

Surviving Breast Cancer Mistakes and All

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INTRODUCTION

I was diagnosed with breast cancer and didn't know what to do. Cancer was an unfamiliar topic for me and it was an unknown illness that happened to someone else. Where would I turn for the information, the comfort, and the support that I so desperately needed? I leaned on many people during my battle with cancer and I would like to take this opportunity to thank them. My struggles would have been harder, lonelier, and more uncertain without them in my corner.

To my daughter, Michelle, who visited me every day even though she had a family of her own to take care of and college courses to maintain. She always found the time to drop by and read to me or massage my weakened legs. Her unwavering support was a constant source of strength for her father and for me. Michelle also brought my then two-year-old grandson, Michael, in for visits so that he would not forget who I was—which was very important to me.

To my son, Scott, who visited me in the early morning hours on his way home from work as a deputy with the Sheriff's Department. He worked the midnight shift and, though he was exhausted, he would quietly wait in my room until I woke up. The mornings were our special time together though few words were spoken. Even without communicating, we shared our feelings, our doubts, and our hopes. I was also thankful for the times he brought my granddaughter, Darbee, in for visits. She was born just two months after my diagnosis, and she was always a precious reminder that life continued.

To my brother, John, who brought Mother in to see me as she no longer drove. And for the many meals he delivered to the hospital from his deli when he came to visit so that Michael could have a break from hospital food.

To my brother, Dave, who rarely missed a day visiting me and always found ways to keep my spirits up. And for the laptop computer that he loaned Michael so that he could correspond with the outside world while he stayed with me in the hospital.

To my brother, Tim, for the courage and patience it took to feed me despite my anger and refusals. For him, no challenge was too great. And for the humor he portrayed throughout his many visits no matter what went wrong.

(Was I imagining it or did the nursing staff have a difficult time telling you guys apart when you were wearing your face masks?)

To my sister, Patricia, who dropped by for visits and took dirty clothes home to wash. And for the many card games we played to keep my mind distracted but alert.

To my sister, Jan, who brought homemade meals for Michael to enjoy when John couldn't and for the tasty health drinks she made me to supplement my intake. For the many times she questioned my medical care and helped Michael sort it out.

To my mother, Marjorie, who called everyday (whether I could answer the phone or not) and visited whenever she could. I was always reassured in her presence and felt stronger after her visits. For all of her financial support as well. It helped not having to worry

about where the additional money would come from when it came time to purchase special clothing, a much-needed wig, or life-enhancing drugs.

In addition, to my family, I want to acknowledge two very special friends from church. To Jody, who assisted me every step of the way as I went through this anguish. She unselfishly called or came by to see how I was doing while offering encouragement and hope. Her knowledge and experience with hospice was a great comfort and resource. I could tell her what I thought and how I felt without being embarrassed. She empowered me when she stated, “There is no such thing as a wrong feeling or a stupid question.” Whatever feelings I experienced were right for me “at that time.” And in being reassured—I could be truthful to myself.

To Sister Maureen, who brought me Holy Communion most every week while I was hospitalized. She knew how much my faith meant to me and was always available to pray with me or to just talk. She encouraged me to record my thoughts and feelings and gave me a journal in which to do so.

To my coworkers, who donated sick time when my hours ran out (it didn’t take long to go through four-hundred-plus hours). To be guaranteed a check each week was one less burden for Michael and me to contend with as the bills piled up. (Too bad there can’t be a time-out on bills while there is a time-out on living.)

To the members of my parish who delivered meals to my home each evening during the first weeks of my recovery.

To the people I didn’t personally know, but who kept me in their prayers. These included a prayer group in Detroit, an Indian prayer lodge in Arizona, and a local Buddhist Temple. I firmly believe in the power of prayer and sincerely appreciate the numerous prayer chains and novenas offered on my behalf. And, to leave no stone unturned, added to this mix of petitions was an Indian power shield that my friend, Nancy, gave me. In Native American culture, a power shield is used to help promote and protect a person’s good health and serenity. I consider all beliefs and intentions worthy of consideration.

Last but not least, I want to thank my husband, Michael. No matter what written words I use to describe all he did for me, it wouldn’t come close to the truth. He was my constant in a world that suddenly changed. He was my provider and my motivator. He literally saved my life, and if not for him, there would be no story. For without him, there would be no me.

