



Perspectives

A Newsletter for Individuals with Alzheimer's or a Related Disorder

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Living with Alzheimer's

By Kris Bakowski

I think there comes a point in everyone's life when we pause to reflect on the past, realize the present and look to the future. That happened for me at the age of 46. I'd been married for over 20 years, our son was in his freshman year of college, I was happy in my job and my husband was looking forward to retirement. We were all healthy, tried to exercise, eat right, and live an active life.

However, in the fall of that year I started to become forgetful – which was not like me at all. I had an almost photographic memory and relied on that all my life. I had a very stressful job and worked long hours, so I blamed that for my forgetfulness. I couldn't remember things like my home phone number, my associates' names or on bad days, how to get home. I remember that many times I would stop at a gas station, and after filling my tank, not know whether I was going to work or coming home from work. I tried desperately to hide it and became pretty good at it! But one day in December, my husband and I were out shopping, and he went to a different department in the store. The next thing I knew is that I couldn't remember where I was or how I had gotten there. It was time to fess up.



Kris Bakowski

I sought medical attention and after eight long months of testing, including all of the alphabet soup tests (EEG, EKG, MRI, etc.), blood work, spinal taps, B12 shots and neuropsychological testing, I was diagnosed with Alzheimer's. It was a relief to me because there was a name to it. Although it is an incurable disease, at least I knew what I was dealing with. My family, however, took a dimmer view. My husband likened it to the Titanic – that the ship was sinking, and he and my son were going to survive and I wasn't. My son re-

lected that it was like his mother was on death row, but innocent of the crime. Alzheimer's does not run in my family, or at least that I know of. My parents both died in their early 60s of other causes. My father was adopted when he was young, so we had no knowledge of his biological family's medical history.

After the diagnosis, my first call was to the Alzheimer's Association in Georgia where I live. My questions ranged from "What's next?" to "What can I do to help in finding a cure?" The staff at the Association were my saviors during the first days and months of my diagnosis. They guided me and were there to hold my hand through the whole "adjustment" phase.

All of that was five years ago, and thanks to the available medicine, I am able to live
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a somewhat “normal” life; although the definition of “normal” changes every day. I’m definitely not the same person I once was. I’m not as outgoing, not as self-sufficient, not as engaging, and definitely not the life of the party! We’ve mourned the things I can no longer do, and we celebrate the things I can still do. I have good days and bad days. I can no longer work because of this dreaded disease, but I still have feelings. I’m still a wife, a mother, a sister, an aunt and a friend.

But this is a silent disease. No one wants to talk about it. They don’t want to admit that they know someone with Alzheimer’s. Many treat you like you have the plague and if they acknowledge it, they will somehow get the disease. That is so hard for many Alzheimer patients. We want people to understand this disease because it is only through educating people that we are going to get the funds we need to help fight Alzheimer’s.

I don’t see a cure in my lifetime, but I’m hoping that by the time my son gets to middle age that there will be more available to him if he should inherit this from me. To me, the worst part of this disease is not what it does to me, but what it does to my family. It is not fair for them to have to take this unwanted journey with me. My son once wrote me this note: *“I know that you worry about your disease and how it affects our relationship, but I want you to know that I do not feel as if you have changed as a mother. I cherish the closeness of our relationship, and I understand the many forces acting on it. But you have remained unflinchingly loving and understanding, and I am indebted to you for it. I owe you my life. What makes me sad is that although I will always love you – in time you won’t*

be able to remember that I do. So, I’ll say it as often as I can now – I love you.” For that, if for no other reason, I hope a cure can be found.

The Alzheimer’s Association has been a partner with me. I have been able to feel helpful being involved in advocacy work, media interviews, speaking engagements, and Memory Walks. If you are reading this story, and are just learning a loved one has the disease or perhaps yourself, I would encourage you to seek help from the Association. If not from them, from other sources so you know that you are not alone. My involvement is my “therapy” because I’m hoping that in some small way I can help fight Alzheimer’s.

Family, friends, and others with Alzheimer’s help get me through the days. Love and support can come in all forms. Reach out to those who love you. You are not alone. I chronicle my experiences at <http://www.creatingmemories.blogspot.com/>. There are also forums on the Alzheimer’s Association Web site for you to participate in. It’s going to take all of us to help fight Alzheimer’s.

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