

Dave's Story

I was diagnosed with MS on March 8, 2013. It is a day I will never forget.

In January, 2013 I was at a family get-together when MS exposed its head. I had severe balance issues, (I fell down,) and slurred speech. Following this rather embarrassing event, I scheduled an appointment with my general practitioner (a different one than the later mentioned.) He immediately recognized my symptoms as concerning but couldn't pin-point the cause. A MRI was ordered. As it turns out, I was in the middle of a relapse; the MRI came back with a definitive diagnosis' of MS. Unfortunately, it was too late for some portions of my life.

Let me bring you up to speed. On June 24, 2011, (it began slightly before,) I ran a 3k Mud Run. At that time my feet were numb however I did not know what caused it. Turns out it was the result of my first noticeable (re)lapse (funny how clear it all is now.) Immediately following the run, I went on vacation. My cottage is remote, so I was not able to see a doctor for 3 weeks. When I returned (I live in the Chicago area,) I saw my (at the time) physician. The physician didn't know what was wrong and sent me on my way. I contacted the physician in about a month explaining I had the same symptoms. I was told it was shingles. Anyway, by November 2011, the worst of it was over, but the myelin damage was done. I still exhibit gait issues.

My last day of work with this employer was December 31, 2011. To their benefit, I didn't even know the cause yet.

The next year went pretty quick, I still had symptoms, but had learned to cope with them. Suddenly things seemed to take a turn for the better, in December 2012, I had two job offers. I took both of them (first offer November 30, Second December 20, 2012,) started first on December 12, 2013, resigned and took the second on January 7, 2013. Then the relapse hit. My world was turned upside-down, I was diagnosed with MS (finally) on March 8, 2013. I went for a steroid infusion and began Tecfidera in May, 2013.

I went back to work. I was able to hide (hiding doesn't appear to be the solution,) the symptoms, but my work output suffered. My last day of work was May 25, 2013. I was let go for non-performance. I had informed the C-suite of my situation two weeks earlier.

I thought I was covered by a disability policy, but that was denied because it was diagnosed prior to the effective date, Ce la vie. I went another six months unemployed, worried about my future (I have a wife and 3 children,) and trying to make SSA understand my disability, (I am currently on my third appeal, they are having issues determining if MS is a disability.) (Since this was originally written, I have been approved, for what I don't know.) I am making ends meet with my retirement savings (it is close to being depleted...)

Then whammo, I had a full blown relapse in November 2013. I couldn't have been at a more awkward time, I had finally adjusted to my new reality with MS, and landed a new job, (albeit temporary six

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weeks.) I went for a steroid infusion. I did not inform my client and went back to work. That work was not extended. I so back on unemployment and SSA treadmill (My last day of work was January 10, 2014.) That's where I am now. I really hope the story has a happier ending, we'll see.

Many, but not all, think there is a pill to make it all go away. Those closest to me had a hard time understanding; it isn't curable (yet.) THERE IS HOPE!

The upside that was unexpected, many people have rallied from places unknown to help. I AM NOT ALONE! My family has become a much larger focus for me. I learned chronic doesn't mean fatal. The reality is life as you (or I) know it is fragile and transitory. I think I found there is some truth in the phrase 'live for the moment, but plan for the future.' I look forward to having others share as I journey though life. I will help when I can and ask when I need it.

Probably the largest issue I have had to accept is my life has changed and I need to make different decisions about almost everything. I finally understand (or am beginning to, the 4 phases.) Some have to be made (coaxed,) to understand exactly what MS is, it even has taken me time to understand it.

I also learned that no matter how smart the MD, you are your best advocate. If you have to have MS, now is not a bad time, there are a lot of treatment options when compared to 20 years ago.

Random idlings: I am also much more in tune with my health and well being. Chasing stuff is over-rated, there are so many more precious things. I would like to play golf again.

Dave



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