These are just some of the ways in which my family, friends, and coworkers offered me their love and support. Their help made all the difference, and I achieved what I did because of them. A strong team is essential in any battle, and cancer is no different.

It is my wish that in reading this story you will find solutions where there are questions, encouragement where there is doubt, and hope where there is hopelessness. You are not alone.

PROLOGUE

When I am asked to talk about my experience with cancer, I’m never quite sure where the story begins. It seems a lifetime ago that I was fighting for my very existence. Many times I wonder how it all happened. I was forty-eight-years-old and going through life

doing what I considered all the right things to stay healthy. I exercised everyday, ate fruits and vegetables, and had quit smoking for over twenty years. Suddenly this disease overtook me from the inside and it was all I could do to stay ahead of it. It became a struggle just to remain a functioning person. All the daily tasks that I had taken for granted were no longer possible.

Stop for a moment and think about how you would feel if tomorrow you couldn't tie your own shoes or get dressed without help, you could no longer feed yourself or take a drink of water without assistance, but most of all, what if you were unable to walk or communicate? Even after all this time, I can see myself in that wheelchair envying others and wondering if I would ever be normal again. The feeling of desperation I felt every time I couldn't feed myself or sit up on my own was overwhelming. It was a nightmare from which I didn't know if or when I would ever wake up.

This is not a story about right or wrong. It's not a story why I survived and someone else didn't. It's a story about coping with life and what it throws at you. It's about staying on the right path through hardships and disappointments. It's a story about surviving cancer.

I am not in the medical profession and therefore may have some of the terms and descriptions wrong. I am not a mind reader and, therefore, may have misunderstood peoples' true motives and thoughts. But I am the survivor in this story and it's a story I need to tell.

This story was written to help people understand that no matter how hard life's journey has become, it is worth the fight. There were times when I wanted to give in to the exhaustion and the pain; I would feel sorry for myself and want to quit. But then I would be reminded of all I had to live for, such as a husband who counted on me, children who needed me, and grandchildren who deserved to be spoiled. In the end, I ultimately picked myself up and pushed forward again.

This story is also a resource for those who may find themselves traveling a similar path. When I first learned I had cancer, I had no one to turn to. I had only known two people with cancer and neither one talked about it. I wasted a lot of time and energy lost in a maze of confusion. I didn't know where to direct my doubts or my questions. I realized that it was up to me to search for the answers that would help me make the right decisions. I quickly sought out survivors and talked to them about how they handled the nausea, the hair loss, and the emotional turmoil. They taught me that the grief and fear I felt was normal and that someday the panic would dim. I was searching for a reassurance that I could believe in a future with some degree of hope.

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“THE BIOPSY SHOWED A MALIGNANT CANCER”

“The results of your mammogram showed a small cyst on your left breast. Come back in six months,” my doctor said. I was frantic. Deep down, every woman fears those words and I was no different. I could barely breathe as I sat on the examination table letting the words sink in. I was only forty-eight-years-old and I was healthy. There had to be a mistake.

I felt frozen and empty as I heard the news and went into denial mode. I falsely convinced myself that the doctor had to be wrong and there was no reason for worry.

After more discussion, I reluctantly agreed to additional checkups, but I would put any thoughts of cancer and death out of my mind. I would get on with my life as normal and not look back. This thought process was proven correct when my next two mammograms over a twelve-month period showed no change in the cyst. There was no reason to worry.

On May 17, 1999, I went for my next annual checkup which included the mammogram. As my last mammogram had only been eleven months earlier, I wasn't too concerned. This was a routine procedure and would soon be behind me for another year. However, that thought quickly changed when I received a telephone call later that same day from my doctor's office. I was asked to make an appointment as soon as possible with a surgeon to go over the results.

Somehow, I had missed a step. Wasn't I supposed to go in and see the doctor first? Wasn't he supposed to inform me of the findings and offer suggestions? Why was seeing a surgeon suddenly so urgent? As these thoughts ran through my mind, I started questioning the nurse and asked her if the cyst had grown or changed in any way. She explained that she could not give me any information over the phone and I was left with no choice but to make an appointment for my surgeon's earliest availability—two weeks away. As I hung up the phone, the fear started to build and spread like wildfire throughout my body. It was a different feeling from before, more desperate and real. What if something was really wrong and this wasn't another false alarm?

