Cautiously Optimistic

July 7, 2015 By Nicole Lemelle

"Hold fast to dreams,
For if dreams die
Life is a broken-winged bird,
That cannot fly." ~ Langston Hughes

Hope can be a dangerous thing. So, I tend to steer away from it. At best, I'm cautiously optimistic. To be clear, I'm talking about dreams. Specifically a medicine to treat secondary progressive multiple sclerosis (SPMS), which is the type of MS I have. The minute I went from walking, to using my wheelchair I became secondary progressive. My doctor said it's when you no longer come back to your baseline after an exacerbation. The relapses and remissions that used to come and go change into symptoms that steadily get worse.

In the past, while in the relapsing remitting (RRMS) stage, I took various routine ms interferons. But I still progressed. I've been on monthly Solu-Medrol infusions or steroids, NovantroneÃ‚Â,Ã‚Â®, AvonexÃ‚Â,Ã‚Â®, RebifÃ‚Â,Ã‚Â®, CopaxoneÃ‚Â,Ã‚Â®, GilenyaÃ‚Â,Ã‚Â®, TecfideraÃ‚Â,Ã‚Â®, TysabriÃ‚Â,Ã‚Â® and BetaseronÃ‚Â,Ã‚Â®.

Since being diagnosed with SPMS, I've started taking RituxanÃ‚Â,Ã‚Â®, which is a drug actually used to treat breast cancer. Why take Rituxan? Well, presently there is no treatment for secondary progressive. So that's the best they can offer me at this point.

Hopefully soon, medical marijuana will be on my list. It was recently approved in my state, so as soon as it's available I will apply to get some legalized cannabis.

The hardest part of having secondary progressive is the decline in various abilities. Due to cognitive problems I can't drive. Talk about life changing events! But I'm so lucky I have a personal driver in my husband. Also, right now I'm using a computer program known as Dragon to type this post. My fine motor skills are so poor; I even need assistance with everyday task like eating and getting dress.

These things didn't happen all at once. It was a slow decline over a period of years. But I'm still here with you managing to get it done.

Thank goodness for my husband. He is good for me and to me. And he helps me keep my hope alive.

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