my third year at college when my grandmother was admitted to the hospital. I was terrified at the thought of losing her. My grandmother spent ten days in intensive care undergoing a battery of tests, which resulted in several diagnoses. All of the conditions were treatable except one — early-stage Alzheimer's disease.

When I was growing up, my grandmother had a pet name for me. She called me "moe chupe, moe chupe," Macedonian for "my girl, my girl." One day after the diagnosis, I turned to my grandmother and said, "You're my chupe; you're my girl." The nickname she had given me so many years ago had come full circle. It was now our turn to give back the love and sacrifice my grandmother had always given us. And so my mom, my brother, and I made a pact that we would do whatever it took to keep my grandmother at home. We prepared for the longest goodbye of our lives.

After her diagnosis, we adjusted our lives to become full-time caregivers. I withdrew from school and eventually my mom had to retire early from her teaching career. We knew we needed to take steps to care for the woman who spent most of her life caring for us, but we didn't know what those steps were or how to make a plan. We didn't even really know what deciding to be a full-time caregiver meant -- there was a long and bumpy road ahead for all of us.

When we were discharged from the hospital, that was it. They gave us our discharge papers and wished us the best of luck. No pamphlets, no explanations, no support. We were fortunate to be near the University of Michigan, which has an Alzheimer's Disease Center, and a neurologist

who confirmed the Alzheimer's diagnosis. That neurologist was great, but again, she didn't provide us with any resources or information on what to expect from this diagnosis or what we were supposed to do next.

There we were facing this life-changing news and having to immediately make one major decision after the other, with no time or guidance to make a long-term plan. We weren't aware of resources that could have helped my mom and me manage the stress of caregiving, like adult day services and respite care. Unfortunately we learned about those too late - after she had passed away.

Fortunately, families now facing an Alzheimer's diagnosis have new options that were not available to my family back then. In 2017, Medicare began reimbursing physicians and other health care professionals for providing comprehensive care planning services to individuals with cognitive impairment – a critical step in improving the quality of care and quality of life for those with Alzheimer's and their caregivers.

Comprehensive care planning is crucial to helping those living with Alzheimer's and their families answer those important first questions after a diagnosis of 'how do I take care of my loved one?' and 'what do I do now?'. A care planning visit includes an evaluation of cognition and function, measuring neuropsychiatric symptoms, a safety evaluation, identifying and assessing a primary caregiver, development of advance care directives, and referrals to community services. Dementia-specific care planning can lead to fewer hospitalizations, fewer emergency room visits, and better medication management. It allows diagnosed individuals and their caregivers to access medical and non-medical treatments, clinical trials, and support services available in the community. Everyone should have access to this lifeline.

However, analysis has shown that fewer than one percent of those living with Alzheimer's and other dementias eligible to receive these services, actually received care planning in 2017. In order for more Americans affected by Alzheimer's to receive these critical care planning services, more clinicians must use the care planning benefit.

That is why I am so thankful to Ranking Member Stabenow for introducing the bipartisan *Improving HOPE for Alzheimer's Act* (S.880), which is already cosponsored by 46 Senators – including many of you on this Subcommittee. This important bill would help achieve that goal by requiring the Department of Health and Human Services to first educate clinicians on the existence and importance of Medicare's care planning benefit; and, second, report to Congress on the barriers to individuals receiving care planning services and how to increase their use.

If this care planning code had existed fifteen years ago, it would have significantly improved the quality of life for my grandma, my mom, and me. Full-time caregiving while navigating the health care system is both physically and emotionally draining. I can't describe the level of exhaustion and desperation we felt.

It wasn't always easy, but my mom and I were able to keep my grandmother at home for her entire journey - from the time she was diagnosed, my grandmother never spent a single night by

herself. If my mom wanted the night off, I would stay home with her. If we went to visit family in Chicago, grandma would come with us.

During the day, when we left for work, we'd leave post-its around the house. Simple things like "remember to brush your teeth," "coffee is made," and "lunch is in the fridge." And that worked for a while. But as the disease progressed, we had to move past the "post-it phase." My mom would call her during the day to ask how lunch was and my grandma would say it was great - but we would get home and her sandwich would still be in the fridge.

