

**Thank you for taking the time to hear our story.**



Although Amy and I live with M.S. in our daily lives, we choose one time every year to help raise awareness about Multiple Sclerosis. While reading our stories we hope you'll consider making a donation to the National Multiple Sclerosis Society.

We've come a long way since Amy's initial diagnosis and although things will never be as easy as life was prior to Amy's M.S., we are once again loving life while coping with her

M.S. We've made a few sacrifices but have found many things that continue to bring joy to our lives.

Below are our personal stories, written years ago, describing exactly what we were going through during Amy's initial diagnosis. I've left both stories virtually untouched.

### **In Amy's own words:**

There's a scene in Breaking Bad where Walter's wife throws him a "Remission Party" and everyone makes him give a speech. Reluctantly he starts by sharing that his first thought upon being diagnosed was "Why me?", but then goes on to wonder "Why me?" again after he's pronounced as being in remission.

MS is currently incurable and usually continues over the years to increase one's disabilities, normally starting with episodes of relapses and remissions. Upon my diagnosis, I was pretty much in denial as to the effect MS would have on our lives. After all, who really cares about a few numb toes, although the hand tremors did have me a little concerned about Parkinson's.

A year after being diagnosed, I easily walked the MS Walk and proudly raised over \$1000. The following year I did it again although I remember struggling to hide my difficulty walking that last half mile or so as I chatted away with a "normie" friend. Then, the following year, as I struggled to use a walker across a room and learned that a wheelchair did not fit down most of our hallways in our current home, Jack took over walking for me as he did so many of my chores that I could no longer attempt.

I was dumbfounded when I read the epic story he wrote on our MS donation page (I had always used the generic wording the MS Society provided). And while I knew what we were going through, hearing our story in his words from his perspective was eye-opening to me. Not surprisingly because of his openness and maybe because a lot of you were familiar with the struggles we were facing, he became one of Michigan's top individual fundraisers that year and has remained so every year since.

Since those early years - it's been nine years already? - I have switched doctors, switched treatments, done chemo, and very slowly began to walk and try things again. While I didn't think "Why me?" upon my diagnosis, I constantly wonder it now: why am I able to walk, drive, and function better when others I know have continued to progress? While initially I was nervous about meeting other MSers who would be confined to wheelchairs or worse, I've found it's actually harder to watch my friends' disabilities progress. And upon learning a friend had been newly diagnosed, I was deeply saddened, not because she was having any noticeable difficulties, but because of what I knew she might have to face in the years ahead.

And yet, despite what you may see, I am far from symptom free, although I think now many of my symptoms are more hidden - the numbness and tingling or overwhelming fatigue, wondering if I'm walking too steady to use my handicap parking pass (I like to think I'm more balanced than I am), knowing where all the bathrooms are in a 50 mile radius, standing and staring at the top of any stairs without handrails until someone offers me an arm, and so on.

I also have delusions of walking the MS Walk again. While I am confident I could do the first mile with my walker, the second would definitely be a struggle, and by the third I'd probably be resting every 10 or 20 feet until the van came along to rescue me. And yet, knowing where I was, and where I could be again tomorrow, I wonder why the medicines have helped me and not others.

So if not for me, please consider donating to the MS Society for our children and friends who have not been helped by current treatments so that they too can wonder "why me?" Or to discover a way not only to halt but reverse our symptoms. Or a way to prevent MS completely. And in addition to research, your donation will help the MS Society offers invaluable support and numerous resources to families dealing with the devastating effects of this horrible disease.

Thank you.

With the obstacles that Amy faces every day as well as the constant reminder that her condition can change at any time, we're doing what we can to enjoy every moment we have now. The story below was written seven years ago and I've left it untouched from a time that was pretty tough for us all. It sure helps to keep things in perspective. I hope you'll take the time to read it (or read it again for those that have visited in the past).

### **A little personal history for those unfamiliar with my involvement.**

My wife, Amy, has Multiple Sclerosis. Prior to 2006 we knew virtually nothing about MS and lived an active lifestyle that included traveling, camping, biking, geocaching, etc. In 2006 Amy started noticing tingling sensations in her feet and hands. She occasionally stumbled when she walked and she became fascinated with the fact that often she would lose control of her writing hand having me watch her write, saying "watch this" and not being able to control her penmanship. Most often, these sensations would disappear within a few days and the doctors we consulted would simply ask her to come back if the symptoms persisted.

Amy's doctor, in casual communication with other doctors, received an opinion that what Amy might be suffering from was MS and the best way to diagnose it would be to have an MRI.

### **My description of MS.**

In my own best description of Multiple Sclerosis, the immune system of a person with MS attacks the spinal cord as if there is something wrong in the spinal cord. The attacks create small lesions which eventually leave scars. These scars are most often visible through the use of an MRI.

Since the spinal cord is used to transmit signals from the brain to the body, these lesions cut off communication between a particular body part and the brain. If the attack is small, the result can be a tingling sensation and if the attack is large the result can be paralysis.

The nice thing about the human body is that it's resilient. If the lesion is small enough, the body can "re-wire" itself around the lesion and one can regain a function that might have been lost. And since the attacks are random and can happen at any time one might be lucky to only have one attack in their lifetime. Unfortunately, with many

MS patients the attacks happen over and over throughout one's life until one succumbs to complete paralysis followed by death. It's simply a miserable disease!

