

A PATHWAY THROUGH BREAST CANCER

from a survivor and thriver

First of all, I am sorry you are here. Its heartbreaking and scary to find yourself in a situation where you are made acutely aware of the fragility of life. When I was diagnosed with triple negative breast cancer in March 2019, I realized just how valuable it is to have good health. As I found my way through treatment, I took notes. I wanted to be able to gift others with my experience in a way that was helpful during a time when having "someone who knows" feels like a warm hug of hope.

The road to diagnosis

Finding my tumor. I happened to find a lump during a self-breast exam, late one evening. It was very unexpected. Shocking, even. I was 35. I had never had a mammogram. I was able to meet with my midwife the next day, she felt it and did not seem overly concerned but sent me for an ultrasound and bloodwork right away. I was really grateful that she took my concerns seriously.

At my ultrasound, the Radiologist told me that my tumor had some suspicious characteristics and scheduled me for a biopsy the following week. After the biopsy, I waited to hear results. This was one of the hardest parts for me, mentally. Finally, 10 days later, my midwife called. From the day I found my lump to receiving my diagnosis it took 21 DAYS!

You have cancer

Nothing can prepare you for hearing those words. My emotions were conflicting and strong. Fear, anger, sadness, envy, loneliness and overwhelming love, I felt them all. It was surreal. At times it seemed as though I was just going through the motions of life and not fully present. Those first few weeks were terrifying and just plain hard. I had to continually remind myself to hold on to hope.

Start taking notes

Once I was officially diagnosed, I became obsessed with learning about my specific breast cancer and treatment options. There were countless appointments and tough decisions to be made. New information each day. Early on, a thoughtful friend of mine gifted me with a 3-ring binder, filled with lined paper and pocket dividers. It was exactly what I needed. I took it with me to every appointment. Kept my lab reports and other important documents in it for quick and easy access. I used the lined paper to take notes, journal and write down questions to ask at future appointments. So helpful.

You have a say

Next I met with a breast cancer surgeon to discuss my options in terms of surgically removing the tumor. A plastic surgeon explained reconstruction possibilities and timelines. My functional medicine doctor served as a sounding board, helping me avoid jumping into anything with eyes shut. And I met with 2 different oncologists to talk about treatment plans. I went to a lot of appointments within that first month. It was really helpful for me to get a second opinion before committing to a treatment plan. Having a second opinion helped me feel more secure in my decision.

Ultimately, I chose a path for treatment that included the following: surgery, chemotherapy and reconstruction.

A proposed treatment plan highly depends on the type of breast cancer, along with the characteristics of the tumor(s), including staging. That being said, while there are usually a few different paths of treatment to choose from, an oncologist and/or surgeon may lean towards one. This is where a second opinion really helps, along with your own personal research. You can also switch doctors. If you are not feeling it with your current oncologist after the first appointment, meet with another one or three. This person will be "in it" with you for years to come so find someone who you feel good about.

Surgery options

Initially my tumor was thought to be slow growing, noninvasive Ductal Carcinoma In-Situ (DCIS) or stage 0. It is possible that DCIS can be cured with surgery alone so I was a candidate for having surgery completed first. My breast cancer surgeon met with me to discuss my surgery options – a lumpectomy followed by radiation, a unilateral mastectomy or a bilateral mastectomy. She expressed that the decision was completely personal, reassuring me that statistically, a lumpectomy followed by radiation and a mastectomy have similarly low local recurrence rates.

A lumpectomy is less invasive with a shorter recovery. It usually preserves much of the appearance and sensation of the breast, but additional radiation therapy is typically recommended, along with follow-up mammograms.

A mastectomy is a more extensive surgery with a longer recovery and possible permanent loss of sensation. Reconstruction is an option but requires additional surgeries. Most of the time there is no need for follow-up mammograms since all existing breast tissue is removed. After careful thought and knowing myself well, a double mastectomy with immediate reconstruction was the choice I made.

Breast Reconstruction

Breast Reconstruction is another very personal choice. Many women go flat and forego reconstruction altogether, others opt for reconstruction using implants or tissue from another place on their body. You can discuss the pros and cons of each with your plastic surgeon. Ultimately, I decided on implant reconstruction and while they do not look or feel exactly like my breasts, I have been pleased with my results. During the mastectomy, my plastic surgeon placed expanders to hold shape and stretch the skin until my implant exchange surgery which occurred 2 months after chemo ended. In my experience, the exchange surgery was a much quicker recovery. No drains needed!

