

Lorraine's Story

My story starts in 1991. Dad called a "family meeting". We never had family meetings. Something was up. I was 18, my brother was 14 and my sister was 10. They told us that Mom, who was only 42, had advanced breast cancer. Chemo was about to start to shrink the tumor. She would have a mastectomy in the spring, followed by radiation.

That was the first time that I wondered if I could get cancer. But I didn't pay much attention to this thought. They reassured us Mom would be alright, the surgery and treatments would work.

Mom started her chemo and my only memory of that Christmas was that there were no pictures because she didn't want pictures in her turbans or the wig that she hated so much. Her chemo treatments made her violently ill. She had surgery but didn't talk about it. Mom was fair skinned and couldn't spend a moment in the sun so the radiation was excruciating for her. She was so burned she ended up with permanent scars. When those treatments were done, that was it. No more talk of cancer. She went for follow up appointments; she didn't discuss it, and I didn't ask.

In the spring of 1995, we got the horrible news. Mom's cancer was back and had spread to her bones. I couldn't believe this was happening. I was engaged, we were planning my wedding. I needed her to be here. My brother and my sister were far too young to not have a mom. I was so angry at this. All Mom and Dad said was that she would beat this too and everything was to continue on. So that's what happened. We kept busy and I found it easy to not even think about what was coming for us all.

I was married in October of 1995 and my mom put on the best party ever. Her foot was broken because of the cancer in her bones but she refused to get a cast, crutches or a cane. We iced her foot, crammed it into her heels and off she went, to party and dance the night away! That was just how she was. No one was to talk to her about the cancer. This was her daughter's day!

In May 1996 Mom was admitted to the hospital with a spinal cord compression. The cancer was throughout her body. We were able to bring her home on a weekend pass but it was time to accept that she would never come home to stay. I remember spending an afternoon with her and she didn't know who I was. On July 1st, 30 days before her 47th birthday, she lost her battle with breast cancer. The day she died, she opened her eyes one last time and looked at each of us in the room – her three kids, her mom, her sisters. She managed a small smile for her husband of 24 years and then she closed her eyes and was gone from us.

Life went on after that. There were good days and bad. I tried to step up and be strong for the family and it took a toll on my marriage, which ended two years later. The entire time a little voice in the back of my mind was driving me crazy. Everyone always told me how much I reminded them of my mom. Was it possible that I would get breast cancer too? I didn't know anything about hereditary risk or genetics. The doctor said that my odds had increased only slightly. But I started thinking about it all of the time. I went to the doctor. She showed me how to do Breast Self Exams. There was a spot that never felt right and I wondered if it could be cancer. I got so scared that I was doing breast exams almost weekly.

When I asked for a mammogram the doctor told me to stop worrying. She said we'd start thinking about it when I was 35 and come up with a screening plan then. Mom was the only one in our family that I knew of who'd had breast cancer. But I persisted and ended up seeing a surgeon about the strange spot I thought I felt. I was feeling the lumpy breasts of a 24 year old, she said.

Then Mom's older sister was diagnosed at 55 with breast cancer. We found out later that one of their maternal cousins also had breast cancer. She was only 42.

I was frustrated that my doctor wasn't taking me seriously. I found a new doctor who agreed to send me for a mammogram. They also did an ultrasound. I went for a follow up three months later because there were a few spots the doctors were questioning. I had cysts and was told that

this wasn't uncommon at my age. I had just turned 28. The technician told me I had dense breasts so it was hard to read the mammograms. My new family doctor and I decided to wait two years for my next mammogram.

By now, Mom's younger sister had gone to the Genetics Clinic. She'd heard about the BRCA1 and BRCA2 genes and was concerned that she might be at increased risk. The genetic counselor told her that our family met the criteria for testing but a relative who had a cancer diagnosis needed to be tested first. She asked her sister and cousin to be tested. Neither of them went.

I remember thinking that even if there was a gene mutation in our family, I wouldn't want to be tested. I assumed that if you had the gene, you would get cancer for sure. I thought, "What good would it do to know in advance? They can't give me a magic little pill to stop it from happening." I was told that there were doctors who would do a mastectomy if you had one of the genes and I wasn't going to go down that road. If I was going to be without a breast it would be because I was diagnosed. I didn't even know there were reconstruction options available. I had this crazy mind set that if I was diagnosed, it would be because it was "meant to be" and I would deal with it all then. I really thought that breast cancer was a death sentence. I didn't even bother getting more information about it. I had the voice saying *when*, not *if*. I was sure I'd be diagnosed at some point.

In December 2002 my doctor referred me to the Breast Centre. I wasn't worried this time. The doctor felt something during the exam. She called it "something funny." She couldn't tell by the mammogram or the ultrasound. Two days later they scheduled me for a needle biopsy. The little voice that drove me crazy now and again was back and screaming, is *when* now? I always thought this would be happening in my 40's like mom. Not when I was 29.

On Monday, January 27, 2003 at 12:37 pm, exactly 3 weeks before my 30th birthday, that *when* became *now*. The "something funny" was breast cancer. And I couldn't even find the lump myself.

They booked me to see a surgeon. Ironically, it was the one I'd seen when I was 24. She had said she hoped she'd never see me again. She showed me the lump and let me feel it for the first time. She believed a mastectomy was my best option. She referred me to a plastic surgeon. I was terrified at the prospect of losing my breast. She also gave me the Hereditary Breast & Ovarian Cancer Society's brochure.

In Feb my sister and I went for genetic counseling and I decided to get tested. I was told that it could be up to two years before we would get the results.

On Feb 13 I had a sentinel node biopsy. And on Feb 16 my boyfriend, who decided to give me a happy memory for my 30th birthday, took me to Vegas. The day we got back from our trip, I got the good news that the cancer hadn't spread to the lymph nodes. That meant no radiation so I could start my reconstruction right away. I went to see the plastic surgeon a few days later. He told me he would insert a tissue expander as soon as the breast was removed and then do "fills" by injecting saline to expand it over the next few months.

I was really surprised by the surgery; I thought it would be worse. I wasn't in any hurry to see my chest. I didn't know how I would react. The home care nurse was a breast cancer survivor and was so good to me. She was with me three days later when I took the first peak. She held my hand while I laughed and cried at the same time. It wasn't so bad! What a relief! It was then that I found the humor that got me through the next little while. When someone would ask what it was like to go for a "fill" I said that it was like puberty in fast forward without the hormones!

I started chemo in May and had to do four rounds. The oncologist recommended it because of my age, and because the markers in the tumor were poor. Chemo was tough. I wasn't sick, just nauseated. I was very tired. I had a bionic sense of smell and taste and my body would ache. I lost my hair. It started to fall out a few days before my second treatment. My sister came over to shave my head and then we went golfing. After that, I mostly wore a ball cap or a bandana. I still

had my eyebrows and eyelashes. Twice I had to wait longer than expected between rounds because my cell counts were poor. Having marked on the calendar when the last treatment should have been, it was hard to see that date come and go knowing I still had one round left. Once my chemo was done, I started taking tamoxifen.

As soon as my cell counts were back up, I spoke to both of my surgeons and decided that I wanted to have a prophylactic mastectomy and reconstruction on my other side. The other natural breast was like a ticking time bomb to me. I never wanted to hear “you have cancer” again. Both doctors agreed and the surgery was booked.

Waiting for the genetic results is tough. My brother is now 26 and my sister is 22. They both want to be tested.

Through this journey, I decided to be in control, to educate myself about my options. I believe with all of my heart that I've done everything I can do. I just want to put the last year behind me and live my life.