
BRCA JOURNAL: CHAPTER FIVE

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(Chapter 5 of 5. Read part 1 [here](#))

I Had a Mastectomy and Lived to Tell About It

On February 3, 2009, I had a bilateral prophylactic mastectomy with reconstruction. I decided to have the surgery because I had tested positive for the BRCA gene. As my previous journal entries attest, it was not an easy decision.

The weeks and days leading up to the surgery proved to be the most emotionally arduous I had ever endured. Anxiety, fear, sadness – you name it, I experienced it. How would they look? How would they feel? Would I ever fully recover from the shock of it all? I never faltered from my resolve to have the surgery, but I suffered many sleepless nights and shed many tears during that period of time.

The Day of the Surgery

On the day of the surgery, I woke up at 4:00 a.m., took a shower, blew my hair dry and kissed my children goodbye. The smell of their sleeping breath comforted me and I felt an eerie inner calm as my husband, Jim, drove me to the hospital. I can't remember what we talked about, but I remember not feeling any of the fear or anxiety of the previous weeks. I must have been out of my head, because it felt as if the car was floating down the expressway.

When we checked in at the hospital and the nurse put the plastic hospital bands on my wrists, the pit in my stomach returned. Those silly plastic bracelets felt like steel shackles to me. I tried to distract myself. I focused on finding my husband the best spot to set up camp in the waiting room, but he picked up on my apprehension and said, "You are going to be okay, honey. I love you and the kids love you and we want you to be around for a long time. You are 100% doing the right thing."

Enter my first tear of the day.

Jim stayed with me as I changed into my gown, the nurse placed my IV and the doctors examined me. He didn't leave my side until I was taken back into the operating room.

My cousin, Couni, would be meeting him in the waiting room and would help distract him from his own anxiety during what turned out to be an eight-hour surgery. Couni, a nurse, had called me months earlier to tell me that she was staying with me during my entire hospital stay and immediate recovery. She didn't ask, she told me. I am so glad that she ignored me when I tried to convince her (and myself) that it wouldn't be necessary.

My last memory was of the anesthesiologist saying, "Okay, we've begun" and me replying, "Does that mean you've started the drip?" I knew with his nod that I was only moments away from escaping to never-never land.

In the recovery room, it took me a while to come through the fog of the anesthesia and appreciate what was going on. As my eyes adjusted, I knew Jim and Couni were there, but then it hit me: I was in pain. Real pain. My chest was sore, as I had expected, but the pain in my arms was like nothing I had ever felt in my life. It was a searing pain that began in my arm pits and went down into my hands. The nurse explained that my discomfort may have been due to the fact that my arms had been spread out at my sides and secured to the table during the entire eight-hour surgery. Discomfort? Please! A blister causes discomfort. I felt like I had been hit by a truck.

A friend of mine who had also had a mastectomy told me that I absolutely had to have someone stay with me overnight in the hospital. She told me that I would feel terrible and wouldn't be able to use my arms. I couldn't fully comprehend what she meant at the time, but now her advice was resonating loud and clear. I was so thankful I had Jim and Couni with me that night. They helped me adjust my position in bed, brushed my hair out of my eyes, handed me water to sip and pressed the nurse call button when I needed it. I couldn't do any of it on my own.

Meeting My New Girls

My first day in the hospital was spent lying on my back drifting in and out of sleep. During the second day, I was able to get up and walk around. I still felt awful but at least I was moving. That night, I told Jim to stay at home with the kids and get a good night's sleep. Couni stayed with me. In a druggy haze, I watched Grey's Anatomy and dozed off.

At around midnight I was woken up by the nurse to take my vitals, so I got up to go to the bathroom. I looked in the mirror. I studied my face and with a sense of resolve, decided it was time. I pulled down my gown, unfastened the surgical bra and looked into the mirror. I felt my throat start to close. I looked down directly at my breasts to take a closer look. I was horrified. It became difficult to breathe. The sharp taste of regret was caught in the back of my throat, blocking my airway. My eyes welled up, but I refused to let myself cry. There was no going back. I told myself that I would just have to make the best of a very bad situation.

