



Silver Linings

By Kat Folland

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Every cloud has a silver lining...

Introduction

I got married on April 26th, 2008. On June 21st, 2009 I found two lumps in my right breast. Mammogram, sonogram and core-needle biopsy confirmed it: I got my cancer diagnosis on July 10th, 2009. I was 38.

By the time my mastectomy surgery came around, I realized that I had nowhere near the necessary energy to give everyone who asked a complete answer about how I was doing. So I started what I called then a “running memo” on a totally no-frills static page that didn't link to anything else. I didn't want to call it a blog, because I'd seen too many stupid blogs.

I wrote each entry as if I were speaking to my friends. Along the way, people started complimenting me on my writing and suggesting that I turn the blog into a book. I laughed the first time someone said that, but after the next, it started me thinking.

What you're about to read has been edited for formatting, with very few exceptions. It nearly killed me to leave the phrasing and word-choice, etc. the way I had written it. When I write fiction I polish and polish and polish. But to really share my experience, I had to leave it in my words as I said them then.

Beyond this introduction, I have added a Prologue and an Afterword. If my story touches you or moves you in some way, I encourage you to share it. You can read it for free on the web, or you buy it on Amazon as an e-book. If you purchase the book, I will be donating 90% of my royalties to The Young Survival Coalition (more on them at the end of the book). It's a very good cause! And seriously, I'll be making like a nickel out of it, so this isn't greed on my part.

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Prologue

I never lived a very healthy life. I never got scurvy, but I often ate like hell. The only time I managed to make myself take vitamins was when I was pregnant, and even then I gave them up earlier than they want you to. Worst of all – though there isn't known a link to *breast* cancer – I smoked. I started when I was 19 and though I tried a few times to quit and never smoked while I was pregnant, I pretty much had smoked for 19 years. Oh, take maybe three years out of that for the times mentioned above, but still... not healthy. In addition to this – though again, no known link to cancer of any kind – I had been taking a variety of mental health medications for seven years by this time.

I had never been afraid of cancer, you see. I had this idea – which is very bizarre in retrospect – that I wouldn't or even couldn't get cancer because I wasn't related to my dad. You see, I'm adopted. My dad and both of his parents had died of cancer... but I wasn't any blood of theirs. Somehow I translated this into an immunity from cancer. Likewise with my mother's side of the family and strokes/heart attacks. Hopefully I won't end up with those, I think cancer was enough to prove my ridiculous theories wrong. I was even a bit smug about my lack of mutual genes between my adoptive parents and myself. I'd been damn healthy in fact, if not in lifestyle. I'd never been admitted to a hospital. My only trip to an ER was from a migraine that had lasted for three days. Now when doctors ask if I've ever been hospitalized I just tell them, “I've always been very healthy, if you don't count the whole cancer thing.”

So this isn't one of those books for the people who say “I've always lived so healthily, eaten right, exercised, don't smoke, don't drink, etc; how could *I* get cancer??” No, this is for the average woman who lives life for living, or just the woman who never thought she could get cancer despite her ways.

This book is also not really targeted at those people who learned to appreciate their life only when it was in danger. Cancer changes everyone in some way, but I didn't need cancer to appreciate my life. I loved my life. It was damn near perfect. I didn't need a life-threatening disease to tell me to stop and smell the roses. The book is about slogging through.

If you're reading this because you have breast-cancer, let me tell you this: you are a survivor the moment you look cancer in the face and decide to fight.

Basic Background (written to introduce the blog):

I found the lump in my right breast by accident/coincidence and the cancer was diagnosed via core-needle biopsy (as a follow-up to a mammogram and ultrasound) on July 10, 2008. I chose UC Davis Cancer Center because Dr. M – my cancer surgeon – was recommended to me by the surgeon who was my dad's college buddy and cancer surgeon.

The core needle biopsy diagnosed the tumors as Er-/Pr-/Her2+. This means my cancer was negative for hormones and positive for the Her2 protein. My cancer was a grade 3 (meaning “aggressive”) type cancer. There was no clinical (meaning “observable without surgery”) evidence of nodal involvement and possibly none of the 6 lesions were in excess of 2cm. “Lesions” meaning, if I understand it correctly, lumps or just areas of anomaly. I can (well, “could”) feel 3 distinct lumps, and I suppose the other three are too small, too far “underneath” or some combination of the two. Based on the physical stats, I was “clinically” staged at Stage I. (The “clinical stage” is determined by what a doctor learns from the physical examination and tests. The “pathological stage” includes the findings of the pathologist after surgery.)

I was tested for the presence of the BRAC1 and 2 genes (which predispose one to breast and ovarian cancer) and was found to not carry either of those genes.

I had an MRI in August which was ordered for the left breast to make sure it was cancer free before the surgery because the surgeon would do a prophylactic mastectomy differently than a regular one. For reasons of their own, the MRI techs decided to do the MRI on both breasts. The left, luckily, continued to look clear as it had on the mammogram previously. The right side showed – in addition to the known cancer -- a possibility of nodal involvement, which would, at the very least, give me a different Pathological Stage.

Insurance changes – as well as some other fiddly things – ended up delaying the scheduling of the mastectomy until September 8, 2008.

Surgery/Hospital Stay: September 8-10, 2008.

The scheduled surgery was a right total and left prophylactic mastectomy, with sentinel node biopsy on the right side, axillary dissection to follow if needed. Well that last bit was, unfortunately, needed. Dr. M found two Sentinel nodes to evaluate – this is done actually during the surgery -- and one of the two had cancerous cells, so he took out two of the three tiers of lymph nodes on the right side. Those nodes have been sent to the lab for pathology analysis. The tumor sizes measured once actually out of me plus the number of positive nodes (in addition to the one sentinel) if any, will give me my final Pathological Staging.

Immediate breast reconstruction procedure followed – Dr. W (my Plastic/Reconstruction Surgeon) put

in the expanders in each breast. For those that don't know, breast cancer breast reconstruction is a multiple step procedure. The expanders will be progressively filled with saline (or something like that) over time until my remaining skin has been stretched enough to accommodate the chosen size implant. As I understand it, the filled up expanders don't do a great job of imitating boobs, but aren't too bad when fully covered. The exchange procedure cannot take place, as I understand it, until after chemo is done.

Olav said I was under anesthesia for maybe 6 hours. Sheesh.

Staff for both Dr. M and Dr. W were prepared to send me home the day after surgery except for my pain management issues. I was in great shape as a patient in all other senses: mobility, eating, nausea, all that good stuff. But they don't want to send you home until your pain is under a 4 on the 1-10 scale and is staying there. And boy do I appreciate that! But it took a while to find the right quantity and timing and type of pain killers in the hospital to manage my pain. And an awful "while" it was. And after we'd gotten it figured out, my nurse either forgot or just experimented and halved one of the dosages and I went all to pieces again. In this type of extreme pain management if you fall behind it can take hours to set right. Likewise it doesn't seem to go wrong right at first either. It's a cumulative thing. Eventually they put me on two different narcotics, every four hours, but offset from each other so that I'm taking a narcotic every two hours and the different kinds help keep it more effective.

Post-Surgery 'How I'm doing' update September 11, 2008.

They sent me home from the hospital with the same "halved" mistake in my prescriptions that the nurse had made and it took me several doses to notice. And, even worse, just about as many doses to fix it. It wasn't quite as bad as the relapse in the hospital had been, because I caught on and was in control of my own medication, but it still sucked. As it is, I'm going to have to call the doctor tomorrow and tell them what happened, because that medication will need a refill, unlike the other four. Theoretically I should have called them today, but it really did take pretty much all of the business day for me to feel even "okay" much less able to talk coherently on the phone. What with all the poor dosing and also the frequency I have to take this stuff (every two hours, on the bleeping dot), I'm also exhausted. But still I felt much more positive this evening than I did this morning.

Post-Surgery 'How I'm doing' update September 12, 2008.

Around bed-time last night I realized I probably hadn't taken my psych meds the night before. Based on how much better I slept last night than the night before I'm pretty sure that was correct.

So the drama of the day was the drains. It wasn't all that dramatic, more just a pain in the butt. Three of my four drains are down to a trickle... so I call Teri, Dr. M's nurse. She tells me that the plastic surgeon has jurisdiction over the drains but that at that rate they should definitely be taken out today. So I call the nurse over at Dr. W's and she says they *never* take out drains in less than a week and then usually only two at a time. So I was to come in for the time I was scheduled to come in – next Tuesday – and enjoy my weekend with those things hanging off my body, now y'Hear. =|

Anyway, Teri *was* able to help me with the messed up prescription. Too bad that medication is the one I like less – it is somewhat less effective at the pain and makes me a little more groggy -- since she gave me 100 ct!! Oh well, at least I know I'll have pain medication to get me through!

The pain does seem to be somewhat less today. Not drastically, but somewhat.

But can I tell ya? The bandage bites. Not literally, but heck, it might as well! Basically the docs made this sort of a halter-top out of bandaging that particularly protects the drain sites –in fact almost sews the drain's stitches to the bandage. Glarhgh. Other than that, it basically just modestly covers up what remains of one's “bosom” heehee. It's constructed of gauze and tape and I dunno, maybe there's something wrong with me or with the construction of this particular bandage, but ... well it's gotten all loose and ITCHY! OH MERCIFUL DEMONS IT ITCHES!!!! Or – she says buffing her nails on her shirt – it *did*. The first thing that occurred to me was packing tape to tape up the tickley loose ends inside. Obviously this wouldn't work. Then I thought of bandaids... and I actually did use two small square ones stuck to the bandage in an attempt to protect my tickled... well for lack of a better word “cleavage”. But then I got smart. I dug up my medical tape. And I started reinforcing here, taping up loose tickly bits there.... and now the damn thing is almost tolerable. Oh, it will probably be a horrible mess again come Tuesday.... but maybe by then I'll have come up with new ideas... or at least new places to put tape. Since those sadists won't let me take off the bandage myself. I must say... everyone is in theory entitled to have a life, but I don't think that I would have authorized my reconstructive surgeon to go on mini-vacation this weekend. ;)

Post-Surgery 'How I'm doing' update September 13, 2008.

I did have less pain today for the most part, and that was due partly to very responsible dedication to the schedule, and also I think I detected a little easing up of the pain itself. I'm still in quite a lot of discomfort, as they like to say. And the psychological pain of having the drains in! And by that I just mean that I find the experience incredibly creepy and I want them OUT! If I had no drains and totally different bandages I might be a lot more comfortable. The “bad” issue of the day was that I was practically narcoleptic. I literally couldn't stay awake. I'd only doze off for a moment, but it was all day, no matter how much coffee I drank. So the absence of that is what I'm hoping for for tomorrow.

Post-Surgery 'How I'm doing' update September 14, 2008.

Missed a pain pill in the night and paid for it, but I am having less pain today, so I'm going to start gradually taking less of the painkillers. The nurse very helpfully reminded me on Friday that the pills only work for 4 hours, so don't spread out the timing, lessen the dose. So that is what I am trying.

I am tremendously more alert today, which rocks.

It actually started to sink in that the little assassins in my boob, that cancer bomb ticking away inside me is *GONE!!!* With the nodes out, it's even possible that all the cancer is out of me entirely. While I

still have to go through treatment it was sort of awesome to realize that the lumps, the horrible balls of cancer, are *not in me anymore*. Hooray!

Drains still driving me insane.

Later that same day...

It wasn't time to lower the painkiller dosage. I lowered my dosage during one time slot, taking 75% of what I'd taken before. I didn't reduce the other medication, so the total reduction was even less than 25%. And it took me all day to recover from it. I even got nauseated again. But so here we are, recovered. Now I'm going to have to ask for a refill of this stuff, dammit. I was hoping to just be better by now. Better enough, I mean. Oh well, I'm not and that's that. I was going to call tomorrow to ask about the pathology results anyway. Hey, at least I'm taking a lot less Ativan at the moment.

