



Caregiving from a Daughter's Perspective

Welcome to alzcast.org providing key insights and perspectives on Alzheimer's disease for nurses, doctors and caregivers. In this broadcast we are featuring Susan a caregiver whose father had Alzheimer's disease Susan will share her experiences and insights regarding the care of her father who suffered with the disease. It's our hope that Susan's insights will help our audience of caregivers.

Jon Merrill: Susan please tell us about your father.

Susan: His parents were Russian immigrants and he had two brothers and two sisters and he lived in Baltimore all his life. And he obtained a bachelors degree in business, served in WWII as a first lieutenant teaching other military personal. He was extremely patriotic. He was married twice and had a son and daughter from his first marriage and six grandchildren which he adored. He owned his own bag business and drove a truck to pick up merchandise. He was very, very involved with his family and friends and very active in the synagogue, he performed religious rituals and was president of the congregation and chairman of religious school. He was a master story and joke teller and had a great sense of humor.

He also had rheumatoid arthritis and heart disease.

Now when I think back its difficult to pinpoint how long Dad has the disease because he was very good at covering and compensating for his dwindling abilities so I would say when he was in his late seventies early eighties we began to notice a mild decline, there were little subtle changes. He was forgetting more, sometimes specific words, sometimes names, sometimes part of an experience and his stories starting to get confused, he would get confused about them and some of these stories we had heard over and over again before his dementia. So we had known all the names of the generals and every thing from the army but he would get confused and he would become frustrated and often agitated when he couldn't remember things and sometimes early on it would come back to him and then later times it didn't and that cause a lot of frustration for him.

He misplace things and had difficulty in finding his own things that caused another frustration for him He accused people of taking things when he could not find them. Many times he was fearful of making a mistake or embarrassing himself so he gave up performing religious rituals at our synagogue and at family gatherings. He began sleeping more and you saw that he had changes in mood some depression and he began taking less care of his personal needs it was easier to sweep this all than deal with it.

Jon Merrill: How did your father's wife and your stepmother cope with the disease.

Susan: So I was not the primary caregiver my stepmom was she dealt with this disease twenty-four/seven. She was in denial and often covered for his inadequacy she began doing more and more for him as he became less and less independent and she took on more of I would say a parental role as the disease progressed. He saw that as an insult that she was mothering him and he saw her more as a parent than a loving partner.

And when I think about my brother who was in total denial he was a little help and he couldn't handle this and he often didn't want to hear anything about it.

You know there was a little bit about family conflict dealing with this, same thing as Dad was aging knowing that this was more than normal aging and normal forgetfulness. We um I know that Mom was having a hard time dealing with all of this twenty-four/ seven when you don't know what the next hour is going to be. Or you know if you're your husband is going to wake up and know that's its morning or night. Or you have breakfast and he says its dinnertime. Or why did you make a bagel when I wanted steak you know.

So I sought out to get help for her and she had some individual counseling from Jewish services and then we met together with the elder care specialist there who was great in giving us tips on what to say to Dad when a confrontation should occur, how to calm him, how to calm ourselves and also the resources that were available in our area. Like adult day care, people that would come in and relieve my step Mom for a little bit and as well she also mentioned having him evaluated at Copper Ridge outpatient assessment. So we had more help from the social workers than the medical community.

Jon Merrill: What was your experience in trying to get your father diagnosed?

Susan: We noticed things you know and would bring this up to the family doctor who kind of shrugged it off as normal aging, who was of little help as we found it frustrating. We were familiar with the outpatient assessment clinic at Copper Ridge. But we knew that he could not go as an outpatient so we elected to have the short stay evaluation at Copper Ridge. And that's when we got more definitive answers because I felt and I was handling all his medical and financial needs as his daughter and having his power of attorney that we needed a better diagnosis to find out what was best for Dad, you know. Could he have care at home, you know if we had extra help. What kind of facility he needs that his needs were going to be met at the level he was at. And what the prognosis was for the future.

Jon Merrill: And having gone through all the issues with getting your Dad diagnosed.

Can you offer up any advice to our audience in terms of what they should do when they are in a similar situation and there not getting the information that they need.

Susan: I think that you really have to stick with this. You have to take charge; you have to have to be an advocate for your loved one when they can't do it for themselves. Um don't worry if you're going to hurt their feelings it needs to be done. When your primary care you're not getting satisfaction there then you need to seek you know other help. You have to find other resources, there are some on the internet but you shouldn't give up. And you need to be the one, you are the one that sees the symptoms so you need to be the one that's going to make the decisions you just can't you know let some one say it's the normal part of aging when you know its more than that. It's just like when you go to the teacher, you know when you have a teacher conference you know your child better than anybody else. They might spend a few hours of day with your child and the doctor spend thirty minutes with the patient you know they don't know everything about them and if there really not listening you have to find someone that does.

I think that you need to keep a log of who you talk to, when you talk to and what they said. You should keep all your loved ones medical records together.

