

My mom, the cancer warrior

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I often daydream that my mom is still here and living cancer free. I like to imagine her teaching art at a prestigious private school in New York City, or maybe retired quilting in a little cottage in Vermont, or at home sketching on her back porch watching her dog playing in the yard. My mother battled cancer for over 20 years; and I find myself wondering what would it have been like to grow up without living under the shadow of the “c” word. How would things have been different? Would my mom still have been the fierce, strong, and passionate woman I remember? She never allowed herself to be a cancer patient. She was a mother, an artist, a friend, a teacher, and a cancer warrior.

My mother was diagnosed with Stage II breast cancer in July of 1991. I was 7 years old and my younger sister was 2. She found a pea-sized lump in her left breast by self examination. Her treatment was to be a lumpectomy and radiation. While in surgery, they found numerous lumps in her left breast as well as her right breast and lymph nodes. My father had to make the decision for a radical mastectomy of her left breast and a partial of her right.

It was very hard to see her going through all of it. I can remember having to spend a lot of time overnight with friends and family. There was a lot of crying and adults whispering. My mom was in bed most of the time and I remember waking up at night to her vomiting. At 7 years old, I knew words like mastectomy and chemotherapy. One night I couldn't sleep and I went up stairs to ask my mom if she was dying. How do you answer that? My pediatrician told my mother to give me a journal so I could draw and write my thoughts and emotions. In the afternoons, the two of us would write in our journals. She kept my composition notebook filled with funny round people and lots of “x”s over my mommy’s “bueb”.

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My mom made it five years cancer free. When I was 13, the breast cancer showed up in her right lymph node again. She was given a treatment to block estrogen as well as a hysterectomy, sending her into early menopause. She would laugh through the hot flashes. She had beaten it once already and she was going to do it again.

It wasn't until many years later while reading her journals that I would learn she lived with the fear of dying every day. I think she desperately wanted to have a normal family life free from cancer. Looking back now, she had an amazing support system but there was nowhere for her to express that fear until she found artistic journaling. Her journals were her salvation. She started journaling after a workshop for an International Baccalaureate art class she was teaching. The artistic journals were a requirement for the students and she journaled with them. She always said if you did something for 21 days it became a habit. Well, I would say that journaling became a permanent fixture. I can remember mom going in for a procedure on the gurney with a pen in one hand and her journal in the other. The nurses would take her glasses and then her journal. It became the place she could dump all those thoughts she would not voice, “Am I going to die?”, “Is it back?”, “Will this be the last time?”

Terminal was another word that was not in our vocabulary. I knew she was in the advanced stages, but I never acknowledged what that really meant. In an era where you could look everything up on the Internet, it might seem strange, but I did not research anything even though my mother was sick for so long. This was one of our rules and I followed it. If my sister and I ever had questions, my mother's doctors were always available to us. My mother was very candid with her illness and never kept anything from us. She always said bad things came from research. So I always trusted her doctors. They were the ones who knew my mom and her cancer.

While a thousand miles away at school, the cancer started popping up more frequently and in places you never want to hear about, like lungs and bones. I moved back after only two years in Col-



FIGURE 1 Steroid Girl.

orado. I needed to be nearby; the helplessness of being so far away was eating at me. She would say “I’m fine. Don’t worry about me and focus on school.” School was the last thing I could think about. Even though she would never say she needed me, I needed her.

She fought so hard for that “normal” life. She would purposely schedule treatments on Fridays so she would have the weekend to recover. She was so excited about Herceptin that she taught her students about how the drug flagged the cancer cells and destroyed them. Her oncologist for 9 years always had something new and great in his magic black bag. She wanted to live a normal life and do all of the things she loved like teaching, drawing, and gardening; and she trusted her doctor to help her do just that.

