
BRCA JOURNAL: CHAPTER THREE

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(Chapter three of five. Read chapter four [here](#))

After testing positive for the BRCA gene and meeting with several doctors, I began to consider prophylactic surgeries.

First I saw Dr. Beth Karlan, director of the Women’s Cancer Research Institute at UCLA. She repeated the same sentiment as my doctors in Chicago—that whether or not I had a mastectomy, I should have my ovaries removed to prevent ovarian cancer. Dr. Karlan knew my family history, the types of screenings I had had and the amount of time I had spent researching my prophylactic options. She summed it up in these words: “Honey, you know the expression ‘shit or get off the pot’? Well, it’s time.”

Dr. Karlan recommended that I have a full hysterectomy instead of just removing my ovaries. I asked her why, and she told me that many times, BRCA patients who get ovarian cancer develop it in the fallopian tubes. If I were to have my ovaries removed, the doctor would also remove my fallopian tubes, but there is a portion that extends into the uterus and cannot be removed, leaving me at risk. She also said that I would be able to take estrogen-only hormone replacement therapy which is often more effective at easing the symptoms of menopause than estrogen and progesterone hormone replacement therapy (women with a uterus must take progesterone in addition to estrogen because of an increased risk of uterine cancer). Furthermore, she examined me and determined that I could have the hysterectomy done laparoscopically, which would mean that the surgery and immediate recovery would be just a few days longer than if I had just had my ovaries removed—nowhere as grueling as a traditional open hysterectomy.

It appeared there was no avoiding it—I would have a hysterectomy and would just have to deal with the symptoms of menopause. I asked Dr. Karlan whether she felt it would be overkill if I had a mastectomy in addition to the hysterectomy. She shook her head and simply stated, “No.” Then she told me a story about a close friend of hers with breast cancer. She told me that despite the fact that they caught her friend’s cancer early and were able to treat it and put it in remission, it took a huge emotional toll on the woman and her marriage. It was not unlike the stories I have heard from other people I know who have survived cancer. They all say it’s the little things that cause anxiety—a pulled

muscle, a pain in the back. They all wonder, did they just overdo it, or is the cancer back?

Dr. Karlan spent some time talking to me about prophylactic mastectomies and reconstruction and told me that while not all results are the same, she has seen some beautiful breasts following reconstruction. I told her that during the course of my research, I had learned that I could have a nipple-sparing mastectomy, where the doctor can preserve the woman's skin, nipples and areola so that the look is more natural when reconstructed. Dr. Karlan recommended against having a nipple-sparing mastectomy because a significant risk of developing breast cancer would remain after that type of surgery.

I was inspired by Dr. Karlan but still unsure of myself. While I had thought I wanted a mastectomy to avoid going into menopause, it didn't seem as bright of an option once it appeared I was going to have to face early menopause after all. In truth, I was still scared to death of having one, and my doubts only multiplied as I learned more about the complexity of the surgery and the variations in results. I was also very concerned about how my breasts would look following the surgery. As one of my doctors put it, there is more to breasts than meets the eye: "They play a functional role, sure, but there is a more emotional element because of their role in a woman's self-concept and during sex." If I had had breast cancer, it would be a non-issue for me. I would do anything I had to do to survive, even if it meant removing my breasts, regardless of the results. But since I was healthy, I couldn't help but worry about how bad the scars would be and how my breasts would look and feel in the end. The plastic surgeon I had originally met with told me that I would have a scar that looked like an upside down omega (Ω) across both breasts, and a large scar across the length of my abdomen from where the donor tissue would be taken if I had a DIEP reconstruction. If I didn't do a nipple-sparing mastectomy, I couldn't imagine how frighteningly unnatural my breasts would look.

Look At These!

Soon after my appointment with Dr. Karlan, a breast cancer survivor I was introduced to learned that I was contemplating a mastectomy. "You have to see my boobs," she told me. "I have a lot to tell you." She had had a bilateral mastectomy, but with a different type of reconstruction done on each breast, so she was in position to educate me about the different types of reconstruction to consider. I was amazed by her generosity. She was giving me an opportunity I had never contemplated.