Recovering from surgery

Since a double mastectomy is a major surgery it took me 8 weeks to fully recover and there were many restrictions along the way. I could not lift anything over 8 pounds including my toddler during that time. Showering was a chore. Getting dressed, almost impossible. Worst of all, I had 2 drains attached to me for 3 weeks post surgery that were annoying and at times, painful. But I was prepared. Before heading into surgery I had done my research. Scouring support groups, blogs and Pinterest, I found and compiled a list of items that might aid in my recovery.

Things that helped:

A foam wedge and a U-shaped pillow – I placed this set up in my bed and it made sleeping, as well as getting in and out of bed a thousand times more comfortable.

A recliner in the family room – I was lucky we already owned a recliner. While I didn't enjoy sleeping in it, I was grateful to have a safe and comfortable spot out in the common living area for when I wanted to be with the family. (Safe meaning, not in close proximity to others and therefore less chance of accidentally being bumped or drains being tugged).

A robe with pockets – I wasn't able to lift my arms for weeks and so getting dressed was really difficult. I loved that my robe was easy to get on and off and that the pockets could easily hold drains, if needed.

Masthead Pink Surgical Bra – I received one of these bras from the hospital after surgery and then purchased a second because I lived in them for 3 weeks straight. They are comfortable, velcro up the front and have plastic rings on each side that open and close so I could clip drains up, out of the way and hidden from view. These made a huge difference for me. I liked having 2 so that I never had to be without one on laundry days.

Button up pajamas and tops – Comfort and ease were top priorities because, for weeks, I could not lift my arms high enough to put on a regular shirt. If it didn't button up the front it was a no-go. Also, trying to pull on jeans, very difficult. Leggings and PJs all day, everyday.

A basic lanyard – Showering is difficult. I used a lanyard around my neck, with a big safety pin to clip my drains on while in the shower. I needed help the first few showers but was able to do it on my own as time went on.

Heart-shaped pillows – Lymph node removal from under my arms and swelling from surgery made it painful to have my arms down by my sides. Placing these pillows under my arms helped so much. I also used one in the car to place between my chest and the seat belt.

Salon visit – Since I was not be able to wash my own hair for a while, it was nice to have a few scheduled salon appointments to get my hair washed and styled. I went to my friend's home salon that was close by and it felt so refreshing.

Chemotherapy

This is a scary word for most people. Chemotherapy is usually the most effective treatment for breast cancer, designed to kill cancer cells everywhere in your body. It can be lifesaving but can also cause permanent damage because it cannot tell the difference between cancer cells and other fast-growing cells. I was told that the goal of chemotherapy is to shrink existing tumors and prevent metastasis. Metastasis is when breast cancer comes back and spreads to other parts of the body. Chemotherapy can be given before or after surgery based on your specific case and what your doctor recommends.

Getting through chemo

After my pathology on the tumor came back post surgery, chemotherapy was scheduled to begin shortly after I had recovered. Depending on the regimen prescribed, there are various types of chemo drugs used to treat breast cancer. Many of these drugs have similar side effects, including nausea, fatigue, mouth sores, hair loss weight gain, bone pain, constipation, premature menopause, increased bleeding and lowered resistance to infections.

Research and preparation depends on the specific chemo drugs that will be used in a treatment plan. My regimen was 4 rounds of Adriamycin (A) + Cytosan (C) followed by 4 rounds Taxol (T) given every other week. It took 3 months total. I had heard that the rounds of A + C would be pretty rough. Adriamycin is also known as "the red devil." YIKES! I wanted to do anything I could to ease my symptoms and side effects so I studied up and kept a journal of what worked well for me.

Things that helped:

Nausea – I was prescribed anti-nausea meds. Used peppermint essential oil, lifesavers, queasy pops, ginger chews and CBD oil. I also tried to avoid triggering foods and smells. For me, some days sleep was the only time I didn't feel wretched. Nausea was really rough for me throughout my A + C infusions and nothing seemed to help all that much but during the 4 round of Taxol I did not experience nausea at all.