May 17 is also my husband's birthday and we always celebrated with family. Michael and I discussed the doctor's phone call and decided there was no reason for anyone else to worry. Best case scenario, it was another false alarm; at the worst, we would have plenty of time to tell people. Ignoring reality, we agreed to believe that this would be another benign cyst and nothing in our lives would change. In fact, we convinced ourselves that it couldn't be anything else. How could there be a more serious problem when everything was fine just eleven months ago? There was no family history of cancer and I always took care of myself. I was too young and too healthy for cancer.

June 1 found Michael and me at our first meeting with the surgeon. As she explained the need for a biopsy, I questioned why she kept referring to my right breast as the problem. The left breast had the cyst. The surgeon explained that the right breast was the area of concern and the cyst in the left breast was unchanged. This couldn't be, I thought, because cysts don't jump around or grow that quick. I tried to tell her that she had the wrong film and that she needed to talk with someone else about having cancer, not me. But she continued to explain the test results and realization finally sank in. I needed a biopsy.

I fluctuated from thoughts of the biopsy being a waste of time to thoughts of it couldn't be done soon enough. I found it hard to contain the fear that consumed me or the panic that was gaining control of my emotions. Every breath I took was one of desperation. How could anyone possibly understand what I was going through?

On June 15, the biopsy was performed. We arrived early and checked in with the hospital outpatient area. Michael was asked to wait while the staff directed me to a small curtained-off room filled with shiny equipment and unfamiliar faces. I was told to lie on my stomach upon a long, cold metal table. Designed into this table was an open area where I placed my right breast. This hole made it easier for the pathologist and/or his

technician(s) to manipulate my breast and insert a needle to remove a sample of the suspicious tissue. Though it seemed like hours, only a short time had passed before the biopsy was completed, and Michael and I were told to come back the next day.

Within twenty-four hours of the biopsy, we headed back to the hospital and received the results. The moment I saw the pathologist, I sensed something was wrong. He had walked into the room, looked around, and left without saying a word. There was no eye contact or communication of any kind. I felt like a shadow on the wall—invisible and unimportant.

Within a few moments, the pathologist returned with his nurse and asked me to lie on the examining table. He stood by my side and started patting my leg as he informed me the biopsy showed a malignant cancer. From shell-shocked eyes, I frantically looked for Michael but was unable to find him. The news had been delivered so fast that Michael was still behind me and unable to reach my side. We both felt disconnected and alone.

After a brief explanation about the malignancy, the pathologist informed me that he had already talked with my surgeon. An appointment had been made for me to see her the following morning for some baseline tests and to discuss my options. His manner was cold and unemotional. There was no compassion or empathy of any kind. It was business as usual as he abruptly left the room. There was no time for “I’m sorry,” or “Do you have any questions?” As I got off the examining table, I became aware of the silence that hung in the air. I cautiously turned toward Michael and saw that he was in the same state of shock and disbelief that I was. This couldn’t be happening. Someone had made a mistake!

I had driven my own car to the appointment because I had planned to meet Scott for lunch (the report was no big deal, so why interrupt my life, right?). As I drove home, I called Scott to cancel our lunch plans and told him that I just didn’t feel up to it. I was doing okay until he started asking about the biopsy results. I realize that there was no easy way to tell my children that I had a life-threatening illness, but I wish I had waited to tell them both in person. Instead, I started to cry uncontrollably and then blurted out that I had cancer before hanging up on him. He proceeded to call Michelle, and again, the news was delivered over the phone. Soon they were both calling to ask what they could do to help. I explained that I needed time alone and would see them later.

Once I arrived home, Michael greeted me at the front door and said he was going to stay home with me instead of going back to work. I asked him to also give me some time alone so that I could come to terms with having cancer. I knew that I had to face my emotions honestly before I could talk about it with anyone else. After some hesitation, Michael left for work but emphasized that we would get through it together. I knew our love was strong and I could always count on him, but at the same time I felt very isolated and alone. I was filled with an overwhelming sense of dread and desperation as I struggled with the belief that I was going to die. I didn’t see much of a future and prayed that I would be allowed three more years—just three years to get my life in order.

