

Cheryl Anne's Story

In 1974, at the young age of 41, my mother died of ovarian cancer. Her younger sister had died at the age of 25 of breast cancer. Another sister was diagnosed with breast cancer and had a lumpectomy. Their mother—my grandmother—had also been diagnosed with breast cancer and had a mastectomy. Cancer seemed to hang over our heads.

When my aunt was diagnosed, her doctor recommended genetic testing for the family. There were three other sisters who were unaffected by cancer so far but there was a very strong family history. It was certainly something worth looking into.

When I was approached about genetic testing my initial reaction was not to be tested. If I tested negative I might have a false sense of security regarding my chances of having cancer later in life. I felt that being careful was the best course of action, having regular screening done and doing self exams. What would I do with the information if I knew that I carried the genetic mutation? I was not ready to have surgery just to prevent something that might never happen, and if I did pursue surgical intervention how far would I want to go? No, just being diligent about screening seemed to be the way to go.

Well maybe not. In February 2001, just four months after I'd had a clean mammogram, I felt a lump in my left breast. I was 47 years old. It was probably just cystic changes related to menopause! Better have the doctor check it out. She thought it was cystic changes, but because of my family history she suggested we do another mammogram just to be sure. The radiologist then wanted to do an ultrasound. There was a mass, fairly small but definitely solid. He recommended that I see a surgeon to have a biopsy done.

The surgeon did a needle aspiration and felt that what I had was a fibroadenoma, a benign growth. I could happily accept that. But when the pathology report came back, it said that there was a suspicion of carcinoma in the tissue. The surgeon then wanted to do a biopsy under a general anaesthetic and perform a mastectomy if there was any cancer in the breast. I agreed and on April 2 at 0800 I went into the operating room to have this procedure done. When I woke up in the recovery room I asked what had been done. The nurse told me that I'd had a mastectomy and that is how I found out that I did indeed have breast cancer. Thinking back on it now I don't think anyone in the hospital ever told me that I had cancer but I knew because a mastectomy had been done. According to my pathology reports, I had Stage 1 invasive ductal adenocarcinoma.

People kept telling me they were sorry this had happened, and how young I was to have to deal with this. I felt just the opposite. While it would have been nice not to have to deal with cancer, I felt that it was being dealt with in the best possible way, with early diagnosis and removal of the affected body part.

I hadn't wanted to know my genetic status previous to this, but now it could have a great influence on what my choices would be. I would be far more aggressive surgically if I did carry the genetic mutation because the chances of developing more cancer would be significantly increased if I tested positive.

My two sisters had already had the testing done and they both tested negative. I was happy for them and never really questioned, "Why me?" It was just my lot in life and I had to deal with it. My brother had died in a motor vehicle accident in January 2000 so he was never tested.

When I found out that I did carry the BRCA1 genetic mutation I decided to have prophylactic surgery done. In August 2001 I had a right mastectomy and in October I had a hysterectomy with removal of both ovaries, thus reducing my chances of getting another cancer. Some people, even family members, thought that having the extra surgery was too much, but it gave me peace of mind to have it done.

But how would my husband feel about having a wife without breasts? I guess when faced with a life with cancer or a life without breasts there isn't really much of a choice, at least to us there wasn't. Breasts are body parts - they do not make me who I am. I chose not to have any reconstructive

surgery because I felt that I am just as much a woman without breasts as I am with breasts. Anyone who would have a problem with that didn't have to be part of my life if they didn't want to be. It just wasn't a big issue. I am happy and confident that I made the right choice for me.

Now there were many other issues to deal with. As a mother of two grown daughters I had to share with them the fact that they each have a 50% chance of carrying this same genetic mutation. They should go for genetic counselling and decide if they want to have the testing done. I wondered about other things. Should I have had children? Should my children have children knowing that this is passed through our family genes?

I felt the need to get in touch with other women who had gone through genetic testing to find out what, if anything, they had done. I wanted to talk to someone who had been there and gotten through to the other side. I called the Cancer Society office in my town and they did not have any information on any person or group that dealt with hereditary cancer. A week after that I got a letter from the Genetics Clinic in Edmonton informing me that there was a group meeting in Red Deer in February called the Hereditary Breast & Ovarian Cancer Society of Alberta. Would I be interested in attending? Yes I would indeed. To be able to talk to others who were dealing with the same issues with health and family history and offspring. How did they cope, what did they do, how can they help, can I help them?

I know that life has tests and trials for all of us and how we choose to react to those trials makes us who we are. We can make these tests stumbling blocks or stepping stones, I chose to step above the trials. One of my surgeons told me that there were a lot of people watching me and they would be able to think of me when they too had a diagnosis of cancer and would realize that it is not a death sentence. Life can go on. I thought that even if it was a death sentence life would go on. It would just go on without me but it would still go on, for my children and grandchildren.

Most of my life it seemed that I was preparing to deal with a diagnosis of cancer and it did not really come as any surprise to me when I was diagnosed. I felt that because of the genetic testing and the surgical options that were available I had such a good chance of overcoming this, and going on to lead a healthy normal life. Chances my mother and her sister never had. It was really not hard for me to face this. I actually felt lucky to live now, not 30 years ago when genetic testing was not available.

Writing in a journal helped me through this experience as I was able to write about my feelings, my family, my hopes, my choices for surgery and treatment, the ups and the downs and the people who supported my family and me through everything. Given the choice I would not have gone through this diagnosis but we don't get to choose every situation in our life. I am just glad that I have come through and two years later I am cancer free. ☀