

My Journey into the Sandwich Generation

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My hope at the conclusion of my testimony is that you will visualize a different future for our senior population as well as family caregivers through the congressional movement in recognizing not only the emotional stress as well as the financial strain that is facing us today.

How do I possibly convey the feelings, emotions, frustrations, guilt, financial concerns along with multiple fragmented thoughts that have flowed through my mind as a primary caregiver for the last four years in my testimony to you today?

First Challenge of My Middle Years

Where do I start? Imagine being at your parents' home for a holiday dinner and having your father say to you, "What am I going to do about your Mom? Something is really wrong and I need your help?" He began to paint a picture of someone I didn't recognize by explaining that she can no longer write her name, drive the car safely, nor prepare a meal. My Dad continued to tell the story which described a typical day and several never-ending nights with my Mom who was not sleeping or able to do her own personal care. As he looks at me with tears in his eyes, he decides that he is going to have to place her in a nursing home, which is something that both of them had promised each other would never happen. Mom and Dad had been married for over fifty years and had never spent more than two or three days apart. They both had also worked all of their lives so that they would have a good retirement "nest egg" to live on and not be a "burden to their children."

Since that day at my parent's home over four years ago, I have spent countless hours playing the part of the family caregiver starting with my caring for my mother in our home alternating with various admissions to the hospital, skilled nursing facilities, and an eventual placement in an assisted living facility due to her rapidly developing neurological disease of Parkinsonism with Lewy Body Dementia.

Because of Mom's disease process taken away her ability to speak, I felt it essential to be with for as many hours as possible to serve as her advocate. Each time that I was placed in this role of primary caregiver I was so grateful that I had a baseline working knowledge of the medical system and how to access the resources that were available in our community. Many times I would find myself wondering how the caregivers that had no knowledge of the available resources were surviving, not only emotionally, but financially as well. Many times people would ask me why I would want to play such an active role in my parent's care. The answer is I can't imagine not doing it! My parents did not ever hesitate to be a supportive presence in my life, so did I not have a responsibility to do the same for them?

My mother's care needs continued to escalate which made it impossible for me to provide her twenty four hour care as well as working full time in a fifty to sixty hour a week job as a Director for a Home Care Agency, full time mother of three with two living at home, full time spouse, and a resource for my Dad. During the time that my mother was being cared for in our home, we had to hire a private caregiver which was costing anywhere from eighty to ninety dollars a day. This financial outlay was paid for by my spouse and me since there was no funding available either through Medicare or Medicaid. We were fortunate that we had the resources to do this on a short term basis, because many families are not able to budget for this responsibility. Our family was certainly not in a position that I could give up my employment to care for my mother on a full time basis.

Second Challenge of My Middle Years

During the time of my mother's progressive illness, my sister was diagnosed with terminal metastatic cancer which required extensive surgery, chemotherapy, and radiation treatment. I would travel to care for her after her surgeries and multiple treatments, which created an extreme emotional pull since I knew that I needed to truly be in five to six places at the same time. Not only did I still need to be very present in my job, but my children, mother, husband, and father also needed a part of me. How far can one person be spread? Much further than you can imagine, actually. After a continued fight to be a survivor, my sister died at our home in March just ten days after my mother's death. All of our family, including her son and my father was able to be with her for her final journey. Our family had been present at my mother's final journey just ten days prior to my sisters. What an honor for me to be there for two very important people in my life.

Third Challenge of My Middle Years

Until approximately one year ago my Dad, who just turned 82, had been living in the home that he shared with my Mom for over fifty years "because this is where the memories are." With my Mom no longer close enough for him to reach out to; He continued to decline not only in health, but in his spirit as well. My husband and I purchased a mobile home for him in our home town so that I would not have to travel for over three hours each way to care for him. Within two weeks of arriving, he was hospitalized and remained within the medical environment of the hospital, transferred to a skilled nursing facility and eventually transferring to the same assisted living facility where my Mom was located. He remained in this facility until after my Mom died on March 3rd of last year. Just recently he was able to return to his new mobile home and is incredibly happy to be in his own space. I visit him almost daily: grocery shopping; transporting him to his medical care; acting as his Power Of Attorney; maintain his living space; buy his clothing-----and the list goes on. Many people ask why I just don't hire someone to do these things for him and decrease my stress. Two words would describe the reasons---love and responsibility. My Dad is also on an extremely limited budget with his care needs costing over \$15,000 since last September not counting his prescriptions which cost approximately \$900.00 a month. If he needed to return to an assisted living facility in the future he would be paying over \$3500 a month. Currently he is receiving less than \$700.00 a month from social security and does not qualify for any

other assistance. He will very quickly outliving the money that he and my mother put aside for their “dream years.” Currently there is no provision for our family or my father to pay for any of these expenses which allow him to remain in his home or ours.

Families of today are at a critical point with the demands being placed on the Sandwich and Club Sandwich Generation. My hope for the future is to see the creation of a tax credit that would provide a financial buffer to not only the senior population but the sandwich generation that supports them.

It was an honor to participate in both my mothers and sister’s final journey. My family and I in our role of family caregivers will continue to provide my father with the love, security and peace of mind he so genuinely deserves.