

**TESTIMONY OF MARIE WOODARD
ON BEHALF OF HER PARENTS WALTER AND MARGARET ESSELMAN
BEFORE THE
U.S. HOUSE OF REPRESENTATIVES COMMITTEE ON EDUCATION AND THE WORKFORCE
SUBCOMMITTEE ON WORKFORCE PROTECTION ENSURING REGULATIONS PROTECT
ACCESS TO AFFORDABLE AND QUALITY COMPANION CARE**

March 20 2012

Mr. Chairman and Members of the Subcommittee, thank you for allowing me to testify today. My name is Marie Woodard and I am testifying on behalf of my family and my parents who received personal care from aides in their home from 2004 to 2011.

My parents were both healthy and active until their mid eighties. My father had Parkinson's disease and Alzheimer's and required home care starting in 2004. We started with having a privately hired aide come 3 days a week to his home for bathing and dressing. As the needs changed, the care progressed to daily aide care 10 hours a day and we hired aides through a private duty agency. In May 2005 my mother had a heart attack and was hospitalized and my father could not be left home alone. We started 24 hour home aide care services in May 2005. My father required 24 hour care until his death in March 2008. Within 24 hours of my father's death my mother was in ICU with pneumonia and not expected to live. Our family was in turmoil arranging for my father's funeral while our mother was dying. We were blessed to have our mother survive this illness but the recovery was extensive and lengthy. We continued to have aides provide one on one care to my mother as she progressed from the hospital to the nursing home then back to her home. We were so fortunate to have the same aides who had cared for Dad now caring for Mom. My mother developed dementia during this illness in addition to her severe heart failure and she required 24 hour care from March 2008 until her death October 2011. I was one of four children, but I was the only child living in Virginia and was very involved in the care of my parents. My parents had consistent aides who worked 12 hours a day for anywhere from 5 to 6 days a week. The aides changed shifts at 8am and 8pm. The day aide, Memunah, worked 6 days a week 12 hours a day from 8am to 8pm. Night care was provided by Harriet, who worked 5 days a week from 8pm to 8am. Their days off were on the weekend and were covered by other aides.

During these seven years I had three major concerns coordinating and supervising the care of my parents. These concerns were the quality of the care my parents received, their comfort level with the aides providing care, and that emotionally my parents could adjust to having the aides with them 24 hours a day. As we began the care in 2004 on a part-time basis the cost of the care was a concern but we had no idea that this care would continue for the next seven years and our out of pocket expenses for this care would be a million dollars.

Consistency of aides was so important for the quality of care provided my parents.

A new aide assigned would require a great deal of teaching and intervention by me to assure that my parent was well cared for. I needed to instruct each aide with the individualized needs of each parent. My parents had unique needs due to their diseases, levels of confusion and anxiety as well as the day to day needs – medication reminders, fall prevention, choking risks related to the Parkinson's Disease, emergency actions to take for medical emergencies that occurred during that 7 years – injuries related to falls, kidney failure, chest pains, heart attacks, episodes of aspiration pneumonia and difficulty breathing. The consistent care provided by the aide and their constant supervision of my parents prevented many hospitalizations and emergencies room visits. My father had Parkinson's disease that caused difficulty in swallowing. To prevent my father from choking, he had to be carefully fed to prevent him from aspirating and developing pneumonia. His feeding regime was very detailed and needed to be strictly followed. It was required that all his food and liquids be thickened, that all food have the right consistency, that he be fed slowly, be closely observed and that he be sitting up and was to never feed himself. I spent hours teaching the aides to properly feed my father. Having the same aide feeding my father most of the time assured that my father would not choke and develop pneumonia. The weekday aides were very skilled in feeding my father due to their familiarity with him and his illness. With my mother's severe heart failure I taught the aides to observe carefully for signs of impending heart failure crisis – the aides took my mother's blood pressure and weight every day and observed her difficulty breathing, shortness of breath, coughing and swelling of the legs and lower back. This was reported to me daily and with this information I and her doctor managed her heart failure on a daily basis to prevent hospitalizations. This required a level of skill on the aide's part, my trust in the aide, and the aide being with my mother on a daily basis to note subtle changes. My trust in the aides and their consistency relieved my anxiety knowing that the aide caring for my parent was familiar with them and knew how to care for both of them and to manage their medical needs.

The consistency of the aides allowed my parents to become comfortable with them.

It was very difficult for my parents to accept care in their home. My mother wanted to be the sole caregiver of my father and was very resistant to "outside" help. Emotionally for both my parents they saw the need for an aide as the loss of their vitality, lifestyle and independence. Both my parents had a great deal of trouble adjusting to the aides and I would estimate that adjustment period took over 12 months as they progressed from aides short term during the week to 24 hour care. The realization that the 24 hour care was permanent was devastating to them both as they accepted their frail health. As they got to know the aides they relaxed a little, but at each shift change my mother became anxious asking who was coming and begging the current aide on duty to stay and not leave her or my father. This anxiety was heightened greatly when an aide was coming that she did not know. If a new aide was assigned I called to discuss the care plan with them as well as went over to see my parents – as much to ease my mother's anxiety and my own anxiety having an unknown aide. We were fortunate that the shift change was only twice a day so the care was consistent and my parents developed a level of trust with the aides. I strongly believe that without the consistency of the aides working 12 hour shifts and

knowing my parents and their illnesses so well that they would have died years earlier. Both weekday aides worked with my parents for many years, Harriet the night aide cared for my parents for over 6 years.

The financial cost of the care provided to my parents was a burden to my parents and the family.

The average costs for long-term care in the United States (in 2010) are:

- \$205 per day or \$6,235 per month for a semi-private room in a nursing home
- \$229 per day or \$6,965 per month for a private room in a nursing home
- \$3,293 per month for care in an assisted living facility (for a one-bedroom unit)
- \$21 per hour for a home health aide
- \$19 per hour for homemaker services
- \$67 per day for services in an adult day health care center

Source: www.longtermcare.gov/LTC/Main_Site/index.aspx. National Clearinghouse for **Long-Term Care** Information website. The U.S. Department of Health and Human Services

- Example \$21.00 per hour for a home health aide is \$504.00 per day for 24 hour care or \$183,960 per year.

Since we started home care in 2004 the cost per hour was less but still our family paid over \$1 million dollars for the care provided to our parents from 2004 to 2011. This was totally out of pocket expenses since Medicare does not cover this type of care and my parents did not have Long Term Care Insurance. The additional cost of overtime pay would have caused an additional financial burden to my parents and our family.

The majority of Americans want to age at home and to stay at home rather than go into a facility. It is important to keep this home care affordable and to ensure consistency of care. When the cost of overtime pay is passed onto the consumer it will force the patient and their family to compromise the quality of care and have multiple aides in their home as well as multiple shift changes per day. The multiple shift changes per day would be very disruptive – I can imagine my parents refusing to go to bed until 11pm to let the night aide into the house. The increased cost may force families to choose care in a facility rather than providing the care in the home. My family was fortunate to be able to abide by my parents wishes to receive excellent care, stay in their own home, to be cared for by caregivers who cared for them as if they were their own mother and father, and to be able to die in their home. It was heart wrenching to watch my parents as they aged and became ill, I can only imagine how hard our lives would have been if we were forced to place them in a nursing home. Having the same aides care for my parents allowed the family the comfort of knowing that our parents were well cared for and when both my parents died at home they were treated with dignity and respect by their beloved aides. The aides were so close to my parents that they also grieved with us as if they had lost their own mother and father.