/I've got silver linings falling out of my pockets today. Don't step on my optimism.

Post-Surgery 'How I'm doing' update September 15, 2008.

I decided last night that my right arm was a little swollen. This does not do my paranoia any good, so I've been telling myself that it's probably totally normal to have some lymphedema-like swelling when still not so long out of a lymphectomy-involving surgery. I'm in a "la-la-la I can't *hear* you" mode to anything not optimistic. So I don't know if it's my bloody-mindedness or reality, but my arm seems less swollen today. Still, I didn't sleep well at all, and part of it was how uncomfortable this damn arm is – and painful. I could not possibly express how much I want to be done with this pain before my body decides the meds are pointless (habituation I mean).

After two tries I got a hold of Teri who scared me by telling me I was taking a really high dosage of painkillers and then felt bad when I started crying at her saying musn't there me something wrong with me? She tried to reassure me that people were all different and Dr. M would help me get the pain management sorted out.

To be or not to be, is that the question? Well it seems to be the answer, actually. My official staging is Stage IIb. My largest tumor measured at 2.5 cm (which was actually pretty much my guess)... bit larger than in the mammogram where it was guessed at 1.7. I think it's at least half a matter of it growing rather than a guesstimate error... the mammogram isn't supposed to be off by THAT much. But better news! Of the 19 nodes that ended up being removed (ow) only ONE was cancerous!! Yay! Thus, IIb... A tumor more than 2 but less than 5 centimeters, 1-3 nodes involved and no evidence of distant metastasis = IIb.

Post-Surgery 'How I'm doing' update September 16, 2008.

I woke up this morning so glad that today was the day for the follow-up with my Plastic Surgeon. I've been waking up in more pain than when I went to bed, so while I didn't know what the visit would

bring, I was hopeful that it would lead to less pain eventually.

So the appointment:

We had to wait forever (okay, like 90 minutes) for our “turn”... but almost the first thing they did was take off my bandage. Bliss! That was the nurse, and then she left us for a while to wait for the doctor. He eventually came in and to keep this moving he decided that three of the four drains could come out. I knew that was the number that was ready, but had been told they had a “two at a time” policy. He wants the drains out as early as possible, despite propaganda to the contrary, I guess. :) However, it's also not the end of the world if they hang out a few days more than strictly necessary. He was pleased that the three were done and told me to remain doing pretty much nothing until the last drain was done. I was told most sternly to not get active. Doctor's orders! Drain removal ... one was incredibly painful, one was mostly just creepy and the last was very very painful (though not as much as “incredibly”). I'm straight up scared about how this last one is going to feel coming out, but that doesn't mean I want to keep it. He said – and I agree, based on my observations – that it will probably take about a week for that one to be ready

Thus I have an appointment in a week.

He said that he really doesn't think the expander on the right side is out of place, it's just that the area is just swollen and painful in general. Not super helpful, but it did mean that I didn't have to undergo painful moving of the expander. So that's good. He wasn't at all concerned about any aspect of my rate of recovery... I'll have to leave the worrying about my pain levels to Dr. M., I guess, as Dr. W found my pain perfectly reasonable.

I asked about “support” for “what's left of my bosom” and found that indeed one can't wear a regular bra while there are drains in place. However, a tight lycra shirt or a “flat” sports bra would work, and he also wrapped me up in a really wide ace bandage for bra-on-the-fly. =P Certainly easier to put on than something that goes over my head.

Got home sore and late for a painkiller dose, so I'm not the happiest of campers right now, but I am very pleased to have lost the bandage and three drains.

Post-Surgery 'How I'm doing' update September 17, 2008.

Less pain today, a little. At least I slept more comfortably and therefore wasn't as painful when I woke up. And I SHOWERED this morning, wahoooo! I feel almost like a human being again. Still hurting, still tired of the drugs, still tired of the one drain left in me, but at least nearly human. Been really sleepy again today, though. Like bad. Oh well, it's not like I'm allowed to DO anything. “Sit! Stay!”

Dr. M just went over the pathology report, nothing new there, and gave me an examination. Said everything looks reasonable. I won't see him again for three months.

Today I bought myself some head coverings for when I go bald. Practical stuff, mostly. Didn't go too nuts. I'll probably get paid again before I need them, but I didn't want to take the risk.

And THEN! A very sweet lady and good friend sent me a care package! 7, if I counted correctly, knit hats, one with a matching scarf! They are so awesome – soft and in neat colors. She rocks. She also sent cookies that look delicious but I haven't tasted yet. =) The hats will be great for when the weather is colder (which I've conveniently timed my chemo for). I can't wait to see what they look like when I don't have hair. Really! =)

Post-Surgery 'How I'm doing' update September 18, 2008.

I think a little less pain this day as well. I also made one of my bandages smaller, but all in all, the itching pretty much continues to suck. I honestly think that my pain will improve drastically when I have the last drain out and my stitches removed and all bandaging off me. Constantly itching has got to be keeping me more than ideally tense, that tension causing a good deal of the pain. If I could just relax... I feel like I'm constantly fighting myself and that seems a logical reason for the pain to continue. None the less, I'm going to try to start lowering my dosage a bit again. I won't have enough to get through the weekend if I don't. If things get bad, an Urgent Care can probably give me a day or two's worth of them. In any case I know that one of my doctors (and can't remember which now) was concerned about the Percoset (the one I'm running low on) because of the Tylenol quantities, so they'd like to see me taking less of it. At this point I'm scared to experiment, but I'd just like to see me taking less drugs.

The cookies were to die for, by the way. ;)

Post-Surgery 'How I'm doing' update September 19, 2008.

Seems like less pain and I've taken one reduced dose of Percoset, with another due in a few minutes. The hour following that is when I'll *really* know if I can handle it. Leaving me enough time to get started back on track by bed time. I've had a lot of fatigue today, don't know if it's changing the meds or a coincidence.

One of my bandages is off and the other one made smaller, so less itching over all. Still too many sources of itching and too many potentially bad complications of unrestrained scratching (such as pulling out a drain, tugging on a stitch or opening a wound – ugh). I think I'll feel like a new person by this time next week.

I am draining less in that last remaining drain, but it's going to have to improve at a faster rate if it's going to be ready to come out next Tuesday. Which means I have to really take it easy. Which is hard after this long.

Post-Surgery 'How I'm doing' update September 20, 2008.

This morning? Tired. Not all that tired from not enough sleep, though I wouldn't have minded sleeping 2 more hours. Mostly I'm tired of the drain I have left and the bandages that accompany it. Also very tired of the pain. But that's lessening and I strongly believe it will drop down to below narcotics levels within a couple of days of getting the last drain out. I'm also tired of being so sedentary in general and even more tired of being useless around the house. I'm sure the man is tired of that too. ;)

Post-Surgery 'How I'm doing' update September 21, 2008.

Tolerating the lowered dosage of the Percoset, but I don't feel ready to drop it down again or decrease the other medication. I've been suffering from clenched muscles, sort of like a spasm or a cramp but less painful and in slow motion. It's a creepy unusual feeling and I feel like it is linked to my continued pain... that if this wasn't happening I'd have less pain and continue to improve. But I have no idea how to stop it. Also no good is that I'm experiencing a bad spell mental health-wise. Not depression, more feelings I associate with a mixed episode. I'm not having some of the other unpleasant issues of a mixed episode, and I want nothing to do with one. I increased my Seroquel last night... I hope increased night dosages will be enough, because if not I'll have to take Seroquel during the day, and if I was bitching about being out of it before ... well hoo-boy, that will look easy as pie comparatively. Shocking, really, to have made it this long into my diagnosis without having mental health issues before. I attribute the holding off to having such a long period of well before then and to Olav for helping that come to be. I think part of the reason I'm having issues now has to do with the ridiculous number of drugs they have me on. The coincidence of timing between starting to trip out and lowering the Percoset dosage strains credulity. Looks like I might need to see a shrink after all though. Having one's medication managed by a PCP is fine when it's easy sailing, not ideal when things aren't good. And my PCP has admitted she doesn't know much about bipolar. Well luckily the cancer center has all kinds of coordination and helpers and stuff to find me someone to consult with that is knowledgeable about cancer.

Anyway! The rest of the post-surgery stuff is pretty much the same today as yesterday. I can't wait for Tuesday.

Post-Surgery 'How I'm doing' update September 23, 2008.

Just wasn't really a lot to report yesterday except that my team wants me off the Percoset NOW and gave me a dog-choking bottle of Dilaudid saying I could even take it every three hours if need be to be off the Percoset.

Fine, fine, and I took the last of the Percoset this morning and seem to be going fine at Dilaudid every three hours. Tomorrow I can see if I'm ready for four hour intervals again. I am hopeful that I will be, since they took out my drain at the plastic surgeon. He waffled at great length because I was still draining too much fluid, but he doesn't like to keep them in more than two weeks. He finally came up with a theory that the placement of the drain was causing the continued fluid production, and that I'd probably be okay with it out. Hopefully this will be the case – if I get all puffed up from fluid, they'll

have to suck some out with a syringe. Blargh. He also took out my stitches but then put stretchy tape right back over the scars, saying it helps them not look so bad. And of course, I have a little bandage from where the drain came out. But oh my gosh, how wonderful to be free of the drain!!! So, a few tickly things still to get rid of, but the worst is over. Oh yeah, the drain removal didn't particularly hurt this time; much like the second time from the first three. So that was good too! I'm to go back in a week to see him again – dunno if he's just going to check on the drainage issue or if he'll start filling then.

Then this afternoon we finally met with our oncology doctor, and he's *fabulous* (yes, that way too). Really, cute in a puppy dog kind of way, but very smart, totally knows what he's talking about. Most impressive was that when he was going through all my test results and pathologies and all that, I think he referred to my file *once* and the rest was by memory. I didn't stop him in his lengthy discussion of things I already knew because it's good to know what *he* knows and the order he put it in unfettered by my commentary had a certain rhythm and logic that went into its creation. I only popped in a couple of times on things that let him know he wasn't covering new ground – and one of those was the SBR score 9 out of 9 badness points for me. He said “at least you're consistent” I muttered something about consistency being the hobgoblin of little minds and he laughed. He drew out all this information for us on the paper that covers the examination table and when he was done, he ripped it off and neatly folded it for us to take home. =)

So basically with my staging and prognosis markers my chance of relapse is 40-50%. We discussed a few chemo regimens and he also gave me a packet on a clinical study I appear to qualify for. It looks like we're probably going to go with the TCH regimen, which involves Herceptin from the start and the T/C chemo (which can be done at the same time as Herceptin) at 6 courses (if I'm using my terms correctly) at three week intervals. He said it would probably be either that or a dense dose regimen.

Meanwhile I have to have more tests! I immediately went downstairs to let them have some blood. And I'm going to have a PET/CT scan that will let him see my bones *and* organs. Hopefully this will just be a good baseline, but it is also being done to make sure that cancer hasn't snuck around us all trying to give me that immediate promotion to Stage IV. None of us think that's likely, but it will be nice to have the scans done.

Also talked about the port for the infusions and he said, as I suspected he might – that they don't really like to do them in the arm, however, he said that if that's what I really wanted we could try it and if it fails we can install the chest port. So presumably that will get done some time in the next three weeks, that being the time frame we're looking at for starting chemo.

Post-Surgery 'How I'm doing' update September 24, 2008.

