The Challenges of Everyday Life With MS

by LEEANNE LAPUM

How I Cope With Everyday Life With MS

I always thought my life would be just like everyone else's. I was young, I was active — nothing slowed me down. I could tackle just about anything.

I had so many plans and aspirations — my future was bright. I felt secure and certain my life was going to be exciting. Little did I know that at 38, everything would change.

A Shift in Outlook

Being diagnosed with multiple sclerosis (MS) caused my outlook on life to change dramatically. There was nothing I could do about it.

It has now been 24 years since I was diagnosed with MS. I am no longer young or active. I've gone from being vibrant and on-the-go to being basically homebound.

I am no longer able to do things on my own — I am totally dependent on others. My thought processes are not what they used to be, partially due to age but also due to the effects of treatments for cancer.

I underwent chemotherapy for MS five years ago, and it affected my body in many ways — some of which linger to this day. I'm not quite as mentally sharp as I used to be; some call it MS brain fog. I find it a little disconcerting. I often find myself uncertain of my sanity, let alone my connection to reality.

Due to my health issues, which extend far beyond MS, I find myself dealing with a great amount of uncertainty.

I'm uncertain whether I'll even wake up in the morning. I'm uncertain what the day will hold. I'm uncertain whether I will make it through the day. That uncertainty haunts me throughout every day.

Waking Up and Showering

Getting me ready for another day differs and becomes more challenging during the workweek. If I'm going to have a shower, we have to get up at the ungodly hour of 5:30 a.m. Fortunately, we only do that on two out of the five days.

I have been blessed with a very understanding husband who is very patient and loving. Two out of the five days he showers me, and most of the time it goes smoothly if we're lucky. From the beginning of the shower until completion of the whole process takes approximately an hour.

Fortunately, we were able to add onto our home to make it ADA compliant. We added a master suite, complete with a roll-in shower.

Although it’s time consuming it’s really a pleasant experience for the most part. Using the Hoyer sling really helps.

Hair and Makeup

Once the showering is complete we move on to the next part, which can be both interesting and very humorous. The first thing my husband does is dry my hair — nothing fancy.

I lost almost all of my hair when I had chemotherapy for breast cancer. It has come back — thank goodness!

My husband discovered something online that helps with thinning hair. There was an article that talked about sulfate-free shampoo; it was supposed to reduce hair loss.

We decided to give it a try because after showering we were getting huge clumps of hair out of my brush each time. Now that we're using the sulfate-free shampoo, we get a very small amount.

Next, my husband does my makeup. He teaches middle school and high school, and asked his middle school girls for some make up tips.

They were more than happy to give him advice. What’s important to note is my husband teaches art — I am his canvas and the makeup is his medium.

He starts with applying foundation — no problem there. We do all of this while I'm suspended in the sling of the Hoyer lift. I turn my head to accommodate whatever step he is doing at the time.

Putting on my eye makeup is very interesting. I'm required to lift my eyebrows in order to get rid of the wrinkles — remember that I'm 62 so I have a few.

He takes great delight and getting just the right color, keeping in mind the perfect blend. Then comes the scary part: mascara! Remember I'm swinging a bit in the sling. I don't have him curl my eyelashes because they would probably be ripped out!

Dental Care

Flossing and brushing my teeth is the next step in our morning routine. I'm very picky about my teeth.

My husband was a certified dental technician before returning to teaching, so he knows all of the terms and exactly what to look for when it comes to possible problems. I'm able to do the flossing myself, but he has to help me when it comes to brushing.

Because I don't go anywhere, getting me dressed is as easy as slipping on my nightgown. With everything complete he can move on to get himself ready for his day.

Keep Going Through the Challenges

I have learned many things over the 24 years I've dealt with MS. Challenges will come and go, and will vary in both circumstance and severity.

Don't give up hope. Seek out positive support in various forms — friends and family will be vitally important.

Allow yourself to fail and find humor along your journey. Allow yourself to be fearful, but don't let it destroy you. Take one thing at a time and move on.

Whether it be minute by minute, event by event, or circumstance by circumstance, it can be conquered. At the end of the day take a deep breath and know you've been victorious. Tomorrow will be another day.