

**Testimony of
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My experience with Alzheimer's disease began in the spring of 1996 when it became evident that my mother, who was 61 years old at the time, was having memory challenges. My mother's best friend called me from San Diego, California, where my mother lived, to tell me my mother's memory was getting worse. My mother was forgetting how to get around in a City in which she lived for over 30 years. For at least three years prior to this, I can remember my mother would ask for my phone number (my brothers and sister made the same observation). In August of 1996 my mother's doctor diagnosed her with 'Severe Dementia'. After returning from the doctor's office, we found my mother's phone was disconnected for non-payment and that she was served with an eviction notice.

At this point my siblings and I were faced with deciding where to move Mom. We no longer lived in San Diego. We researched the possibilities of long term care facilities available in our respective cities. At that time, if there were assisted living facilities available my mother's finances would not afford her the opportunity to reside in one. I looked at a nursing home in the San Diego area and determined my mother was not ready for nursing care. My mother needed a secure environment, to ensure that she did not wander off and not remember how to get back home as well as make sure she was eating balanced meals. My mother was still aware of her surroundings and her greatest fear was that she would end up in a nursing home.

I returned to Cleveland and found that there were not many options for someone in the beginning stages of the disease, who may require some prompting, a secure environment and the ability to socialize with others in the same or similar condition. At this point, due to my mother's income, the level of care proved, necessity for a secure environment and the potential for my mother to live with other residents at her level, I chose to move her in October of 1996 to R & R ElderCare, a group home in Brunswick, Ohio. My mother was aware of the fact that we moved her and was very angry and upset. I think on some level she knew the move was in her best interest, but she was a very independent woman and had a difficult time giving up her independence. This was a distressing time as well as a disturbing move for all of us.

At the time I lived in Westlake, Ohio (a suburb of Cleveland) and noticed a new Alzheimer's Assisted Living Facility, Arden Courts, was scheduled to open in Westlake early in 1997. The concept of the facility sounded wonderful. I was told there would be two caregivers in each house for first and second shifts, as well as a LPN on duty from 8:30 a.m. to 8:30 p.m. Prior to move-in, the Wellness Director would assess my mother to determine her exact needs and the level of care would determine the monthly rate. The five levels of care along with the monthly rate were in the brochure. What I did not know was how the level of care was determined. The marketing director explained the level of care was determined by my mother's needs, but until the assessment I would not know exactly how much assistance my mother would need and the cost associated with the care.

In August of 1997, I found that my mother was physically abused by a caregiver at the group home. I was mortified. A few weeks prior to this incident, my mother received a sum of money that would allow her to move into ArdenCourts. My mother was able to live in a beautiful new facility and I was confident she would receive good care. Overall, I was very pleased with my mother's stay at Arden Courts. She was happy. She bonded with another female resident and the two became inseparable. That was comforting to me to know my mother had someone else to spend time with.

I became frustrated at times with Arden Courts when I would stop by after work or in the evening and I

could not find a caregiver for her house. If the caregiver had to provide one on one assistance for another resident, there was no one else available. This was contrary to what I was told. The facility apparently was not prepared for call-offs or a termination; they said they were having difficulty hiring staff. In January of 1998, I entered my mother's cold room and determined the heater was not working. The heater was not repaired for one complete week. They tell me, they asked my mother to sleep in another room but she refused. This did not surprise me since she was confused about the colors of the houses and frequently went to the same room in another house and thought it was her room. This was aggravating for my mother because she often entered another resident's room and was told she was in the wrong room. The fact that it took one week to repair a heating unit in the middle of winter was unacceptable. My mother did not have the ability to tell staff that her room was cold. She depended on others (mainly me) to speak for her. I paid the facility to take care of my mother while I was not there.

In August of 1998, a change in the service level was necessary. This was explained to me and we reviewed my mother's needs and the monthly cost of the new service level. The next bill I received indicated there was an adjustment but there was no justification or reason. I asked the business manager for an explanation, she said she would look into it. I never received a response.

I believe twice a year, Arden Courts invites family members to participate in a focus group. In September or October of 1998, nine family members met with the Vice President of Operations and identified the following major concerns: housekeeping, lack of adequate caregivers, and missing personal items. We were told that per the staffing models provided by Manor Care, there was adequate staff.

In November of 1998, I was called by the wellness director and was told my mother was losing weight, she lost approximately five to six pounds in three weeks. She needed assistance with feeding (more than just prompting). I did observe that if there were one caregiver in the house she or he would have twelve to thirteen residents to feed. By the time she or he was done with preparing and giving the residents their meals, she or he might have to prompt a resident to eat, get more of a beverage, etc.

My mother is now 64 years old and lives in a nursing home. I moved her in February of this year. She still does not eat much but the assistance is there and she is given, as much time as necessary to eat whatever she wants to eat.

In summary, my mother lived in two different assisted living for a total of 30 months and we wrestled with the following issues:

- 1) Assisted living is expensive and not available to those of modest means.
- 2) It was difficult to predict the expected cost of this care, because it is dependent upon an assessment of need, which can change frequently for an Alzheimer patient.
- 3) When service levels did increase, it was not clear as to why and what additional care was being provided.
- 4) The level of care was inadequate because of a shortage of paraprofessionals; one caregiver frequently had to feed a dozen residents, which allowed no assistance to those with dementia.
- 5) The level of maintenance support was insufficient; it took a week to repair a heater.

The concept of assisted living care is wonderful; the reality of it for a middle income person with

dementia is far from perfect.