

STATEMENT OF -----

-----, IOWA
for

**SOCIAL SECURITY ADMINISTRATION'S COMPASSIONATE ALLOWANCE INITIATIVE
HEARING ON**

YOUNGER-ONSET ALZHEIMER'S DISEASE AND OTHER DEMENTIA

JULY 29, 2009

My name is ----- and I have Alzheimer's disease. (----- is assisting ----- with this update about life with Alzheimer's.) Life has not been the same since the day we got the diagnosis of the BIG A – Alzheimer's disease in June of 2003.

For ----- life has moved from independence to increasing dependence on those around him. He stopped driving and rode this bicycle everywhere. When he became aware that he was no longer able to process information fast enough to be safe riding a bike he quit and started walking everywhere. At some point he stopped walking independently because he could no longer determine where he was going. At this point he remains able to walk but only does so when someone leads him and tells him when to "step down" or "step up." He now needs assistance to be seated in a chair or to get into bed.

Likewise, his other activities of daily living are now only done with assistance. Gradually, bit by bit ----- has lost his ability to manage his life. Bathing, dressing, eating, toileting, shaving – all are now done with help, usually -----'s help. At this point ----- is able to wash himself once assisted to get in the shower. He cooperates with dressing by raising his foot or pulling up his pants. He uses an adaptive spoon to feed himself when there is enough time for him to do so. Otherwise ----- feeds him. He cannot find the toilet himself, get his clothes pulled down without help or wipe himself. ----- shaves him with an electric razor (and this guy was a brush

and mug shaver). He cannot take his medication without instruction and being handed each pill individually.

----- no longer can go visit his friends in the community or at the courthouse. His friends now come to the house to visit or pick him up to take him to lunch, coffee, etc.

Financially we have been fortunate. -----'s entitlement to a ----- pension (even though reduced because he hadn't been ----- very long), and money from three long term disability policies (purchased when he was an attorney in private practice) along with full social security disability made the loss of income about 50 percent, less than it would have been otherwise (approximately 80 percent) and because his salary as a -----was good it has been possible to "live on less." However, ----- has remained working when she had intended to retire.

Post diagnosis life has been stressful but maybe less stressful for us than for others as we have had more financial resources than some and as a social worker, ----- has been able to find other services that have been helpful to us. Both of us were outgoing, social people who were very involved in our community prior to the diagnosis and our friends and associates have remained involved in our lives and are very supportive. We often wonder what people do when they don't have financial means and don't know how to locate and use resources. We fear that they may become financially strapped and also isolated.

We have also been fortunate in that the type of Alzheimer's ----- has allows him to be able to appreciate and still thank people for helping him. He has no acting out behavioral issues typical of more traditional Alzheimer's disease.

While we continue to do activities, we now do everything differently. We continually define a “new normal” for ourselves. At the current time I see a client early in the morning and then come home to help ----- get ready for the day. I either take him to a day program for adults with disabilities or greet the respite worker who comes to help ----- do something active. I then work for several hours and go get ----- from the day program. I now work only three days a week as it makes it more possible to handle all the new responsibilities I have. We continue to bicycle but we now do it on a side by side tandem bicycle that is relatively difficult to crash. We continue to socialize but since ----- now has great difficulty with word finding I handle conversations for both of us.

I now handle all the financial and household management chores and make decisions for both of us.