

Maimah Karmo, Breast Cancer Survivor Story, June 2007

It all began during a routine self examination in the shower. I found a small lump in my right breast. It was so small that I almost missed it. I believe that if my mother had not educated me the way she did, I would not have noticed the lump in time. From the time that I hit puberty and began to develop breasts, my mother, a registered nurse, had taught me to do regular self examinations. When she first showed me, I was about twelve and it was rather embarrassing, having her tell me what to do and then standing there watching me to make sure that I did it right.

At that time, I didn't really understand the importance of a breast exam. My mother told me to make sure I knew what my breasts felt like normally and to tell her if I found something that didn't belong there, like a lump or irregularity. I was sure she was nuts, but I did as I was told.



After I found the lump, I went to see my family doctor to check it out. Surely, she would tell me it was nothing. These kinds of things never happened to me. I was the epitome of health. I got a cold maybe once a year. I did weights 4 to 5 times a week and ran four to six miles per workout. I took my vitamins, drank the recommended eight bottles of water and ate my broccoli and carrots. I had the occasional pizza or McDonald's, but eating healthy was the norm.

The morning of my biopsy, I woke up to a sense of foreboding. It was an average day outside. Normally, I would be happy and jamming to music in the car. Today, my mind was on other things. I looked at other drivers and wondered what they were thinking. Where were their destinies leading them or driving them away from? My drive to the doctor's office was easy, and I got there on time. By the time I got in the examination room, my heart was pounding so hard I thought everyone could hear it. Usually trying to get a laugh out of someone or laughing about something myself, today, I was quiet. My breathing was shallow and my nerves were strained. The doctor examined me and then told me I needed to see a breast surgeon, but to have a mammogram done first. My mind could not comprehend what I thought she was saying. Breast surgeons? Mammograms? What was going on? Perhaps it was a mistake.

After I left that appointment, I scheduled a mammogram. Then I made another appointment, this time with the breast surgeon. The lump was still there when I went to meet with the breast surgeon. She examined me. "You have a lump, but it is nothing. It is only a cyst. You are young and are in your prime child-bearing years. Women like you can have benign cysts. It is nothing to worry about. If it bothers you, we can try to aspirate it and it will go away." I did not believe her. My stomach was churning. My mouth was dry and tasted metallic. It felt like a storm was coming. It was coming my way and there was nothing I could do to stop it.

I made a follow-up appointment for the aspiration. I was a nervous wreck. I just felt that something was very wrong with me. About two weeks later, I laid on the doctor's table. She was having a difficult time aspirating. I urged her to do a biopsy, but she refused. Again, I insisted; so did she. She looked at me and again told me I had nothing to worry about.

"But I am very worried," I told her. "You are young, healthy, have no history of cancer. You're fine. You're just being vain. It is just a cyst and it will go away. Make an appointment for us to try to re-aspirate."

"Being vain?" I thought to myself. "I can't believe she just said that." I left her office very worried. I felt that something was very wrong, but she was a professional. She was a doctor. I was just me. I would wait a few months for another follow-up. This time, I went home with a band-aid.

Months later, I was back for my check up. An ultrasound found that the lump had doubled in size. “We need to do a biopsy.” I said. “No, we need to do a re-aspiration.” She countered. “Why are we not doing a biopsy?” I asked. She re-iterated the reasons why not. I insisted that we do a biopsy. Even from a layman’s perspective, things looked a bit shady. Emotionally, I was frantic. It was my body. Why wouldn’t she just do the procedure? “I assure you, nothing is wrong with you. In the future, if it really is a bother, we can remove it, but I suggest you leave it alone. You can schedule another appointment with the nurse on your way out for the re-aspiration.” Sure, I thought. I spoke with the nurse and scheduled an aspiration/biopsy.

When I left the appointment, I remember getting in my car and just sitting there, willing myself to breathe slowly. I tried to seem calm on the outside, but inside it rained. I was terrified of what the doctor would find. Some part of me knew that it was cancer and no amount of positive thinking would will it away.

The morning of the biopsy, when the doctor walked in, she seemed annoyed. She couldn’t understand why I was insisting on the biopsy. She told me that she was sure I was fine and that I had nothing to worry about.

On February 28th, 2006 at 4:45 p.m., I got a call. I was at work on a conference call. I recognized the number. My heart began to pound. Now I knew. The call went to voicemail. Next my cell phone rang, same number. I didn’t answer the phone. I was determined to finish my conference call uninterrupted. I knew that this would be the last “normal” thing I did before my life changed forever. It was only a conference call, but once I called the doctor back, I knew that my life as I knew it would never be the same. I knew I had cancer. I calmly finished my call. As it was finishing up, the phone rang again. This time, I picked it up.

“Hello?” I said.

“Hello. We got your test results back. You have breast cancer”, the voice said. The words cut into my flesh, cut into my soul and cut away the world that I existed in before they were uttered, cut away me. My body cringed and curled into a fetal position, as if I was being physically attacked. I rocked myself.

How could this happen? I thought of the horror of what I was going to face. I thought to myself, “I am 32 years old, I have a daughter. I have cancer. My body and my breasts have betrayed me. I am going to die. I am going to die.” My eyes were shut and my hands went to my head. I realized I was shaking my head, inwardly screaming; every cell in my body saying “no”. I wanted the time to go back, to before the phone call. Before I knew cancer was inside of me.