My breasts had been reconstructed with temporary implants called expanders. A few

weeks following surgery, I would return to my plastic surgeon's office once a week to have the implants filled until my breasts reached my desired size. Eventually, I would have a second surgery to replace the expanders with permanent silicone implants, but the expanders were needed to stretch my chest wall so that my pectoral muscles would be able to hold the permanent implants in place. Eventually, I would have perky, no-bra-required, beautiful boobs, but what I saw before me was grotesque. Intellectually, I knew that it was all part of the process, but I wasn't prepared for what I was seeing. My breasts were shrunken and deformed.

After a few deep breaths, I put my bra and gown back on and opened the bathroom door. By then, Couni was sitting up in her cot.

"Are you okay?" she asked.

"No," I said. "I made a mistake."

That is all that was said. Couni didn't argue with me; she just quietly helped me back into bed and kissed me on the forehead. I squeezed back the tears that were burning the corners of my eyes and hit the button for another dose of morphine.

Not Ready Yet

Drains had been placed in each of my breasts to collect excess fluid. The drains would have to remain in place for about two weeks. It turned out that the drain on my right side was hitting a nerve and causing disabling pain. They could not move it or re-insert it; I would just have to deal with it until it was time for it to come out. Though I was expected to leave the hospital after two nights, I had to stay an extra day until I could get the pain more under control. Truth be told, I didn't feel much better on day three, but I was definitely ready to escape the dreary walls of my hospital room.

Fortunately, before my surgery I had made arrangements to stay at a hotel for two more nights before returning home. I originally made the reservations because I didn't want my kids to see me if I was feeling terrible. I had gone back and forth on whether to keep the reservation, but in the end, I was very glad I did.

Couni and my dear friend Rose stayed at the hotel with me. They helped me take my first shower, figure out a system to hide my drains (I was obsessed with making sure the kids couldn't see them) and got me on a pain med schedule so that the pain was under control by the time I returned home.

They also helped me mourn. I had experienced a real loss with the surgery and needed to grieve. They never offered any hollow attempts at consolation. There was no "There, there, it will be okay" or "Don't worry, it will be fine." They listened to me (at all hours of the day and night) and reminded me why I had chosen to have the surgery in the first place. We wound up having some great laughs amidst it all, and eventually they got me to a place where I could accept my situation.

Time to go Home

Five days after my surgery, I returned home. My brother had taken the kids out for a while so that I could get situated before they saw me for the first time. When they returned, hearing that I was back, they ran to me and immediately began competing for my attention. They were all speaking at once and handing me pieces of candy to unwrap. "Open this, mom." "Here, mom." "Here's my wrapper." They were completely unaware of the emotional and physical hell I had been through. To them I was the same. As I unwrapped the candy, I smiled, knowing that I would never let them know otherwise.

Having delivered me safely at home, Couni and Rose returned to their families and my Aunt Gail, cousin Pam and girlfriend Laurie flew in to take their place. I am a very independent person and am usually the last person to accept help; however, I can say with authority that a mastectomy is not a surgery that a person should attempt alone. While I had originally resisted all of their offers of help, it was a tremendous comfort to have them.

Though I wanted to jump back into the mommy role completely, I just couldn't do it physically. I still had the drains in, and I had to be on heavy doses of pain medication, which caused me to be drowsy. I also couldn't use my arms fully yet. I was unable to lift my children (a six-week restriction per the doctor's orders) and had a severely decreased range of motion. Gail, Pam and Laurie helped with the kids, drove me to appointments and helped pass the time with plenty of laughter. Additionally, unbeknownst to me, my friends had gotten together and created a dinner schedule for us. For two weeks upon returning home, one of our friends or family members would bring over a complete dinner for our entire family. It was absolutely amazing. My advice to anyone else having a mastectomy would be to accept all of the help you are offered – you will never regret it.

The Pathologist Says *What?*

Eight days after surgery, I returned to my breast surgeon's office to have my drains removed. As I waited for her in the examining room, I heard her footsteps approach, then step away before she finally entered ten minutes later. She explained that she had just been paged by the pathology department and it just so happened that they were calling about my pathology report. I was aware that she would be sending the breast tissue she removed to the pathology department after my surgery. What I wasn't expecting is what she said next.

"Well, it turns out you had DCIS in your left breast."

"Oh," I said. "What is DCIS?"

"Cancer."