Doing okay, down to every four hours on the Dilaudid for the moment. I think it's enough, though. Feeling stronger. Starting to feel impatient already with waiting for tests and results. Probably nothing is going to change what we already discussed with Dr. C (the oncologist). But I'd like a firm plan and a firm date. Oh well, it's not super-urgent with any luck. ;)

Feeling a bit stronger, but still trying to be a good girl and take it easy. I've almost had enough of that, I tell you what. I'm more than a little ready to be able to drive again, for instance. And it would be useful

around the house if I could at least do the dishes. * Sigh * Waiting is.

Post-Surgery 'How I'm doing' update September 25, 2008.

Port installment scheduled for Saturday (woah) Oct. 4, meeting with Dr.C again on the 7th. I have at least one other thing to schedule between now and the 7th, and I guess I better call by the end of the week and get an idea of where they're at as far as scheduling that.

Much less pain. I *knew* my pain would decrease quickly once that last drain was out! Still dealing with some creepy feelings, physical and mental. The mental bit hasn't gotten worse, but I can't say for sure if it's gotten better. I'm not really nuts about putting myself in situations where I could find out... gun-shy you might say.

Post-Surgery 'How I'm doing' update September 27, 2008.

I'm doing so much better! I just knew I'd improve rapidly once that damn drain was out. It *had* to be the most uncomfortable one that was in the longest, didn't it? Even since yesterday I feel stronger, much stronger. And I'm having quite a bit less pain. I think I will make another step down on the amount of painkiller I'm taking. Yay!

My chest muscles do this sort of slow-motion spasm I might have mentioned before. It's uncomfortable but not nearly as much as it was before. Still I hate it. I find Ativan helps with that, which gives me the idea that the origin might be psychological in nature, at least in part.

Post-Surgery 'How I'm doing' update September 30, 2008.

I have virtually no pain! Or at least until I went to the Plastic Surgeon today. ;) But really, before that I was getting my strength back and went, oh I dunno, 18 hours without even thinking "wow, I guess I haven't been taking my pills for a while! Cool!" So then I went to the PS today. I had, as I well knew, a fluid "seroma" (I think) build up on the right side and was hoping/dreading that he'd drain it. More hoping though; I looked lop-sided. So he did that as well as give me about 80ML of fill. So now I'm about a lumpy A Cup.

Oh well. I assume that if they don't fix themselves during the fill process, the doc will take care of the lumpiness during the exchange. Not loving the lumpiness. However! I'm trying to do the silver lining

thing though. I LOVE tops that show my collarbones and shoulders, and I could never wear them because they make bras impossible.... or at least extremely tacky. =P I got one as a hand-me-down from a neighbor (was actually supposed to be from her grandkids to my kids, but this shirt, another and two pairs of pants fit me well, thank you!). And I bought three today at Good Will. I think such things will have to become part of my wardrobe. I love not wearing a bra, I'll tell you that. I never hated my bras, never. I appreciated their efforts in my fight against gravity. At the moment, I am not in an adversarial relationship with gravity, and I am enjoying it immensely.

I'll get my port put in on Saturday the 4th.

Post-Surgery 'How I'm doing' update October 1, 2008.

Woke up in pain this morning, delayed reaction from the fill I guess. From the intensity of it (not too bad) I think it's very possible I'll feel fine tomorrow.

Today, though, I have been taking medicine for it. I'm pretty sure I'm filling up with seroma again, so I look lopsided again, but not as badly. =P

Had a bit of a melt-down last night, though. It's horrible, feeling weak/useless and maimed. I try to look for my silver linings, but I was having a moment of feeling like a heck of a bad bargain as a wife. And I feel so helpless in comforting my husband when he has his bad times too. I'm not the one with a beloved that has a horrible disease. I don't know what that feels like. I just try to ... be there.

Intermission 'How I'm doing' update October 2, 2008.

I figured since I wasn't really having much pain from the surgery anymore – some soreness from range of motion increasing, and certainly still a lot of weakness, but not really pain – that it didn't make sense to call this “post-surgery” anymore.

I *thought* I was having my port put in on Saturday, but as it turns out it is my PET scan that is happening on Saturday. My port won't be installed until the 9th. Which is not good timing at all for me, but that's just the way it goes, I guess.

A little achy from the fill still today, but I didn't take any painkillers. I might before bed though.

Intermission 'How I'm doing' update October 6, 2008.

The PET scan was nothin'. I slept through it, literally. First they shoot you up with the nuclear stuff and you have to remain still for an hour. I have to wonder if he put a benzodiazepine in there, or maybe I was just tired, cuz I was asleep about a minute after he shut off the light. =P Then we walked over to the PET scan trailer and I slept through the scan as well. I didn't see any reason to stress out about the results because A) I am not really worried that the cancer has gone metastatic; and B) because I know I will know the results tomorrow. I have stressed out on the results of many a test so far and no doubt will again, but for this once, I am not.

I did still have pain on Friday from the fill and seroma draining, but not as bad. I have to do the same routine tomorrow and am now out of pain pills, so I guess I'll have to ask Dr. W. for them.

Also tomorrow, as I implied above, I meet with Dr. C. We'll go over my test results and make a final decision about chemo. I'll report back.

As for the mastectomy pain, it's pretty much gone. I still have these weird clenchings of my muscles across my chest which are uncomfortable and creepy-feeling, but they seem to respond to Ativan. My arm and chest muscles are still weak, but I've been starting to use them, as much as Olav will allow. Reaching above my head – to get something out of a cupboard or hanging things up out of the dryer is difficult, but, again, is more a matter of strength than pain. Depending on how much seroma Dr. W. sucks out of me, I'm hoping he'll give me leave to start exercising. I've done a little looking on my Google map to see what routes in the neighborhood give how much mileage, so I can do some walking – with a mind to the streets that are safer to walk on; we aren't chock full of sidewalks around here. When my arms are stronger (and this will be delayed again with the port implant) I can start riding my bike as well. Also I've looked into getting some exercise videos; mostly yoga, but I'm also intrigued by a video that claims to combine yoga and Pilates. Good rainy day exercise. =)

I'm really trying to re-evaluate my health habits. I never really concerned myself with them before, considering that while I wasn't in great shape, my heart was and I wasn't in *bad* shape either. But I know that some of my habits – or lack thereof – could be revised to try to minimize recurrence... or at least make myself stronger for treatment. So I'm learning how to eat fruit and trying to think about how to add more veggies into our diet. We eat veggies, but could eat more... we're not exactly at the recommended daily amount. Also, as noted above, exercise. At least twice in the hospital and occasionally at other times I've had doctors and nurses ask me if I jog or work out – due, I think, to the healthy condition of my cardiovascular system, even my respiratory system when they had me blow into that lung-strength device post-surgery. While the good shape of my heart will help with the Herceptin (known for causing heart problems), I know I could be in better shape in general. So regular exercise and better nutrition has got to be added to my life. Besides, the literature says these things will give me more energy and help me tolerate chemo better. I don't know how they think they know these things, but I figure it can't hurt.

As for my mental health, while I still feel that mixed episode looking at me, looking for an in, I seem to be doing better. Backed down on my Seroquel when I realized I was feeling absolutely zombie like all day – always a sign. If I take that much and still have my normal amount of energy, that means it's the right amount or not enough... but if it zonks me out, I'm taking too much... even if that was the right amount the day before. It's supposed to help me sleep through the night, not make me want to sleep round the clock. I've been having a lot of mood swings, but not ones that feel bipolar to me. They seem perfectly reasonable under the circumstances. I have a lot to feel positive about, but no shortage of things to bring me down, either.

Intermission 'How I'm doing' update October 7, 2008.

Another big entry for today. Two appointments today.

First was with Dr. W, who drained off about 55 ML of seroma and then gave me 80ML fills. He likes to only fill every two weeks, so I was "lucky" to get one today... I wanted to look a little more like... or maybe I should say "less different" to my kids. The doc decided that Valium would be the most effective thing to deal with my post-fill pain... I took one like 90 minutes ago and am not convinced, shall we say. Not that the pain is horrible... I just can't tell ANY difference since I took the pill! There's something wrong with me, isn't there.... As I type I have just taken another (though they are supposed to last 8 hours)... if this doesn't work I'll have to get something else, even if it means turning in the Valium... I mean, if I can't feel it anyway, why not?

Oh, and grrrrrr he said *two more weeks* of no activity!! I've gained weight, I want to exercise for possibly the first time in my life and I can't. =P I asked him, "Does this mean that if I want to take my kids to the park a half a mile away I should drive?" and got a wide-eyed "Oh yes." * sigh *

So I go back there in two weeks unless seroma build up becomes intolerable.

Second was with my oncologist, and that was a great appointment. He is so perky.

First order of business was the PET/CT scan. No evidence of metastasis, woohoo! Had a little last minute anxiety about that today, so good to hear the news.

Anyway, he answered all my questions, of which there were many of greater and lesser importance. I feel very happy that he is on the same page with me about minimizing steroid use. That part really bothered me for some reason, and he, for his part, seems like he wishes it weren't involved in the process at all. But he said first time out, we try it, because I might need it. However, he did have the NP put in a half the dose that is normally used.

So yeah, will be, as expected, doing the TCH. There will be 6 infusions at three week intervals. I will be doing the Herceptin weekly while in chemo; after chemo I will probably do it every three weeks. He told me to expect 3.5 to 4 hours for the first chemo infusion and about 2.5 thereafter. The Herceptin infusions run about a half hour. I told the appointment scheduler that I was considering moving in. She's probably heard that one before. ;)

He also ordered an echo-cardiogram, since I hadn't had that done yet. Baseline to keep an eye on potential heart damage from the Herceptin.

Intermission 'How I'm doing' update October 9, 2008.

Well the nurse tried to talk me out of the arm placement for my port. I countered with saying I'd go somewhere else if the doctor there wasn't comfortable performing the procedure. I got my arm port and hopefully the surgeon did a good job. I can't take off the bandage until tomorrow. The arm hurts, but not as bad as the last surgery, of course. More later – or revision – when I'm feeling more perky.

Intermission 'How I'm doing' update October 12, 2008.

So after I wrote the 10/7 update I ended up taking two more Valium about 90 minutes later... and it was like slugging 6 cups of coffee. I was actually fairly manic that night. So no Valium for me. I called them and told them I needed something else and ended up with the lowest dose of Vicodin out there. When the port-placement people didn't give me anything for the pain, I called my onc (who had previously said to call him if that happened) and he phoned me in the good Vicodin. I'm pretty resistant to it, so the more Vicodin and less Tylenol the better. So the better drugs and the more intense pain in my arm have pretty much over-shadowed the discomfort from the fill. I'm still taking Ativan for the muscle clenching thing. Clearly Dr. W was wrong that Valium would be better than Ativan for that. I'm going to suggest a *real* muscle relaxant for next time if he thinks that's the approach, instead of a benzodiazepine which really isn't designed for that anyway.

Anyway, the arm is being really slow in feeling better. I think it's just... like a big ol' deep bruise. So it will probably hurt a little more than usual to use it tomorrow, but hopefully by next week it will be healed.

So yeah, first chemo tomorrow. I'll report back. ;)

Chemo 'How I'm doing' update October 14, 2008.

So, first chemo is done. If anyone is curious enough to mention it to me, I'll put in a more detailed discussion of what it was like, but we'll start with this.

No biggie.

So far, anyway! It hurt while the nurse was squishing up my bruised flesh to get the port located and held ready, and then after asking if I was ready, he poked a very short needle through my skin and through the port and it stopped hurting. The flesh on my arm hurt for a while just because it is so bruised but that faded. From time to time I had terrible itching/tickling but I had that before I was hooked up; it's from the healing wounds. An itch ya can't scratch. But once the port was in he just had to pinch tubes here or turn valves there or attach things in this other place and he could do it all. Drew my blood, -- two vials I know not what for – gave me the premeds, and then one after the other the slow drips of the T, the C and the H, as I call them. My nurse thought my mental block against remember what the T and C stand for were funny, but they persist. The H is the Herceptin, which I will

be getting weekly. In any case, the port made it so easy. I felt nothing, and when he wasn't doing anything with it, just letting it drip, the lines were taped to me so that I could use my arms just fine. Olav went with me and had a very boring day, I'm sure. But I'm glad he was there, I might have been nervous otherwise.