“Hello, are you there”, she said. My heart and my breathing had stopped, the room spun around and up towards me. The floor was rushing up. I couldn’t breathe. I had dropped the phone. “Hello” said the disembodied voice, “hello”, “hello”. I picked up the phone and said “I will call you back”. The phone slid out of my palms. They were sweaty, yet cold. My forehead fell to my desk. I hadn’t breathed in what seemed like forever.

I have learned a lot of things since then. What I will share with you now is this – there are some critical things we need to change as we fight to eradicate breast cancer.

1. Know Your Breasts. It is estimated that 1 in 7 women will be diagnosed with cancer in their lifetime. At the onset of puberty, teach your daughter what a self examinations is and why it is important. It is the onset of puberty that accelerates hormones like estrogen in women, which is a major factor in breast cancer growth and development. Early detection can save a life.

Get routine physical exams and mammograms. Routine exams such as these greatly increase early diagnosis and treatment. In certain cases, knowing your breasts well enough can help because there are times, like in my case, when even a physician can misdiagnose. If you ever doubt what your physician says, get a second or third opinion.

National statistics tell us that after 40, women should have a mammogram every one or two years. They also tell us that breast cancer incidences are higher in women over 40, but what people don't know is that cancer can take many years to grow. When I was diagnosed, I was told that the cancer had probably been growing for years. Prevention is better than cure - knowing your body can allow for early detection and possibly save your life.

The lump in my breast had doubled in size within the span of months. When I first detected it, it was 2 centimeters or less, which means that I was at Stage I. At Stage I, there is no cancer in the lymph nodes. When I was diagnosed it had progressed to Stage II. At Stage II, the lump is between 2 and 5 centimeters and it has most likely spread to the lymph nodes. The next "level" is Stage III. At Stage III, breast cancer is more than 5 centimeters, and has spread to other breast tissue and nodes. At Stage IV, the cancer has already spread to other parts of your body. Knowing your breasts leads to a higher probability of early diagnosis, which could mean saving your life, and the lives of yet unborn generations. Don't take any chances.

2. Become Educated About Breast Cancer. For most of us, words like cancer and death are most unpleasant to hear. No one likes to think of being ill or dying; however, when it comes to your health and breast cancer, education is key. According to www.breastcancer.org, all women have the potential for cancer in their bodies. I didn't know that before I began my journey. I thought that if no one in my family ever had it, if I exercised, ate healthy, and lived a positive lifestyle, I would be okay. However, there are other factors, like high stress, the environment, diet or medicines that can increase the risk of breast cancer. You can't afford to live without knowledge that can save your life.

This means that when you visit your doctor, ask for information about breast cancer. Ask what you can do to lower your risk. There has been a multitude of research done about breast cancer. There are websites like www.breastcancer.org, www.cancer.gov, and www.komen.org, among others provide valuable knowledge and resources. I am sure that you have heard the overused phrase "knowledge is power". Your quest for knowledge can lead to a cure that could save the lives of the women and men in your life. Yes, men get breast cancer too. If you're surprised then you're not educated enough on the topic. Do your research.

3. Exercise Personal Responsibility. What this means is that with knowledge and education come responsibility and accountability - responsibility and accountability to yourself, your loved ones, your daughters, future generations and society as a whole.

And, for those of us who have been diagnosed with breast cancer, we have the biggest responsibility of all - to tell our story - because we are in a position to apply the lessons we have learned, not as victims of this disease, but from a position of authority and strength, as women redefining our lives and those of others in the world around us.

After my second chemotherapy treatment, I knew I had to do something to change the way people perceived breast cancer. My life was different now. It had new meaning and purpose. There were millions of women dying from this disease and I was not going to stand idly by. A part of me now felt responsible to all the women who would be diagnosed, even as I celebrated and rejoiced in my healing and reclaimed my life. Today, my life is dedicated to connecting with other survivors, the breast cancer community and working to eradicate this disease. In June of 2007, I founded Tigerlily Foundation (Tigerlily) (www.tigerlilyfoundation.org), which is dedicated to doing just that. As a partner with other organizations, Tigerlily promotes breast cancer awareness globally, and advocates for survivors and families of those who have lost their lives to this disease. We are all interconnected. At some point, this disease will touch us all. Become more aware - for yourself and for those you love. You never want to get that call.

I would never wish breast cancer on anyone, but I am thankful for my experience and would never undo it. Going through breast cancer and the subsequent treatment not only cleansed me of the cancer in my body, but what I like to call life cancer - cancerous people that were in my life and situations that were not beneficial to me. Whether it is a friend that sees your sun rising and tries to put you down, a spouse that does not support you or is abusive, family members that bring negativity, any relationship that does not

reflect value, support, love, uplift you, or leaves you feeling diseased - those situations and people need to be eliminated immediately. Life is meant to be lived – fully. You must be alive, authentic and connected with positive things and positive people. Your flower can't bloom if it is in a bed of weeds. Cut out the cancers in your life.

I have never felt more alive and than I do now. I was living my life asleep, now I am truly present; I can see and appreciate all the beauty and wonder around me. Today, I live in gratitude for every moment. Every time I look at my daughter's face, I give thanks to the Universe. Every time I see someone smile, I give thanks. Every morning when I get out of bed, I realize that I have a choice in how I will live my life and I promise myself that I will live it well. With every breath that I take, I choose to create something better; for the truth is this – it is not how long we live, but how we live every moment that determines the fullness of a life.

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