You should get copies when you see a doctor of all the reports, all the lab work and you know in one compiled place so when you are talking to another physician you can talk intelligently about what's going on what's previously happened because giving a correct history is important. Um then you should seek out help for yourself. You should still remain social. Many often time family members, the extended family doesn't know how to deal with it doesn't know what to say to you so they kind of back away. Friends tend to back away. So you need to find other ways to maintain your own independence and sanity. Don't forget who you are while your caring for your loved one because you can loose your identity because this is twenty-four seven draining disease.

Jon Merril: Susan I'd like to ask you now if you can share some insights in the best ways you were able to cope with your father's Alzheimer's disease and help him make his way through this very devastating illness.

Susan: As his disease progressed I spent more time with him taking him out more. Now that was always a pleasure he had something called Susie and me day Some days you did not feel like dealing with his reputation or have the patients to wait while he gets ready cause it takes more time or hear the same stories over and over and over and sit there and pretend like you just heard them. But on those times my dad because of his sense of humor and warm personality he was the one who usually lifted my spirits so it really became a wonderful day. I tried to engage him in activities that hopefully would spark his memory while still preserving his dignity and self worth. I didn't want to do anything you know read books that were to babyish, we reminisced a lot, we read articles of interest together, took him to familiar attractions and called

him more often. When he called me because he was upset because his wife wasn't home at the time he thought she should be home even though he was not on the correct time or didn't know what time of the day it was, you know I would reassure him that things were going to be ok when he became upset and confused and we tried to find creative ways in the home to make things easier for him like color coding the TV and VCR. And he had difficulty hanging up the telephone the handset and the base so I tried to color code that so that you would line up the blue with the blue and the red with the red. I made big yellow day glow signs as reminders and medication list that were posted in the bathroom and in the kitchen for him just to, so he could have some normal routine and maintain his dignity and then I was helping him later on as his disease progressed with his check book and his banking and you know taking care of bills. So it required a lot more patients on my part and I sort of resurrected all my teaching skills so that I used in kindergarten. You know particularly when he was exhibiting childlike behavior I didn't talk down to him but I tried to use some of those the skills I had as a teacher to talk to my Dad. And then you'd see the role reversal and you're not always prepared for that. Well I can honestly say we were quite fortunate that my Father did recognize my brother and I because he knew us longer than he did his second wife and he would sometimes get her mixed up. One day she came in and he did not recognize her and he said to her I'm looking for my wife. So you can imagine how that makes her feel. But he's thinking about that he's married to some one who has dark hair and she has blond hair. So he's in a different place you know, further back. So we were quite fortunate that my Father could recognize us and hold a conversation with us. It might only be for thirty seconds remembering what we just told him but he could have a conversation with us and we were blessed that my Father could still read. So I could write letters to him and he would read which is unusual with patients with dementia or Alzheimer's.

So he was cared for in his home until he was about eighty-five and then he spent one year in assisted living for mental impairment before his death this year.

You know we know our parents are going to age we know they are going to pass away at some point in their life but you hate to see it this way.

Jon Merrill: Susan you've gone through a very difficult period and I am sure that there's a lot that you can share to others that are going through similar crises and issues in facing a loved one that has Alzheimer's disease. Can you share with us some of the resources and trends that you see in the field of Alzheimer's treatment and how these can impacted one's ability to be a caregiver.

Susan: Well I think that there's more awareness about memory related illness' especially Alzheimer's. However I don't think we are aware how many people will be impacted by these diseases in the near future as more and more baby boomers come of age and as more and more of us live longer. So I think the public needs to be more aware of the warning signs of dementia for early detection I think that's important. I

think primary care physicians need to be aware of resources in their community to guide their patients and their families.

There needs to be more training for physicians and nurses, therapists and social workers and more training for support groups for caregivers so more patients can remain at home when possible. And then I think the infrastructure we need more and more facilities, we need more adult day care centers and facilities specializing in dementia care and of course we need the research to understand the disease. I think even when you have an insurance person to come see you and wants to sell you a long term care policy and you think like what do I need it for it's so expensive right now that everyone should consider the long term care policy it makes a huge difference. It can also make a huge difference in you getting into a facility because you have a long term care policy because this dementia care is expensive, residential care is expensive it can be draining on your resources and some times it was tough. You know deciding when you have to crunch the numbers and medications are expensive. I think that there are a lot of Veterans that don't know they can get their medications through the VA.

Jon Merrill: Susan from your perspective what we can do at alzcast.org to improve the site and offer functionality that others could benefit from.

Susan: Well if someone could sit in their own home and get on the internet and find out information and resources in their particular area and absolutely get the support from other people you know you don't have to be sitting across from the person you can get it on line and you know almost have a one on one with the person. You know if you have a place where you could e-mail a question to and you could get a response when you are having a difficult situation I think that all would help you know, the more that's out there the more knowledge you have it'll be better for your loved one and easier on the entire family.

Jon Merrill: We very much appreciate the insights and perspectives that Susan has shared with us. Please continue to tune in for other broadcasts and resources on alzcast.org to gain additional viewpoints and information about Alzheimer's disease.