Testimony of Lisa B Capp (Lisa M. Beilstein)
Surviving dementia & Alzheimer's Caregiving

November 1, 2019

Senator McSally, Senator Collins and distinguished guests, thank you for the opportunity to testify about my experience as my mother's caregiver.

I'm a blogger, an activist and a dementia caregiving survivor after an 18-year journey through the disease with my mother, Vera Cappelletti. After her death in 2015, Chairing the Board of the Vermont Alzheimer's Association and a move to Phoenix, I'm now Co-Chair of the Desert Southwest Alzheimer's Association Board. I write and speak regularly on the subject of dementia caregiving. Why? In 2014 comedian Seth Rogen addressed lawmakers in Congressional testimony about the care of his wife's mother who was diagnosed with young onset Alzheimer's. She was in her mid 50's. Back in 2014 Seth said, "I think until you see Alzheimer's first hand it's kind of hard to conceive how brutal it really is." Today dementia caregiving remains equally brutal around a still stigmatized disease driving family caregivers deeper into emotional, physical and financial hardship.

Mom came to live with us after my dad passed away and at the time I was advancing my career in high-tech. I was lucky, my husband Tom shared fully in my role as caregiver. And without children due to my infertility we didn't count ourselves among those in the sandwich generation of care. My mother's dementia began with whimsical imagining but turned to terrifying delusions and hallucinations. Tom and I continued care in our home until crisis left us with no choice but to involuntarily commit my mom to a psychiatric ward to stabilize her condition. My siblings, although living in other parts of the country, participated in many ways but most notably in the family decision to move our mother not back home from the hospital, but instead to live the remainder of her life in fulltime memory care.

As my mom slid deeper into her dementia, her invisible battle became a struggle I had to watch progress while plaques and tangles took over her brain. We were blessed by a relationship with a skilled geriatric psychiatrist who helped me to understand my mother's world just a little bit better.

Dr. Paul Newhouse asked, "Do you know what déjà vu is, Lisa?" "Feeling you've been somewhere before, that it's familiar," I answered. "Yes, déjà vu means that the strange is familiar to you. Do you know what jamais vu is," I shook my head no. "Jamais vu is what our family and friends experience in dementia – the familiar becomes strange. Imagine every moment of your life struggling with something you know, that you've known for your entire life, but now it's strange to you," the doctor shared.

My life was busy and I didn't understand the nuances of my mom's brain disease. With the stress of having to leave work early to get mom to one of her many doctor appointments, she might pick up a comb and look at it as if she'd never seen it before, confounded by its very function. I'd grab the comb from her hand and smooth her hair as we rushed out the door late to our appointment. Waves of guilt kept building. The emotional web between someone you love living with dementia and you as the unexpected caregiver are made up of strands spun from loss, despair, sadness and intense feelings of inadequacy.

I think about the arc of my mother's life from wife, mother and career; through the hallucinations and delusions; and onto the advanced stages of dementia. Bedridden with her ability to speak gone, I'd lay my iphone on her pillow and play Frank Sinatra's "Fly Me to the Moon". Her beautiful green eyes would open and light would dance in them from a deep and far off place.

Dementia is a set of perpetually evolving diseases requiring the act of caregiving to be both collaborative and yet codependent. As someone living with dementia progresses, so does their caregiver along paths of physical, spiritual and emotional coping. As one individual declines, the other must advance. And the end of caregiving isn't rewarded with a sense of freedom; it's marked instead by deep and intense grief at yet another loss to this despicable disease.

But I'm hopeful, more hopeful than I have ever been that I will see the first survivor in my lifetime. The unprecedented funding you and your fellow legislators support is leading not only to critically important research discoveries, but a renewed hope among caregivers for earlier detection, prevention and an ultimate cure. I thank you.

I thank you Senator Collins for your leadership as Chair of the Senate Special Committee on Aging and for your support to programs, policies and funding critically important to the Alzheimer's Association and those in our nation requiring their services. I thank you Senator McSally for your support to the younger onset bill (HR 1903/S.901), which passed the House this week. This bill will give access to critical resources for those living with dementia under the age of 60 as part of the Older Americans Act. And I welcome the opportunity to work with you Senator McSally on initiatives that continue to benefit our great state and nation.

There are still so many opportunities yet to exploit. We need to educate and train primary care physicians, first responders, ER and hospital staff, caregivers and administrators in local care facilities, major employers and small business owners for whom caregivers currently work, barbers, lawyers and bankers; all who see the impact of this disease in their day to day lives and work. I applaud Mayor Mitchell and the city of Tempe for their work in becoming a dementia friendly city and to Mayor Gallego for considering similar steps for Phoenix. These actions enabled by your support to The Hope Act (H.R. 1873/S880) go a long way in removing stigma around the disease and make life a bit easier for caregivers.

I'll end my comments by sharing although my legal name is Lisa Beilstein, I write and am active as Lisa B. Capp to honor my mom's memory. Thank you for inviting me to speak, listening to my story and for all you have done and will do in the fight we share to live in a world without dementia and Alzheimer’s disease.