### **Amy's diagnosis.**

Sure enough, scars were found on Amy's spinal cord during the MRI which confirmed our worst nightmares. As a side note, doctors also discovered thyroid cancer during the MRI and Amy was quickly scheduled for surgery to remove her thyroid. She now lives without a thyroid which means daily medication to regulate her metabolism. We can also now say she's a cancer survivor. Honestly though, that event happened so quickly and with all the bad news at the time we didn't think much of it. Cancer found, cancer removed, cancer free, over!

### **What now???**

We now had a diagnosis of MS and Amy started seeing a neurologist from the University of Michigan. Amy was given a library of reading material and told to "pick a course of action". It was stressful, but we soon learned that with some of the latest treatments, Amy had a great chance of living an attack free life. She chose a course of regular self-induced injections of Rebif, the latest and greatest of the MS medications.

But something seemed wrong. Soon after starting the injections, Amy's abilities began to deteriorate on a daily basis. Her daily walks around the block turned into one walk around the block. She soon realized she couldn't even make it around the block. Using our treadmill, she recorded her daily regression as she was able to walk less and less each day. It got to where she could only walk a few minutes until fatiguing and/or losing her balance. (Eventually she did lose the ability to walk.)

The annoyances started to become problems when her abilities started to affect her daily living. She learned to use walls for balance and struggled when she brought our youngest daughter, Jessica, to preschool. When Jessica's teacher pulled me aside one afternoon to express her concern I knew things were getting out of control.

For me, the scariest night of my life occurred when Amy had gotten out of bed to use the bathroom, fell and didn't have the strength to get up. I quickly got out of bed, carried her to the bathroom and then carried her back to bed. Everything in my mind started to spin out of control. With two very young girls at home how were we going to survive if Amy couldn't even get out of bed? As a pilot I'm required to be away from home for long stretches at a time. My job provides our income as well as the medical insurance that would be of extreme importance thus changing jobs would be

out of the question. Who would be able to take care of Amy and the girls while I was away?

There was really no time to stop and think. As she was quickly losing the ability to use her legs, she made the smart decision to stop driving and as we live in a two story home with a full basement, she quickly became confined to one floor (although she literally dragged herself up the stairs at night and down the stairs every morning). All this happened in the span of a few weeks. We needed help.

When we called her doctors, we were quickly reminded that they were there to provide medical services and since my questions about daily survival weren't medical, they couldn't help. They didn't have a list of referrals, pamphlets to hand out, resources, ideas, etc. We were on our own.

### **The MS Society.**

I called the MS society in desperation and found the most knowledgeable, helpful, friendly people on earth. They had databases of home health aids and visiting nurses in our area. They had advice for selecting this help. They provided information regarding financial aid for medical supplies that we would surely need. They had lists of things to think about that we hadn't even thought of. The most important thing they provided was stress relief. Amy and I had so much going on simply struggling with her condition that the added stress of regular daily life was becoming overwhelming. No mention was ever made of charging us for the hours they spent on the phone with us, the hours they spent emailing and faxing information to us. We haven't had to use them lately but I will be forever grateful for their existence.

The MS society relies on the financial support of donors and without these donations the MS society might not exist. I can't imagine how much harder our lives would have been had the MS Society not been available to us. Not only is the MS society seeking a cure, they help everyday people like us in horrible times. Thus I ask that you visit my site and help with a donation knowing that it's not only going to a great cause, it's helping someone you know.

### **Living with Multiple Sclerosis now.**

Things have progressed well since our scariest moments. It's been many years since Amy was at her physical worst (early 2008). The outpouring of help from friends and family has touched me in ways I truly can't describe. We were overwhelmed by the

number of people willing to offer their assistance. We'll never be able to fully express our sincere gratitude to everyone that has helped and continue to help on a daily basis. It's very hard to ask for help... Especially when you know you're going to need lots and lots of it.

When we came to grip with the fact that Amy needed a wheelchair, we also came to grip with the fact there would be no way we could stay in our current home. We looked into modifying it and recognized it as not feasible. We also searched for homes on the market only to realize that most homes in our area are not built for people in wheelchairs. With such great friends in the area we decided we should build locally and we started looking for available lots as close to our home as possible. At the same time we designed a home based completely on Amy's needs including possible future needs. We contracted with an outstanding home builder and we were able to find a lot within a five-minute drive of our current home. Our home was completed in June 2009 and we moved in soon thereafter. The home is completely wheelchair accessible and although Amy's needs no longer require her to use one, we feel we've planned properly for the future.

We were able to have Amy's car modified with hand controls and she's now been driving for years with a modified car. Although it's still tough for her to get around once she drives somewhere, she's at least able to get out of the house while I'm gone.

In early 2008 Amy changed doctors and treatment plans. Instead of the Rebif, which never seemed to work, Amy started a six-month chemotherapy treatment and has just recently begun daily injections of Copaxone. She survived the chemotherapy extremely well, all things considered, and has very slowly gained back a lot of her mobility. Although she was wheelchair bound for a few months, we were able to return the wheelchairs (one powered chair that she never used and a manual one) and over the last few years she's regained to ability to walk short distances unassisted. We're very hopeful that in the coming years she'll regain the strength in her legs and attain complete and full mobility. We're even more hopeful that with more support to the MS society, someone will find a cure.

**Thank you so much.**

Jack and Amy Everett