Selected posts by Amarantha on BreastCancer.org
February 2014 to October 2019

February, 2014
Hi friends. I'm an American living in France, where I am being treated for breast cancer. I have not been told I have Inflammatory Breast Cancer, (the doctors seem unwilling to admit as much) but ALL my symptoms EXCEPT for the redness match IBC.

I had my midway MRI, and it did not show much improvement (no more than a 20% reduction), so I was expecting that the oncologist would choose a different cocktail for the next few sessions, maybe attack with dose dense, or try something more aggressive, but instead she said that probably it wasn't worth doing any more chemo, and I would probably move directly to

I mean I sort of gathered that there were all sorts of new and different kinds of chemo that could be tried. I'm so scared, because from what I've read (in France they don't want you to read anything!) I understand that IBC is much more survivable if there is chemo first. I'm very scared that if my cancer hasn't responded well enough to the chemo that I'm doomed. What can you tell me?

March, 2014
Three weeks after the first Taxotere … met today with the oncologist, who sees things a bit differently from the surgeon, and wants to see if she can get the cancer to melt away (fondre) a bit more before the eventual surgery… therefore we will be moving onto a new protocol of chemo + radiation. It will be Taxol + Cisplatine, every 21 days…with a supplementary dose of Taxol. The chemotherapy will be complemented by radiation, beginning probably the second week sometime.

May, 2014
I had my surgery yesterday, and already feel quite fine. Almost NO PAIN. The surgeon told me she made a horizontal scar (I will see it tomorrow) - the size she drew in the air with her hands looked like about ten inches - and from this same incision she took out the whole breast as well as a wad of tissue under the arm containing lymph nodes. There is a drain and it is draining. The surgeon (a lovely lady surgeon) said she wanted me to have the prothesis in hand before she showed me the scar, and she wanted to show me the scar before I went home, because she didn't want me to have to face seeing it for the first time alone. Is that amazing or what?

I told my husband not to look, thinking, it would be horrible for him. But to my surprise, he said no, he wanted to see it. So, he looked, and was so taken with the admirable scar, that he forgot to notice the breast was missing. And then to my amazement, the fact that he saw it and didn't think anything particular about it, was a huge relief to me.

December, 2016

Gadzooks, Sulette, I have exactly the same thing, red and thickened skin over the mastectomy scar as well as in the previously unaffected breast. I will be having skin biopsies on Monday. I hope yours is nothing. I have a bad feeling about mine.

Dear Sulette, I am sorry that the biopsy shows a recurrence, however on the bright side, it is better to catch it and treat it, than for it to remain nebulous and untreatable. I am so glad they have caught it. I am really glad you shared your results with us. Thank you. I should know something about mine tomorrow hopefully.

Merry Christmas to my fellow IBC travellers. I am back on these boards ... recurrence of IBC diagnosed just a few weeks ago. I look forward to your company.

January, 2017

Treatment is going okay, all the usual side-effects from Afinitor, my energy has returned thank goodness! However, I have no assurance it is working. I have tried to raise the alarm in phone calls to the oncologist and oncology nurses but only get the usual 'il faut laisser le temps au temps" - allow time for time.

February, 2017

Welcome to this thread, MsSherman, that is quite a story. You've been through tough times. We'll all be waiting for your results with you. Coping strategies for waiting? Mine are lots of hugs and cuddles with hubby, listening to great music, listening to horrible murder mysteries for distraction, and long walks in a most beautiful place. Contact - any and all contact with friends and family feels comforting. And dreaming of getting a puppy dog ... I hope your wait is not too long.

October, 2017

I'm not impressed that the Afinitor/Aromasine treatment is not working, because I was sure that the skin infiltration was growing worse every month on the site of the scar. The PET scan did show almost NED last month, however the skin infiltration was clearly not better in my sense of things. It is now finally bad enough to actually alarm my onco, and the right breast now looks just like the left one did at the beginning of IBC. She was kind of stumped. Anyhow, she is considering this a clinical failure at month ten, and we are moving on to Ibrance and Faslodex.