Fatigue and Anxiety – I tried to learn what to expect, exercised, went for walks, took Ativan (before infusions to calm nerves), and meditated. Sleep was the most healing for me, I embraced the calm it brought with it. I slept a lot.

Gut Health - I took a daily probiotic and magnesium (laxative) or stool softeners (constipation) as needed. I tried to focus on eating whole foods when possible, but also ate pizza when I wanted pizza. If I felt like eating anything at all, I considered it a win.

Dry Mouth and Mouth Sores – I would use Biotene mouthwash when my mouth felt like cotton and sucked on pebble ice during Adriamycin infusions. I started taking 500 mg of L-Lysine supplements 2 times daily a week before chemo began and continued throughout treatment. I was really grateful that I never dealt with mouth sores.

Hair loss - The thing I thought most about from day one was losing my hair. I did not attempt using a cold cap (which can sometimes prevent hair loss). It was expensive, not readily available to me and I read mixed reviews about its effectiveness. I did lose all of my hair. It was sad. However, I felt prepared because I had cut my hair pretty short before I even started chemo. Emotionally that helped me accept the hair loss when it came after my second round, 17 days after chemo had begun. I was able to purchase an amazing real hair, lace front wig. I REALLY loved my wig. It looked and felt very natural. I also chose to have my eyebrows micro-bladed (a semi-permanent tattoo) before diving into chemo. One of my favorite decisions ever because I always feel a bit more like myself with eye brows.

Skin and Nail Health – I took Vitamin E, used coconut oil body wash and moisturized often to prevent dry, cracked skin. I painted my nails with dark colored nail polish to protect my fingernails and cover up discoloration. My skin did experience dryness but it never got too bad.

Neuropathy – (possible side effect of Taxol) – I took 300 mg of vitamin B6, 300 mg of magnesium and 30 g of L-glutamine daily throughout the Taxol regimen. I used cold therapy (ice packs) on my hands and feet during each infusion because there were some studies that showed that it could help prevent neuropathy. It was cold and uncomfortable but I did not develop neuropathy so I consider it worth the effort. I've heard acupuncture can also help but did not try it myself.

Bone Aches – My doctor recommended Claritin, as needed, for bone pain. After each round of chemo there were a few days when my entire body would just hurt. The bone pain wrecked me for a day or two but then would ease off. Warm baths helped me the most during that time.

Chemo induced menopause – My period stopped altogether once chemo began. I kept a handheld fan near me at all times because -- hot flashes. Ugh. They would come on fast and furious. For me this was one of chemo's gifts that seemed to stick around for a while, even post treatment. Be sure to chat with your doctor about early menopause, infertility, hormone changes and bone health from the get go. Chemo messes with all sorts of things so its best to be informed before you begin.

Emotional Health – To ease my anxiety, I started going to therapy, did yoga, read inspiring books, listened to healing music and chatted often with a (new) friend who "knows what its like." I realized that it was a very important time to take care of my well-being so I made it a priority.

Radiation

Radiation is meant to kill any cancer cells left after surgery in the area where the breast cancer was found. It can also help protect you from a local recurrence – cancer coming back in the same place. Radiation is usually recommended after a lumpectomy or if cancer was found in your lymph nodes.

I can't speak from personal experience here because I did not require radiation. However here are some tips from a few friends who have been there.

Prep the Area – Moisturize the entire area (shoulder, breast and part of your back) with E45 cream or pure Aloe Vera gel before and after each treatment.

Avoid Hot Water – When bathing or showering, try to keep your breast out of the water to avoid worsening the redness and soreness. Also avoid soaps and shower gels that could aggravate the skin.

Take it Easy – Radiation has a cumulative effect. Meaning it may not feel like its affecting you very much at first but the tiredness can hit you like a truck, pretty suddenly. Get as much rest as possible.

Targeted therapies

Depending on the stage, grade and receptor status of the tumor, other treatments are available. Like chemotherapy, targeted therapy is a treatment that uses drugs, but these drugs work by targeting the cancer's specific genes, proteins or tissue environments that contribute to cancer growth. Your doctor will discuss options with you, if you are a candidate. Being Triple Negative, I was not.

