

**The Emotional Functioning of People with Young Onset Alzheimer' Disease**  
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**Chicago, IL**  
**July 29, 2009**

Esteemed panel, thank you for the opportunity to speak with you today about the emotional functioning of those individuals journeying with young onset Alzheimer's disease and how their emotional functioning impacts their ability to work. As you will hear through each testimony today, young onset Alzheimer's disease is a devastating, progressive illness which will force affected individuals to stop working at a young and often unexpected age. As they apply for Social Security Disability, these individuals will greatly benefit from inclusion in your Compassionate Allowance program.

I am Susan Frick and for over twelve years, have worked as the social worker at the Rush Alzheimer's Disease Center in Chicago. During that time, I helped to develop and maintain a support group for individuals and family members who live with young onset Alzheimer's disease. Our group, called Without Warning™, has met for over 5 years and works to provide education and support to the individual with young onset Alzheimer's disease as well as their family members and friends. Our group was appropriately named *Without Warning*™ by Sandra, an elementary school teacher who was diagnosed with Alzheimer's disease at the age of 54. She felt as though this disease was a catastrophe that enveloped her life without warning. Over the years, the average attendance at our monthly support group meetings has grown from 15 to 45. This number includes both the individuals with Alzheimer's disease and their family members and friends. Because we have come to realize that young onset has a significant impact on the entire family unit, we now also offer a group for the adult children (those who are college age and older), a group for the younger children (kindergarten through high school), and a finally a group called Sin Aviso™, which means without warning and is for people who are Spanish speaking.

One of my roles in the Without Warning™ program is to facilitate the support group for the individuals with young onset. In our monthly meetings, they share their experiences of living with this disease. It is from their insights that I can share with you now some of the emotional needs of the people living with young onset Alzheimer's disease and how these needs impact their ability to work.

Alzheimer's disease is associated with significant *cognitive* loss. But it also impacts emotional functioning. People who live with Alzheimer's disease experience a far reaching impact to their emotional functioning, which not only significantly erodes their personal relationships but also their ability to work and relate in a job setting. For example:

As a result of the cognitive losses, one's ability to handle stress and frustration often decreases substantially. For people with young onset, who are still working, the stress of performing tasks can take a great amount of effort and concentration. Because of this

increased effort, it is common for people with Alzheimer's disease to become more easily frustrated or stressed. Individuals with Alzheimer's disease often report feeling overloaded or tired. One member of our Without Warning™ group said, "I feel more tired than I have in my life. Things that were automatic before, I now have to think about. . . it is just a constant drain."

I'm sure each one of us here can think of times when everyday tasks have seemed to overwhelm. During those moments, it is difficult to concentrate and a feeling of panic can often set in. For individuals with Alzheimer's disease, these moments are common and occur in situations that would not have overwhelmed them before.

As a result of the reduced ability to handle stress or frustration, a person might move more slowly through their normal work tasks. Being able to complete assigned duties might take significantly longer or be impossible to complete. Jim, a Without Warning™ member, who was 36 years old when he stopped working as a foreman, said, "As a sheet metal worker, you were taught to look at things in three dimensions. You can picture how things are going to look when it is done. But now when I look at things, I can't do that. That is really frustrating. I could do something in a couple hours and now it takes several days."

This decrease in the ability to handle stress is evident in the story of Ted. He is one of our Without Warning™ members and had worked for 10 years in a local hospital running one of their computer systems. When Ted developed Alzheimer's disease, the job became too difficult for him and he was fired. He then worked at a Wal-Mart for nine months, first as an evening supervisor and when the demands of that position were too great, he worked as a greeter. Learning the responsibilities of a new position and how to navigate through a new system overwhelmed Ted, and he had to stop working entirely at the age of 51. For people with young onset Alzheimer's disease, it becomes difficult to learn new tasks, even if these tasks are easier than what they had been accustomed to.

One Without Warning™ member commented on this change in handling stress when he said, "It seems like the mind goes along on a trail, and you have to follow that. You get disturbance on either side. It completely throws you off."

The difficulties of Alzheimer's disease uncover many emotions. As tasks which had been routine to complete now become more and more difficult, the person feels a sense of shame, embarrassment, loneliness, sadness, anger or helplessness.

Individuals with Alzheimer's disease have mentioned how self-doubt can become prevalent. One member of our group stated that, when you have Alzheimer's disease, every incident of forgetting becomes a reflection of who you are as a person. Even people very early in the disease process talk about feeling different—that they no longer have a place in the world around them.

These emotions can have a profound effect on one's job performance. Lisa, who was 49 when she stopped working, spoke of the embarrassment she felt when she said "I was an

assistant principal in a large, 3,000-student high school, and I was not doing the job I was suppose to be doing. It came on slowly, but more and more people noticed. I was thinking that I was doing a good job but my job was not good. I'm a high achiever and how could this happen to me? And then people were starting to talk about me and I'm really a private person. It was just devastating."

Marty, an executive in a major health insurance company who was 48 when he stopped working spoke of feeling shame and anger when he said, "The fact is that I could do this before and today I can't. And I hate that. I just hate it on the days when you can't get it together. You just can't focus; you just can't make it come together. You just can't do it."

Kevin, a salesman who was 53 when he stopped working, spoke of the frustration of trying to perform everyday tasks when he said, "I was in the office, and I went out for lunch to grab a sandwich and driving back a route that I have taken 1000 times or more. I stopped and where am I? Nothing looks familiar. And I did what any other guy would do. I kept driving. I found a landmark and then I knew where I was."