I tried to calm down and get control of my fatalistic thoughts. I knew I needed to think beyond the present moment and believe in a future. I filled the tub with hot water, lit fragrant candles all around the room, and put on some music, something soothing and without words. I went over everything that I had ever been told about cancer and tried to

make sense of it all. I spent most of the afternoon in that bathroom crying, thinking, and crying some more. I still had a difficult time believing that this had happened to me. I had doubts about being strong enough and I didn't know if I wanted to try. I questioned everything I had heard about cancer. If I had to have chemotherapy, how bad were the side effects going to be? Was I going to lose my hair? Would I lose my breast? What lasting effects was all this going to have on me? How I was going to tell my mother and the rest of the family? I saw my life shattered before me and I didn't know how to put the pieces back together. There seemed to be no answers.

TIPS TO CONSIDER: Take the time to question your doctor, your surgeon, or your pathologist as you are going through the biopsy and the results. Questions unanswered can cause unnecessary frustration and unwanted baggage. Don't keep quiet with your doubts and confusion. Ask for explanations and help.

Your comfort level is more important than the doctor's; insist on having your support person with you at all times and don't be rushed.

Faith is the realization of what is hoped for

And evidence of things not seen.

—Hebrews 11:1

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NOTIFICATION

The next morning, Michael and I were back in the surgeon's office. We discussed the benefits of a lumpectomy versus a mastectomy, we learned what happens if the lymph nodes were positive versus negative, and we scheduled the surgery. There were many decisions that had to be made and we suddenly had to rely on someone else's opinion instead of our own. We were the novices with no expertise and no time to research. But what was the rush? Would a couple of weeks really make a difference? Once these basic medical decisions were made, we started dealing with the insurance company to learn what oncologist, radiologist, and/or hospital our insurance allowed.

The next day I had planned to meet with my siblings. In the last few months, we had all started seeing signs of age-related problems with mother and knew steps had to be taken soon. We had scheduled this get-together before my biopsy appointment had even been made and it seemed like fate that I would now use this opportunity to tell everyone about my cancer. Although I had doubts that I was emotionally prepared to discuss this so soon, the time was now—like it or not.

Everyone was there: John, Dave, Tim, Patricia, and Jan. We casually sat on the floor eating pizza and drinking beer. I tried to concentrate on the issues being discussed but not much was sinking in. After a couple of hours, the discussion came to an end and someone asked if we needed to discuss anything else before leaving. I quietly spoke up and stated, "There is one more thing we need to talk about. How are we going to tell Mother that I have breast cancer?" I saw the tears and disbelief on their faces as I shared the news. They all asked what they could do and offered their support. Little did I know how much I would come to rely on their love and support over the next nine months (how appropriate for a new life).

The next order of business was to tell Mother the news (my father had passed in 1997). Michael and I made arrangements to meet my sisters at Mom's house on Saturday, June 19. The plan was to tell Mom I had cancer and what decisions I had made, and then leave Patricia and Jan to handle the questions and the emotions. I knew I wasn't strong enough to deal with any more tears, hers or mine. As I left the house, I heard Mother crying and realized again how thankful I was for my family who was already doing so much.

The following Monday, I informed my workplace of my illness and filled out the necessary paperwork to secure my job under the FMLA. Because cancer is a life-threatening disease, the FMLA (Family Medical Leave Act) would hold my job in case I had to be away from work for an extended period of time. I had no expectations of being away from work and using the FMLA, but it was a necessary precaution in case something went wrong. After all the paperwork was completed, I sought out a friend who worked in the office. I needed to talk to someone who wasn't a family member and someone I didn't have to act for. This was a convenient opportunity. Terry and I didn't talk long however, because I quickly became too emotional. Having cancer was still very hard for me to discuss. I left work knowing that word would soon spread about my illness, but I didn't have the energy to care. I needed to concentrate on what was right for me and what lay ahead, not what was in the past. It was now time to prepare myself for surgery.

TIPS TO CONSIDER: Share your insights and feelings with whoever is your support system. Help them to feel important to you and what you are going through. Don't be afraid to ask for assistance.