It didn't take but half a second for the tears to start streaming down my face. I cried and cried as she explained that they had found several cancerous areas called ductal carcinoma in situ (DCIS) in the breast, the largest 1.7 centimeters long. "But it was non-invasive and we got it all," she said. "You won't need any further treatment – you saved your life."

I continued to cry and cry. After a few moments she asked, "Are you okay?"

I looked up and almost shouted, "Oh my god, yes! I'm great! Really. I am! This is why I had the surgery in the first place. Thank you, thank you, thank you." I hugged her with all my heart.

I then had to go get my husband from the waiting room to join us. As we walked back to the examining room where the doctor was waiting, I looked him in the eye and said, "Honey, you aren't going to believe what you are about to hear, but just know walking in there that I am completely fine."

His mouth literally dropped open when she repeated what she had told me. He held my hand and wiped away a tear of his own. She spent a lot of time with us describing DCIS, where they found it and why they were so confident that I would require no further treatment. She also shared with us why she believed my MRI and mammograms had failed to detect the cancer. DCIS is a very early stage of cancer, considered to be Stage 0. My cancer probably had not calcified, which is what the tests would normally pick up. It made no difference to me at that point. I was just happy that they had got it all and I would need no further treatment. Jim and I walked out of the room puffy-eyed, but with sly smiles on our faces, like we had a great secret we were keeping.

Except that it wasn't a secret for long. I called every person I knew to tell them. I started with the doubters. When I made my decision to have the surgery, so many people thought I was crazy for even considering it. Most of them opined that I should just go in for regular testing. As if I wasn't already doing that! In fact, I was part of a study and had been screened even more often than most high-risk women. During the year preceding my surgery, I had had a mammogram and two MRIs of my breasts. My last MRI had been performed just three months before my surgery.

On the car ride home, I called my dad first. I reached him at his office. "Dad," I said, "close your door." I explained everything the doctor had told us. Through his tears, he cried, "I am so glad you were always smarter than me, honey." God, that felt good.

So Long, Regret; Bye-Bye, Uncertainty

At the exact moment my doctor told me the pathologist had found cancer in my left breast, all of my regret, doubt and uncertainty about having the surgery flew right out the window. The surgery really had been the right thing to do. If I hadn't had it, who knows when the cancer would have been caught. It could have been too late for me, like it had been for my grandmother, aunt and cousin.

The regret that had previously consumed me was immediately replaced with a great sense of resolve. I didn't feel great yet, but I knew I would get through it. I was healthy and I was strong – if not physically, then mentally. When I couldn't reach a coffee cup in the cupboard as I always had before the surgery, I laughed at how goofy it was that, at 5'8", I had to climb up on a step stool to reach it. When I didn't feel comfortable driving, I took a cab. When I got stiff from having to sleep propped up on my back night after night, I just shrugged it off. When I tired easily and had to take a nap, I didn't fight it. In time, I knew all would be well.

As the weeks passed, I became stronger and everything just seemed better. I began the process of having the expanders filled, and my breasts began to again look like breasts as I had known them. I was able to drive my kids to school, work out and go back to work. I could even reach the coffee cups.

Now, except for some tightness in my arms and chest, I feel as good as ever. I can carry the kids and the groceries – sometimes both at the same time. We go to the park, the zoo and the museum. Jim and I have resumed going to parties, events and out for our weekly date nights. I have planted the flowers, cleaned out the closets and tried new recipes. I took the kids on vacation, began potty-training the baby, threw a birthday party for my eldest and watched my son play his first game of T-ball.

In short, I have been living life – which was the whole purpose of the surgery in the first place.

My second surgery is coming up at the end of May. I do not feel any of the trepidation I had with the first one. In fact, I am looking forward to it. It's just another step toward getting back to normal. Okay, maybe a little better than normal – I will have the boobies of an eighteen-year-old, after all. (Did I mention no bra needed?)

Oh, yeah, and I will be healthy, too. That's not so bad either.

Michelle Meklir McBride is an attorney in Chicago. Michelle has helped make SU2C a reality and was instrumental in aligning SU2C with Major League Baseball. She sits on the boards of two cancer research foundations: [Little Heroes](#) and the [Noreen Fraser Foundation](#). Michelle dedicates this piece to her husband and three kids.