It was, in the end, just a long day and while I had brought plenty to do, I was still bored of being there at least an hour before I was done. All I had left to worry about was after-effects.

I haven't been queasy! I've been taking anti-nausea medications by the clock, as per my instructions and haven't had worse than passing feelings of a sour stomach. I'm told to keep this up through Thursday and I will probably be past it. I've been feeling a little tired, but not particularly more than could be explained by some poor and insufficient sleep. The nausea is supposed to get easier as time goes on and it hasn't been a problem. The fatigue is supposed to get *harder* as time goes on, and at least there's room to imagine that I can still live with it. =)

So that, if you can believe it, is the short version. But the long version isn't very interesting. =P

Chemo 'How I'm doing' update October 15, 2008.

I spoke too soon. I feel craptacular this afternoon. =(

Chemo 'How I'm doing' update October 18, 2008.

Still feeling bad. Queasy and hurt all over. And very tired. It's been sort of like a combination of the flu and food poisoning. Only, count our blessings, without the snot. I ache enough to mimic the fever that comes with flu, but have not been running a fever – in fact, my temperatures have read below normal, consistently. The aches and even stabbing pains could be caused by either of the chemo drugs or even the Herceptin, though adverse effects from Herceptin are not as common. Or, possibly, they are from my blood being all wonky. I suppose they'll draw some blood before they hook me up with the Herceptin on Monday. Anyway, feeling crappy. Hope to feel better soon.

Chemo 'How I'm doing' update October 20, 2008.

Physically speaking, yesterday was the worst day of my life. I started vomiting around 2AM and didn't stop until maybe 9PM. I don't think I've ever had a nausea that wasn't at least somewhat improved for at least a short while after puking, but I'd feel just as bad after. I made Olav call the insurance's nurse advice line and the cancer center weekend number. Cancer center's on-call doc called me in some Compazine in the suppository form. I tell you what, I had NO problem inserting that thing when the

alternative was taking another pill that I'd probably puke up anyway. We just kept rotating through; meds that are supposed to keep nausea from happening, breakthrough meds (which I didn't have prescribed! my onc's first flaw lol)... what finally started to help was the Ativan, actually. I don't know how much anti-nausea action it had, but it calmed me down so I wasn't crying. I cried for hours, I felt so bad.

Anyway, I emerged from bed very carefully today. One med at a time. =P And I'm doing better, that's for sure, but still feel bad. Not helped by waking up with a migraine. I probably had that yesterday too, I remember my head hurting horribly, it just didn't matter compared to the nausea. Luckily I have migraine medicine. Still I'm sitting here with my sunglasses on inside. =P Olav had to drive me to my Herceptin infusion today, missing more work. I just wasn't up to it. Oh well, at least I know I'll be able to drive myself to and from chemo and probably the Herceptin before chemo. And hopefully I won't feel this bad after the next one! The chemo nurse conjured me up a scrip for oral Compazine, and when I got home I found that I had gotten that from the hospital so I still had some around. I wouldn't have been able to hold it down yesterday, but at least it means one less thing to worry if it will be at the pharmacy when I get there. I do need to pick up a refill there later anyway... it just doesn't matter now if it's today or tomorrow.

Oh, and accessing my port was much less of a problem today – though it wasn't that bad last time, except for my bruise! -- this time, although that was helped by me showing the nurse exactly where it was. Gods I love my port, no vein hunting and no big scabs on my hands from having a big ol' IV cath line in there. * shudder * I highly recommend it for anyone who is going to have a year's worth of infusions. I suppose if I was having a total of 6 infusions I might not want to bother.

Chemo 'How I'm doing' update October 23, 2008.

I'm not better yet. I can't remember how the rest of Monday went, but I started throwing up in the night again that night. I managed to get my symptoms under control in time for the afternoon appointments on Tuesday. Yesterday I felt horribly crappy again, but actually only puked once. Today I spend a long part of the day feeling okay, more of a sour stomach thing than actual nausea. Until it started getting dark. Now I feel all yucky again. I'm so tired of this. Constant nausea is hideous.

So anyway, back to Tuesday. Plastics guy drained more seroma and then gave me fills. Also a scrip for Flexeril, seeing as how Valium was clearly the wrong choice. The Flexeril seems to be doing the trick.

Later that same day (I didn't bother going home, just had Olav meet me there) I met with my oncologist again, Dr. C, as I've taken to calling him. [Editorial Note: When transforming my blog to this form, I went and did a find-and-replace to refer to doctors by their initial only. We really did call my oncologist "Dr. C," though.] We went over the course of my reaction to chemo and he told me I had classic delayed nausea and vomiting. I guess some people feel sick right away, some people feel sick a couple days later, and then there was me, feeling at my worst at the time when other people would be totally recovered. You can bet I'm going to keep that in mind and do things if I feel like it the day of chemo and the next day, and possibly the day after that as well, before things start going downhill. We're going to try me on Emend this time around... it has a very good reputation, but is not really aimed at people who get sick as late as I do, so we'll have to see. Dr. C made no guarantees, but it was the logical next

step. I'm somewhere between scared and horrified that I have to do this again... repeatedly. However, hopefully this one change will work, and if not, hopefully there will be something else we can try – other than admitting me for IV drugs, which is an idea I was starting to get behind on Sunday. If anyone had even hinted that I could do that, I imagine I would have.

Today I had a follow-up appointment with the radiological intervention folks (they put in my port)... they just wanted to see how it was doing. It's doing great, as I've mentioned. Tomorrow I have my echocardiogram. Whee.

Chemo 'How I'm doing' update October 25, 2008.

I felt pretty good all day yesterday and feel better still today. I think I'm past it for this round. Yahoo!!

Chemo 'How I'm doing' update October 27, 2008.

Yup, all better, thank goodness. Today I have just Herceptin. Next Monday we start all over again, hopefully with more tolerable results. I went for a walk yesterday evening near dusk and intend to try to get in that habit, now that I'm allowed to be active. Also will be starting to try to get more strength back in my arms, mostly by doing housework, but I might also carry something when I walk like cans of soup – on the premise that we keep cans of soup around and not hand weights. I'd feel a little silly carrying soup around, though, so we'll see. =)

Chemo 'How I'm doing' update October 29, 2008.

Well I'm shedding in earnest now. Not patchy at this point, like I hear some people get; seems to be pretty uniform. Still have to shave, but a lot less hair is growing in, that sort of thing. Not ready to take the shaving cream to my head just yet, I'll be bald as an egg up there soon and long enough.

I'm quite lop-sided in the slopes, though. I see the plastic surgeon tomorrow and he'll be getting an earful. It's mostly seroma, but since this keeps happening, sheesh, put a little extra on the other side for now! I HATE this.

Chemo 'How I'm doing' update October 30, 2008.

So the visit to the Plastic Surgeon was interesting. I had quite a lot of seroma – I can't remember the exact amount, something in excess of 200 ML. But the interesting thing to me was that the expanders are twirling around in there! Not flipping over, which would make them impossible to fill, just rotating. The one on the right is altogether upside down now and the one on the left is sideways. This makes me look a bit funny. Not as funny as I did before the seroma was drained, though, I'll say that. I'm much more even. I'll be really glad when this is all over, but, sadly, that will be after chemo is done, which seems like a long time from now. Anyway, he put in another 90 ML on each side and I see him again in two weeks for another fill, but was told I could call and come in sooner for seroma draining if the build-up was making me uncomfortable. We discussed the procedure that could be done if the seroma doesn't stop flowing, but it is not easy for the docs and is surgical... clearly not something to just jump into when waiting will probably solve the problem, annoying as it is.

The plastics office was able to see me early so I could make it to my other appointment on time (barely) and we were called fairly quickly, we then waited in the exam room for a long time. And the nurse, for some obscure reason, got it in her head that the NP would want to examine me so she had me halfway undress. Burrrrr! When the NP finally did come he couldn't stand to see me shiver for very long before he told me to put my clothes back on. I had thought the appointment was a bit silly, since we'd sort of gone over all the nausea stuff before, but I was much clearer headed today, so it was, in fact, a useful appointment. The NP went over the schedule of anti-nausea medications that you take to prevent nausea and then into a little more depth in the best ways to use the breakthrough stuff. He basically said to go as heavy on the Ativan as seemed to help, since you can't do that with the Compazine. He said to make sure I wasn't constipated because that would make things worse and recommended products and courses of action to help with that. He also recommended B6. So I have a wee shopping list for next week. The last thing we discussed was that I was probably going to gain weight. I already gained back everything I lost during the last barf-sesh. I suppose that was mostly water even if I didn't get really dehydrated. But the way I ate like a PIG after my appetite came back probably had something to do with it! He said, though, that it had mostly to do with the way that chemo has a cumulative fatigue effect and that I was probably going to find myself being pretty sedentary by the end of it. And that it would be a little difficult getting back in stride after it was over. Like I'm all that athletic now. =P Well, I'm going to try to keep my walking up – they do say that keeping active makes chemo feel easier. I don't know how they could know that for sure, but if it *might* it certainly seems worth it to try.

Tomorrow I have to go let them draw some blood. If the appointment had ended at a reasonable time today I might have been able to get that done while I was down there, but the lab was long since closed by the time we got out of there. Le sigh. I don't know if the chemo nurse will tell me anything about the bloodwork results or if I'll have to wait until my next appointment with Dr. C. I guess if there is anything pressing in the results someone will tell me. The primary possible problem is my blood counts, particularly the white count. There is a drug called Nuelasta that is given by injection (I believe) the day after chemo if needed to treat this. I hope I don't need it, it can have some unpleasant side effects, and aren't the ones from chemo bad enough?

Chemo 'How I'm doing' update November 2, 2008.

As it turns out, I couldn't really have just dropped into the lab for the blood draw; not if I wanted them to use my port. You have to have that scheduled, because the infusion folks do that, not the lab folks. Who knew? Well, everyone but me, it seems. I almost slept through my appointment, but realized in time and made it there on the dot. The nurse had me talk with her to another patient and his wife about my port. I love it so much I could do commercials about it, so that was good for the nurse's point of view. => I'm pretty sure we sold them on the idea.

Tomorrow starts chemo cycle two, and I am so not psyched for it. Also, I just looked at the calendar and realized that the one after this one is right before thanksgiving. Last thanksgiving I had strep – and possibly the flu – and was incredibly sick. If this trend keeps up I'm going to develop a complex about that holiday. =P I'm trying to think positive about this cycle, that things will go better, but it's hard. It's hard to deliberately poison yourself. Even in a good cause. Oh well, it's got to be done. At least the infusion itself is no biggie. Just a long boring time in the chair. Maybe I'll try to nap this time. But I'm definitely bringing things to do; laptop and book.

The Plastic Surgeon gave me Flexeril for the fill pain and it's conked out on me. Just not really doing anything. It did that before when I had it for my neck. I was being foolishly optimistic when I requested it, I guess. Now I'll have to ask for something different and he's just not that into prescribing. In general. Oh well, if he lets me down I know Dr. C will help me out. After all, that's who got me the painkillers after my port implant.

Chemo 'How I'm doing' update November 3, 2008.

Not much to say about the infusion. It went perfectly smoothly. Even the needle poke didn't hurt. Have I mentioned I love my port? I think I might have once or twice ;) Now is the hard part. Religiously taking anti-emetics as preventative measures and aggressive attacks on nausea if it comes. I think it's probably a “when”, but I'm trying really hard to be optimistic, so I said “if”. We'll see how this cycle compares to the last one.

