

Alzheimer's Disease:
MR. BOLTON'S STORY

Initially, I could not place what was wrong with my husband; he seemed a little more confused than usual. I thought he might be having a transient stroke because of his history of high cholesterol and hypertension. I scheduled an appointment for him to see our family physician, but every medical test came back normal. He became increasingly confused and forgetful. He would leave the house to go to the grocery store, and then would call me to say that he could not find his way to the grocery store he had been going to for years.

He loved to do things around the house, especially minor repairs. His favorite store was the hardware store, and he always looked for a reason to go to the hardware store at least once a week over the course of our forty-eight years of marriage. He would leave the house and not be able to find his way to the hardware store; he would have to ask for directions over and over again, which was very frustrating for him.

Around the house, he would misplace his glasses, his wallet, and other small items, and would have absolutely no memory of where he had put them. He would schedule appointments for people to come and work on the house, but when they showed up at the door, he would have no recollection of ever talking to them or asking them to come and do repairs for him. He would forget telephone numbers that he had dialed for years. When friends and family members called, he would not recognize who they were, or he would confuse them with someone else.

I was getting more and more worried and scared because it was becoming increasingly dangerous to leave him by himself. I took him back to the doctor and explained how his symptoms had progressively worsened since our last visit. At this point the doctor suspected dementia, in the form of Alzheimer's. He gave my husband some questionnaires to answer and repeated some tests. At the end of the visit, the doctor broke the sad news to me that my husband had Alzheimer's disease.

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I was not very well informed about Alzheimer's at that point in time. I knew it involved a form of memory loss, but I never imagined it would happen to my own husband who was always so quick to remember even the smallest of details.

The doctor explained that it is a degenerative brain disease, which causes the brain to lose the vital brain mass responsible for our ability to function. He pointed out that my husband was going to get worse because there is no cure for Alzheimer's yet. I was so devastated to hear this news. I couldn't imagine him being worse than he already was.

My husband was very energetic, hardworking, and full of life. He loved his family and took very good care of me and the children. We had worked together as a team for many years, but I was more dependent on him. The first question I asked myself was, "Where do I go from here?" It was very difficult for me to accept this diagnosis. I was in denial and quickly concluded in my mind that the doctor's diagnosis must be wrong, so I decided to get a second opinion from another doctor. Lo and behold, a second doctor confirmed Alzheimer's disease, despite my efforts to downplay the symptoms with the second doctor, in hopes of getting another diagnosis.

After working through the denial, I realized that I had to face the fact that my husband had Alzheimer's disease. This horrible illness has completely changed our lives forever, just at the time we were supposed to be enjoying the fruits of our hard labor in retirement. It was like a gradual death; you watch your loved one dying every day. I decided to keep him at home as long as I could. It was physically, emotionally, and financially draining. He got worse and worse every day because he became increasingly confused and forgetful. Initially, he was in and out of lucid or clear-minded moments, but the situation grew worse gradually. By lunchtime he could not remember what he had eaten for breakfast. Eventually he stopped asking for food even when he was hungry. I had to offer food to him, and if I put the food right in front of him, he would not know what to do with it unless I fed him. He was incontinent with urine and feces since he did not remember to ask to use the restroom. (He certainly did not go to the restroom of his own accord.) When I tried to change his wet or soiled clothes, he sometimes became combative. I think he must have felt that his privacy had been invaded because he was completely unaware of his incontinence. I had to bathe him and attend to all of his hygiene needs.

The most difficult part for me and the children was the fact that he did not recognize the children when they came to visit. Gradually, he completely lost memory of who I was. The grandchildren were especially hurt because they could not understand why Grandpa would not play with them. He used to play with the grandchildren a lot. He built a tree house for them in the back of our yard. We have

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a stream that runs through our backyard, and he used play in it with the grandchildren; they reveled in playing in the mud with Grandpa. The grandchildren also enjoyed running errands with him to the grocery store and the hardware store. With his completely altered personality, they complained that Grandpa was not fun anymore, and we had to explain to them, at their level of understanding, what was wrong with Grandpa. Understandably to the grandchildren, at their level of comprehension, this change would hopefully be temporary, but each time they came back, Grandpa was still the same way, if not worse. Whenever they came over, our four-year-old grandson would ring the doorbell and immediately ask, “Is Grandpa better now so we can play?” That really broke my heart. I had to put dead bolt locks on the doors and install a security alarm because he wandered away from the house many times.

As much as I loved him, I felt stuck with him in these circumstances because I was always afraid to run short errands. I am thankful for the blessings of good friends — some of my friends would come and sit with him so that I could run errands.

