

How many times have we heard: "Check your breasts monthly for lumps" and "have your yearly mammograms"? Every time we turn around, we hear those comments. What we don't hear and aren't told by our doctors is "Check your breasts for any changes and tell your doctor when you notice them" and "There's a form of breast cancer that doesn't usually show up on a routine mammo". Ever since I saw a slight pinkish-red blotchiness on my right breast in early July 2007 and my daughter-in-law and I did some online research, I had the feeling that I had IBC (Inflammatory Breast Cancer), a rare and highly aggressive form of breast cancer. Some of the signs and symptoms of IBC are:

- rapid increase in breast size
- redness, rash or blotchiness on the breast
- consistent pain and/or soreness of the breast
- lump, or thickening or dimpling of the skin of the breast
- warmth or tenderness of the breast
- lymph node swelling under the arm or above the collarbone
- flattening of the nipple or discharge from the nipple

I only had one of those symptoms: the blotchiness. Many women have most of those symptoms. IBC cells grow in nests or sheets rather than a solid tumor, which is why a routine mammogram alone is not normally reliable for finding IBC. A doctor will do a clinical exam, but biopsy, diagnostic mammogram and breast ultrasound can confirm the diagnosis of IBC.

At age 65 I contacted my doctor's office about blotchiness on my right breast and was told it was an infection; that I had to have a 10-day antibiotic treatment to see if it would get rid of the infection. After being treated for "mastitis", an inflammation of the milk glands usually found in young nursing mothers (two different 10-day cycles, not just one cycle), I then had a "diagnostic mammo" specifically looking for the sheeting or nesting of IBC. The report said it was possible that I had IBC and recommended I have a biopsy to confirm it or rule it out. The biopsies the surgeon performed confirmed that I did have IBC. Well, I'd told them that in early July and it's now six weeks later.

After consultation with an oncologist, I actually started my chemotherapy treatments in early September. I dreaded starting chemo, but also knew I had to do it. I feel I was very lucky in that I hardly had any side effects from the chemo, other than losing my nice thick hair. I would have my treatments mid-morning, then my hubby and I would go out and eat lunch before heading home. The chemo was finished in March (that was a very long six months), and I was set for surgery on April 18, shortly after my 66th birthday.

I had several tests and procedures done prior to my surgery being started about six hours later than I had expected. The mastectomy was performed and I was put into a room for my overnight stay. Since I was starving, not having anything to eat in over 20 hours, I was given a sandwich because supertime was over. I remember seeing a nurse the next morning before I checked out and went home with very little instruction on what to do. Luckily, my sister had flown in from TX to help out and had experience taking care of post-surgical patients with drains. I was so thankful for the 4 days she was with me. We took her to the airport and picked up another sister who flew in from MO to help me for a few days. I am so thankful for all the help from my hubby, my sisters and my cousins, and for all the information that I got from my online support groups. The unknown is always scary. They all relieved much of my anxiety.

After my drain was removed a week following surgery, I started on one tiny little white pill daily...good old Arimidex, which is supposed to keep my cancer from recurring. It's something I'll take for at least the next five years. Maybe I had it easy with the chemo and even the surgery, but this one little pill really knocks me for a loop at times. I never know which of these side effects will hit me, but they all manage to at one time or another: nausea, vomiting, diarrhea, sleeplessness, weight gain, stiff joints, incontinence, and others that I can't even think of right now. If that little pill does its job, it's well worth all the side effects that come with it.

In June 2008 I started 6-1/2 weeks of radiation therapy. The people at that facility were so nice that you could almost look forward to going there for treatment. I got some extra burn up around my collarbone and had to put off

further radiation in that area until the end of my treatment. When I was presented with my "certificate of completion", I let out a big sigh.

My oncologist said he'd see me in a year (that's already next month now). My surgeon actually ordered an MRI on my chest area and it came out as clear. I was now NED (no evidence of disease; or, as I like to say, "no expiration date"). That's what we'd worked toward since August 2007 when I had my first chemo treatment.

The thing that amazed me the most throughout the past 18 months is the lack of knowledge about IBC (Inflammatory Breast Cancer) in the general public and in the medical profession. Every time I go for any appointment, I talk to whoever I see about IBC. If a telemarketer calls me, I will only listen to their spiel if they'll listen to me talk about IBC. I almost cried when a worker at the American Cancer Society told me she had never heard of IBC. I pass out brochures about IBC everywhere I go. I don't want to see another woman get misdiagnosed, have her diagnosis delayed, or be diagnosed as Stage IV because her doctor isn't aware of the signs and symptoms of Inflammatory Breast Cancer. As it is, IBC is at least Stage III when diagnosed. Regular breast cancer can be as low as Stage 0.

My mission in life now is to educate anyone I can about the signs and symptoms of Inflammatory Breast Cancer. I started with my primary care physician after the biopsy confirmed I had IBC. I let her know that rather than starting with surgery as in "regular" breast cancer cases (as she told me I'd be doing), I would be starting with chemo prior to surgery. IBC is aggressive and you have chemo first to reduce the tumor size prior to surgery. My doctor did not know this. At one point, I even advised my oncologist of a new revised protocol/guideline for IBC treatment that had been in place for a month or so. I knew about it because of my online support group. It's a shame he didn't know about it also. Of course, he did admit that he'd only treated about one IBC patient each year in his 21-year career. What I'd like to do is somehow make doctors aware of the signs and symptoms of IBC and also aware that you don't have to have ALL of them to have IBC.

Next month (August 2009) I will see my oncologist again after a year of not seeing him. I was told in August 2008 that I looked good and he'd see me in a year. I'm nervous about that, but God has watched over me this far and isn't stopping now.