



Contents

Acknowledgments	v
Introduction	1
My Story	1
Family First	2
My Amanda	3
Our Tragedy	6
My Family Grows	9
My Career	10
My Fight Continues	12
Anne's Reflection	13
Chapter 1. The Cancer Diagnosis	15
Chapter 2. Getting on With Life	45
Chapter 3. The Return	49
Chapter 4. Happy New Year!	125
References	165
Photos	177



Chapter 1.

The Cancer Diagnosis

September 2, 2009

Today is my youngest daughter Ashley W.'s 17th birthday. Today is the day I hear those words every woman dreads . . . "You have breast cancer."

I talked to Carol at the oncologist's office at around 9:30 am. She is the oncology nurse who told me the news by phone (as I requested when I was in the office). She said I have infiltrating lobular cancer, the second most common type of breast cancer. All I could say was, "Oh shit." I joked with her about not saying the "F" word. She told me a lot of people say it. I'm sure it will come out of my mouth sooner or later. She also told me that my tumor is estrogen receptor positive (ER+), meaning the circulating estrogen in my body is feeding the tumor.

Despite being the second most common form of breast cancer, invasive or infiltrating lobular carcinoma occurs in only 10%–15% of women with breast cancer. It often is multifocal with irregular borders and feels hard to palpation. The hormonal status of the tumor also is very important; Liz's tumor was ER+, meaning the tumor needs estrogen to grow. This is a good sign, as these types of tumors usually are sensitive to medications that reduce the amount of estrogen in the blood, a hallmark of adjuvant endocrine treatment with drugs such as tamoxifen and/or aromatase inhibitors (see pp. 46–47) (Yackzan, 2011).

It doesn't really feel like I have a tumor. There were tiny calcifications on the mammogram I had on August 20 (my husband's birthday) that were not there last year. I have these mammograms done religiously every year. I didn't feel anything, and you could barely see anything on the film. The physician I see every 6–12 months for this testing saved my life by seeing these tiny dots. I plan to send her a thank-you card (which I did).

Screening mammography is used in healthy women with no family history of cancer as part of routine preventive health care. The frequency of these mammograms is a controversial topic. Recent recommendations from the U.S. Preventive Services Task Force (2016) state that mammogram screening every two years in women aged 40–49 should be done based on an individual woman's values and circumstances (that is, not routinely). For women aged 50–74, screening should be done every two years; it is this age group that sees the maximum benefit from screening in terms of mortality. Harms associated with screening exist, including psychological effects, increased imaging and biopsies, high false-positive results, and unnecessary treatment and radiation exposure (U.S. Preventive Services Task Force, 2016). Reducing the frequency of mammograms to every two years decreases these harms by half while retaining the benefits of annual screening.

The American Cancer Society (n.d.) recommends a slightly different schedule for screening, with yearly mammograms beginning at age 45, then reducing in frequency to every other year at age 55 or annually depending on individual preference.

Many women and healthcare providers question these recommendations. Changes in breast tissue can happen in the intervals between mammograms, as Liz experienced. Women may be fearful that a longer interval between

screenings may result in a bigger tumor and/or a later stage at diagnosis; however, for some women, lengthening the time between mammograms appears to make little difference in outcome and may lessen the anxiety of having the screening test.

The other kind of mammogram is called a diagnostic mammogram. This essentially is the same technology, but the images are viewed in real time. A radiologist will ask for additional images if something abnormal is seen. This may result in a biopsy from a concerning area of breast tissue, which is then examined by a pathologist. A biopsy is a definitive test for breast cancer, confirming or excluding its presence.

I came home and talked to Hipp (my husband) and Patty (my sister). I got a bit tearful as I was apologizing to my husband for “defective merchandise.” We have been married for only two years. He told me not to be ridiculous. My sister and I ended up laughing, as I was really making fun of myself. I’m going to rely on these two quite a bit. I have so many things planned for September and October—two conferences, two classes at school, etc. I decided not to cancel or rearrange anything today because I don’t really know enough details yet of what will happen to me. I put on a happy face and went to lunch with Ashley W. (my biological daughter, as she calls herself), Ashley E. (my stepdaughter), and a bunch of their friends to celebrate Ashley W.’s birthday. It actually was fun, and I did all I could to block the news out of my brain.

I told Patrick (my son) when he got home from work. As my oldest child, he deserved to know first. I explained to him that I would not be telling the Ashleys for a few more days. Between Ashley W.’s birthday today and the first day of school tomorrow, I did not want to cause them any more stress.

FYI—I have called my breasts “the girls” ever since I can remember. I named them Thelma and Louise (from the movie). Thelma, on

the right, is the bad one (where the cancer is located). Louise is on the left. I always joke around about them with the Ashleys and their friends. I even asked my friend Monica how her new “girls” were when I saw her on August 9, as she just had reconstructive surgery after going through this same nightmare.

September 3, 2009

I went to the breast center in my neighborhood, which is part of a university and multihospital organization, to get a breast MRI (actually, both breasts). I saw the words on my forms, and it started to sink in . . . “Newly Diagnosed Breast CA.” It started to feel much more real.

A magnetic resonance imaging (MRI) study is a highly sensitive scan used (in addition to traditional mammography) to identify physical characteristics of a tumor. It has a higher rate of false-positive results and generally is not used as a screening test for breast cancer. It is used in women with newly diagnosed, biopsy-proven breast cancer to check if there are other small tumors in the breast and/or if the contralateral breast is cancer-free.

This wonderful nurse, Carol, came out to meet me. She is the woman who gave me the news yesterday over the phone. She almost started to cry. She gave me a big hug and then handed me this whole packet of information to read. Wow. It *is* real.

