

**STATEMENT OF -----**

-----  
-----, ILLINOIS  
for

**SOCIAL SECURITY ADMINISTRATION'S COMPASSIONATE ALLOWANCE INITIATIVE  
HEARING ON  
YOUNGER-ONSET ALZHEIMER'S DISEASE AND OTHER DEMENTIA**

**JULY 29, 2009**

I am both a registered nurse and the sister of a person with early onset-Alzheimer's disease who has gone through the very difficult process of trying to get help for my sister.

My sister, -----, was diagnosed with moderate Alzheimer's at the age of 57, though she displayed many difficulties for at least 3 years before the diagnosis. She lives in ----- with her husband and the difficulties that we encountered with the health care system in just getting a diagnosis were huge. Unfortunately my sister also has a history of breast cancer, so when the memory and cognition changes started, we were not sure what the cause was.

No one in my family had Alzheimer's disease prior to my sister. I fought (letters and a conference call where I had to BEG for an MRI to be done) to get her the proper healthcare to even make the diagnosis. I made many trips to ----- and accompanied her to her primary care doctor to try and get her the help she needed. I, as a nurse, knew that there was something very wrong, yet getting the physicians to look beyond her age was difficult. At one point I said that I would pay for the \$1800 MRI to ensure that there was not something else going on. Fortunately, the situation did not come to this.

After the devastating diagnosis, there were many other issues that needed to be addressed, like day care since her husband still worked full-time and by now she could no longer take care of feeding herself or toileting. Due to her young age, she was turned down by facility after facility. I spent 5 days in ----- trying to get her in a day care program, to no avail. I even went through

the phone book, just trying to find one that would accept her. Finally and thankfully, we found a daycare in -----, that not only took her, but (again, thankfully) provided decent care until she was too debilitated to remain in day care.

Then another battle began, when she no longer was able to walk and needed to be fed, moved, bathed, and her husband could no longer care for her in the evening and on weekends at home without assistance. Another trip to ----- to look for a nursing home that would take care of her. We went to one where we were told that she would be transferred out if she became too much trouble or she ran out of money (really takes the compassion out of the care, doesn't it?). Eventually, after an exhaustive search, we did find a nursing home where she was admitted - 6 years ago this month.

Currently, ----- is not able to speak, talk, cry, move or feed herself. She is confined to a chair or the bed, as she no longer remembers how to move. She does not recognize her husband of 42 years, her two sons or her sister. My sister, for all intents and purposes, is gone, but her body remains. This disease robs the mind, but at the age of 67 her body is still functioning.

PLEASE, please provide the help for those afflicted with early-onset Alzheimer's disease, so another family does not have to go through the hassles that we did. Thankfully, as a nurse, I knew how to fight for her, but what about other families that do not have the benefit of having a health care provider and advocate in the family? I think funding was a major issue in not getting or having to fight for the health care services to be provided. Please help other families so they do not have to go through this. Please pass the recommendation for compassionate allowance for early-onset Alzheimer's. **I ask that you think of the health care that you would want your family member to receive if faced with this disease.** Give them the chance to get the services that are needed without having to be told NO, or have to beg for them.