



VESTIBULAR

DISORDERS ASSOCIATION

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A Patient Speaks About Her Family's Burden

By Sharon Yarrington

As a person who has had a vestibular disorder for many years, I must say I am glad that you are asking US how this insidious condition affects our family and friends. I, for one, am so weary of reading stories of people who smile every day, can still swing on a trapeze, run a marathon, or perform on Broadway with this disease. For every ONE of them, there are probably a thousand of US who are happy to just make it through the day without some "balance-brain-anxiety/what is happening now?" event.

When I first was diagnosed almost 10 years ago, I do not think my family and friends believed me, as most people have never heard of "vestibular" anything in their entire life. They wanted to treat me as though I was normal and kept continuing with our regular routine. I dragged along with them, getting ill in large places and stores, holding the wall in the shopping mall and pulling off the road while driving.

As the years passed, instead of travelling together or vacationing, we have reduced our family to gathering at my brother's home where I am comfortable and we can eat dinner without too many physical side effects.

I believe they are saddened by this disease because I used to be a vibrant, confident person and now that person is gone. This condition is most difficult for my husband because he is the one always at my side, taking me to the store, doctors' office, therapy...nowhere that is actually enjoyable, such as a vacation, the theatre, or a nice restaurant. He vacations by himself by visiting his brother because I am never sure of how I will be or if I have the stamina to experience an event so far from my home. Some years we have a "Christmas" and some years I cannot bend over to get the ornaments out of the box and on the tree without becoming ill.

My husband cried when my neuro-otologist announced that there was nothing further that could be done for me. Any further treatment or surgeries could leave me worse than I currently am. We had always hoped there might be an answer. My treatment is to lie down on the floor when I am having a vertigo attack to make contact with as many nerves in my body as possible. Now, that certainly is not an act that I can perform in the airport, mall or anywhere but home. I once had to do it in the grocery store and it sent everyone into a panic.





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This disease can make one look like an idiot. Sadly, many friends have moved on because I cannot participate in activities. They tell me that "we always know that you are missing when we are together." Even with my hearing aid, I still have difficulty understanding, and so many times, I just fall silent. I try not to burden my friends and family, because I know how difficult it is to watch someone you love continue to struggle with an incurable condition. I cared for my mother as she was dying from cancer. After her peaceful release from this world, I thought that a vestibular disease is just like cancer - no cure, lots of struggle and very little hope. Even though I am aware that research continues for this condition, at my age, I doubt that my family and I will ever see the day when I can join them again.

Thank you for your concern for the families and friends of those burdened by this condition.