Are Headaches a Symptom of MS?

by LIBBY SELINSKY

Multiple Sclerosis Headache

I remember a strange thing that happened to me shortly before my first MS relapse began. I had the most painful headache of my life!

This was notable to me because I used to be one of those people who rarely got headaches, and when I did, I never needed an aspirin. However, this one was different.

It was at the base of my skull, and it came upon me suddenly. I felt an intense pressure, and the pain was so great that I buckled in two and placed my head on a chair, tears running down my face.

My husband rushed over to see what was wrong, and, as he held me, I felt something pop and a chemically feeling ran down the inside of my neck, but the feeling was followed by a sense of relief. As quickly as the multiple sclerosis headaches came, it was gone, and I felt fine again.

A responsible person might have gone to the hospital to make sure that everything was alright. However, I was twenty-seven and still believed that I was invincible. Besides… I felt fine, right?

Why overreact and make a ruckus?

Two months later, my first relapse began. I haven’t thought it a coincidence at all that my lesions are on my shoulders and nothing in my brain. I have a suspicion that gravity decided where my lesions would be.

My neurologist didn’t pretend to correlate my MS with that headache. I can only say, these two events happened in short order of each other.

Headaches Aren’t Classified as an MS Symptom

We do seem to get migraines more than the normal population. Again, we run into the problem of correlation vs. causation. Is it just something that happens to us more often, or is there a cause for our headaches that branches from our disease? I don’t know.

I can say that there are many things we have to deal with that are going to cause more headaches. Medications, stress, lack of sleep, stress, visual problems, stress, brain lesions… You catch my drift.

Trigeminal Neuralgia and MS Headaches

Trigeminal neuralgia is a symptom that I have from time to time, and it triggers terrible headaches. The trigeminal nerve is the main nerve that covers half of our craniums.
Trigeminal neuralgia is when a part of the trigeminal nerve becomes inflamed. Pain will radiate from the inflammation outward. The pain of trigeminal neuralgia is debilitating, and my body reacts with an intense migraine.

There are times when I wake up feeling like I have been punched in the head. The act of brushing my hair triggers a feeling of PTSD, and I will stand at the mirror, staring at my hairbrush, and weighing the pros and cons of leaving my hair a snarled up mess for a few days, so that I can avoid feeling my scalp wince in pain.

Migraines and MS

The migraines are quick to follow. I feel like there is a haze over me. The world slows down, and I feel like there is too much going on outside of my head that is trying to get in. Sounds are too loud or sharp. Lights are too bright and reading words on paper feels painful. The letters seem to shrink and bend, or they just don’t make sense.

The first visual migraine I ever had seemed to creep up out of nowhere. I had been struggling with my trigeminal neuropathy, but I thought I was managing well. I decided to go out for lunch with my husband and son. It was when I was reading the menu that I realize, half of each word looked bent and squished. The waitress looked a bit embarrassed for me when I told my husband, “I can’t read.” She left us and came back later.

It is scary to have those moments pop up. The moments where life is beautiful and “normal” for a minute, and the next, everything seems to have turned upside down because my body had decided it cannot work properly for one reason or another.

Now, that I know what a visual migraine it, I am more worried about the lack of warning that I am of a headache itself. Visual migraines do not leave damage to your brain or your vision.

Stress Is a Trigger for Headaches

Stress is another trigger for the headaches I get. It is the most common reason for my headaches. Multiple sclerosis is a stressful disease to have. I am doing well managing my condition, but that management takes a lot out of me. I know that I am not alone in this situation.

The doctor appointments, the medications, arranging for life to continue as well as possible, day in and day out, is a very stressful experience. For years, I carried bottles filled with ibuprofen everywhere I went, because the threat of a headache was always there.

In the years since my diagnosis, I have had to learn techniques to cope with the stress and lessen my need for medications to make it through my day. I have had to learn how to sleep through the night, drink more water, eat healthier food, and get out to exercise more. I know it is not easy, exercising with MS, but a little bit every day can change how life feels.

Exercise makes it easier to interact with the world, and it also makes sleep come easier at night. The daytime brain fog and grogginess are significantly lessened by diet, exercise, and sleep. The reduction in headaches is a bonus!

Medications Can Also Be Headache Triggers

I wish that I could help to get rid of every medication that we need to take. For the most part, I avoid taking any medication that will only treat my symptoms. I just hate the way that medicines make me feel.

Fortunately, the disease-modifying medication I am on currently does not give me headaches. However, I spent years taking Rebif. Those years were spent with headaches nearly every day. Spending three days a week with...
the interferons triggering flu symptoms and the days between recovering, left my head reeling and tired.

Additionally, anytime there is a relapse, the dreaded prednisone infusions are sure to follow. I prepare myself or a week of complete pain when this happens. That prednisone is a beautiful drug because it shortens the timeline of my relapse, but I hate the process all the same. The migraines of my last infusions brought me to tears.

**MS Headaches Differ From Person to Person**

Multiple sclerosis headaches affect every individual differently. MS seems to like to be that way, in every way. There is never a clear path. A clear reason. A clear solution.

I find myself trying to come up with some wisdom or advice to convey. In the end, I feel myself at a loss for anything more than my story, my experience, my solutions.

Managing MS can feel like a game of darts. We keep trying new things and hoping they stick and land in a place that will help and be good.

MS is very isolating in its individuality. We are all on our roads and wondering if it is a path at all like anyone else’s. I am not one for group therapy, but I do see the value of knowing other people’s struggles.

**How to Recover as Quickly as Possible from a Headache**

The trick is to understand how to best ride out a multiple sclerosis headache and recover as quickly as possible.

For me, a nice nap, someplace that is quiet and dark, helps a lot. I also drink plenty of water, take a few aspirin as soon as possible, or I eat something with caffeine and sugar. I will still be in for a rough few hours, but at least I can save myself from an extra half a day of pain.

**In Conclusion...**

I am sure that I have not touched on how headaches affect people living with MS. Honestly, I do hope that some of these words have helped you find a connection or a pathway that can help you, even if it is just a little bit.

I have realized that most of my stress over MS has reduced by understanding and embracing this lonely path and not seeking isolation. After all, I am reaching out to all of you. However, I do find solace in my space, and I find safety within the uncertainty. Mainly I just try to remember that this headache, this blurred, bent vision, this groggy, foggy headspace, will to pass.

In that light, the world, and the hours, minutes and seconds that will pass during my lifetime living on it, will all move too. I find peace in understanding that it all changes. The world is changing every day.

It is in the moments of white, hot, pain when I close my eyes and seek inward to remind myself, pain is temporary. This will pass. The day will be better, and the pain will fade.