Well Hully Gee (also 11.3.08)

Olav and I just realized that I never mentioned that I shaved my head! Well yes I did. On the 22nd, as best as we can recollect. Not down to the skin with shaving cream. Just to a #1 guard. I usually wear a scarf type thing when I go out, though if it starts to itch too much and it's warm enough, I'll take the dern thing off! I am not embarrassed by this. I don't look that bad and any bad I look I will cavalierly toss it off to chemo. As I mentioned on the 29th, I am shedding quite a bit, but mostly uniformly. And,

like I said, I just don't care – it's not a fashion statement, it's chemo, and anyone who doesn't like it can take a long walk off a short pier.

With today's chemo infusion and also the drug Emend (which also has hair loss as a side effect) I figure this slow shedding will continue and then one day soon ... * poof * !!! all gone. Such is my guess.

Chemo 'How I'm doing' update November 5, 2008.

Downhill has started, but it's not too bad yet. Just a slightly sour stomach and fatigue. I felt worse at this point last time. I got a giant pill counter, one with four boxes for each day to keep all this chemo week crap straight. I also made myself a med schedule so I could check off when I take the medications. I want to really stay on top of things in hopes of it making a difference. Who knows, maybe it already has?

Chemo 'How I'm doing' update November 7, 2008.

I'm weak as a kitten, and don't feel great, but doing a lot better than last time. I have only just now taken my first queasiness pill, and the aches that had me so unhappy last time are mere ghosts on skin, not even worthy of the word ache. And I have hopes that the longer I feel better, the less bad I'll end up feeling. So I'm no barrel of monkeys, but at least I don't feel at death's door.

Chemo 'How I'm doing' update November 9, 2008.

This time last cycle I was curled around a bowl, sobbing and puking and wondering how many times I would have to hit myself over the head with a hammer in order to achieve sweet sweet unconsciousness... boy is this cycle a change for the better! Oh, I've had a never ending headache, I remember that from last time, and it wasn't from trying the hammer trick, but I just didn't care that much in light of the worse symptoms. And I've felt as strong as a cooked noodle. But I haven't puked at all! And have only had the teensiest nausea here and there. Once that started happening I started taking the Compazine and that worked. Also munching on a ginger snap really helps. It seems to make the tummy forget what it was talking about. Ativan is another good tool, I've been taking that liberally as the NP told me to do. I really think it is a combination of all these tools that has made the difference, though I wouldn't for a second try it all without the Emend. Even though I took my last one of those on Wednesday, I still can't forget that that is the one *major* variable we changed.

I even went for a mile long walk yesterday. When I left the house I had intended to do maybe half a mile to be nice to my weak self, but my route soon made that unlikely. I stopped a few times to take pictures (gray day though it was) and that was enough to make it not too taxing. I will walk again today, I think. I missed some of my walking earlier in the week due to poor weather and a sense of waiting for the other shoe to drop.

Chemo 'How I'm doing' update November 11, 2008.

I guess fatigue was the worst of this round. I walked another mile on Sunday and yesterday I walked with my bike for a mile to the gas station to get air for the tires and then went for a five mile ride. A very slow five mile ride. I'd really already gotten my exercise, so it was more or less just for fun and optional transportation at that point. Today I only did housework. I suspect I was meant to be a housecat, but I can't live like that any more, I have to keep active... got to keep strong to survive chemo better and to increase my chances of surviving longer in general. Oh well. However! I did contact a cleaning service that does free housekeeping services to chemo patients... might as well take all the help I can get, right? Still not sure they operate in this area, but I'll find out soon.

Believe it or not, the only other doctor appointment I have this week is with the plastic surgeon for a drain and fill. And yet more discussion about what might work to help with the pain after, since Flexeril has conked out on me. I'll bring the mostly full bottle with me. This is getting annoying, maybe I should just get real narcotics this time. Anyway, that's on Thursday.

Chemo 'How I'm doing' update November 12, 2008.

I've had a migraine-ish headache for days. It's migraine level today for sure. I want it to go away, but I'm plum out of ideas. The possibility that it could be medication side effect related is there, though at this time I am no longer taking anything unusual, no need for more nausea meds or anything. I don't know if it matters why I have it, I just want it to go away. I have migraine medicine, but the damn thing just keeps not completely going away.

Reconstruction 'How I'm doing' update November 12, 2008.

Dr. W. drained about 180 ML of seroma from my right side again today. I tell you, it gets uncomfortable. In fact, in light of that, my next appointment is in a week and a half instead of the usual two weeks – that should help. He keeps hoping that if he fills the expanders more, there just won't be

room for the seroma, but this theory doesn't seem to be holding true. Oh well, there's a lot of time between now and exchange... if there *must* be a surgery to correct this, I guess we'll have plenty of time to be sure it is necessary! In the meantime, we have actually reached the size I want to be, if not the shape! I put on one of my bras today after my fill and it sort of fit. I could tell that there was enough there there, so to speak... it just wasn't in the right places, the right shapes. My slopes look like boobs to a casual glance through clothing, but unclothed they somewhat resemble an art student's early work. Not really as bad as when I described them as "lumpy As".... but I don't really know *what* to call them now. However, Dr. W. said that if I was happy with the size he'd be putting in a little more (common procedure, although with some plastic surgeons they like to do a little *under*) next time. So that's going to feel weird. One step will be done.

Having no other ideas, he gave me norco for the discomfort. At least it's working. Mostly.

Expander slopes, for you my readers, bear little resemblance to breasts beyond a casual clothed glance. The spinning I mentioned last time just makes matters weirder. There are a few main things. I guess first is that there are no nipples... earlier today I actually thought the words "Wow, if I had nipples, they'd be hard" from being in a cold room. So.... no matter how cold an expander gal gets, you won't get the visual cue. Second is for us older gals... these things defy gravity. I haven't worn a bra since my mastectomy and now I'm sporting Cs. They're pretty much as high as a good bra. But the most important difference is that they are hard as rocks. Well maybe not rocks. Maybe bicycle tires. Really hard. Not soft and feminine at all. I almost feel guilty when I hug someone.

Oh well. Once chemo is over, I can have the exchange. And hopefully the implants will be great on the first try and they will have settled in time for a nice Anniversary Dinner.

Reconstruction 'How I'm doing' update November 15, 2008.

I'm really not sure why, but I've had a lot more pain this time. I'm glad I got better drugs. The pain has woken me at night last night and the night before. More on the right side than on the left, for sure. Which makes sense: that side gets poked twice. On the other hand, it doesn't get as much new stretching, so... just goes to show that it always has been about the muscle poking not the skin stretching as far as my pain goes... dunno if that is true for every woman. When I read about this procedure, I imagined the skin hurting. I also imagined stretch marks, like when breasts grow fast during pregnancy. Neither of these things have turned out to be the case for me, at any rate. You know what else oddly doesn't seem to hurt? The sort of jarring that is normal to walking. I'd have thought that would hurt, but it doesn't seem to be part of the issue. Being squished hurts, but not that sort of minor jarring.

I think I sort of ... overstated the difference in appearance between what I've got and real breasts in my last message. Not intentionally, it's just that ... well there's nothing like a real breast, now, is there? But as I was taking my walk today I looked at my reflection in various cars and realized... I look normal. Maybe I wouldn't in summer clothes, but it's not summer and I'll have my exchange before then. It's winter, and at least in these clothes... I look normal! How strange.

Treatment in General 'How I'm doing' update November 20, 2008.

This is going to be a long one folks! Having conquered the puking last cycle, I came up with quite the list of questions for my appointment with my oncologist today. And where I had questions, he had answers – except on one thing, and he's going to look into that for me. So, in no particular order...

Oh, but can I say first what a doll Dr. C is? When he finally came into the exam room – guess he was running behind today – it was with both arms open for a hug. He said something like “are you glad to see us?” and I said “I love you guys!” which tickled him. I wouldn't really want Dr. W or even Dr. M giving me hugs, but Dr. C is a total doll and if he is feeling huggy, that's fine. He gave me another hug when the appointment is over.

I've been having headaches every day and migraines as many days as not lately, so I brought that up. I do take a drug intended to prevent migraines, after all! So on the chance that it was something that they were doing to me -- “we do give you a lot of drugs” Dr. C said – I thought I'd ask. Looks like, from the timing of it all, stress is the most likely culprit... and there are things I can try to do about that, certainly, but it's not an *easy* fix. I didn't really think there would be one, but you can't win if you don't play.

Segueing into a differing kind of pain... I asked Dr. C if he had any thoughts about fill pain since Dr. W was fresh out. He offered me a Percoset prescription, which is basically more hydrocodone without more Tylenol, so I said yes.

To refresh my memory I asked him about the recurrence stats he quoted me in our first meeting. I couldn't remember if he told me the time frame they represented. They were five-year numbers. I recently heard someone say that people with my type of BC tend to have a recurrence by 7 years if they are going to have one. Not to say you're home free after that, but that it is apparently pretty unusual after that. However, all the stats for my type of cancer are pretty much bogus and useless because Herceptin was only introduced as a standard therapy a few years ago. I will be one of the people that sets the numbers for all that. Watch me, world! There's really nobody for me to watch.

I told Dr. C I was having “issues” ... that I was already scared about leaving treatment – and he made the point that I'd be on Herceptin until next October, so finishing chemo wasn't the same as being done with treatment, which is certainly true – and I just felt like I needed to talk to someone who had cancer experience, which they have there at the cancer center. I don't know how much it's coming out in these memos, but I'm a mess sometimes. Maybe therapy will actually be useful for once in my life.

I also asked for a referral to the oncological nutritionist. I feel like I need to know more about good nutrition. Both the shrink and the nutritionist will be calling me to set up appointments. The cancer center is so convenient that way, so organized.

I've been having some period-like bleeding... way too soon for a real period. Apparently this is my body's interpretation of chemopause. Yay. Some women just stop getting their periods. I guess I got one of theirs. I didn't really think I'd escape chemopause, but I did have a wee hope... because I'm afraid that chemopause could go right into menopause, even though I would be young for it. It's certainly

been known to happen. I am not ready for that.

I read about this program associated with the cancer center with the sappy name The Triumph Fitness Program or something like that. It's for people who have just been through cancer treatment. You sort of get a combination personal trainer/physical therapist who helps you figure out your needs and goals to get you back in the groove post treatment. This was the one thing Dr. C hadn't heard of, so I told him he had homework. "I love homework!" he said. The program seems like a really good idea, but I am not reassured by Dr. C not being familiar with it.

The last thing was almost a whim question... I was thinking about how wiped out I am during chemo week and how that is supposed to get worse and I have 4 more to do! So I asked if it was totally lame to ask for a temporary handicap placard and Dr. C didn't think that was unreasonable at all, so he filled out the form and I just have to take it to the DMV. It will be the kind that hangs from the mirror, so we could use it in either car. I would never use it when I didn't feel like I needed it – seriously, that's just wrong – but now I have it if I *do* feel like I need it.

I guess that covers it. Tomorrow I have the bloodwork for this cycle.

Oh yeah. There *was* one more thing. I told Dr. C that I'd asked for the results of my blood work from 10/31 during one of my Herceptin infusions. I said that I figured if anything important was wrong someone would have said something, but that I noticed that there were a few items flagged as "low". So we went over the results, and a couple of them were dietary (which segued nicely into my request for the referral to the nutritionist). Another was my carbon dioxide was low, which I guess the medical profession doesn't really know what to make of but doesn't worry about; they worry about high. Also low was my Mean Platelet Volume (MPV), but apparently this is because my platelets were small, not because of an insufficient quantity of them. Not a matter for concern. In fact, Dr. C said "Who cares?" in his cute way. He showed me the areas of the report they are concerned about, but I don't have the thing in front of me and it didn't stick in my head – interestingly it wasn't white count, it was something else. Although I'm sure they are concerned about my white count as well. I'll put it in a later entry.

