

October 2016

I miss my dad. This is the truest way that I can begin this story. My parents did not marry and I grew up with him being a plane ride away. He always made sure that for winter and summer vacation I got out to see him. I think growing up with him always being a bit out of reach made this that much harder to accept, and his history made it seem impossible. My paternal grandfather only recently passed at age 92 and my grandmother is still alive at 95. My dad had a lean build and for extra income maintained yards. He was supposed to be around for much longer.

The first migraine I remember my dad having was when he was around 38 years old. He had driven us back from the mall where I had collected at a minimum 10 fragrance samples. He had to pull over from driving and asked that I throw away the papers. I did and when we got back to the house he still had to lie down for a bit. It wasn't until many years later that he had another one and asked if I ever experienced similar pain. I told him no, to which he responded with good. My dad always thought of me and wanted everything to go my way. As a kid willing to push limits I did not deserve such kindness but I am forever grateful.

One summer I had gone to visit my dad and we had to go to a doctor's appointment. I remember him saying that he watched as black squares turned white and vice versa. I am not sure of what other tests were done but he was diagnosed with MS. When he told me about his diagnosis he immediately said that it is not hereditary. This once again proved to me how in his coping he still thought about what it meant for me. His MS was described as not typical. For a few years after his diagnosis everything seemed to go on normally. He did what dads do by making fun of me, telling me how proud he was of me, and to his pleasure I am sure heard me talk about boys. At 53 he came to my college graduation and I finally saw a change. He said his legs were stiff from sitting on a plane all day, but during his entire trip he never walked typically.

I had already decided to move from the southwest to the Midwest to be closer to him. It was still a five hour car ride, but compared to before the car ride seemed manageable. In my first year he even made the trek to see how I was living. A year later everything had changed. It was 2012 and my father had sent me a birthday card that was late and basically said IOU. This was not something that had ever happened. My dad had his routine and very few things ever broke it even when I came to visit. I believe it was within the week of this birthday that my dad entered a nursing facility and would never return home again.

I went to visit him and the thinking then was that he would be looked after for some time before returning to work and his home. I tried my best to do what his siblings had told me he needed to do in his recovery. I cannot remember if that weekend was the first I heard of CADASIL. The test I had heard was expensive and from what I thought unnecessary since it was hereditary. The test was performed and it was positive. Gone were the hopes of a recovery much less a speedy one. We knew then that this disease would kill him.

I continued to make trips to see him and in the following years the disease progressed. In early 2016 he suffered a major stroke which left him bound to a wheel chair. I had planned to take a trip to see him on the weekend after he passed away from a stroke at age 57. My last memory of him he was still able to walk and he tried to cheat me at cards. I am grateful for that.

His brain was donated and so his legacy continues. His legacy was always thinking about others.