Part 1: Why Isn't Chemo-Induced Peripheral Neuropathy Taken More Seriously?

One of the scariest things about receiving chemo is not knowing how your body will react.

January 4, 2022 By Megan-Claire Chase

One of the scariest things about receiving chemo is not knowing how your body will react. I was hit by a motherload of side effects from 4 Adriamycin and 4 Cytoxan and felt like those would kill me. So, when it was time to begin 12 Taxol, my oncologist said the side effects would be a cakewalk compared to what I had just been through while on AC. I distinctly remember sighing with relief when she said it would be easier to tolerate.

My oncologist also said that chemo-induced peripheral neuropathy (CIPN) might occur while on Taxol but not until around the 8th treatment or so. She said any CIPN would more than likely be mild and go away. I wish that had been the case. What happened next was something no one could predict or prepare for.

It was December 2015. I was beginning to feel drowsy from the Benadryl that was infused through my port before receiving the Taxol. My fabulous infusion nurse began to slowly infuse the first Taxol treatment. After about 15 minutes, something terrible happened. The best way to describe it was a strong current running through my entire body. I literally felt my nerves dying. I started freaking out and my infusion nurse called for my oncologist.

The CIPN happened so suddenly and so severely that there was no way to stop it or slow down the reaction. That moment changed my life and not for the better. The CIPN damage has been so bad, especially in my feet, that I've experienced the following:

- Severe numbness in my feet to where I have no feeling from the ball of my feet to my toes
- Sharp and stabbing pain in my hands
- Permanent handicap sign
- Multiple falls
- Sometimes walking with a cane

- Difficulty buttoning clothes
- Difficulty putting on earrings, bracelets, and necklaces
- Constantly dropping everything from dishes to medicine bottles
- Grade 3 sprain in right ankle in January 2021

My experience with CIPN isn't unique. It appears that many oncologists aren't seeing it as a priority to address since their main focus is to keep us alive. Many don't seem to worry about the painful damage and severe side effects of chemo. I was never referred to a specialist once I had reached the survivorship stage. Instead, gabapentin was thrown my way. I was told to take L-glutamine and B12. I was given topical ointments. None of those worked. I only received PT after the grade 3 sprain I had in January of this year which did help a little with my gait. Not one specialist ever took my CIPN seriously. They never even did any testing to determine how severe my nerve damage was and just kept throwing medicine at me or dismissing me outright.

The downstream consequences of chemo need to be talked about more. Just because cancer and chemo treatments didn't kill me doesn't mean I should continue suffering from the side effects. There are no robust programs in cancer centers for neuropathy, at least not in Atlanta, GA. My oncologist and the rest of my medical team have failed me. How?

- Failed me by not sending me any referrals
- Failed me by not addressing the actual nerve damage and lack of blood flow
- Failed me by thinking the CIPN would go away on its own

I had given up hope for a long time until last month. What has changed? I made the decision that I needed to find a holistic way to help deal with not only the pain of CIPN, but ways to manage my fibromyalgia, and pain from my left lumbar facet joint.

I found a chiropractor whose specialty is chemo-induced peripheral neuropathy, not just diabetic neuropathy, and other traditional treatments. I went for a consultation and my mind was blown. Why?

He actually believed me.

He was concerned for me.

He treated me with utter respect.

Here's another hint of another one of my multiple treatments with the disclaimer these may not be for everyone with CIPN.

Who is this amazing chiropractor? I'll reveal that information along with my consultation results

and new treatment protocol tomorrow!

Until next time,

Warrior Megsie

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