March 2018

Hello everybody. Well, I'm kind of wondering how this is going to go down. Since my first IBC diagnosis in 2013, it returned in end of 2016, it has now spread to bones and lymph nodes and skin, and has now entirely taken over my remaining breast. The chemo I'm taking is Eribulen - Halaven, it is working to reduce the ganglions (lymph nodes), but not stopping the spread and worsening of my right breast. We just had biopsies to determine the exact profile of what is in the right breast but it is clearly still IBC, the lack of clear lump, the thickened skin, the hardened tissue inside the breast - made it almost impossible for them to do the biopsies (I almost wrote autopsy) they had to push the needle thing super hard to get it through the cardboard like tissue. I'm guess I'm wondering where they can possibly go from here… Is there anything left to try? Ideas?

April, 2018

Good news folks! the recent PET scan showed that the Halaven has made my cancer in the lymph nodes (which had spread pretty much ever where) has completely disappeared, or completely disappeared from the PET scan radar. Meanwhile, it did show progression in the right breast, which appears to have a different profile, but that seems to be localised. My oncologist called today that it would be a good idea to go ahead and take off the right breast - and that as soon as possible.

Thanks Theresa. It is rather unnerving to wait and see. Now I am getting desperate to get this breast off of me, it has now swollen up, is all hard, and getting redder and redder. I see the surgeon on Thursday, I sure hope he will act swiftly !!

May, 2018

Well it turns out, Traveltext, you were right, the inflammation has inflamed too much, now they cannot operate, and are going to try "cooling" the disease with CEF - the first chemo I had back in 2013 - and then will operate as soon as possible, as soon as the redness calms down. I have my first infusion on the 11th, and I have a trip to see an opera in Bordeaux on the 14th. I hope to goodness that this will not make me so sick that I cannot take the train and sit through an opera. On the other hand, if I am going to be sick, I might as well be sick on a train and at the opera ... I'm disappointed but not surprised since I could see the breast getting redder and redder. Argh.

Big month coming up several opera trips planned, plus my mother is coming from California! - I've been having weird-good pain in the affected breast, which I hope is the dying screams of little cancer molecules in terror at the big guns bitch chemo which just hit them. Please say it is!

I write for an opera website called Olyrix.com. Its so coo ! I don't get money for it, but I get free train rides and hotels, and opera tickets. It's a real breath of fresh air, the train is so expensive otherwise, without these opportunities I'd hardly ever get out!

Hello folks, well I've one more week to wait before my next chemo. My IBC breast is rivalling football hardness. It needs to come off yesterday ... the treatment is visibly having zero effect, it’s just getting worse, so hold on to your hats, I predict a rough ride. Meanwhile, I'm hurrying up to live, in between chemos I will have been to Bordeaux, Toulouse, Dijon and back to Bordeaux to review various operas, have received the visit of my darling mother, and will have written four articles. Physically I've felt mighty strong and upbeat.

June, 2018

Moreshoes, sbelizabeth, Traveltext, LoriCa, Valstim, well the bumpy ride shall begin in two weeks! I was very happy to arrive for my consultation today with the oncologist to find she had invited the radiologist to the session, both agreed with me, that the state of the right breast is a catastrophe. In two weeks, we will begin combined radiation and chemo - five weeks of daily radiation, plus weekly Cisplatin for at least five weeks. That also involves three days of steroid infusions following each chemo. The Cisplatin involves a 24 hour stay in the hospital each time, and the three days following the chemo involved heavy home nurse intervention. I had the two home *nurses of our town come over this evening and talk through all that they will have to do, it is rather complicated. In any case I am thrilled that the doctors have decided to change tactics and pull out all the heavy guns again to try to cool down the cancer in the right breast so we can eventually take it off!*

This combined Cisplatin and radiation is a treatment I had in 2014 for the left breast, which worked to some degree (though not as much as they would have liked) and I lived to tell the tale, but found it quite difficult to tolerate. At the end, I was really ready for everything to be over, death seemed like a fate preferable to one more treatment of Cisplatin, but last time they did not give me anywhere near this much anti-nausea and steroids, so hopefully it will make this all more tolerable this time round. I'm very hopeful!