Put yourself first.

For then you shall forget your misery,
or recall it like waters that have ebbed away.

Then your life shall be brighter than
the noonday;
its gloom shall become as the morning,
And you shall be secure, because
there is hope;
you shall look round you and lie
down in safety.

—Job 11:16–18

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COVERING THE BASES

For the next two weeks, my life went on as normal—or at least as normal as I could make it. But no matter what I was doing, I couldn't get the word cancer or death out of my mind. I felt it with every fiber of my being and with every breath I took. The depth of desperation that I felt went beyond words. It was like being in a pit of endless black and

not knowing which way to turn. In the absence of light, it was hard to stay focused on the right path.

One afternoon before surgery, I arranged to have lunch with Scott. I wanted him to share his thoughts and feelings about my cancer and how it was affecting him. I knew he was having a difficult time accepting the news and he was angry. At one point during the lunch, Scott looked at me strangely and asked how I “would ever go to church again because of what God did” to me. I was shocked by this statement and that his thinking had taken that route. It never occurred to me to blame God or that anyone else would. I tried to help Scott understand that cancer happened to me for a reason and I was determined to win. In helping him to accept this belief, I also helped myself.

I had always been an introverted person, and it was very hard for me to ask for advice or assistance. But I knew early on that only a cancer survivor could provide me with the information I needed. I hoped that in learning from their past I guaranteed my future. I forced myself to make uncomfortable calls and attend support-group meetings. I continually strived to reach outside my comfort level and it became easier over time.

My need for knowledge and answers quickly expanded to the Internet and to books. Much of the information was helpful, but distributed between the good was the bad. Some of the material was so disturbing that a feeling of hopelessness would cover me like a heavy blanket that never went away. It was all about complications, hardships, and death. I became so afraid that I wanted to give up before I had even begun. If I was going to survive, I needed information with a positive message. There was enough negativity within me; I did not need to keep reading about it.

I talked openly about my cancer when people asked questions. There was nothing to be silent or ashamed about. I knew that most people were genuinely concerned and wanted to understand. And the ones who stared at my baldness or made cruel comments were soon ignored. I didn't have time for insensitive people, and what they didn't understand was that someday they could be wearing my shoes. Cancer didn't discriminate.

I explored many possibilities for coping with cancer. I was open to anything that brought me hope. I attended healing Masses and wore a medal of St. Peregrine (the patron saint of cancer) that my sister, Jan, had given me, and I hung a Native American medicine wheel on my wall that my friend, Nancy, gave me. I tried to cover all the bases and provide myself with not only the mental and emotional health but the spiritual as well.

As word got out that I was sick, people started sending me cards and letters of support. At Michael's suggestion, we displayed each card on the dining room table to be read and reread. Soon, the top of the table was covered. I couldn't believe the number of people who cared enough to take the time to send a card and wish me well. Whenever I was in a low mood, I would go into the dining room and read one of the cards, letters, or e-mails. I found encouragement in each message, and many times it was just what I needed to keep going. I was not in this alone!

TIPS TO CONSIDER: If you are the friend, family member, or coworker, take the time to send a note. Make it cheerful or funny. You would be surprised at just how much that small gesture could mean.

If you are the survivor, display your messages of love and support wherever you can. Openly remind yourself that you are in people's thoughts and prayers.

Prayer to St. Peregrine

(Patron Saint of Cancer):

O God, in Saint Peregrine You gave us an outstanding example of faith and patience, we humbly ask You that by imitating him and by the help of his prayers, we believe more fully in Your healing help, bear the suffering of this life without wavering, and come with joy to the peace of heaven. We ask this through Jesus Christ Our Lord.

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ADJUSTING FROM SURGERY

July 1, 1999, my surgery date finally arrived. I had decided to have a lumpectomy with node biopsy because it was less radical than a mastectomy and I had been assured that the survival rate was the same. I knew I would have to have radiation if I chose the lumpectomy, but I felt that it was an acceptable trade-off. I convinced myself that because a lumpectomy was less invasive, it wasn't as serious.

