

OHIO STATE REPRESENTATIVE BARBARA BOYD

Statement Given to the Senate Special Committee on Aging

March 23, 1999

Thank you for the opportunity to address the Senate Special Committee on Aging. I have no charts, no percentages to give you. There are plenty of people here today to provide you with those. I am here to put a face on the problem. I am here to stand for people like Sarah Hamlet and caregivers who need to know that somebody cares.

I was a primary caregiver. Six years ago, I did not even know what a caregiver was. However, on June 30, 1993, my mother, Sarah Hamlet, was diagnosed with Alzheimer's Disease. We immediately decided mother was going to be taken care of at home. My two brothers went into instant denial of the potential progression of the disease. Her progression was rapid: agitation and behavior swings, pacing from one room to another, pouching of food, destruction of jewelry, clothing twisted and tied in knots, a packed suitcase - for home was never where she was, papers shredded. She literally destroyed the chair she sat in, thread by thread. She became proficient in profanity, we learned to laugh when she could not get it right the first time, but eventually she did get it right. She started wailing as she lost the ability to converse and forgot how to hold a glass in order to drink. As she progressed, feeding her took up to 30 to 40 minutes. Incontinence and the use of depends (diapering your parents as they are still walking is a quick adjustment!). She was incontinent within a year and a half of diagnosis. In Fall of 1994, I discovered two cancerous masses in her right breast. The masses were removed one morning and I took her home by five in the afternoon. No treatment was prescribed, for an anesthetic her could have further diminished her capacity. By the end of 1995, she had to be catheterized for fear of skin breakdown as her fluid intake diminished. As a caregiver, I discovered I had to make life plans, nutritional plans, health and healthcare plans, family participation plans, and final day plans.

As a caregiver I found myself often alone in making decisions. My family became dysfunctional. Any decision I made was met with resistance. Denial led to fear because of the abrupt change in a woman who was the bridge that brought the family together during our lives. My parents' goals were basic: pay your bills on time, do not over extend yourself, give your children an education for building a life and the "American Dream", own your own home, but that dream became a prison in which she was locked in and locked out. They had saved for the retirement years, but it was just not enough.

As a caregiver, I was confronted with how to provide her with the best of care. I found barriers that I did not know existed. Health Care Financing Administration (HCFA) has never clarified the definition of homebound. For example, if a patient is determined to be homebound by a home care agency, HCFA can later rule the patient not homebound and take away services. In addition, Alzheimer's is a disease not recognized by HCFA. Medicare B provides no prescriptive care, neither does Medifil. Alzheimer's drugs are very costly, \$100 per month. Tamoxifen for breast cancer is the same. Roxanol, a liquid morphine, and duragesic patches are approximately \$200 a month. Incidental antibiotics for urinary tract infections and other infections, drugs for constipation (a result of morphine), depends, chucks or underpads, ointments to avoid skin breakdown, powders for yeast infections, liquid food supplements such as ensure, sustecal, and more. Mother's social security check was initially \$480 per month and increased to \$540 per month in five and a half years. It provided her with a sitter from 11:00 am. To 4:00 p.m., Monday through Friday. She had approximately \$20,000 in assets and savings. I was constantly transferring money from the savings to the checking account, "Robbing Peter to pay Paul". It cost \$168 every other month for her Medifil. I took care of her prescriptive costs out of my pocket, as well as the caretaking of her home. I never carried her as a dependent. Respite gave me a break from the daily, often

never-ending, tasks of caring for someone with Alzheimer's disease. Caregiving truly is a "36-hour a day" job. The aging of the baby boomers and changing family structures make respite an invaluable resource for caregiving families.

Home Health Care was a lifesaver. In the morning one hour and in the evening one hour, she returned to infancy. Pedicare, bed baths, and feeding were important. I cooked, they blended the food.

I am a legislator. My mother held the Bible as I was sworn into the General Assembly in January 1993. I thought I knew a lot about how things work. However, I was helpless in the web of Medicare. Ambulance transportation costs mounted as she became atrophied. That is 20% out of pocket. One morning I questioned whether God had forgotten me. My brothers, financially, did not come forward, and mine is not an unusual case in the real world of caregivers. One brother lived in her house, but he could not come out of his denial. The other brother just excluded himself from the situation. When I realized my circumstance, I called a family meeting in 1996 and ultimately decided to pre-pay her final day service. She was indigent but the final plan was in place. Mama passed over on October 21, 1998. We were there in her bedroom with her at the final breath. I gave her the final bed bath and clean gown. I lotioned her body. Then we waited.

I regret nothing. She gave unconditional love, I could do nothing less. She was cared for at home, ever a bed sore, never a skin breakdown, and nutritionally sound. I have exhausted my savings but will honor her debts.

Thank you for your kind attention. I truly appreciate the opportunity to share my experiences with you. I will be happy to take questions.

LEGISLATIVE RECOMMENDATIONS

- Redefine Alzheimer's Disease so Medicare can apply.
- Prescription drug assistance.
- Voluntary disclosure statement identifying provisions provided in facilities that market themselves as "special care units" for Alzheimer's.
- Respite care for caregivers.
- Employee flextime for elder caregivers.
- Allow elderly at the point of retirement to know what prescriptive care is available through Medicare and Medifil.
- Enact a new homebound definition that does not restrict access to the Medicare home care benefit.