Traveltext and Sbelizabeth, thanks so much for asking how I'm doing. Sigh, I've been doing so well all this time, but now still feel constantly somewhat nauseated, and haven't even begun treatment, I can't believe I have to wait another week until treatment begins, the infiltration on chest and breasts is just getting gradually worse... if I go off line, I'm just coping as best I can.

July, 2018

Good gnus, folks. I had my third chemo and 13th radiation today. Everyone (nurses, radiologists, interns, chemo doctors, radiation doctor) has been freaked out about how red everything is, but my oncologist, who came to see my in the hospital yesterday, said though the left side is a bit worse, it is not freaky worse, and that since she saw it before everyone else, she has a better ground for comparison, that we should not worry. And furthermore, she observed with me that the right is now beginning to show signs of improvement: whole white spots are now appearing on my breast, which was entirely red two weeks ago, and there is a hollow spot now in the breast where clearly the cancerous tissue is melting back. Actually, a reaction! Amazing.

Suddenly so much more hopeful, and feeling really good. Happy to be in France, happy to have a zippy beat up little old car to drive, with fake screeching noise (from my lips) around corners. Happy to see the love in my husband’s eyes. Happy with our little solar fountain in a blue basin. Happy with the little hoppy birds I've come to call my clients. Happy with the newly blooming flowers, some white hollyhocks, some red gladiolas, some pink cosmos coming out, white ones on the way, and magenta already. Turtledoves in the birdbath with the thirsty wasps. Some flowery tree blooming over the fence ... a good day. May we all continue to find joy from moment to moment.

I have a meeting with the surgeon but not until the 30th of August, the radiologist wants us to wait a full month before showing it to the surgeon to see if he thinks surgery is possible (he did have a meeting with him last week and the oncologist), because at this point surgery is still out of the question.

I am hoping the oncologist will be more optimistic, she always is. And hoping that in four weeks it will not be ten times worse.

Meanwhile, I think we MUST start doing something for the left side or I'm toast. And if they can't do surgery in the right breast, I think I'm major toast.

My worst fear is that they will send me home and say we cannot do anything more. But they wouldn't do that, would they, as long as I am willing to keep trying stuff?

September, 2018
Hi everybody! I'm alive, surgery was difficult according to the surgeon. Now I have a big hollow on the right side of my chest like the crater of a volcano! Feeling great though, and have a lovely English-speaking roommate.

October, 2018
The report shows that the heavy chemo and radiation treatment was only partially successful (less than 50 percent) but the surgeon got clean margins than goodness (although just barely). I've been feeling pretty horrible due to the infection above the scar, but much happier now, that I've seen the surgeon, talked to the oncologist, gotten treatment, plus new chemo schedule on the horizon. If all goes well, I start Halaven again this Friday.

January, 2019
Well folks i had a scan today, and well, it seems the thing has gone into the lungs, and into the internal layer of the visceral layer of the sack containing the heart. That sounds scary all of a sudden. Well I am probably not supposed to have seen this, and the oncologist will explain it all to me on Thursday. I'm feeling kind of hmmm about this; a little scared, but the feeling hasn't totally destroyed my naturally good mood - yet. Will keep you all posted. It occurred to me that I had several months without treatment which had to have led to all hell breaking loose, but this doesn't tell us if it is worsening or bettering.

February, 2019
I can no longer lie on my right side. I talked about this with the pre-chemo consultation intern yesterday, whose only reaction was to prescribe more pain meds. I am always shocked by that. I want to say, "no, no, no, I do not mind the pain, I just want you to have this information, I want to find out why it is there.". And she seemed to think another month to wait before seeing the oncologist was just fine and not to worry. But anyway, basically I'm just fine, with nothing much to report. Sorry to be so boring!

March, 2019
Hi folks, I just saw my oncologist. We are changing to Xeloda. New adventure.

The pain killers add to the problem of course. I can either be awake with pain, or a zombie with no pain. I have knife-like pain in my side - the doctor said it is "adhesions" - I'm supposing it might be nerves coming to life as well. In any case, I feel like I'm being stabbed with long needles over and over. They've given me different things for the pain, but they all make me feel like a total zombie and also slow my digestion to a standstill. I've gained so much weight and fat around my middle, I can't even recognise myself. I'm like wearing a tire!