For a period of time he had a good *remote (long-term)* memory, so if I showed him the pictures of the children when they were younger, especially in the toddler years and the elementary school days, he would smile. He would also sometimes make a passing comment about an interesting event that had happened during that time of the children’s lives. When I played his favorite old music, he would get up and dance and even sing along. I always experienced mixed emotions, both joy and sadness, to watch him respond to anything. Eventually he lost the ability to remember any information, old or new.

After six years of taking care of him, I became exhausted and ‘burned out.’ I realized that I was not getting any younger myself, but it was not easy to let go. Early in our marriage my husband and I had made a promise to each other to be there for each other, no matter what. I hired a housecleaning service to come twice a week, and four of my friends volunteered one day every month to come and relieve me. My daughter would also come on some weekends to sit with him. While this was a viable solution temporarily, his health continued to deteriorate until I knew I needed help on a full-time basis.

Watching the daily downward decline was also very difficult; he was talking less and less, and when he did speak, his words did not make sense most of the time. Eventually he became mute with no communication at all, and he did not recognize me as his wife. I cannot begin to convey how painful this was for me. I could not afford to hire full-time help, as I had almost depleted all of our savings from taking care of him.

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I finally reached a turning point and had to make the decision to place him in a long-term care situation. Frankly, he needed more than I was able to give him. Although this was really the only choice I had, I experienced tremendous turmoil over it and felt as though a dagger through my chest might have been less painful. I never knew a day like this would come. Living with him and watching him decline with this illness was like a first death, but making the decision to put him in a nursing home was like a second death. I felt so guilty that I could not take care of him anymore, especially in light of our promise to take care of each other until the very end. Other people around me, such as my friends, community members, and my family, reminded me that if I were to die from exhaustion from taking care of him, he would have to go to a nursing home anyway.

With the support of my family and dear friends, I found a good nursing home near our house, so that I could go and see him every day. I reluctantly put him in the nursing home.

Finally, I have mentally accepted his new home. The staff is attentive to his needs, and I also go there to assist with his care, especially to feed him at meal times. I have also realized that although my husband and I are not living under the same roof, I can still be with him until the end.

I still cannot help but wonder about this illness called Alzheimer's disease; looking at my husband is like looking at an empty shell—the body is in one place, and the mind is locked up somewhere else. The memories of the good life we had together before his illness keep me going now, and sometimes I debate in my mind that maybe it was good for him that he was not aware of his own decline. He was a man with a lot of self-pride, very independent, and always preferred to serve others rather than be served.

During the early stages of his illness, I joined a support group for family members of people suffering from Alzheimer's, which was one of the wisest choices I made during this experience. I learned a lot from the group, and hearing the stories of others helped me to endure this hardship. I continue to monitor the medical news about this illness regularly, and I read a lot to gather information about what research is going into the studies of Alzheimer's. I pray that a day will come when there will be a cure for this devastating mental illness.

If this story sounds familiar, please get help. If you feel that you have reached the end of your rope in caring for a loved one with Alzheimer's, from physical or nervous exhaustion, or from depleting your financial resources, it may be time to find an assisted living situation for him or her. You can still be with your loved one until the end.

Quotes of Encouragement...

As the wind blows harder and the story of Mr. Bolton sounds familiar to you, remember the following:

“We must have strong minds, ready to accept facts as they are.”

~ Harry S. Truman

If you have Alzheimer’s, remember there is no cure yet, and the memory loss gets worse as the illness progresses. Face the difficult reality and be prepared for this unpleasant journey with Alzheimer’s, put your house in order, make preparations for end-of-life issues, have a living will, durable power of attorney, and a personal will. If you so desire, make a documentary of good memories for your family which will give them a reminder of happy memories to hold on to as they gradually lose you to Alzheimer’s. (LB)

“The most important thing in life is not the triumph but the struggle. The essential thing is not to have conquered but to have fought well.”

~ Baron Pierre de Coubertin

With Alzheimer’s, there is no triumph until a cure is found, but do not be buried in your grief and forget to reflect on the good gifts that life has given you. Be thankful for the many blessings over the years before Alzheimer’s, and do not see Alzheimer’s as a dead end but as another difficult phase in the journey of life. Be able to say “I have fought well with the things I could control, and the things I cannot control I will leave alone.” (LB)

“How strange is the lot of us mortals! Each of us is here for a brief sojourn; for what purpose he knows not, though he senses it. But without deeper reflection one knows from daily life that one exists for other people.”

~ Albert Einstein

As you struggle to take care of your loved one living with Alzheimer’s, and you feel the tiredness and the exhaustion, remember that living for one another usually comes with a price called sacrifice, and sacrifice requires the willpower and strength to do things that are not convenient for us. (LB)