All these individuals speak to the difficult and painful emotions felt when trying to perform in a work setting while living with Alzheimer's disease.

Depression is another area of emotional functioning which is common for individuals who have Alzheimer's disease. Living with depression can greatly impact a person's ability to work. Symptoms of depression include both emotional and physical symptoms. The emotional symptoms include sadness, diminished interest, feelings of worthlessness, excessive guilt, decreased ability to concentrate, and recurrent thoughts of death, and anxiety. Physical symptoms include general body aches, headaches, gastrointestinal disturbances, changes in appetite, and changes in sleep patterns.

One Without Warning™ member said, "I have some days that I can take the tiger by the tail and some days I don't give a care. I have a hard time making myself feel motivated. Things I cared about I just don't bother."

Brian, a high level executive who was 55 when he stopped working, said "I feel numb. It is not good. I just struggle with it mentally. I feel more tired. I push myself to do things."

Problems with communication can begin early in the disease process. These changes have a strong impact on emotional functioning and how a person interacts with others. From very early in the disease process, both the ability to think of words and the ability to understand them are compromised. In almost every work setting, being able to communicate is a necessity. Individuals with young onset Alzheimer's disease struggle to think of words they want to say. They require a longer period of time to process what is being said to them. Because of the short-term memory loss, they forget conversations, which result in repeating themselves or asking others for the same information multiple times.

Individuals with young onset Alzheimer's disease often need people to slow down and speak in a more deliberate, concise manner. They might need people to repeat themselves without sounding frustrated and show patience if it takes longer for them to express a thought. It is difficult to expect co-workers to accommodate these communication needs when in a work setting. Individuals with young onset experience high amounts of stress when interacting with others who do not understand the changes created by Alzheimer's disease.

Kevin, our 53-year-old mentioned, "When I was employed, there was a situation where I asked the guy that I worked with a question three times in a five-minute period. And, he said what the hell is the matter with you?"

And finally Mike, a former supervisor with a large construction company who was 63 when he stopped working, said, ". . .the biggest thing that I find—I can't handle the commotion. Because you are trying to do things, and then so many things are coming in, and I can't process it and keep them in order. I am getting a signal over here and a signal over here, and I just can't keep up with it. And it makes me a nervous wreck." Working as a supervisor on large construction projects, Mike was used to commotion; but now, living with young onset Alzheimer's disease, he is no longer able to process the words quickly enough to keep pace when many people are around him.

Individuals can experience change in their personality. Jim, our 36-year-old, said, "Sometimes when we have company over, and I just go in my room. You isolate yourself; I do. For me when there is it too much information coming in. It is like a sponge and you are trying to get the last bit of water off the table. And it won't get it. It is overloaded."

Interpersonal relationships can also change. This includes relationships in the work setting. Relationships that might have been easy can become strained. For the person with Alzheimer's disease, they might feel out of step with their co-workers and others around them. For the co-workers, they might feel frustrated with the person who no longer is performing at the same level. One Without Warning™ member described telling co-workers about her diagnosis of Alzheimer's when she said, "I tell people at work, but the reactions are mixed. Some people don't talk to me anymore or ask me to do anything." And yet another individual said, "I was an engineer, and when I stand there with a three minute pause in your talk, they don't have much confidence in you anymore."

And finally, another change in emotional functioning is loss of purpose and identity. Marty, our 48 year old, once said, "I try to be strong because I am a strong person, but some days you just don't know where you are, not just in this spot, but where you are in the whole world. One day I could be doing a simple task and then the next minute you say where is it? You are in this hole and you cannot get out of it. It just drives me nuts." Ted, our 51 year old, also said, "Your self esteem goes down because I used to be able to do all these things. Deep down in the core of your being, it's hard." Another member said, "I was the one that supported my family, but now I might get \$10 a week."

Jim, our 36 year old, commented, “It is very frustrating. It is very painful. I can’t be the man that I was, and I realize that. I have three children that depended on me a lot and still do, but I can’t do what I did before. I can’t even take them to McDonalds because I can’t drive, or I can’t be by myself. I was on the top of everything. I was doing million-dollar jobs. And now I can’t walk to the park bench. It is difficult for me to accept.”

As we have heard today, cognitive loss is the hallmark of Alzheimer’s disease. You can see, however, that there is a profound impact to emotional functioning for the individual with young onset Alzheimer’s disease. These changes to one’s emotional functioning greatly erode the individual’s ability to work and relate in a job setting. Such areas of emotional functioning can include a reduction on ones’ ability to handle stress; an increase in emotions such as shame, embarrassment, loneliness, sadness, anger and helplessness; an increased risk of depression; changes in ability to communicate; and finally a dramatic loss in one’s sense of purpose and identity.

Alzheimer’s disease is a devastating and progressive illness. Just as cognitive functioning will decline over time, so will these areas of emotional functioning. As a result and usually early in the disease process, all people with young onset Alzheimer’s disease will have to stop working and will begin the application process for Social Security Disability. Esteemed panel, thank you for considering the unique needs of individuals living with young onset Alzheimer’s disease and how this disease impacts their ability to work. Individuals with young onset Alzheimer’s disease would be good candidates for inclusion into the Compassionate Allowance program.