We Need to Talk About NED

A survivor of breast cancer with no evidence of disease (NED), Megan-Claire Chase, aka Warrior Megsie, recounts the turbulent relationship.

June 10, 2024 By Megan-Claire Chase

There was a time when I proudly shouted from the rooftops, “I beat cancer,” “Fight like a girl” and “I’m in remission.” I felt bliss for the first six months of my breast cancer survivorship until reality began to set in. I distinctly remember when my vocabulary shifted to no evidence of disease (NED). The more I processed the struggles, pain and stress caused by active treatment and the two-plus years of advocating for myself before receiving my invasive lobular carcinoma diagnosis, the more I realized this breast cancer path is ongoing. I call my blog Life on the Cancer Train because there’s no final destination where everything will stop and I can get off and never look back.

To keep my sense of humor intact and grapple with survivorship, I like to think of NED as a relationship. Honestly, it’s the longest active relationship I’ve ever had. It has been quite turbulent, because I still don’t know this post-cancer body.

Fasten your seat belts, because here’s everything I have dealt with post-cancer: chemo-induced peripheral neuropathy (CIPN), infertility due to hysterectomy (removal of uterus, cervix and fallopian tubes), oophorectomy (removal of ovaries) due to high risk of ovarian cancer, secondary radiation rash on the left side of the neck, contact dermatitis on eyelids (now allergic to dye in antibacterial soap), removal of fat necrosis in the lumpectomy area, removal of hematoma that attached to fat necrosis, loss of jobs and health insurance before COVID-19, racism in some private breast cancer groups, loss of job at the height of COVID-19, Grade III sprained ankle due to CIPN, medical bias and racism, resigning from jobs, onset of fibromyalgia, onset of back pain, loss of savings, ongoing nausea, financial toxicity, weight gain, constipation, depression, painsomnia, dizziness, anxiety, grief, PTSD and rage.

I had to take a deep breath and wipe away some tears reading this list. This isn’t pretty or pink or fun.

This Is My Survivorship

Most people would never know how much I have been through and continue to go through because most of these are invisible. I've learned how to mask the daily pain, tighten my protective cloak and develop a much thicker skin to deal with the never-ending racism, tokenism and oppression due to existing as not just a breast cancer survivor but as a BLACK breast cancer survivor and as a BLACK woman.

I don't need to be told, "You're stronger than this" or "Just ignore them."

I'm human and have feelings.

I'm not a superwoman.

I deserve…

to be supported;

to be believed;

to be vulnerable;

to be accepted;

to be loved;

to be heard;

to rest.

It's important to acknowledge that these added stressors and trauma are real, draining, discouraging and ongoing. I know I've accomplished so much as a patient advocate, subject matter expert, speaker, blogger, storyteller, activist, professional and more, but all of it has come at a cost. It's a lot to take in, but this is my survivorship and daily existence.

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http://beta.docker.realhealthmag.com/article/need-talk-ned