I learned to live in the moment, figuring out what to do as I went along, because I didn't know how much time I had left with her. We kept on fighting. We held on tightly as the disease stole her from us. I felt like I was living the same day over again for years, struggling to keep her alive and healthy. But even as she forgot who we were, there was no question that my grandmother loved us. We loved each other until the very end.

It wasn't until seven years after her diagnosis that I found my purpose in life, thanks to the Alzheimer's Association. As my grandmother's cognition and memory declined, I wanted to learn more about the disease. I set out looking for information. Somehow I knew that purple was the color of Alzheimer's awareness. I Googled "purple Alzheimer's shirts" and the Alzheimer's Association was the top hit.

Poring over the Association's website, I learned about the Association's Walk to End Alzheimer's and reached out to my local chapter. I educated myself, spoke with families going through the same hardships, and fully committed myself to spreading awareness of the disease. I've been a volunteer, fundraiser, and advocate ever since. I'm proud to have led the planning committee for the annual Walk To End Alzheimer's in my hometown of Brighton, Michigan, which raises awareness and funds for Alzheimer's care, support, and research. I eventually became involved with the Alzheimer's Association Advocacy Forum, where I've made huge strides in advocacy.

Even as I watched the person who meant the most to me slip away for 15 long and brutal years, I knew that I had found my niche, my purple tribe, to help me through the hardest years of my life. Though there is no cure, treatment, or prevention for Alzheimer's, that didn't mean I would go down without a fight.

In 2017, my grandmother declined into the late stage of the disease. My mom and I had handled the day-to-day care of my grandmother together for 15 years, but we had reached the point where we decided we needed the help of hospice care. By definition, hospice provides comfort to both the person dying and to the family, but our family had a terrible experience with it.

I had a bad feeling right off the bat. The social worker talked to us for about an hour but not once sat with or visited my chupe.

The next day there was another knock at the door. This time it was Adult Protective Services, responding to an abuse and neglect complaint filed against my mom and me by the hospice care

company. We were stunned. We spoke with the agent at length before he turned his attention to my grandmother. The pair was soon singing and clapping.

We knew we needed Medicaid coverage to help cover the cost of her care, but there was a six to 12 month wait. The agent told me to keep this horrible, false abuse and neglect complaint on file, because as embarrassing as it was for us, it meant she would get bumped to the top of the list.

The agent offered reassurance on his way out. "If only everyone could be as loved as her," he said. "Keep doing what you're doing."

We also applied for help through our local Area Agency on Aging. A caregiver who was contracted through one of the authorized companies called my mom to set up a time for our first home consult. But, she never showed up for the visit and when my mom called to check on where she was, she told us she had taken another job. That meant we went back on the wait list and my grandmother died before we got any help. I wish we had had the lifeline that Senator Stabenow's *Improving HOPE for Alzheimer's Act* would provide for families. Having a caregiving plan rather than muddling through day by day would have been such a relief.

My chupe started dying on a Saturday. She had lived with Alzheimer's for 15 years, and passed away on June 3, 2017, at age 97. I crawled in bed and laid my head on her chest as she was taking her final breaths. I told her through tears that it was OK to go. And I promised her that I would never stop fighting for her, for the three of us, and the immeasurable bond we shared.

I am determined to fulfill that promise. It is why I continue to volunteer hundreds of hours each year as an advocate.

Today, more than 5 million Americans are living with Alzheimer's. The number of Americans living with Alzheimer's is growing - and growing fast. With the aging of the baby boom generation, the number of Americans aged 65 and older with Alzheimer's is expected to dramatically escalate. By 2050, nearly 14 million Americans may be living with Alzheimer's.

That is why it is so critically important to prepare now. To increase awareness of and access to important services like the Medicare care planning code. Robust care planning is the first step to learning about and selecting appropriate, patient-centered supports and services for persons with dementia, families, and caregivers. It was overwhelming when my grandmother was diagnosed. It can be difficult for families to juggle the stress of a diagnosis with the immediate care needs of their loved one living with Alzheimer's while also trying to research services such as adult day, home health, respite, skilled therapy, residential facilities, and nursing home care.

Thank you for holding this hearing today and I respectfully request that you continue to make Alzheimer's research a priority and work together to pass critical legislation like the *Improving Hope for Alzheimer's Act*. We must do all we can to ensure the best quality of care and quality of life for those living with Alzheimer's and the people who care for them. Again, thank you for the opportunity to share my story. I look forward to answering any questions you may have.