

TESTIMONY OF LYNDA GORMUS
RICHMOND, VIRGINIA
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TO SENATE SPECIAL COMMITTEE ON AGING

Mr. Chairman, Senator Breaux, Senator Warner, thank you for giving me the opportunity to share my family's experience with long term care costs and its effects on my parents' financial situation. Being able to share our story so that it might help someone else is part of my healing process. My name is Lynda Gormus. I live in Virginia with my husband of nearly 36 years, have five sons and three grandchildren with one more on the way. My only brother lives out of state but visits when his schedule allows, I have volunteered for the Alzheimer's Association for several years and was part time staff for a three-year period. I co-facilitate a support group for the adult children of Alzheimer's and related disorders victims for the Greater Richmond Chapter. I work part time when life allows.

Dad passed away in January 1992 after having Alzheimer's for approximately 11 years. The last year and one month of his life was spent in a nursing home. He was a private-pay patient until his funds were exhausted

My mother is 90 years old now and has been diagnosed with Parkinson's disease. She, also has a brain tumor, coronary artery disease, artrial fibrillation, and left temporal lobe seizures and takes multiple medications. She also exhibits symptoms of dementia which often accompany Parkinson's disease. She currently resides in an assisted living facility.

We were considered to be a typical middle class family. My mother stayed home to take care of my brother and me, while my father worked to take care of our monetary needs. We took family vacations, but nothing extravagant. We always seemed to have what we needed to be comfortable. When Dad retired after more than forty years of service with DuPont Mom and Dad had their own home and lived a happy, conservative lifestyle on Dad's pension and Social Security. At one point, Mom worked part time and so did Dad, but I understood that this was more for something to do, not because of financial need.

In Virginia there are nearly 400,000 family members whose loved ones have a form of dementia. I would say that my parents' financial situation was probably fairly typical of the majority of families. Dad was in his seventies when we began noticing behaviors that were questionable. Mom took care of Dad at home for the major duration of his illness. During that time she became increasingly isolated from friends but was determined that she could take care of him, even when he became completely dependent on her.

Mom was 11 years younger than Dad but had her own physical problems. In the early 80's Mom began having periodic seizures. A brain tumor was discovered near a main vein located just to the left side of the brain. However, this was not considered to be the cause of the seizures, and the search for answers continued. In 1987, it was determined that the seizures were located in the left temporal lobe area and were classified as epileptic.

Caregivers of someone with a long illness know too well the physical and emotional toll it takes on the entire family. The primary caregiver is the second victim of the illness and too often becomes physically unable to continue caregiving for their loved one. Even when a loved one is placed in a facility, caregiving responsibilities continue.

Mom took care of Dad at home as long as she could. Although expenses were less in caring for him at

home, they still exceeded what they would have been if Dad were not so ill. The spring or summer before he went into the nursing home, he became bedridden and was basically comatose. My Mom was concerned that he was not eating as much as he should. He was on medication for an infection; his feet, legs, and stomach were swollen; and a rash covered a good portion of his skin. When finally admitted to the emergency room, we learned that he also had pneumonia.

After being hospitalized for several days, with little or no verbal response, he remained home in what we thought was a close-to-terminal condition. His DuPont insurance covered eight hours a day of hospice care. This gave my mother a little relief. Several weeks passed. Somewhere around 9 or 10 pm every night Mom would get Dad ready for the next few hours. If the hospice staff was no longer there, my husband or I would go over to help Mom with this bedtime procedure. She set her alarm clock so she could get up in the middle of the night to turn him. The pneumonia disappeared with no treatment other than Mom's established ritual. Services could no longer be provided through hospice because Dad had recovered from the pneumonia. Because of her own health problems Mom's only option was to place him in a nursing home.

As Dad's Alzheimer's progressed, I became more concerned about Mom's health. He was getting the best of care from her, but she was killing herself. One of our sons is a photographer and did a picture story of my Mom caregiving for my Dad. Mom saw slides of these pictures, and asked me the identity of a person in one of the slides. "That is you, Momma," I said.

It is hard to determine which of the many stresses of long term care is the greatest. While the emotional toll is significant, it's even tougher when the money is limited. Mom and Dad had what I am sure, they considered to be a good savings. Having been born in 1906, he was a young adult during the depression, so his perspective was different from most of us today. He remembered when \$6 was the price of a man's suit.

Shortly before Dad was placed in the nursing home, Mom began looking into their financial situation. We tried to educate ourselves about the complicated Medicaid rules and regulations. We compiled the necessary financial documentation and applied for Medicaid on Dad's behalf. Social services reviewed the application to determine if he was eligible. They informed Mom that he did not qualify, but to reapply when he was closer to having only \$2,000 left.

Dad qualified for Medicaid in less than a year after entering the nursing home. The nursing home costs were approximately \$3,000 a month. Under spousal impoverishment rules, Mom was allowed to keep their home, car, and half of their assets.

I had hoped that Mom would regain her old stamina once her caregiving responsibilities stopped, but she never has. I began to notice symptoms which were soon diagnosed as Parkinson's disease. A couple of years ago, a financial planner assessed her situation and recommended ideas for investing what was left of her savings so that there would be greater potential for growth. We hesitated. A little over a year ago, she had her house appraised to see what she would be able to realize from its sale. We hesitated, again. She had been in her home for more than 30 years, it was hard to make a move. Her modest savings and her home were all she had left of her more than 50-year marriage, except of course for family and memories. She sold her car when she realized she was no longer able to drive safely. This helped reduce her expenses.

Mom had fallen several times due to the imbalance and instability caused by Parkinson's and had been fortunate not to have any broken bones. Her luck ran out in June of 1997. She fell, broke her hip, had surgery and in-hospital physical therapy, from there she was admitted to an assisted living facility for

more rehabilitation. She stayed for several weeks, appearing to be doing okay. In late September she returned home, only to decide after less than a week that she would be better off living in the facility.

We put her home on the market. Her monthly living expenses are more than twice her income and her savings are disappearing rapidly. I'm concerned that her savings will run out before her home sells. She needs a large degree of assistance, and I really don't want her to have to leave where she is. She is safe and has 24-hour assistance. I have thought about the possibility of moving her back home and getting a reverse mortgage to pay for in-home care, but know that situation would not be as secure as where she is now and would be more costly. I have approached the Administrator of the facility to see if temporarily reduced payments would be acceptable until her home is sold. The owner has agreed to write a contract placing a lien on Mom's home, so that they will be the first to get paid when the house is sold. This seems workable.

Once the house is sold, I will investigate her best options for investment and hope and pray that her money can be extended to meet her needs. If not, she will have to turn to Medicaid, like my Dad did. My Mom is my best friend, and I miss the person she used to be but thank God that I have memories of two wonderful parents.

Thank you for listening to my story.