Cancer Health™

When Trust Is Gone

I kept pushing for answers because I knew in my gut that something was very off in my body.

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Was there ever a time when one could just be the patient and trust the doctor would take time to review their chart and make customized recommendations of treatment?

I was born three months premature, so I was a sick baby and little girl. I was always going to the doctor for tests, infections and surgeries. I have fond memories of my pediatrician, Dr. Tift. He always wore a bow tie and had the best bedside manner. I trusted him.

Once I graduated from college and had to find my own doctors, I was still that trusting little girl at heart. I really had excellent doctors in LA and GA during my 20s and early 30s. I felt like a person. I had so many issues with my ovaries, uterus, cervix and painful periods. They knew I was at risk for those cancers. I had more vaginal ultrasound action than sexual partners!

All my gynecologists over the years truly made me feel like they were doing the heavy work and monitoring my health. I trusted them.

Fast forward to the three years before my breast cancer diagnosis. All that comfort and trust was diminished.

I remember being told by countless doctors — primary, endocrinologist and dermatologist — that I was overreacting and needed to reduce my stress level and exercise. I was so angry and wondered why they made me feel like it was my fault for gaining weight, hair changing texture and falling out and irritability. I’d never been an overweight person in my life until six months after my 34th birthday. The dermatologist said there nothing she could do about my hair falling out or give me a reason. All she said was I should invest in Rogaine and eat better.

I was beyond devastated, yet I kept pushing for answers because I knew in my gut that something was very off in my body. It’s only when those tiny green bruises appeared on my left leg that I was finally taken seriously.

Why wasn’t my word and other symptoms enough to warrant concern from the start?

Why did it have to get to the point of feeling miserable and lethargic to be taken seriously?

“Oh, let’s get her a blood test here and there to shut her up,” is the vibe I consistently felt during that time until I physically felt the mass in my left breast that August 30, 2015.

During active treatment for my breast cancer, I felt heard and heavily monitored. I felt like I was a person again and not just a number. I was a well-cared for patient.

Then I enter post-treatment and just feel thrown out into the sea with no life jacket. I'm now swimming with millions pushing and shoving to be heard.

I thought palliative care would be different. I started out feeling heard again regarding my chronic pain from fibromyalgia and neuropathy thanks to chemo and multiple surgeries. I felt comforted knowing I was wrapped in this extra level care. I naively thought the relationship with my palliative care doctor would be different.

Instead, I'm consistently dealing with managing my own health and presenting outside the box ideas to help manage my chronic pain.

Get ready for my rant…

Why am I paying the copays when I'm presenting research to my doctor about new treatments for my case?

Why do many of my doctors look shocked when I make a suggestion?

Why aren't any of these doctors' part of cancer support groups to read what other patients go through?

Why does the doctor always ask why I'm there even though I've stated it in the portal, filled out the stupid paperwork and told the intake nurse?

Why are they so quick to dismiss my ideas or when I'm experiencing a side effect?

Why are they recommending medications within the same family when I've already shown the first option didn't work or was allergic?

Why am I having to beg for x-rays and scans and other procedures?

Why aren't doctors staying up to date on the latest research?

Why are doctors using Google on their phones to look up medications and the side effects in front of me?

More importantly, why aren't they listening to the patient?

I no longer trust that any of my doctors truly have my best interest at heart. They are being mandated by insurance companies to push certain drugs. They aren't taking the time to review my chart before walking into the exam room.

I didn’t set out to be my own doctor. I no longer have the mental bandwidth to stay on top of it all but I must because none of them will.

When will these doctors stop trying to cookie cut my treatment? I’m a square Meg who can’t be pushed into a round hole.

Until Next Time,

Warrior Megsie

This post originally appeared on Life on the Cancer Train. It is republished with permission.