

STATEMENT OF -----

-----, **COLORADO**
for

**SOCIAL SECURITY ADMINISTRATION'S COMPASSIONATE ALLOWANCE
INITIATIVE HEARING ON
YOUNGER-ONSET ALZHEIMER'S DISEASE AND OTHER DEMENTIA
JULY 29, 2009**

I am a person living with Alzheimer's. Like my grandfather and my mother before me, I have Alzheimer's disease. I was diagnosed at age 55 in 2007, in the prime of my life, not at age 70 like my mother or most sufferers of Alzheimer's disease.

Alzheimer's disease is a terminal condition. I will never get better or stay at one level of cognition for very long. The disease never stops destroying the fabric of who I am.

There will never be a period of remission for me. There are no periods of recovering lost memories or functions that I can look forward to. I am on a one way trip to the hell of not knowing who I am, who I love, or what I've accomplished in my life.

The issue for those like me that have younger-onset Alzheimer's disease while in the prime of our lives is disability insurance. I was incredibly fortunate to get through the diagnostic process prior to being fired for my failures at work. If I had been fired before that point in time, I'd be destitute, maybe on welfare, living on the streets and unable to even apply for Social Security Disability benefits. I would never have been able to receive Social Security disability benefits because the process is much too complex for me to have worked through by myself.

In my case I did have disability insurance through my work because I paid for it out of every paycheck I earned. Wonderful you may think but there is a problem that I know

impacts many if not all of us with younger-onset Alzheimer's disease. The problem is that buried in the fine print is a clause that limits the disability insurance payments to the amount of money above and beyond the estimated Social Security Disability payment. In my case this withheld amount is in excess of one third of my benefit. To go from a well paying job to 66% of my final salary only to discover that I would really only get less than 60% of that amount is a very real hardship.

Most younger-onset Alzheimer's disease sufferers get fired prior to a diagnosis and lose any access to disability insurance they may have been paying for years or decades. The COBRA plan does not address life or long term disability insurance, only health and drug and if you can afford to pay even more, dental and vision.

It is a burden for all like me to go on for years while our cases work through the Social Security process. For those of us that may have no supportive families to fall back on, the process is as incomprehensible and daunting as to be unattainable. No one has a count as to how many folks are unable to get through the red tape to access what may be the only coverage they have.

Social Security needs to recognize Alzheimer's disease, and the other degenerative brain disorders, on the list of Compassionate Allowances. This would greatly improve the lives of us that can no longer deal with the application and appeals required to ultimately have access to our Social Security Disability coverage. Please remember that my cognitive abilities are declining on a daily basis, it a downward slope that I will never climb back up. No one survives Alzheimer's disease on this planet.