



April 29th, 2024

Hello. Thank you for the opportunity to speak here today. My name is Cara Armstrong, and I am the mother of a young adult with Down syndrome from Thousand Oaks California.

I am speaking to you today as an advocate for the Down syndrome community and an ambassador for the National Down Syndrome Society. Not long after my daughter with Down syndrome was born, my dad began to show cognitive impairment and shortly after receiving a diagnosis of Alzheimer's disease. His trajectory with the disease was typical and heartbreaking. I watched my father decline as he lost so many of the skills he once had.

I also watched my mom go from having a richly meaningful life to suffering the isolation and despair of caring for a husband who was slipping further away each day. After my mother passed away from pancreatic cancer, I became the sole caregiver for my father when he moved in with me. But after many months, his agitation and impaired mobility were too much for me and our children. Placing him in a memory care facility felt like a broken promise, but keeping my kids safe was more important. Alzheimer's disease had turned a man who had never uttered an angry or unkind word into someone none of us recognized. He passed away six weeks after entering the care facility.

As my knowledge of Down syndrome and the associated medical conditions has grown, I was terrified to learn that the lifetime risk of Alzheimer's disease is over 90% for individuals with Down syndrome. It was agonizing to watch Alzheimer's steal my father's fun-loving personality, to see him become a burden to my mother, to witness his transformation into a scary figure to my own children whom he adored. Even worse is that now I have to worry about my beautiful daughter. Will this be her fate, too? I fear for so many others like her, many of whom will contract Alzheimer's by their 50's. Yet, it feels like our community has gotten little attention from broader Alzheimer's response efforts.

But this council and each of you have the opportunity to change that. I am here to implore you to change that. Today, I ask you to ensure that individuals with Down syndrome are appropriately included in clinical trials and research, that they have access to new treatments and adequate clinical care and that there are much needed supports for caregivers like me who care tirelessly for our loved ones who are irrevocably changed by this disease. My daughter does not deserve to suffer like my father suffered. She and other members of our amazing community deserve so much more. Thank you for your time.

Cara Armstrong

Mother, Writer, Advocate