

Ellen B.



Born and raised in Houston, TX, Ellen is a wife, mother, and grandmother. Ellen, who is 74 years old, has three children and five grandchildren. She graduated from Texas State College for Women in Denton, TX, now known as Texas Woman's University. She previously worked for the Spring Branch school system for 26 years before retiring. Ellen enjoys traveling the world with her husband of 53 years. She currently stays active by working for her husband, going to museums, and the symphony. She describes herself as "just a regular ole gal" and a strong Christian, but others also see her as a kind, light-hearted and outgoing person.

Objective 1: Identify factors that motivate individuals to seek diagnosis

What was happening in your life that prompted you to seek a diagnosis?

I was diagnosed in April 2005. So I have been with this about five years. My mother died of Alzheimer's and her mother died of Alzheimer's and her sister died of Alzheimer's.

I feel like I get along as well as I can and I do keep pushing.

So you recognized some similarities in you like your mother?

Yeah and my husband and I talked and he would say "You sure are forgetting; your short-term memory is getting pretty bad." I was getting things mixed up and couldn't think of words; that has still hung on with me, to recall the name of something. I can see it, but I can't tell you what the name of it is; it's blank up there. So I went to my doctor and said this is what I am experiencing and he then sent me to a neurologist and she sent me through a lot of tests. The last test was the PET scan and it actually shows something in the brain that is Alzheimer's so she thinks she is right on with her diagnosis, which she is.

Objective 2: Describe the emotional experience of a person who has recently received a diagnosis of Alzheimer's

When you first learned your diagnosis of early memory loss (or Alzheimer's), what was your immediate reaction?

I wasn't surprised at all. I kind of figured like I'd already made that diagnosis. I self-diagnosed and the doctor just confirmed it.

So you weren't sad or angry or anything else?

No. I already knew that this might well be my fate. And so I wanted to check it out and find out for sure, because if there was anything that would help me to put this off, I wanted that medication.

How do you feel about your diagnosis today?

See I write down everything. I think that is how I have managed to tolerate this situation. I am not ashamed of my diagnosis. I use it as a crutch, you know like an excuse for not remembering something, and I can forget something in about a flash. My husband will say why don't you bring me something and I'll go do something else and once my mind is going in another direction I don't have a clue what he told me to do. I can't but one thing at a time. I am not real good with numbers anymore. They still let me write checks, but I don't do bank statements.

I don't take stress really well. Stress to me is like I've lost something and I should know where it is and I go to the file and its not there and there is absolutely no place in the world it can be expect there. So that kind of thing drives me nuts. I go lie down for a little while, close my eyes and think about something nice, take some deep breathes and then I go back and start over. So I think I handle it pretty well.

Sometimes I get really upset to the point that I cry. It's like a lack of total control. I can't always maintain this attitude that I like to have, but like I said I go in my bedroom and lie down and regroup.

I am fully aware of what is wrong with me. I think that is really important. And I work at staying active.

Objective 3: Recognize social stigmas and provider assumptions related to AD

Can you tell me how your family behaved when they learned about your diagnosis?

Well, see they all knew that my mother had this disease. We didn't make any big announcements. My 15 year-old granddaughter probably told her mom she knew Mimaw was making some mistakes. She had already recognized that I had a problem. We took the kids to visit my mother so they have been exposed to someone that was pretty deep into the disease.

We are really hoping that they are going to come up with something that is bigger and better than what we got right now, then it might just put it off long enough that I'll die from something else. That is kind of what I am looking forward to, because it is a nasty death. Your brain just quits doing all the things that it's supposed to do.

So you don't feel like your family treated you any differently?

Haha no, they still expect me to pick them up and cook for them and take them shopping.

What about your friends?

Well, I have a lot of close friends. I had a couple of friends that I went to elementary school with, worked in the library with, and went to church with and the only reaction a lot of them had was “I don’t believe it.” They would be like you don’t have Alzheimer’s and my husband would say yes she does. Haha.

But my husband has just been wonderful. We went to a course Teri had for 7 weeks that divided up the caretakers and patients and we learned a lot. I thought it was a good deal. I would tell people to go.

Objective 4: Identify benefits of early diagnosis.

Do you think it was helpful to learn about your diagnosis early?

Yes, definitely. I am going to send my daughter pretty soon. I am serious she is 44 or 45, I can’t remember how old my kids are, but I have it written down in a little book. I mean that is all you can do. I cover over my problems by just writing it down first. Then you don’t have to wonder, “Well when is Allison born?” I don’t know, but I can tell you. I keep all that little stuff in my purse.

I have a hard time sometimes thinking of the name of something. When I was having therapy for my hip, I kept saying I was going to gymnastics. I was trying to say therapy, but what came out was gymnastics. So it is a big joke. You know, we kind of make a joke out of what is happening to me. You know, its like oh gosh she is at it again or she is having a bad day.

My husband and I work together a lot to my problems not go away, but to make it easier on both of us; we make it manageable.

Can you describe how finding out about your diagnosis early has helped you?

We got it pretty early. I’m sure it has helped me because I have been able to get started on different types of medications and I think my doctors are pretty good.

You see, I would have all the time been thinking “I know I have Alzheimer’s,” but at least now I’m on medication and I am doing everything I can. I exercise, take my medicine, and eat healthy.

Well sometimes it is like how do you know to go. I had a lot of things that made me say my mother or my grandmother, but a lot of people don’t necessarily have that hereditary factor. And everybody forgets stuff, so it is hard to come up with an early diagnosis probably. But I do think it is important. I do think that getting me on the medication has helped.

Well is there anything you would like people to know about living with Alzheimer’s?

It doesn't get better. But I just think you have to have a good attitude and laugh at some of the silly things you do and stay around people. I don't want to become a recluse.

I have a really good life despite Alzheimer's. I am pretty happy and I don't feel sorry for myself.

Right now I feel I am fine and I have been diagnosed for five years; and I think it is because I have had my medication since then.

I know that my husband doesn't think that I am doing very good with numbers. There are a number of things that he notices and nobody else does. It is not really as evident to others; I hide it pretty well. Well it's not hiding, we just don't dwell on it. We don't want people talking like "oh well she's just got Alzheimer's;" just treat me like a regular person and they do.

I have a good life, Alzheimer's or not. I think the most important thing for me is to stay active and to stay happy and to accept the way life comes and I'll get along just fine.