We went into the bathroom and she took off her shirt. I forced myself to relax. I was nervous. I didn't know what to expect and I didn't want my face to betray any signs of disappointment or, god forbid, disgust. Based on my conversation with the plastic surgeon and the pictures he showed me, I was expecting a lot of scarring. When I looked at her breasts though, I almost giggled I was so relieved. They looked great. She complained about certain skin changes because of her radiation treatment, but I honestly couldn't see what she was talking about.

As she discussed the different types of reconstruction done on each breast, I studied

her scars. They were barely visible and completely different than what I had expected. Then she told me that her nipples and areolas had been reconstructed, which took me completely by surprise, because from looking at them, I thought that they were hers naturally. Seeing a real life example of the surgery was completely different than the pictures I had seen. I wouldn't say that the experience got me excited about having a mastectomy, but it certainly enabled me to embrace it as an option.

Contemplating My Future

With my new found sense of comfort about having a mastectomy, I went to see Dr. Fumni Olopade, Director of the Cancer Risk Clinic at the University of Chicago, where I would ultimately decide to have my screenings and surgeries performed. In one last effort to avoid going into early menopause, I asked Dr. Olopade if she thought it prudent that I have a mastectomy and leave my ovaries intact. Like all of the doctors before her, Dr. Olopade was adamant that I should have my ovaries removed.

She felt that a mastectomy was a reasonable option if I wanted it, but regardless of whether I had a mastectomy or not, I needed my ovaries out. Dr. Olopade referred me to a gynecologist who could perform a hysterectomy, and a breast surgeon and plastic surgeon who could perform my mastectomy and reconstruction.

Hysterectomy

After discussing the opinions of all of the doctors with my husband, I scheduled a laparoscopic hysterectomy. We decided that, since all of the doctors were in agreement that the most important preventative option was having my ovaries removed, I should have the hysterectomy first. I have to say that the day I scheduled the surgery, I felt a great sense of relief. However, it was a rollercoaster of emotions up until the day of the surgery.

I told my friends that I wanted no sympathy and no pity if I called them upset about having to have the surgery, that instead I wanted tough love. I e-mailed one of my best friends, "Freaking out today about going into menopause." She wrote back, "Would you rather go into menopause or chemotherapy?" Needless to say, they kept me on my toes. The weekend before my surgery, a dozen or so of my friends met my husband and me at a bar to bid adieu to my organs. It was quite a going-away party with plenty of shots of Tequila being shared by a traditionally more composed group.

The surgery went well. I spent only one night in the hospital and recovered at home. I felt about 98% back to normal within a week. At first, I thought that I must be one of the "lucky ones" who doesn't experience any menopausal symptoms, because I felt exactly the same after my surgery as I did before. But after a few weeks, I felt my first hot flashes. They were and continue to be very mild. My doctor said that she has noticed a trend in her younger patients—that they don't generally suffer from hot flashes as severe as her older patients. As my estrogen levels continued to decline over the next month or so, I definitely noticed more menopausal symptoms. At times I noticed that I was more irritable than usual, and I had greater mood swings. My doctor put me on a low dose of estrogen, which has helped improve my overall disposition. I began seeing an

acupuncturist who, in addition to acupuncture, gives me a formula of Chinese herbs that has helped tremendously. Now, I generally feel as great as I did prior to my surgery.

I don't want to make the experience sound like a picnic. It is a process and one that should be contemplated seriously before beginning.

Mastectomy

I have often heard that the most important part of any surgery is to make sure that you select a great surgeon. Everyone I have ever spoken to who has had a mastectomy reiterates that sentiment with fervor. I would require two surgeons: a breast surgeon to perform the mastectomy and a plastic surgeon to perform the reconstruction.

The plastic surgeon I was referred to, Dr. David Song, is one of the best in his field, and I immediately felt at ease after meeting with him. He spent a lot of time talking about my options for reconstruction. He is a specialist in microsurgery and while the DIEP flap was an option for me (the procedure where the surgeon uses tissue—aka fat—from the patient's abdomen to rebuild the breasts), he suggested that I might want to consider implants because I may not have enough tissue to make my breasts large enough for me.

I am naturally larger breasted and I had told Dr. Song that I want my breasts reconstructed to a similar size, because that is what is natural to me. I really didn't like the prospect of having implants but I absolutely LOVED that I didn't have enough "tissue" to rebuild my breasts to the same size. I called all of my girlfriends to brag about it and spent the night laughing about it with my husband.

