

Turning a “Wasted Day” Into a “Healing Day”



I knew things weren't right even before I opened my eyes. There was painful pressure in the back of my head, always an ominous sign for me.

The small beams of light that escaped from behind the black-out blinds covering my bedroom windows hurt my eyes once I opened them. The simple act of shifting my gaze across the room caused an ache.

Then I sat up.

That's when tiny blinking lights appeared in the periphery of my vision and a wave of nausea coursed through me.

This was going to be one more day - a wasted day - in bed.

Every so often, my MS symptoms pig pile on top of me, rendering me unable to read, to walk around or to focus on anything of substance. When light sensitivity and nausea become particularly egregious, I must either don my sleep mask or pull blankets over my head until it passes, sometimes in an hour, sometimes in a day.

In the first few years after being diagnosed with relapsing-remitting MS, when a critical mass of my symptoms would manifest all at once, I'd slip into fitful anger. MS was indifferent to the plans I'd made for the day; it didn't care about my disappointment. The only thing getting

furious about the collective resurgence of symptoms did was drain my limited energy reserve.

I fought my MS symptoms for an embarrassingly long time before I learned that fighting didn't make them dissipate any faster. Before MS, I was a highly caffeinated multi-tasker who plowed through garden variety, non-MS fatigue in order to successfully tackle the many things I had on my daily "To Do" list while juggling work with raising my three kids. Adjusting my life to fit the new needs of my MS reality took time.

So when I recently awoke on my favorite morning of the week – Sundays, when the two newspapers I read are thick and full of great articles – I had to leave those newspapers, unread, on the kitchen counter. With my vision temporarily impaired, reading newspapers, books or magazines, or even scrolling through my phone were all impossible. But instead of getting angry that my plans were involuntarily altered, I made myself a cup of coffee, fetched some Excedrin Migraine, and returned to the warmth of my bed.

My patience cracked about halfway through the day when I was restless because my symptoms hadn't faded yet. I started walking around the house and took a shower to see if those things would help. (they didn't). From that point on, I forced myself to adjust my attitude and to listen to what MS was telling me.

This isn't a wasted day, I told myself. **It's a healing day.**

I gave myself permission to turn on the TV and haphazardly watch or listen to (depending on the severity of my light sensitivity at the moment) whatever was on. This led to me watching or listening to the movie "Joker," and random parts of "Michael Clayton," "Breakfast at Tiffany's," and "27 Dresses."

In between flipping through the stations, I thought wistfully about how much I'd accomplished the previous day: I read the Saturday newspapers, graded student papers for the classes I teach at a university, dropped off signed copies of a book I recently wrote at a local bookstore, and brought a milkshake to my nephew who'd his wisdom teeth removed. Later that night, in 40-degree weather, my husband and I sat around a firepit and socially distanced from two friends we haven't seen since March.

As I reflected, I wondered if all that activity somehow brought on these symptoms. **Had I done too much and was now paying the price?** Then, almost as quickly as that thought crossed my mind, I abandoned it because trying to discern a cause for the appearance of my symptoms was a rabbit-hole down which I didn't have the energy to explore.

Later Sunday evening, my husband brought me a plate of plain pasta (all that my nauseous stomach could handle) and he watched some episodes of "Schitt's Creek" with me, and wasn't one bit aggravated that I'd had to spend the whole day in bed while he painted our family room.

As we shut out the lights and went to sleep that night, another thought came to me: **My MS told me what my body needed. I'm glad I listened.**