Treatment in General 'How I'm doing' update November 23, 2008.

The nutritionist contacted me on Friday and gave me a nutrition primer over the phone, telling me I could call her any time with questions. Except next week, because she's on vacation. Too bad, that, because I came up with some already, but it was a good starting place. I do feel like I know more than I did.

I was wrong about the Percoset, it's actually oxycodone, not hydrocodone, and my body is even less impressed with it, apparently. Ugh. And furthermore: sigh. It helps a little, no more than the norco, and then a bit later I get this hungover feeling. Yay, just what I need, right? Gratuitous hangovers. =P
Chemo again tomorrow. My how time flies.

Chemo 'How I'm doing' update November 24, 2008.

It seems I just couldn't wait to get started on feeling bad this chemo cycle. I threw up at 5:30 this morning, three hours *before* my appointment! I also had a fever, with wretched body aches. I haven't thrown up since; I think I've just turned into Sammy (my daughter), just puking any time I get sick, no matter what kind of illness it is.

I dutifully reported all this to my chemo nurse when I arrived and she put me way back in the corner in case I have something contagious. She went and looked up my bloodwork from Friday and found that my white count and neutrophils (I have no idea how that's spelled – when I find out, I'll either fix it or remove this sentence, whichever is appropriate) were low. So she figured I was having a neutropenic fever. So she says I need to have blood drawn and my counts done and Dr. C called before we can start chemo. As if I didn't spend too long there on chemo day as it is. Anyway, to my great pleasure my counts were back in normal range today: go me! So then it was just the endless time in the chair. I felt crappy so I tried to nap. I think earplugs are called for; the recliners are reasonably comfortable as are the pillows... hospital standard; likewise the blankets – I had her bring me two. While I was there my fever broke and I actually felt better when I left than when I arrived. It didn't last, but it was an improvement.

I thought for a while there that I was going to be told I had to get the Neulasta shot, the one that makes your body make white cells. It has some unpleasant side effects and that, combined with an aversion to any more medications, dammitz, has made me really hope to be able to avoid it. Coming as close as I did this last cycle, that being only the 2nd of 6, I suspect that I won't get through the whole regimen without having this shot at some point, but at least I escaped it for another cycle. Pros and cons... I probably wouldn't be sick right now if I'd had the shot, but from what I understand the shot side effects sound a lot like this illness.

So I went and refilled my norco prescription. It might not be perfect, but at least it doesn't make me feel hungover.

Eventually I got home and filled up my chemo week pill counter, with its four chambers for each day. And updated its attendant checklist. It's a lot of work making chemo tolerable.

Reconstruction 'How I'm doing' update November 25, 2008.

We think we know why I've been running a fever. It looks like the area that has been producing all that seroma has developed an infection. Dammit. It's not 100% unmistakable, so the doc is sending a sample to the lab to find out, but signs point to yes. I don't usually dress in front of a mirror and furthermore don't really care all that much for looking at the foobs all that closely on those occasions when I *undress* in front of a mirror before a shower, so I don't know if it was visible before today, but when I took off my shirt to get in the gown at my appointment today, I noticed that there was a marked pink cast to the right foob. Again: dammit. Dr. W had to poke me in three different places to drain the seroma. It wasn't that there was more, just that, for whatever reason, it had sort of sectioned off

somewhat, though not entirely; just enough to be a pain. Literally. So he did that, ordered the labs and sent me in a prescription for antibiotics, not wanting to wait for the lab results, especially with the holiday coming up. I have an appointment for a week from today, but was instructed that if things look questionable I was to make an emergency call for an earlier drain, even if it was during the holiday weekend. I might actually get faster service that way, as I'm double booked for my appointment on Tuesday. Sigh.

Draining the seroma more frequently will decrease the bacteria's ability to grow (if indeed it is in there). However, if we can't lick this with draining and antibiotics, a surgical solution will be necessary. Yet again: Dammit. You don't really want surgery while you're doing chemo, but you probably want an infection even less.

I left a message for Dr. C to let him know what was up and specifically that I had been prescribed antibiotics. That information is, of course, in the computer system for all my doctors to see, but there wouldn't be any particular reason for him or anyone on his staff to look at it any sooner than Monday. At this point I'm really glad my white count went back up to normal... unless it did so primarily because it was trying to fight this infection. Of course, its ability to do so is a good sign in any case, but still. I just seriously don't need this right when my white count is about to plummet like a stone. Again: sigh.

[You're-kidding-me-right-? 'How I'm doing' update November 29, 2008 - more than the usual adult language](#)

This should have been a chemo update, but it's been upstaged.

This is so bad that I feel like it is premature to write about it, but the whole point of this memo is so that I don't have to write out the long answer every time I'm asked.

Well after I last wrote Dr. W called me up and said he didn't want me going a whole week without medical oversight, considering the infection and all that, and could I come in on Saturday. He'd discussed my case with the on call doctor and they think I should be seen. That's all well and good and I'm glad Dr. W cares enough to think about me after I leave and make arrangements for when he won't be around. Well, I'd like to be glad, but right now I can't. But that's getting ahead of myself. So I agreed to meet this other doctor in the hospital lobby at nine this morning. Meanwhile I spent the next few days kind of stressing out about this infection, being a bit cranky because of it. Although I'm sure some of my crankiness was just due to it being chemo week.

So this morning comes and Olav and I go to the hospital where we are met by someone, a resident I think, who takes us into a dimmed and closed pre-op area, and into a semi-private room, and Dr. Idiot shows up. Without doing a play-by-play, Dr. Doy didn't take very much time examining the boob to see where he should try to get the seroma out of me, and, when he tried, he popped my goddam expander. I didn't watch him put the needle in me, because I'm squeamish that way, but I was skeptical of his location to poke as well as curious about the slight differences in equipment and as to what the seroma would look like, so I turned to look. Almost immediately he struck blue. I said "that's not good," as if

saying it politely would make it un-happen. Then I started to cry.

That numbskull then proceeded to say that there wasn't enough seroma to send it to the lab. Not that I wanted him and a needle anywhere near me at that point, but wrong! Cowardly and inept. I feel like I shouldn't have let this guy touch me, but Dr. W gave me the feeling that I could trust him. That makes me feel betrayed. I know it was an accident, but he *was* careless. He didn't take his time. Dr. W approached aspiration of the seroma as something he did reluctantly and very carefully. This guy well now I need another surgery, thanks dipshit. As we were sort of ushered out of there, he told me that he'd be telling Dr. W what happened that morning and that he thought Dr. W would be calling me that morning as well.

Well got to be around 2 and I hadn't heard anything, so I called and got to talk to another doctor, yay, who didn't know anything about any of this. I'm not sure who he was or how he got dragged into it, since Dr.Dimwit was still the on-call guy. I cried at him and told him how I had been left without knowing if there were any things I shouldn't be doing or should be doing or what because of this puncture, and did it affect my infection issues at all. I guess Dr.Loser just handed in his balls, because Dr. Helpful called me back and used some very hedging language about Dr.Butterfingers and then told me that I would be hearing from Dr.W on Monday, don't lift anything heavy, no big stretches, and don't worry, it's okay.

IT. IS NOT. OKAY.

Yeah, maybe it's okay in the sense that I don't have to run off to surgery tonight or I'm going to die, sure, if that's all it takes to be "okay" we're golden.

But I thanked Dr.Helpful for calling, since at least he DID call instead of pussying out. And now I have to sit on my ass until Monday, when, I'm betting, Dr. W will be hearing this story on his voicemail for the first time because Dr.SausageFingers was probably too cowardly to try to directly contact him and tell him he fucked up. Meanwhile, no blood was taken from me, no seroma was sent to the lab.... they didn't even take my damn vitals. How do THEY know I'm okay? Dr.DiplomaMill really ran and hid on this one. I don't think Dr. W is going to be pleased.

And I'm sure he isn't going to be pleased to have me and my waterworks in the office. Although perhaps he'll be relieved that it wasn't he who punctured me.

I am upset beyond my ability to encompass it in words. I have to have *how* many more surgeries because of this idiot? I don't even know, and that's part of the problem. The one he broke has to come out. Maybe I can go ahead and have the full exchange and they can sort out the infected area all in one go, maybe they can do this now instead of making me wait until the end of chemo. That's the only way there would be NO more surgeries. More common when an expander is punctured or torn, there is a surgery to replace it and then that one has to catch up, although it can be implanted more filled than the one being replaced was originally filled. So that would be just one extra surgery. And all this is supposing that the infection problem can be reached from the expander pocket... which if memory serves, Dr. W didn't think so. But because of boy genius' timing, it doesn't strike me as impossible that they could take the expander out, and *leave* it out until they are sure the infection is done. Oh sure, that sounds smart and all, I can't argue with that, but does it sound like something I wanted? NO! NO NONONONONONO! And then what, another surgery to put an expander in and then wait for exchange? I am a very very unhappy camper here. I didn't want any extra surgeries. I didn't want any more challenges for my PS in the scar department. The scars across my foobs may look

frankensteinien, but they are thinner, neater, tidier scars than the one for my port or my axillary dissection, or even my drains! I don't know what else he knows, but he seems to know how to minimize the scars... But I really don't want to challenge him in this arena... having to go through the same place twice already was bad enough. (well it would have been twice with the exchange before all this happened). I am sad and angry tonight. Scared too, but more angry and sad.

Oh yeah, guess I should say that chemo week is going fine. Just feeling worked, no energy at all. I've taken maybe one "breakthrough nausea" pill if you don't count Ativan, which I don't. I've been holding to my schedule, and taking all my meds and supplements on time and it's going fine. I'm glad I don't feel like this ALL the time, but it's do-able. Maybe that's the problem, maybe I'm only allowed to have things I find intolerable, and everything else will be taken from me. Yes, I'm feeling very negative right now, I think I mentioned that.

You're-kidding-me-right-? 'How I'm doing' update December 2, 2008

I finally got to see Dr. W today. He was very apologetic about what happened. Upon examining me, however, there was some good news. I might have dodged a bullet for the time being. It looks like the expander hasn't leaked since the puncture. Dr. W speculated that Dr.Dingdong might have gotten lucky and hit one of the thicker areas of the expander bag. They had expected me to be totally deflated and I really haven't lost anything you can SEE. Just a bit of a difference in feel and obviously no chance of adding more at this point. The infection, too, seems to be under control, but he's having me stay on the cipro for another week. Based on all that, he released me to normal activities except the strength and reach of my right arm. I can still exercise and do other kinds of chores. So it's not as bad as it was.

Still, the thing wants to move around and feels even more wrong than the one on the other side, and that's creepy and I wish I didn't have that on my plate for another 2-3 months. It might drive me batty. Oh well, I go back in a week to drain more seroma.

Chemo 'How I'm doing' update December 3, 2008

I'm now pretty much past the worst of chemo effects, though still dealing with fatigue. As I was told it would, it gets to be more of an issue as time goes on. I barely had any nausea this time; I think I only took a Compazine (the breakthrough nausea medication) two or three times. However, today brought with it a migraine... and it occurred to me that this is the time in the last cycle when I had migraines for a week or so. So I think that the meds DO have something to do with it, but just in a way that didn't occur to me before – or, apparently, to Dr. C. I now have to wonder if it isn't being ON the medications –whichever is the culprit and my money is on the steroids – that gives me the migraines, but rather stopping them. Oh well, if so, it probably can't be avoided. However, possibly a greater attention to eating enough and drinking water will help. Other than that, just downing fioricet and narcotics, I guess.