Letting people help

As news of my diagnosis spread, I felt an outpouring of love with people wanting to help ease my burden. The good news was there were several ways they could be helpful. In my experience, when I reached out to others with a specific need they jumped at the chance to help. It was relief for both sides because most people want to be of service, they just don't know how. Here are some helpful ideas that worked well for me.

Create a MealTrain – I created a profile and chose the dates. Then when people asked what they could do I sent them a link where they could sign up to bring a meal when convenient.

Scheduled Childcare – I had small children at the time, so I made a calendar showing what days my husband could be home. Then I let family and friends know times that I would need to have help with kids - during appointments, post-surgery, chemo infusions days and a few days following each infusion. One thoughtful friend offered to take my daughter to her weekly violin lessons for the entire summer. I was so touched at the outpouring of love.

Chemo Friend – I was able to have one or two people come to with me to my chemo infusions. I asked friends in advance if they would like to be my “chemo dates” for specific infusions.

Grocery Pickup – I would submit my grocery order online and asked a neighborhood friend to pick up my groceries each week. Another friend would call me when she was headed to store and ask if there was anything she could grab for me and drop off.

Cleaning – I had multiple people offer to come give my house a good cleaning, do laundry or wash dishes. This was especially helpful post-surgery when my arms were pretty much useless for several weeks.

Cancer Fund – There are so many non-medical expenses involved in cancer care and treatment. I quickly realized that some extra cash would be extremely helpful. I mentioned that to a close friend and it snowballed into a group of friends donating to a fund and making life just that much easier. I was able to pay for a summer nanny, 4 months of cleaning service, and a real-hair wig. It was an incredible gift. I also created and shared an Amazon Wish List for post-surgery care. Items from the list were sent to me from loved ones near and far.

Checking In – What it really boils down to is feeling connected. I felt connected just by knowing someone was thinking about me. Since treatment felt like it lasted forever, someone checking in every once and while made me feel known. They realized my life was never going to be the same and wanted me to know how much they cared. Those friends are keepers. I responded when I could and was sure to express gratitude for their continued support.

AFTER CANCER LIFE

Health is everything

I took good health for granted until I was sick and then suddenly, I was very aware of its importance. This is something I have become passionate about now. I would give anything to go back in time and make better choices and possibly prevented myself from getting cancer. ANYTHING.

Once you are sick, in some ways you are past the "prevention" point and can only move forward from where you are. That's where I am now. But I'm giving myself the edge. I'm determined to be in the tail of the curve, where statistics don't apply to me because I'm doing as much as I can to prevent a recurrence.

Here's what I do:

- I know my body. I know what is normal for me so I'll recognize any changes or new symptoms. When something changes, I don't hesitate. I get it checked out right away.
- I visit my doctor. I do preventative screenings, yearly checkups, bloodwork. It can be annoying and takes time but I do it anyways. If I have new symptoms I GO get checked TODAY.
- I try my best to eat plant based. Eating the rainbow and piling on the fruits and veggies makes me feel better. I eat meat sparingly and have tried to really cut back on processed foods.
- I exercise daily, try to reduce stress and bask in the sun. Sweating is really good for all parts of me; therapy works wonders and research suggests that vitamin D is vital in preventing cancer growth.
- I reduce toxins in my environment by reading ingredient labels, eating whole foods and being smart about the products I use in my home and on my body.
- I also try to educate myself. I know my family history and read lots of books.

My goal is to be proactive and live smarter.

Something I did not know before, about breast cancer, is that there is no "going back to normal" after treatment ends. For some women, treatment continues on and life is visibly altered. For others, like myself, after active treatment ended I felt a bit lost. I was done with everything but left with feelings of fear, anxiety and confusion. Where do I go from here?

Plain and simple, my life is forever changed. But that doesn't mean I can't find beauty and happiness on this new path. I have realized that it is possible to find joy in a life I never imagined. I took my time easing back into everyday activities. With the help of a therapist, I challenged myself to process all of the emotions I was experiencing and move forward at my own pace. One thing that my cancer diagnosis did was gift me with a greater prespicitve, I still hold on to that.

At the end of the day, remember, while what you are going through is really tough, it is not impossible.

You got this.

I'm totally cheering you on.

xoxoxo Liz

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