I then met Mel, the MRI technician. She started an IV and ushered me back to the room. When she put in the needle, it really hurt. I asked her, “Was that a 12-gauge?” (For all of you nonmedical people, this is a larger needle used for trauma patients.) She said, “No, it’s only a 20-gauge (which is small).” Holy crap. If a 20-gauge nec-

dle hurt, what the hell am I going to do about real pain? I hate to be in any kind of pain!

I had to lie on my stomach with “the girls” hanging down through two separate holes. It actually was pretty funny, and I joked around with Mel about it. I quickly saw that I will lose any of my modesty. After about 40 minutes of very loud banging noises, I was all done and had one hell of a headache. I joked around some more about the headache and told Mel she will be in the book I plan to write. After I was dressed, I saw Dr. G. out in the hallway. She was jogging outside between appointments and was all sweaty. She came over and gave me a big hug. I didn’t even mind the sweat. She was the physician who did the biopsy on August 28. She said she was so shocked that the pathology report came back showing cancer. Me too.

Waiting for the results of diagnostic testing is highly anxiety provoking and distressing (Montgomery & McCrone, 2010), even with an understanding of the medical issues, as Liz has. Anxiety exists during the testing phase of the diagnostic journey and is decreased only by a benign result. If results show that the person has cancer, anxiety remains high, no matter how quickly the process unfolds (Brocken, Prins, Dekhuijzen, & van der Heijden, 2012). Distress is very common in women newly diagnosed with breast cancer. In one study, 77% of women studied reported distress, manifesting as worry and nervousness (Mertz et al., 2012).

Labor Day weekend, 2009

We had my mom (Helen), my dad (Bill), my brother (Charlie), and some friends over this weekend. We swam, cooked out, and had a great bonfire on Sunday evening. The weather sucked all day Mon-

day (rain), so we stayed inside. I played cards with my mom, which was fun and reminded me of much younger days! Having all of us together was very encouraging for me. Even though I was so afraid to have any surgery, it was reassuring to know that my family was going to help me however they could. I still am very frightened and unsure about what happens next. Will I need chemotherapy? Will I lose my hair? What are my chances for survival?

Coping after a diagnosis of cancer has been widely studied. How a woman copes in the initial days and weeks after hearing the words “you have cancer” may affect her ultimate survival. Watson, Homewood, and Haviland (2012) concluded that poor coping may lead to a poor outcome. The converse, however, does not apply; good coping does not mean better survival. The authors concluded that poor coping is associated with depression, sleep and appetite disturbances, unhealthy lifestyles, and an inability to ask for and access help—all of which may contribute to poor outcomes.

Other researchers have found that a sense of personal control is a positive factor (Henselmans et al., 2010); women who have a greater sense of control in their lives are more engaged in their social lives during active treatment, helping them to control anxiety. Controlling anxiety through distraction and by accessing social support when necessary may lead to better long-term outcomes. How a woman initially reacts to a diagnosis may influence her well-being as many as three years later (Hack & Degner, 2004). These researchers found that women who respond to a breast cancer diagnosis with passive acceptance and a resigned outlook have poorer long-term adjustment.

One of the critical tasks for women after a cancer diagnosis is maintaining a sense of self-integrity after the shock and threat to life (Lally, 2010). This is theorized to happen

through a process of acclimating to the diagnosis by surveying the situation, taking action, and emerging as a new person, stronger than before.

September 8, 2009

Today is my second wedding anniversary. My husband has been terrific so far with this mess. I know that God brought him to me in preparation for this latest battle. I really am blessed, even with this latest challenge. God must have other plans for me. Today, I thought a lot about my kids and my husband. As a blended family, we still are working through some issues. I can't imagine the four of them (my two children, my husband, and his daughter) trying to get along without me there as the peacemaker. It was a very scary feeling and one that I quickly dismissed.

The support of a spouse and other family members is very important during the diagnostic phase and through active treatment. Most spouses are supportive, but evidence exists that conflict can arise, particularly as treatment continues over months. In one study (Sprung, Janotha, & Steckel, 2011), some spouses became abusive and controlling; however, this may have been reflective of their usual personality traits. *Couples coping* is based on how each member appraises the threat from the cancer, how they communicate their fears, and how they create meaning from the experience. Of particular interest from this study was that some participants felt that their healthcare providers missed opportunities to address stress within their relationships. This occurred when professionals either ignored statements from the patient or did not offer support to the partner/spouse, even when it was disclosed that the partner was experiencing stress. Evidence exists of

interdependence of patient and partner distress as they adjust to the diagnosis, particularly in physical symptoms such as loss of appetite and nausea (Segrin & Badger, 2014).

Family members may have a variety of unmet needs, including their own emotional response to the diagnosis and the accompanying distress. They may need help with accessing information about the cancer, the treatment options, and what to expect (Schmid-Büchi, van den Borne, Dassen, & Halfens, 2011).

September 10, 2009

I'm finding it very hard to concentrate today, as the thought of cancer fills my mind. In 2008, I started an online program to get my doctorate. Right now, I have two weeks' worth of homework due by Sunday night. I just can't get into it. Instead, I am doing some research on breast cancer.

September 10 was supposed to be exciting, as it's the date of the first Steelers home game since their sixth Super Bowl win in February 2009. Instead, it now has more personal meaning as "the day before I see the surgeon." However, I still plan to enjoy the Steelers game tonight and will try to worry about that other "stuff" tomorrow.

GO STEELERS! Trash those Titans!

To keep reading, purchase your copy from www.ons.org today!