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Web Exclusive: A Lymphedema Saga

BY KATHY LATOUR

When I was diagnosed with breast cancer in 1986, my surgeon told me about lymphedema in a post-operative visit to my hospital room—I think. I say, I think, because so much of that week was a blur of information and fear. I was diagnosed at the beginning of October, and for two weeks I was under the impression I had the best-case scenario: small tumor, contained, perfect for a lumpectomy and radiation.

But the reality was different: small tumor with long tendrils, one clearly malignant lymph node more than two centimeters, all of which pointed to a mastectomy and chemotherapy. And, because I had a surgeon who listened to her patients, I had to have a second surgery when the first choice wasn't going to work. The reason: Just as they were wheeling me into the operating room, women's intuition told me it was worse than they thought, I panicked and told her not to take off my breast without waking me up. Because she couldn't go through it all there, and because she was new (she told me later she learned a valuable lesson with that promise), she agreed.

So a lumpectomy on Monday and a mastectomy on Wednesday and chemotherapy in front of me meant that information about my arm swelling had to take a backseat to the mind-numbing fear that I would not be around to raise my 1-year-old.

Fast-forward to 1990. It's a celebration of a new baby for a friend who had tried for years to get pregnant to no avail. The baby shower was great. I was great; no recurrence and back on the mommy track big time. It was a beautiful day and I was having a wonderful time except for a silly hang nail that was making me crazy. It felt like it was infected and my usual remedy of running it under hot water was not working. It really hurt. I made a note to myself to put antibiotic ointment on it when everyone left.

In the meantime, I had pulled out the recipe for my famous hummingbird cake, but as I went to open a can of crushed pineapple, I realized my hand was sore between the thumb and first finger. It felt like a pulled muscle—or like I had hyperextended my thumb.

After the baby shower ended I realized that my forearm was really sore. I didn't connect the hand with the forearm and didn't connect either with the hang nail, and I am fairly certain that nowhere did I think about my arm and infection and lymphedema.

That evening, in the middle of dinner with friends, I suddenly felt like I did when my blood counts would drop during chemo. I knew my body was in trouble. I turned to my husband and said, "We have to go home." I thought I was coming down with the flu. Still no connection. I went home, took two aspirin and vitamin C and went to bed.

The next morning, which was a Sunday, the underside of my right arm had a bright red, 2-inch wide stripe from the wrist to the armpit. Near my shoulder, the red strip banded around the arm completely. I had a fever of 105 and felt awful.

I called my surgeon who said it sounded like I had cellulitis, an infection that is very serious and moves quickly. She reminded me that I was at risk for this kind of infection because I had no lymph nodes left in that arm, which can cause the buildup of protein in the arm tissue. And infection loves that environment.

She called in a major dose of the strongest antibiotic out there and told me to come to the office first thing on Monday. My husband had the prescription filled and I took two immediately, and one every four hours. I spent the day in bed feeling rotten. By the time we got to her office the next morning, the red had moved onto the chest wall, my fever was 106, and I would have had to feel better to die.

She took one look at my chest (and the proximity of the infection to my heart, I would later learn) and said very matter-of-factly that we could probably get it under control with antibiotics but she would feel better if I were in the hospital on an I.V. I think I began to consider it might be serious when she called her nurse in and said she would be back in a while and SHE walked me through the maze of office corridors to the hospital, picking up a wheelchair so she could go faster.

I was out of it, burning up, and not caring anything about anything. I was plugged into I.V. antibiotic where I stayed for five days, longer than my mastectomy. When the cellulitis finally cleared up, I was left with a swollen arm. Welcome to lymphedema.

A Chronic Condition

In the next five or six years I had three more bouts with cellulitis, none of which I could connect to any event, skin break, or infection. I was exceedingly careful of my arm and followed all the rules. The swelling eventually settled into about 1.5 inches larger than the other arm, which was unattractive to say the least.

I underwent manual lymph drainage with a pro who was able to get the arm down considerably. But I was what she called a poorly motivated patient. Because my lymphedema was not bad I wouldn't wear the compression sleeve. I tried to point out to her that a compression garment and 104-degree weather don't go together, and I already had sleep issues, so going to bed with my arm wrapped like a mummy was not going to work. I tried, I really did, but I would always wake up

with a little pile of bandages beside the bed where I had peeled them off.

I bought a 10-chamber sequential pump, which I wore in the evening while watching television for a few hours. It would fill the chambers one at time as it moved up my arm to push the lymph out. But being strapped up to a pump really tethers you to one spot, and I got the majority of things done in the house on commercials so I didn't like that either. And, I am now convinced I made my lymphedema worse by using the pump when I didn't know what I was doing. I remember ramping it up to higher pressure on the arm, thinking if a little pressure was good, a lot was better. Not true. Lymph drainage takes a soft touch.

I finally stopped all form of identified therapy for lymphedema, with my only concession being to wear the sleeve when I flew—if I remembered to take it with me. My arm was manageable; it wasn't huge and that was OK with me. I swam, which helped tremendously with range of motion and that feeling of heaviness that accompanies lymphedema.

Long-Term Effects

My bouts with cellulitis ceased about five years after the first one, and I went for years, 17 to be exact, before I faced it again.

In January 2008 I was in New York City doing a story when I woke one morning with cellulitis on my right forearm from just above the wrist to just below the elbow. No warning, no preliminary feeling like the flu, just bam—a nasty bright red, hot rash!

I had a mastectomy on the other breast just two months earlier after a diagnosis of ductal carcinoma in situ, and I can remember thinking, "Great, at least it isn't the left arm." I had chosen a sentinel node biopsy for the second mastectomy, hoping that if there were some lymph nodes remaining the arm would have a better chance. I could avoid another arm where I would have to deal with lymphedema.

Ironically, when my arm became infected I was the house guest of Lauren Shaiova, MD, who is director of a palliative care program in New York. I had an appointment with her staff that day to talk about a mutual friend who had died last year. I got dressed and began making my way to the hospital, running through the possible scenarios and thinking how much I didn't want to be hospitalized in New York City. When I walked into her office, she was interviewing an infectious disease specialist and both of them gasped at my arm. I didn't even have to explain since Lauren has worked with cancer patients for many years.

The two of them conferred on the kind of antibiotic I would get and then decided the arm looked and felt bad enough that they should do a shot instead of pills. After the shot and a prescription, they sent me back home to bed but not before Lauren drew a line around the infected area. She looked me in the eye and I knew what was coming.

"If it's larger tomorrow, you go in the hospital." Luckily, the shot did it.

Don't Leave Home Without It

I had another scare in September 2008 while riding a motorcycle up the coast of California from Los Angeles to San Francisco with Amazon Heart Thunder Ride. We had cut inland a little to enjoy the redwoods and at one point were experiencing a number of wild bees. I was riding along in full jacket and helmet when a bee managed to fly up my left sleeve. The bee was no happier about this than I was and began stinging me. While still moving at around 35 mph, I started batting my arm against my side, trying to kill the little sucker before it stung me again.

Had that been my right arm, I would have been heading for the nearest hospital. Again, the angels were there because one of the riders was a doctor and she had an antibiotic pack with her. So I dodged the bullet again.

But I did learn one lesson. After the first bout with cellulitis I began carrying antibiotics with me when I traveled. Time had diminished the concern and I had stopped when the last prescription expired. This situation reminded me not to leave home without antibiotics ever again.