Hm, the phrase “eating enough” made me wonder if my eating lightly for a week could be a contributing factor – or even the cause – as well. I eat a weight-losing amount for chemo week... then have typically compensated for it the following week. I haven't yet started totally pigging out this time, though. However, if that's the case, there isn't much I can do about it... I'm not going to try to force foods.

I started tracking my eating at sparkpeople.com. I'm not using all the features of the site, particularly the social aspects, as I don't want to get obsessed. I just want to get a better idea of how I'm eating and to build good habits. It has been fascinating to me that I barely made it into the calorie range they suggested for me for more than a week. Under eating, I guess. However, I've been eating in a more balanced way than is my history. It's a chore to get everything in there, but the site keeps track of it all for me, and I just have to keep up. The site will also track exercise and that sort of thing, but so far I haven't really been moved to do that.

Apropos of nothing, I thought I'd mention that I still have hair. Not very much, but at this point I don't know if “bald as an egg” is actually going to occur. The remaining hair is almost exclusively white. My hair that remains has actually even grown! I've taken to calling myself Dandelion Head, as the end result reminds me of a dandelion puff inexpertly blown away. =) My armpit hair seems content to remain gone, and my lower leg hair tries to grow enough sparse hairs to motivate me to shave about once a week or less, likewise bikini area. I still have my arm and upper leg hair, as well as my eyebrows and eyelashes. I hope I keep those last two the whole time at least!

Chemo 'How I'm doing' update December 5, 2008

I'm sick with something. Signs point to neutropenic fever. My temperature has been elevated since yesterday, peaking around 8:30 this morning, though happily it has gone down since then. Possibly because I took some Tylenol. I put a call into the nurse adviser line at the cancer center around 8:30. The nurse took down all the details and said someone would be calling me back. It's been two hours. A slight fever wouldn't be cause to call the doctor ordinarily, but you're supposed to report these things when you're going through chemo, since white counts can drop so drastically. I have no idea what I'm going to be told when my call is returned, but hopefully it won't involve checking into the hospital. Hospital? Yes hospital. The treatment for neutropenic fever is hospitalization -- in an isolation room -- and IV antibiotics. Hey, two things I hate: taking antibiotics and being in the hospital! Hopefully my situation will be deemed under the threshold for such drastic treatment. I mean, I feel like crap and I want to feel better, but ugh. (As someone pointed out to me, at least with the isolation I'd have a private room! Small consolation.)

Who knows how related it is, but my migraine is still with me. Hey universe! I could use a break here...

Later that same day:

No hospital for the moment. The NP who called me back was concerned that the cipro I'm on isn't doing the job for me, so he called in an additional antibiotic for me to take. He said to call if my temp hit 101. He didn't say what would happen then. He said they'd get my counts on Monday when I went

in for Herceptin. One of the girls in my chemo group got stuck in the hospital with a temp of 100.4, but I guess my doctor is less extreme than that. I have to say I'm glad; I don't want to go to the hospital unless it really is a matter of my life is in danger. Are you getting the impression that I don't care for hospital stays?

Currently I'm waiting for my latest Tylenol doses to lower my temp again. It didn't get up as high as it was this morning, only to 99.8. Still, that's almost three degrees higher than my "normal", so I feel crappy.

Chemo 'How I'm doing' update December 6, 2008

Waaaaa!

That about sums it up. My temps seemed to be trending downward, but they've either taken a break from that or just quit it altogether. I got up from a nap and was back up to my previous high of 100.6. Still too low to call in. Quite high enough to make me feel crappy. I've already taken the Tylenol so it's too late, but it occurred to me that if I had left my fever alone maybe it would have gone up and I could have just gotten this taken care of for good and all. I don't want the damn hospital, though. Besides, it would be stupid to NOT do something to lower my temperature. I'm not talking about jumping in a bathtub full of ice-cubes, here, just a simple easy everybody-knows-it remedy.

Incidentally, anyone who tries to get me in a bathtub full of ice-cubes is going to get hurt. Don't say you weren't warned.

Chemo 'How I'm doing' update December 8, 2008

I went in for my Herceptin infusion this morning and they drew blood for my counts. Let me lay down the numbers for ya, just for fun. Normal range for white blood cell count is 4.5-11.0 and mine were at 1.5. Normal range for neutrophils is 1.8-7.7 and I was at .2. Yeah, the decimal is before the two. However, I was basically told all the same things I was told on Friday as far as the neutropenic fever signs to watch for and to call if my temp hit 101. They had me pee in a cup to check for bladder infection, just because that's common, but considering that A) the test takes a few days to complete and B) I'm already ON two antibiotics I'm not sure what the point was. Oh and C) I don't actually have any current symptoms for that. I had some burning when I peed on Friday, but that stopped. I've had an intermittent sore throat, but I guess it has to be, er, worse? I dunno. I mentioned that I've had it and I guess they don't figure it counts. Maybe it has to have the high fever with it. Oh, I don't really care, I don't think they can make me feel better right now anyway. All I can see them doing is the whole hospital thing and frankly being in the hospital is going to make me feel worse in the short run. And in the long run I'll get better on my own anyway! Eh, who knows. It's ucky, but I'll live.

I see Dr. W and Dr. C both tomorrow (not at the same time). I suppose that next cycle it will make

sense to have the neulasta shot, since my body seems to be handling chemo worse each cycle as far as my white counts are concerned. Odd when I'm feeling so much better in other ways. Funny how I get past the side-effect yuck time and then start feeling bad. Ironic.

Chemo 'How I'm doing' update December 9, 2008

I'm feeling weak and tired and bummed today. The tedium of all this, the fact that I'm only almost half way done with chemo and even THEN I'm not done done, I'll still have the exchange surgery and recovery, not to mention 8 more months minimum of Herceptin. Olav was talking about going to the driving range to work off frustration and get some exercise, but I can't do that until after exchange now that my expander is punctured.

But even before that conversation I was just plain bummed. While Dr. W drained my seroma I just laid there with tears running from my eyes into my ears, which tickles but I couldn't do anything about it because I couldn't move because he was draining me! Which made me sadder. A bad cycle, and a pathetic one. Tears in the ears indeed. It was just so disheartening, being there, doing this painful thing again, knowing that the seroma was just going to fill up again and I'd be there next week doing it again. And again.

One good thing, though. The seroma was totally clear. So of my various defects at the moment, at least that bit isn't infected.

Later in the day was the appointment with Dr. C. Unsurprisingly he was very concerned about the white counts and neutrophils. He told me the options were lowering the chemo dose or doing neulasta or that other one where you have a shot every day. He recommended against lowering the chemo dose, though, saying there was a fairly narrow window and it could be lowered to the point where I could still have adverse side effects and not be killing cancer cells. So I'm going to be calling my insurance company to find out what's covered. I think what I'd LIKE, oddly, is the option where I self-administer the every day shot. Dr.C said that there is only one "size" of neulasta, but that if I started to get side effects (eg: bone pain) with the other option then I could stop taking the shots, rather than be committed to neulasta's time release system. Which, incidentally, is a really nifty mechanism! But I could live without the bone pain. On the other hand, would it be worse than how I've felt for the last five days? I'm thinking it's not likely.

I addressed my norco use with him, because I've been taking more than the prescribed amount in order to have an effect. Not only does this use them up too fast, but it also puts more Tylenol in me than I care for. And I found, as I feared, that the next step was a big one. And I found that I don't care. Dr. C is fine with prescribing me Morphine, fine, I'm okay with taking it. I've taken a shitload of Vicodin in my time and never gotten addicted to it; I know that doesn't mean I'm immune to addiction to Morphine, and I'll be mindful of that, but I'm not going to let fear of it keep me in pain.

He told me that I don't have to keep myself in a bubble though. Apparently the most likely things to bring you down are bacteria you're already carrying around. And that certainly seems to be true with me. I have little infections in an ear piercing and something which is tooth/sinus/whatever manifesting most obviously as a swelling on my face. Both are things that I have a history of, not something I

caught off of a dirty shopping cart or shaking someone's hand. He said to obviously stay away from anyone obviously sick, but otherwise to not stress about it.

So he wants to see me again in two weeks, which will be just a week after my next chemo... not sure how useful that particular time-slot will be, all things considered, but he wants it, he gets it. And that about sums up the day's appointments.

Chemo 'How I'm doing' update December 11, 2008

Queasiness ruined my night last night. It was Olav's company Christmas party and since Dr. C said I didn't have to keep myself in a bubble, I got all dolled up and went. And I was fine until I took my first bite of dinner and then I dashed off to the bathroom and knelt in the stall of the fancy restaurant in my high heels and wondered how loud my puking would be. I didn't throw up, though; the moment passed. I wasn't able to eat the dinner, though. I think I took long enough that Olav pretty much got to eat his. I did throw up later that night, another abrupt spell of queasiness, this time not remotely a false alarm. Better to do it at home, though. And not in high heels. I don't know why, but the idea of throwing up in high heels just seems so pathetic.

I seem to have turned into a person who throws up all the time for any reason or no reason at all. I didn't used to be that way. I could speculate until the cows come home, but the truth is I have no idea why exactly I was pukey last night. Could be the Morphine, could be the antibiotics, could be any damn combination of things I might never duplicate again.

Have I mentioned the [Young Survival Coalition](#)? It's a group for women under 40 with breast cancer. Primarily online. I have, there, a group of women who started chemo in October like I did. I think there are 7 of us. Anyway, it seems like we're pretty much all hitting a low right now, halfway through our chemo regimen. It's hard to look at "half way" as a positive; it feels like forever, especially with several of us essentially wearing out, getting low counts of this or that. It's so good to have people to talk to that are going through the same things at the same time, even though it's horrible that anyone has to go through anything like this ever.

Introspective Interlude December 14, 2008

One of the ladies over at YSC was frustrated with her friends from before her diagnosis, saying that they couldn't or didn't or wouldn't relate to her issues and she no longer had patience for their issues which seemed so meaningless to her. Below is my post in response not just to her but to the thread as a whole. Most of the ladies were saying they were right there with her, but there were a few voices for "give them a break, it's all they know".

I think a person can only truly understand and measure suffering by their own experiences. Their own yardstick is what is the worst they have suffered and what is their greatest joy. I've got my gals over in

my chemo group feeling sorry for me for all the crap I've gone through in my last cycle but I keep telling them not to throw me a pity party because I am probably not feeling any worse than they are, I'm just carrying different things in my load. And maybe they weigh less heavily on me than they would on someone else. How can I know?

For some of us, losing our hair is a horrible traumatic experience that causes us to weep and makes us feel ugly, etc. For me, I kind of found it fun! I kind of wish I didn't have to have it during the cold time of the year; I underestimated how much hair keeps your head warm! And I'm not looking forward to how long it will take to grow my hair back to the length I had it at before. But really, that was an absolute no biggie for me. So: same problem, different burden level.

Our friends, relatives and acquaintances who haven't had cancer or some other debilitating condition or some other life-changing tragedy simply have a shorter yardstick. Things that to us have become far from the worst are still much closer to the worst for them. Likewise for the other end of the yardstick.

Now some people just have petty interests, that's true. Gossip, status, fashion... And when we are distracted by pain both physical and emotional it can be hard to focus our minds for conversation on anything that lacks substance. It seems like a waste of time and energy to us.

But the people who are more genuine and still seem to just chatter (from our perspective of HELLO, CANCER HERE) are speaking from their shorter yardstick lives. Their children and their husbands are their greatest joys and their greatest anxieties.

It can help one empathize to try to imagine where on your own yardstick such a feeling would be.

I'm not saying this is going to make every human interaction tolerable. But it might help.