Michael and I drove to the hospital where we met Michelle. I was so absorbed with conflicting thoughts that my walk became slow and awkward. One minute I would be optimistic and believe everything would be okay and then the next second I would spiral downward and believe my luck had run out. It became difficult just to put one foot in front of the other. I was a bundle of nerves with no immediate relief in sight.

Scott as well as other family members arrived throughout the day to join in the long, tedious wait.

Before going into surgery, I had to have a "wire local." This is where the doctor inserts a very thin wire into the cancerous breast to pinpoint the exact location of the tumor. This procedure helped the surgeon get as close to the tumor as possible and not take any more of the breast than was necessary.

I was back on the same table as when I had the biopsy and the memories were not comforting. My recollection was crowded with images of doom and gloom. Before I knew it, I was given a shot to numb the breast and the procedure began. The pathologist had barely started to place the wire into my breast when the nurse noticed that I was in pain. Everything then stopped in order to administer more drugs.

The second shot did very little to relieve the pain, but there was no choice but to continue. The wire was again slowly inserted into the area of the tumor. At the end of the wire was a tiny metal clip that would be deposited into the affected site once the goal was reached. This clip would appear on a monitor during surgery to direct the surgeon's hands and minimize the guessing. Once this procedure was completed, and before the clip was dropped, I was given a mammogram (on the breast with the inserted wire) to ensure that the wire was where it was supposed to be in relation to the tumor.

Michael, Michelle, and I waited in stony silence for the film to be developed. There were no words to ease the fear. It hung stagnant in the air around us. "I don't think I can go through with this," I said honestly.

The mammogram results brought more bad news. The wire was not as close to the tumor as the doctor desired and he wanted to reinsert it. I repeated to the pathologist what I had said a few moments earlier in the waiting room. "I can't go through that again. It was too painful." He told me that the choice was mine, but the closer he could get—the better for surgery. He promised to give me more drugs to numb the area even further. I reluctantly agreed and the procedure was done a second time. Now it was time for surgery.

I don't remember much as I waited for surgery to begin. But I do remember being surrounded by people, yet feeling alone, and being afraid to get started but wanting it over with. I couldn't see beyond my own curtained-off area, but I could hear other patients being reassured as they were taken to surgery. Soon it was my turn and sleep came easily.

While I was in recovery, the surgeon told my family that all had gone well. We would know the next day if there were any positive lymph nodes (positive lymph nodes would mean that the cancer had spread outside the breast into the lymph system). She reassured them that she was able to get a "clean margin" and believed that she had gotten it all. Everyone felt relieved and thankful.

I was relieved, as well, when I heard the news. The cancer had been caught early and I was going to be fine. There was no reason to think otherwise. I held on to this thought because it kept me in Stage 1, and I wouldn't have to go through chemotherapy. My surgeon had told me that the decision to have chemotherapy or not would be mine if there were no positive lymph nodes. My answer was no.

After I checked out of the hospital, I went home to wait for a phone call that determined my future. The hours stretched by endlessly as Michael and I paced the floor and waited for the phone to ring. It was late afternoon when the surgeon called and informed us that I had positive lymph nodes. I was Stage 2. In an instant, my world changed again.

On July 6, Michael and I again met with the surgeon to see how things had progressed and to have the drain tube removed from the surgical site. Needless to say, I was still in shock. I had walked around in a daze for five days and needed answers. This was my opportunity to ask how all this happened so fast. How could I have a clean mammogram in June of '98 and now have a two-centimeter tumor with positive lymph nodes in May of '99? My surgeon picked up the mammogram film from 1998 and closely reviewed it. She pointed to an area and said, "Here it is, right here." For the first time since my ordeal had begun, I was angry. If the infected area was that obvious, why hadn't the doctor, the pathologist, or whoever read my film caught it in '98? Did they see the cancer and neglect to notify me? If there had been any concern, no matter how slight, couldn't they have monitored the area and ask me come in every six months to check for changes? Someone had carelessly overlooked the cancer and, in doing so, changed my life forever, and I was being forced to deal with their carelessness in a serious, life-threatening way.

A week after surgery, I went back to work and started exercising again. I wanted to stay as healthy as I could to face what was to come. Besides, for my own peace of mind, I needed to get back into a routine and exercising an hour a day was something that I had always done. If I acted normal, maybe my life would be normal.

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