

## Child of Alzheimer's

By, Mary Jo Hefferan

*Alzheimer's disease is a progressive, degenerative disorder that attacks the brain's nerve cells, or neurons, resulting in loss of memory, thinking and language skills, and behavioral changes.*

- *It is estimated that Alzheimer's disease currently affects 2.4 million to 4.5 million Americans.*
- *It is projected that the number of Americans with Alzheimer's disease could more than triple to 16 million by mid-century.*
- *The incidence of the disease doubles every five years after age 65.*
- *It is estimated that one to four family members act as caregivers for each individual with Alzheimer's disease.*<sup>1</sup>

Recently I had lunch with a friend and we ended up discussing his mom's Alzheimer's disease. Although she is in a care center it still does not alleviate many of the concerns and problems with being a child of Alzheimer's. As Kirk and I sat discussing what he was going through, I couldn't help wondering if I could have been this strong should I have been put in his position with my parents. I also had an aunt with Alzheimer's.

I asked Kirk some pointed questions about his feelings and his advice to others who are caregivers for an Alzheimer's patient. His answers were straightforward and very honest, and I could see they 'came from the heart'. Here are some of the questions and his comments:

### **Do you ever feel overwhelmed or guilty?**

"This disease is more difficult on the family than on the patient. Yes, it is sometimes overwhelming to know that you are making the decisions for another person. You have 100% responsibility for their life without their input." He said he has no guilt because this has been completely out of his control.

### **Are you confident in the care your Mom is getting?**

His father retired from the Navy as a Captain so his Mom is covered under their insurance. He went on to state that the Navy has made great strides in setting up "senior programs" and have recognized the need for care for Alzheimer's patients. Kirk also stated that their doctor was transferred to Japan so a new younger doctor took over. He said it was quite a process to get from point A to point B: he had to make the doctor understand that they had "been there, done that" with treatment. Many medications had been tried without any luck, and to impress that to the doctor was challenging. Even things like "don't give Mom a message to give to me – SHE HAS ALZHEIMER'S and won't remember." He said that comment finally hit home. They are now all on the same page and very comfortable with her treatment. One thing he said that really made sense: "educate yourself as much as you can about the disease. Do research, read up on the subject, ask questions, but become knowledgeable. Also, make sure that patient's physician is very well educated about the disease."

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<sup>1</sup> From Alzheimer's Foundation of America website. <http://www.alzfdn.org/>

### **Does your Mom get angry or moody?**

“No, but she will say anything to get you off her back. She is stubborn, not angry.” He went on to tell me about various times he has had to go at a situation from a different direction because his Mom has changed her mind at the last minute. Even sitting outside the doctor’s office because she decided upon arrival that she doesn’t need to go in presents problems. An approach from a different angle got her into the doctor’s office – finally! Many instances of this type of behavior have begun to occur. He said you can’t get angry with her; you just go with the flow and figure out another way around the situation. Kirk also pointed out that many times when his Mom is lucid she realizes that she has a problem and that upsets and frustrates her.

I remember my aunt showing up in her room with someone else’s clothes on, or hiding her roommate’s glasses. It had become a game to her as the disease became worse.

### **What other advice would you give others who are caregivers?**

“I strongly urge that more than one person take care of their parent, if possible. No one person should be responsible for everything. There should be checks and balances with regard to money situations. It is too easy for someone to abuse the trust, and with two or more people having responsibility, it should help lessen the opportunity.”

### **Finally, I asked the big question: Are you ready for the day your Mom doesn’t recognize you?**

After a long thoughtful pause Kirk began, “I’m as ready as I can be. I know it’s coming and I’ve prepared myself. When it happens I’ll probably take a step back, but, yes, I’m prepared.”

So many people are going through the same thing every day. I hope this helps some of you who are just starting the journey.

Thank you to Kirk Jenkins of Scottsdale, Arizona, for the insight, sharing his feelings, and for a great lunch.