April, 2019
Here I am at 4 in the morning, not sleeping because of pain: the war on pain has begun, I guess. The sharpest is skin burning/searing, and then lower and upper back pain, plus crazy pressure around upper chest and of course the abdomen. I'm unsure how much Tramadol I've already taken; I took some Aleve, now what?

I'm just really glad you guys are here hanging out on this thread, it’s amazing what a relief it is just to be able to come here, it feels like we're all in some sort of lounge together. I wish you all the best.

I've just returned from the Emergency Room, we were seen almost right away. I went for the pain in my back which had become unbearable. I had called my oncologist directly on her phone this afternoon about it, and she answered on the first ring, recognising my voice instantly, and agreed to notify the emergency people that I was coming. Of course. I was hoping they could do something for my huge tummy, but they determined after much poking and an ultrasound that I did not have ascites, so my huge abdomen could not easily be explained that way unfortunately or could not be relieved by a hole punch in the middle and an outgoing tube ...

They did prescribe me some dissolving-on-the-tongue morphine, actual oxycontin, for my intractable back pain, and when I left, I felt much relieved. Tonight, I am feeling about as great as ... the last time I had morphine. It certainly is nice to be reminded what life is like when feeling good instead of miserable. I'll have that and a cocktail of other things for pain relief and then will see my oncologist in real life in two days for the next steps.

June, 2019
Hi everyone, thank you for thinking of me. I have been in the hospital since May 2. Today I am enjoying a one-day home visit with permission. After the exam of the pleural effusion it was found the meninges were affected. So, I am receiving Decadron, and have been hospitalised continuously since then. Very weak and cannot climb stairs so expensive house revisions are happening before I can come home for good. I am grateful for the visits I have had and am trying to stay positive.... love to all.

July, 2019
Hi Folks, well I'm home after three oops, I spent two months in the hospital, continuing treatment on Decadron daily, and chemotherapy. I feel like a paper doll. I can take pain med boosters every two hours. This is very trying on my husband and my relationship. It has been just awful. But OK so I can still take a joke. Love to all.

I feel like my life is over and my relationship is over. Not sure how to find the silver lining in this.

I'm trying to regain strength after my two-month stint in the hospital. I don't understand why my body is so week, the cancer, or the hospital stint, the ongoing chemo, or something else but I don't believe my body is going to get better by itself. I try to take little tiny walks that wear me out, then start up again when strength returns. At least I am not in pain! This is growly, growling time for me.

August, 2019
I'm struggling to regain strength for walking and standing upright after my two months in the hospital. I did not have much encouragement from the doctor on this score, she looked to think I was asking too much when only a two months ago I was what, a larvae, no one will tell me. I can walk, but not with pleasure, and am out of breath after one block. My thought is to regain, little by little, even if just ten meters a day; and why not use painkillers to help get there since they give me so much. The doctors look away and seem like they want to eat their beards when I ask if any improvement is possible. I want to feel there is something I can work for. And I still don't really understand what happened to me on May 2, that was the day it all started. Chemo should help, or not? I just want something positive, anything to hold onto.

HI TT, sorry no to be clear. I am at home with lot of visiting nurses and aides coming to help me, and being given all the pain meds I need, but have chemo in the hospital once every 15 days. I just had my chemo day, so had a visit with the doctor. You are right, an exercise physiotherapist is what I would like to see. I do not know why they chose against spine rads, perhaps fear of making things worse. I think the primary goal was to stabilise me. I am wondering if it is a legitimate use of pain meds to voluntarily put myself through pain (exercise) with the help of the pain meds (the extra pain meds that are optional, that they give me to use in between doses. 'Interdoses' they are called.
I need something to hope for and something to work towards.

September, 2019
Today for the first time in all my treatment since 2013 I had to skip chemo because of low *plaquettes*. Still I spent like five hours at the hospital snoozing and waiting for a new appointment date.

October, 2019
I've received the "nothing more they can do" speech. Referring to curative chemo. Well, we knew this already, but now what?

FINAL POST