A Personal View of Living with Early Onset Alzheimer’s Disease

Opening A Door to New Understanding

October 2000
Jan's Story
This story is true, written by a 50 year old woman, Jan, who was diagnosed with Early Onset Alzheimer's Disease (EOAD) when she was 45 years old. She invites you to read her story and to e-mail her with your comments at: cwaedphill@aol.com. You are also invited to visit her website at: www.ycsi.net/users/laura/janmina.htm.

My name is Jan and I have been diagnosed with Alzheimer's Disease (AD). I want to speak openly about having AD for several reasons. First, I feel a need to put a 'new face' on AD -- to let people know that it is not an 'Old Timer's Disease'; AD strikes many in their 40's & 50's and some even younger. I want people to realize that this is not a disease of hopelessness. Second, many of my peers are unable to speak for themselves anymore. Third, the drugs used for the treatment of AD have little or no effect if they are started later in the disease progression.

Alzheimer's Disease (AD) changes each person differently depending on the brain cells it chooses to attack -- each victim different and yet the outcome will probably be the same. I think many of us with AD try hard to be seen and recognized as still important. We are so frightened about having AD and since we know the consequences, we strive to be recognized and validated as alive, rational, and productive human beings. Some people in our lives choose to ignore or to hide from AD -- denying its existence. It is hard because once diagnosed with Alzheimer's our views are discredited and our thoughts are discounted.

For instance not long ago I was invited to attend an AD conference, not to speak this time, just to attend. As usual there were the exhibitors and professionals with displays. As I made my way around the room perusing and stopping at each display, people were friendly and we had great discussions. Of course they wanted to know my affiliation -- which company or organization I was representing. Invariably when I disclosed that I was the patient, the one diagnosed with Alzheimer's disease, they become stuttering messes!

Many professionals offer and advertise patient services, products and special homes. They offer information about caregiver resources and supports, but they can't figure out how to converse with a patient!
Once I tell people that I have been diagnosed with AD, even if we have been having the most engaging, wonderful exchange, the conversation ends abruptly. At times it is amusing, and always disconcerting, because people like these professionals gather together specifically for AD awareness and yet they themselves are at a loss for how to act with one who lives with the illness. I sometimes wonder -- how can I expect more of the general populace? I could choose not to identify my diagnosis, but what is the value in that? My hope is that maybe these people will see that AD is not just a product, not just a service, not just a means to make a dollar, but that AD is real -- alive -- a human being.

At this point in my life I am also choosing to be alive. One of the hardest things about being diagnosed early is that I have had time to ferret out knowledge of the disease and to understand its progression. I have been involved with peers and caregivers who are farther down the road with this disease. It is so hard to witness and to experience the reality that once you are diagnosed you are discounted and others act as if you are invisible during most conversations. It is as if we are not there!

Another thing, the guilt that is heaped upon the patient is enormous, not intentionally perhaps, but it is there because we have AD which will cause untold misery for our caregivers. This picture of misery for your loved ones is hammered into you as you seek advice from healthcare and legal professionals. It seems ironic that because we exist with a certain diagnosis our caregivers get to join organizations like the Alzheimer’s Association where they receive support and counseling.

I have never heard support or sympathy expressed for my losses. Where is the dignity in a life that because of a diagnosis has no value? Only my caregiver's needs were given any validation through the support, counseling, and respite offered. Oh yes, there is no question that my family will need the support, but I am not incompetent just because of a diagnosis. I do not want my husband, children, and grandchildren to suffer through the end of this disease with me. And yet I am selfish enough to want to be here and enjoy them as long as I can. For those of us who know the consequences of this disease, and the devastation it reeks upon all who touch it, and the guilt with which we live, just being alive with the AD diagnosis is a choice I often question.
If I could chose how I wish we were seen by those in healthcare, I would ask that we be viewed in an optimistic and not a fatalistic light. Now with the rapid discoveries that are coming, AD may soon be seen as a manageable and treatable disease. Yes, I know that there is still no cure, but, there is no cure for diabetes either and yet there are courses of treatment that will control and manage it to a degree. Perhaps this approach will take the stigma away from the disease, and get more people to come forward, and to accept and seek diagnosis at a younger age when drugs can be effective.

We have come to accept the death of a person with AD as matter of fact and have prepared the road well. Some of us are not following the same pathway and this challenges the medical and Alzheimer's Caregiving Community to revise and renew their thinking. I hope people will consider the needs of people living with AD such as: patient support, crisis intervention, and family, marriage and legal counseling. We need to maintain our dignity as viable, productive human beings - not life's discard because of a disease.

*Sincerely, Jan*

*Nothing the heart gives away is gone, it is kept in the heart of others...The Heart Remembers. Contentment is not the fulfillment of what you want, but the realization of what you already have.*

**RECOMMENDATIONS FOR HOW TO BE WITH SOMEONE WITH EOAD**

1. Do not discount someone because they have a diagnosis of AD.
2. Ask for and listen to the person's opinions and perspectives as you would anyone else.
3. Please remember that AD is not an older person's disease; it strikes many people in their 40s and 50s if not younger. Consider the unique needs of younger persons living with this disease as defined by them.
4. Respect persons living with AD who are real, alive, human beings wishing to maintain their dignity as viable, productive human beings.
5. Offer support to persons living with AD as well as their caregivers.
7. Consider the fact that many persons living with AD are eager to help researchers, health caregivers and all interested persons. be it through interviews, drug studies or the internet.

*This pamphlet was created through the collaboration of Jan and some nurses at Sunnybrook & Women's. We hope it helps enhance understanding of what it is like to live with Early Onset Alzheimer's Disease. We believe understanding can change the world.*

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