

Inflammatory Breast Cancer—Spread the Word

I found the lump in the shower. It was early Saturday morning, Thanksgiving weekend, 1994. I noticed my nipple was retracted. A sudden feeling of dread and fear enveloped me as I crept back into bed beside my husband. Once I had convinced him it might be serious, we hugged silently.

Fast-forward to my bedside at Women's College Hospital after my biopsy, as my oncologist stood before me to give me the news. It was worse than I had ever imagined. She told me I had Inflammatory Breast Cancer (IBC), a rare and aggressive cancer I knew nothing about. Never heard of it. I asked her for the odds. Well, 25 to 40 per cent of IBC patients survive five years she told me. I was quiet, as I tried to absorb it all.

For several years, I did not come across any women who had IBC. I found it hard to find information about it. Usually, it would be a measly sentence or two in books about breast cancer. Access to information about IBC is much better now, especially on the Internet. But, I still hear dreadful stories of women being misdiagnosed because it is still not that well known in the medical community and because of the way it presents itself.

So, I have two reasons for writing this article. First, I want to spread the word. Second, I want to give hope to anyone unfortunate enough to get IBC. I am living, breathing proof that you can beat the statistical odds. Someone has to, so why not me, why not you or your friend?

IBC is rare—2 to 5 percent of breast cancer is IBC. It grows in tumour cell clusters, nests or sheets that clog the dermal lymphatics, causing skin changes. There can be a lump as in my case, but there is frequently no detectable lump. It has a faster doubling time than other breast cancers and IBC is more likely to have metastasized at the time of diagnosis than non-IBC cases. This is serious stuff.

Here are symptoms to watch out for:

- Rapid increase in breast size
- Redness, rash, blotchiness of the breast skin
- Bruises in the breast area that do not go away
- Persistent itching of breast or nipple
- Lump or thickening of breast tissue
- Pain, soreness, aching of breast
- Warmth to the breast (inflammatory)
- Swelling of lymph nodes under the arms or collar bone
- Dimpling or ridging of breast
- Change in nipple, flattening or retraction

And here are a few other facts:

- IBC is more common in younger women than other forms of breast cancer, and it has been discovered in women who are breastfeeding, as young as 25, although this is rare.
- Women can get IBC when they already have another form of breast cancer.

- Because of its nature it's often been diagnosed as an infection or abscess. It could be an infection but a biopsy is best because it doesn't show up well on a mammogram or ultrasound.
- Now, the five-year survival rate for patients with IBC is between 25 and 50 per cent, which is significantly lower than the survival rate for patients with non-IBC breast cancer.

The standard treatment protocol for IBC is different too. It usually starts with chemotherapy followed by surgery, radiation, and perhaps hormonal therapy—prescription of Tamoxifen, and/or Letrozole (Femara) etc. I was on a clinical trial and ended up on the high-dose chemotherapy group of the study, which meant I was receiving double the standard dose in half the time (3 months), then surgery, radiation, followed by Tamoxifen.

I started my treatment in the late fall of 1994 and finished in June 1995. Later, about four years after treatment I had reconstruction—the tram flap method. I got tired of the prosthesis. One day after it slipped out and landed on a pile of leaves as I was raking and bending over in the front yard, I decided. O.K. this is enough. I want a real (well, sort of real) breast to go with the other one. So I went to see Dr. John Semple at Women's College Hospital and looked at his before and after pictures, was impressed and signed up.

I've been on a double-blind (neither patient nor doctor know if the dosage is real or a placebo) study for Letrozole and after five years, am now on a second study looking at the benefits of an additional five years of Letrozole. I found out I was taking the drug rather than the placebo during the first study and now suspect I am taking it again but don't know for sure.

Of course, we all have to be relentless when it comes to our own health. This means leaving nothing to chance and listening to that little nagging voice that tells you something is wrong. This is especially true when it comes to IBC because you don't want any delays in getting treatment.

Since IBC can look like a breast infection, there are more cases of misdiagnosis than there ought to be. Too many women are being treated with antibiotics or being told to keep an eye on it. Or worse, a doctor is telling a young woman that she is too young to get breast cancer.

Here is a quote from an IBC patient that I think says it all.

“Before my own diagnosis of IBC, I had not known that you could have a negative mammogram and not have a lump, and still have a very aggressive form of breast cancer called Inflammatory Breast Cancer. Now I, too, know what IBC is. My prayer is that information regarding this aggressive form of breast cancer be given to all women young and old, that family physicians be made aware of this aggressive form of breast cancer, and that they would impress upon their patients the importance of seeing a surgeon immediately...”

Carol Mutton