

February 1st, 2017

Where do I begin? It's been a while since I wrote this and wanted to update this.

Steve gets very tired easily now and has to have a nap everyday for at least 3 to 4 hours per day. I can come in from work and he will be asleep and wake him up at 7:00 p.m. and still can go to sleep at 10:00 p.m. It helps with his illnesses but very frustrating to me. But we learn to adapt to the situation. You see I love him. He has headaches but not so much more of migraines. My daughter who just turned 33 years old has started with migraines headaches. She was confirmed with CADASIL in 2013. She has two children so they have the 50% chance of having CADASIL. Just this past week, Natalie had a 2 day migraine and Aleaha my 13 year old granddaughter took care of her and took care of her brother Darrius who is 10 years old. You see my daughter is a single mom. Why! Why! This is so hard to write.

Steve mom died recently and we went home the funeral, Out of 5 siblings 3 have CADASIL, Steve, Victor and Lorraine. We went to visit family I saw Lorraine's who is about 52 years old and she get tired very easily and has two part time jobs with flexible hours. Victor who is 58 years old is in nursing home he had a stroke and left him unable to do anything. Then there's my husband Steve. I knew Victor was bad but did not expect to see him as he is now. When we visited Victor's there was Steve, Lorraine and me. I looked at all three who have CADASIL, and think will they be like Victor, bed ridden can't talk and have to be fed by a spoon and look like a Skelton. Lorraine sees her brother every week and talks to him and shows her love. I admire her strength and courage.

Steve is still on disability and I work full time and run the nonprofit. I know I had not updated my story for a while and remember this is the unedited version.