Of course, then began the serious conversations about whether or not I should have my breasts reconstructed with my own tissue or with implants. If I used my own tissue, my breasts would look and feel more natural but would leave me with much smaller breasts than I wanted. The surgery would be done under a microscope, would take up to 16 hours to complete and would require a much longer recovery with pain in my breasts and abdomen where the donor tissue was taken. If I used implants, my surgeon assured me that he could create very natural looking breasts and the surgery would be much simpler. But it wouldn't be a complete piece of cake. The implant process would require two surgeries, the first to insert expanders to stretch the chest wall, which would remain in for a painful six weeks, and then a second surgery to place the permanent implant.

The thought of two surgeries was troublesome for me until I mentioned it to my friend who had shown me her breasts. She said, "Just remember this: The one thing that they don't tell you is that you never have just one surgery and you're done. There is always at least one or two follow up surgeries to tweak something or even something out so you will have at least two surgeries regardless of which type of reconstruction you choose." I mentioned her comment to Dr. Song and he agreed that it was a fair statement. I was glad I had the information before I began the surgeries so that I was prepared for it.

I mentioned once again to Dr. Song that I might want a nipple-sparing mastectomy. He

suggested that I speak to my breast surgeon about it in more detail. But he said, as each doctor I had previously consulted with, that while the results are aesthetically very nice, in order to keep the nipple the breast surgeon has to leave in a significant amount of breast tissue, which would leave me at a significant risk of getting breast cancer. I finally decided for good that it would be foolish to have such a major surgery and still leave myself at risk.

When I met with the breast surgeon, Dr. Nora Jaskowiak, I was given a bit of good news. She informed me that a recent study found that the areola could be left intact during the mastectomy without a significant elevation in breast cancer risk. In essence, she proposed performing an areola-sparing mastectomy. A small hole would be cut to remove the nipple, but I could keep the areola, and a new nipple would be created. The effect would be to help me achieve more natural-looking breasts. This new development greatly encouraged me. I felt more confident that if she performed this type of a mastectomy, regardless of the type of reconstruction Dr. Song performed, I could achieve a very natural look.

Before I left, Dr. Jaskowiak told me that there was one more issue for me to consider. She wanted to know if I would like her to remove my lymph nodes during the surgery. The risk associated with removing lymph nodes is adema, or extreme swelling in the arms, but having them removed would help further reduce my risk of developing cancer. I had not yet considered having my lymph nodes removed, but I would then begin to spend time researching the issue and contemplating a decision.

Final Thoughts

I have decisions to make regarding what type of mastectomy I will have, what type of reconstruction I will have, and whether or not I want my lymph nodes removed. But the big decision has been made. I am going to have the surgery. A prophylactic double mastectomy. I am going to do it for my family. I know it won't be easy, but I think that it will be a lot easier on everyone if I have a mastectomy done now, while I am healthy, than if I risk getting cancer and putting my family through the stress of everything breast cancer could entail: chemotherapy, radiation, mastectomy, and of course, possible death.

I scheduled my mastectomy and reconstruction for January 2009. I have spoken to people, cancer survivors included, who think I am crazy for doing this to myself; and I have spoken to people, cancer survivors included, who agree with my choices. I am not a pioneer here. Many other women have made the same decisions as me. Some, armed with the same information, have made completely different choices. I respect them all. I just know that for my own piece of mind, I have to have the surgery done. I have come too far to turn back.

I scheduled the surgery several months out so that I could give my body time to fully adjust to being in menopause and my brain time to mentally prepare. I know that I will change my mind a thousand times between now and then; I will doubt myself and then feel reassured, pity myself and then feel empowered. It won't be an easy process, and

neither will the surgery. But I know in my heart of hearts that I would much rather go through this anguish than have cancer. I am trying to break a pattern that is woven into my genetic fiber. Hopefully, I will be around to watch my kids grow up. And through the hard work of people like the folks working on Stand Up To Cancer, I will witness my daughters experience a freedom from the worries I have endured and the choices I have had to make.

Michelle McBride lives in Chicago with her husband and three children. Michelle has helped make SU2C a reality and been instrumental in aligning SU2C with MLB. She sits on the boards of two cancer research foundations: [Little Heroes](#) and [Noreen Fraser Foundation](#). Michelle dedicates this piece to her husband and three kids.