Her sense of humor was revealed in her art. In order to describe her symptoms, she developed a cartoon character, Steroid Girl (Figure 1). Steroid Girl made her appearance on paper, in wood, in fabric, and in clay; and one such clay pot made its way on to her doctor’s desk so he could remember her sense of humor. My mother loved to laugh. For those of you who work in or have been to an infusion center, you know it can be a very solemn place and rightly so, but we were the ones in the back getting loud. She would tell jokes to the nurses and doctors. We



FIGURE 2 What cancer cannot take from you. (One of my most favorite journal entries.)

were veterans. Everyone at the cancer center knew my mom. It was like an extended family. The nurses and doctors would take time to always ask about me and my sister. No matter how busy they were, they always got an update on her journal and the new drawings. The nurses always joked to stay on her good side because you never knew what might end up in her journal (Figure 2). Whenever there was a new patient, the nurses would sit them next to my mom to help cure their jitters. You couldn’t help but smile when you were around her. She so loved to laugh.

Things were looking up. The two nodules on her scalp, were decreasing in size and height. While mom was visiting at Christmas, I got engaged and asked her to make my dress. She was an amazing seamstress and had made her own wedding dress. I couldn’t imagine wearing something made by anyone else; and, of course, the fabric had to come from New York City. We went for the weekend and it was perfect. You would have never known she was on chemo or that she had major bone lesions. The

only difference was that we took cabs around town instead of walking 50 blocks like we did the previous trip.

A month later, I receive a phone call from her doctor. It was 3:00 AM and I was so frightened. My mom had a major bleed out in her lungs and she was in critical condition. Apparently, the Avastin was doing its job killing the tumor, it was just that the ruptured tumor was in my mother's lung and there was no muscle tissue around the tumor to stop the bleeding. She was in surgery for several hours and they were able to stop the bleeding. She then spent 7 days in the ICU on a ventilator in a medically induced coma. I was there every day. I didn't want her to wake up alone; I wanted to be the first thing she saw. When the doctors finally woke her up, she couldn't move her arms or her hands. My mother the artist could not use her hands. She told me stories how she would draw in bed as a child when she was supposed to be sleeping. She won the scholastic art award in High School. She was an art teacher unable to use her hands. If it weren't for her hands being paralyzed, she would have gone back to work like nothing ever happened. She tried right away to draw and journal. But frustration set in as she could barely hold the pen, let alone write. She couldn't feed herself, bathe herself, or get herself dressed. No one really ever figured out what happened but they seem to think it was a noxious brain injury from the loss of blood. Our lives changed forever. I left my job and she moved in with my then fiancé and me, and I became her caregiver. Our days consisted of pill schedules, doctor appointments, and trips to the hospital.

She spent a month throwing up three to four times a day. Then one day when I came into her room and the lighting was just right, I saw she was yellow. I had no idea what the symptoms were. She had complained of being itchy, so I changed her body wash, and we used different laundry detergent. I would have never guessed her liver was not working. The cancer had spread to her liver. Radiation and a pill form of chemo was the treatment. We would take one step forward and then something else would happen and we'd take two steps back. I have so many mixed emotions from that year and a half. I was so happy to have the time with her, but there were also so many days I was exhausted and wanted to pull my hair out. She still never gave up. She practiced and practiced everyday and with the help of two great therapists she was able to walk, drive, and most importantly draw again. She even danced at my wedding. She looked amazing in a beautiful fuchsia dress and a huge smile. She kept telling her doctors you have to get me to my daughter's wedding. And she was there, with no wheelchair, and on her own power (Figure 3). This is the memory I hold on to dearly; it is something the cancer will never take from me.

My mom started experiencing fainting spells and was admitted to the hospital on July 16, 2009. The doctors



FIGURE 3 My mother dancing at my wedding.

thought the cancer had moved into her spinal fluid but they couldn't be sure without a spinal tap. What was the prognosis? The doctors presented two options: with treatment through a spinal port she would have a few months but she would never leave the hospital or she could have a couple of weeks at home without treatment. All of us decided it was best if she came home. Hospice was brought in and we got an overnight nurse. On August 5, 2009, my mother passed away. She was surrounded by people who loved her. She had all the pizza and ice cream she could eat. She laughed and lived until the final day. Cancer didn't take my mom from me; cancer made her a warrior and my hero. She taught me to never stop living, to always give all of your heart, and to always dance my "happy dance".

My daughter turned two recently. Every once in a while she will look at me with a cheeky little grin and I see my mom. It hurts that she will never meet her grandmother, but my daughter will know her through the pages of her journals, the people my mom inspired, and the ones who love her.