What Does MS Feel Like?

by DEBRA ROBERT

Understanding What MS Actually Feels Like

I have always been an artistic and non-conformist individual. I have always worn expressive clothing and I cut my hair in far from conservative styles. This independent streak, expressed via appearance, has always been my calling card.

I cannot say why, but through all the decades of drastic style changes, I have never touched my hair color. To my surprise, multiple sclerosis (MS) did that. MS turned my hair purple.

MS Is Unpredictable

None of us can predict our own future, but for those of us with MS, we face seemingly endless layers of the unpredictable every waking day.

Sure, we look forward to events and occasions. We set the dates on our calendars and plan on what we are going to wear to work the next day. We run errands, we care for our families.

What sets us apart (sometimes a little, sometimes a lot) is that we can never really do any of these things with even a tinge of the certainty and expectation we took for granted prior to diagnosis.

MS Doesn’t Care About Your Plans

Recently, I went through a tumultuous and frightening MS flare up. I missed out on some wonderful opportunities and it seemed to take forever before I felt right again.

I felt feeble and useless. I felt like canceling the rest of my calendar year because crushed expectation is a lousy thing to repeatedly experience. MS doesn’t care about your plans. It always tries to prove it has control.

Still dealing with upper body tremors and a numb right leg, I began to recover. I began to put my family and friends back at ease. I began to take back my days.

I also began to feel a bit angry. I just could not get past missing out on the few meaningful occasions I really had my heart set on attending. They will never happen again. Thanks a lot MS.

We all know MS can be infuriatingly unpredictable with all the physical and cognitive challenges we face every single day. MS also brings with it a seemingly unpredictable and endless series of coping cycles we also must contend with.

Our states of mental wellbeing and fortitude can be challenged with constant bouts of denial and acceptance, frustration and victory, fear and contentment, hopelessness and joyfulness. These mini-battles are all layered on

top of the physical and cognitive drains, not to mention our already regularly scheduled life programs.

So, Why Is My Hair Now the Color of an Easter Egg?

I rebel when I get backed into a corner. Luckily, I usually do so in positive (or at least harmless) ways. MS, the Mack-Daddy of all things unpredictable, had me in that corner.

My rebellious, tenacious side grew to overtake my down-in-the dumps, why me, state of being. I built up some steam, looked right square into the face of MS and said, “You want to see unpredictable?” Take that, MS. Purple hair.

Thus, with my crazily painted walker to support me, I stepped out of my salon, my hair hitting the sunlight in all its neon glory. I felt liberated and open to life.

I took back my independence and regained control of my free-spirited, uninhibited self.

Next page: MS is not all bad, and more on what MS feels like.

So, Why Is My Hair Now the Color of an Easter Egg?

I see now what happened here. I was burying my head in the sand over missing out on a few fantastic opportunities.

It wasn’t long before I realized the pity party had to end. So with my usually quirky way of coping, I rebelled. I took my head out of the sand and turned it into a bright beacon of self-expression.

Thank you MS, I love it. My hair is purple.

I am learning there is a kind of contract you must sign between yourself and multiple sclerosis. I say to myself every day, whatever I can do, I can do.

I go to bed with a plan in my head and then see what my body's reaction is to the alarm clock going off in the morning. I check in with MS, to see how it’s doing, then we come to an agreement as to how to approach the day.

MS Is Not All Bad

I have always been adventurous, yet highly analytical. I have been daring, but never without a strong sense of responsibility.

There is no right way of knowing how to deal with MS, but I've found positives while learning to cope with it all. Since my diagnosis, some of these traits and modes of being don’t fit my mold anymore. I’ve developed new gateways into thinking, coping and strategizing.

I hesitate a lot less, I am more expressive, I throw caution to the wind on things I may have felt self-conscious about in the past. I am more interested in the subtleties of life.

I like this side of me. I have the opportunity to learn how to become more authentic. I happily no longer have the luxury of taking things for granted.

MS to me, with all its awfulness, is also a permission slip of sorts. It is a permission slip to try on different ways of living, a different pace of being.

Before MS, everything just whizzed by at the speed of my career. Now, things whiz by at the speed of the bees

and butterflies in my yard. I actually do stop and smell the roses.

Does MS Make Me Feel Like a Different Person?

If anything, I'd say MS has allowed me to live life more in the now and certainly with a deeper connection and drive for self-discovery. I'd say MS has made me more approachable, more mischievous and more curious about life than I have ever been.

I feel as though I am exactly the same person I have always been, but my compass has been turned inside out. Whereas before, I lived a very large and adventurous life, seeking out adventures around the physical globe in order to pull them in and ingest their teachings.

Now, the adventures come from inside. I look out to the world from deep within my spirit and venture out from the teachings within. I would not have had this new way of seeing the world had it not been for lousy MS.

As I sat in the salon chair, saying goodbye to my dark brown hair for the first time, I felt liberated. There are so many things I can no longer do it is practically maddening, yet I see that MS allows me to try new things. So I seek out new experiences and find ways to look at familiar things in entirely new ways.