Cancer Health

# Toughest Role Starring ME

From chronic pain to neuropathy to thin and wonky hair to burns, I continue to feel like an actress playing the greatest role of my life.

March 1, 2020 By Megan-Claire Chase

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My 4-year chemoversary was on February 26th. I confess I had many mixed emotions and flashbacks on that day. Anyone who has been reading my blog for some time and/or follows me on social media has seen numerous posts about the chemo curls and how I've hated them from day one. Looking in the mirror every single day and not recognizing myself has caused major trauma to my psyche.

Last year was the first year I was able to wear my hair straight without looking like a mushroom head. I was so excited to post the first pictures of my hair blown straight because I recognized my reflection for a brief moment. Though I know none of the comments were meant to be malicious, I confess I was deeply hurt when soooo many commented the straight hair was nice, but I looked cuter with the chemo curls. If I'm being honest, it felt like a slap in the face. Couldn't they see these curls are a constant reminder of the most painful and horrific time of my life?

I had wanted and needed so desperately to connect with some part of me again. My hair has always been important to me. I come from a long line of women on my mother's side with glorious hair inherited from my great-great-grandmother Ella. She was Cherokee. Anyone who knows me from when I was little saw how long my mother's hair used to be. My hair had grown to my shoulder blades and super thick by the time I was 9 years old, but I cut it when I was 10 after seeing Anne of Green Gables. It was the scene when she had to cut her hair into a bob because she wanted to dye her red hair black like Diana Barry, but it turned green. I always had at least a chin-length bob or longer.

No one has seen the tears when I realized my hair when worn straight isn't thick like it used to be. The right side isn't growing fast at all and looks odd. That's why I started wearing it curly again. I'm waiting for that right side to catch up.

Here I am 4 years later, and the curls seem to be permanent. The only reason I can handle them at this moment is because I do have the option to blow it straight even with the wonky right side. I didn't realize how much I needed to know I had options again.

Those 16 rounds of chemo I had to receive were the hardest and scariest 5 months of my entire life. I didn't know I could feel such pain in my body. I had the motherload of side effects, aside from the hair loss trauma. I went back to my journal during that time and compiled a list of ALL the side effects I experienced while on Adriamycin, Cytoxan and Taxol.

Dizziness.

Nosebleeds.

Chemo brain.

Severe anemia.

Rapid heartbeat.

Godawful nausea.

Loss of appetite.

Tongue would swell.

Bottom teeth ached.

Toenails turned black.

Loss of taste and smell.

My tongue turned black.

Terrible and painful constipation.

Bone pain from the neulasta shots.

Loss of control of bowel movements.

The palms of my hands and feet looked burned.

Hair growing back completely different and curly.

Fingernail beds lifted and ultimately fell off and so painful.

Weight gain from all the steroids infused before each chemo.

Lack of sleep from all the steroids infused before each chemo.

Dark circles under my eyes — still have them but not as panda-like.

Physical weakness to the point I had to use a cane and could no longer drive.

Hair fell out everywhere — head, eyebrows, nose hair, lashes, legs, underarms and lady parts.

Mouth sores (those in chemo now, ask about Gel Clair and use it with the magic mouthwash).

Neuropathy in hands and feet — permanent nerve damage to my feet. Zero feeling from upper balls of my feet through my toes within the first 15 minutes of that very first Taxol chemo.

Ultimately chemo induced fibromyalgia that appeared a year after finishing treatment but not properly diagnosed until two years later.

So, when others think I should just move on or not focus on the negative, what they don't comprehend is I have permanent damage ALL stemming from the chemo. As a former dancer and musical theatre actress in my younger days, to not feel my feet every single day is traumatic. The days of ballet, musical theatre, swing, salsa and tap days are over. I used to walk so gracefully. Now I have a hard time walking across a parking lot because the numbness can also move up my legs and I'll fall over. That's why I have a permanent handicap sign for my car. I feel like I'm 543 instead of 43 now.

No amount of gabapentin, acupuncture and any other "magical" treatment will work because my case is severe and permanent in my feet. The nerves are dead.

The nerves in my hands are still regenerating because they often sting and feel like tiny knives stabbing me. Even as I type this piece my left fingers are rather stabby and hurting. I had to learn how to button clothes and put on earrings, bracelets and necklaces again. I have multiple burns on my left arm from when I've lost all feeling in my right hand and dropped the iron. I have a new burn on the left side of my neck from losing feeling in my right hand when using the curling iron a few weeks ago.

My body is permanently changed from the chemo, from head to toe. This is one costume I've never desired to wear. From chronic pain to neuropathy to thin and wonky hair to burns, I continue to feel like an actress playing the greatest role of my life — ME.

Until next time,

Warrior Megsie

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