Chemo 'How I'm doing' update December 14, 2008

Well, I start another cycle tomorrow. Yay. I guess that makes today officially half-way done. Yay? People seem to think I should be happy about this. Ya know, looking back on how it's been so far, the idea that I have just as long to go doesn't fill me with joy. However, I do know that the nausea that made Cycle 1 so awful is licked. And with the Nuelasta the infections, fevers, and complete lack of energy of this cycle should be vanquished. I have decided to try the Nuelasta, and, having made that decision, found that it seems to be the only option covered by my insurance. Good thing I decided that way then, eh? =) I just figured that even if I had the painful side effects that sometimes accompany it probably wouldn't be any worse than what I went through in Cycle 3 and I'm already taking painkillers full time anyway, so maybe I shouldn't be afraid of the pain! On the off chance that it really is awful or does something unlikely like over-produce white cells, I can look into getting the other drug approved for me. Meanwhile I might actually feel good for a couple of days before chemo takes me down again... just in time for my girls to arrive. Oh well, at least if the Nuelasta does its job I'll be feeling better by Christmas.

Chemo and Reconstruction 'How I'm doing' update December 16, 2008

Infusion went fine yesterday. The only thing of note was that the pharmacist from down the hall came by to tell me that my Nuelasta shot would be there ready for me the next day (today). I was pretty tired during infusion. I put on a movie (Crazy People) and considered closing my eyes for a nap, but managed to stay awake. Oh, and my infusion schedule, which I have pretty much gotten completely used to is going to be all wonky next cycle. They had to put me on an afternoon slot for chemo, and one of my Herceptin infusions is being bumped a day because of MLK Jr's birthday. So I can totally see myself showing up at the wrong time or even the wrong day if I'm not paying attention!

So today I went to the pharmacy at the cancer center and picked up my shot. Then upstairs to meet with one of Dr. C's nurses who showed me how to give myself the shot by giving me the shot. ;) It didn't hurt at the time, though a short time later the area seemed to radiate out a mild crampy sort of pain. Not actual cramping as far as I could tell, just a pain reminiscent of cramping. That was probably due to the medication not being at room temperature. Bloody stuff is expensive!! I asked the nurse to reconfirm with the insurance company that this is the cheapest way short of mail order. If so, we're going mail order! It would save me 100\$ anyway.

Went for my seroma drain with Dr. W this afternoon as well. Going in I reflected that the seroma build-up hadn't bothered me as much this week. I speculated that either there had not been as much build-up or the Morphine was doing it's job in making me more comfortable. I figured I win either way, but it would surely be better news to find that I was producing a meaningfully less quantity of seroma. Alas, it was not to be. I actually had *more* than last week, though only a little. Within margin of error, said the doc, or something to that effect. In any case, not less, no matter how you look at it. My disappointment was tempered by my pleasure that I finally have a painkiller that is working! I still have discomfort, but it's under control! Yay!

Then came the bad part. I asked what impact the continuing seroma was going to have on the scheduling of the exchange. He said that the exchange couldn't take place until the seroma was taken care of. He told me to discuss it with Dr. M – and said he might give him a call himself -- who I am meeting with tomorrow. Dr. W thinks that the area the seroma is coming from is from the axillary dissection and therefor hopes that Dr. M will have some great insight on treating it. Well so do I, rather! But considering that the amount of seroma being produced on a weekly basis by me for three months now is not a positive sign for it drying up by Friday. Dr. W thinks that if it doesn't go away by itself then it has to be surgically dealt with, and he doesn't want to be the surgeon who does it. I don't want him to be either, if he doesn't want it! Noooooo thank you. Hopefully either Dr. M will have the experience to feel comfortable doing the surgery or at least familiar enough with the problem to know who to send me to. Or, of course, better yet, some magical *non-surgical* means of handling this.

Chemo and Reconstruction 'How I'm doing' update December 17, 2008

So I saw Dr. M this morning. He gave me a basic examination and apparently found nothing

remarkable, since he made no remarks. We primarily discussed my seroma situation. (Dr. W *did* call, by the way.) Dr. M feels as though the logical next thing to try if it doesn't go away by itself in the meantime is to put a drain back in. He thinks that if the pocket is kept empty it will adhere to itself and heal up. I am not in the least bit thrilled about this plan for a number of reasons. First, I have to wait until after chemo to start and that means that however long this stupid drain process takes is just that much longer before I can have my exchange. But probably more important is that that area hurts all the time as it is. Putting a drain in there is almost certainly going to make it much more painful. It is my firm opinion (and I don't even play a doctor on tv!) that the terminal end of that drain inside me is what caused this situation in the first place. As long as they don't try to lodge the terminal end in exactly the same place I suppose the method might work, but any way you slice it (sorry about the pun) it's going to hurt. And... well I think I made it clear months back in this memo that I *hate drains!!!!* However, this plan is the one that might save me from an additional surgery. So we're going to try it. Also, apparently it's much easier (usually!) to let the body heal these things than to do it surgically. I don't want surgery, and I don't want the drain, but after three months of seroma hanging tough where it is, I don't have a lot of faith that it is going to heal on its own. So I made an appointment to have my blood counts taken for three weeks after my last chemo and an appointment with Dr. M for two days after that so we can either put in the drain or schedule a time to put in the drain.

I also discussed my lymphedema concerns as far as air-travel to go see my mom when things settle down health-wise. That time seeming to be ever further away. Anyway, he said that the cabins are pressurized and that in that case the potential of a poorly fitted sleeve was worse than the potential of lymphedema.

I also mentioned the thing with the tendon that runs into the shoulder blade on my right side. He said they are very careful not to *cut* that tendon and clearly hadn't in my case, but that it can be stressed as a result of the procedure. He said it will improve with time and that PT would help. Of course, this is PT that I can't do while I have a punctured expander. This is an additional source of pain for me that has become more pronounced since the puncture.

Good thing the Morphine works!

It really does take good care of the background pain. The breakthrough pain is a different issue. Dr. C gave me liquid Morphine for that. Well that stuff works too, but it makes me all groggy. I can do anything I want on the pills, but the boosts? No way. Not okay to drive or operate heavy machinery. First time a non-IV drug has done that to me ever as far as I can recall. Also, it upsets my tummy somewhat. I've taken to taking a tummy pill before the boost, and that helps somewhat. I think it is time to really fine tune and experiment and see what is the smallest dose I can take and still have it do the trick. Carefully and not more than twice in one day at the most, even though a boost lasts 3 hours max. My body just doesn't like it enough for me to take it more than twice a day at the amounts I've tried it with (which, btw, do not exceed prescription).

Chemo 'How I'm doing' update December 21, 2008

Oh, it doesn't get old, this whole thing. Never two cycles alike, nope.

Not too much nausea this time, but I didn't expect it. However, I feel like I have a cold.... except that I don't, I don't think. Oh I don't know. I have a sort of a sore throat and that odd feeling you have when you've been swimming or crying. I don't like it and don't know how to make it go away.

So sore throat pain in addition to the boob pain has made me a bit cranky. I'm going to ask Dr. C if there is something I can take for breakthrough pain that I can actually sleep on. The boosts aren't upsetting my system as much as at first, so that's good, but I can't take them more than once or twice in a day (usually fine, but...) and I can't take if I want to go to bed in the near future.

Chemo and Reconstruction 'How I'm doing' update December 30, 2008

This is all so freaking old.

Chemo-wise this cycle wasn't too bad. I didn't have any side-effects from the Nuelasta that I'm aware of, unless those "cold like" feelings were side-effects. I think I might have gotten to the point where "perky" ain't gonna come back until I'm done with chemo. But I'm not miserable all the time. Just blah and no energy. Partially, though, this is depression. I'm not severely depressed, but yes, this has gotten me depressed. Constantly feeling bad, constantly feeling pain, restrictions on what I can do... I think these things would depress anyone. I don't see a reason to medicate these feelings... while it seems like forever until chemo is done and I can get the seroma taken care of and have my exchange surgery done, it really is only a matter of a couple of months. When you stack that against a medication that might take a couple of weeks to take effect it just doesn't make sense to start.

I did throw up this cycle, though. Christmas eve. Ah, memories of childhood. I didn't take any nausea preventatives that morning, thinking I was probably in the clear by that day (10 days out from chemo), but apparently I was wrong. It was nothing like the round of horror from my first cycle. In fact, out of 6 dashes to the bathroom, I only puked thrice. Not fun, not expected, but not the end of the world.

Today was the usual Tuesday appointment with Dr. W. I didn't report back after last week's, but at that appointment I finally had a reduction in the amount of seroma drained! I had been draining about 180ML pretty consistently, with about a 10ML margin of variation. It was only 145 last week and that was a wonderful surprise! It was as if my body was trying to avoid the drain Dr. M suggested as a solution. So I was cautiously optimistic going in there today. I could tell I was pretty puffy, but the Morphine keeps the pain manageable most of the time. So I was surprised and very disappointed when he pulled out 285 ML for a new record today. And, as follows, the worst breakthrough pain yet, as the pocket emptied. 285 ML takes up rather a lot of room.

I dislike people feeling sorry for me through all this. Not saying I want to be treated heartlessly! Just saying that I can bear it. Yes, I cry. I may even cry frequently. I have to, so what. Yes, this sucks, but there are a lot of things in life that suck. I also have a lot of things in my life that are wonderful, and I don't ever forget that. I do, though, always, every time, appreciate well wishes, good thoughts, prayer if that's your thing, that people send my way. So, my readers, hug someone, tell your family that you love them. I'll be all right.

Ha! Just noticed how the opening sentence of this entry and the last one seem to contradict each other. Different meanings of “old” with more than a dash of sarcasm in the last entry's comment.

Chemo 'How I'm doing' update January 1, 2009

Happy New Year!

I don't have much to say today, I just was giving a quick perusal of recent entries and didn't see any reference to the outcome of asking for a breakthrough med that I could sleep on. I actually saw the NP that day. While I don't like him as much as I like Dr. C, that's not his fault; he's very knowledgeable. It's just that Dr. C rocks! Anyway, we went with Norco. I went off that because I was taking so much I was concerned about the Tylenol's effect on my liver, especially with all the other things I'm threatening it with, but since I'm not trying to take the Norco around the clock, I'm considerably less concerned about it. I only take it if the breakthrough pain occurs late at night.

I'm still needing to take Compazine with the breakthrough Morphine, though, especially if it is a second dose. Otherwise I'm likely to puke. And it's a surprise puke, usually. I'll be okay and then with about 90 second's warning I have to dash to the bathroom. I guess if I have to puke it's better to not feel horrible for hours. ;) The Compazine is reasonably good at heading it off as long as I actually take it. Failure to remember to do so is pretty ineffective.

Can I just take a moment to beg my female readers to do their self-exams? Finding my lump(s) earlier would not have changed my prognosis all that much because I would still have have the same type of cancer, but I might at least have avoided having it spread to my lymph nodes and thereby avoided the axillary dissection. Not only is the axillary dissection responsible for my seroma issues, but it has also essentially crippled me for life. I can never again have my blood pressure taken in that arm or have a shot or an IV in that arm. And any time I get a scratch or a scrape on that arm or hand I have to slather it with antibiotic and stick a band-aid on it, even if it's teeny. The seroma thing is a short-term problem, but the rest is for life. You do not want this. So don't let this slide, ladies. It's easy, and it could save you lots of trouble, if not your life.

Introspective Interlude January 3, 2009

One of the girls in my chemo group asked today:

“Does anyone get down like that? Sometimes I get so MAD at myself. I seriously can NOT believe I have/had fucking cancer. What the f????? I feel like a freak. How did this happen? Am I a genetic mutant or something????”

My reply was:

*I get down and I get angry, but I don't get angry in quite the same direction you do, I think. I feel angry that cancer invaded me. For a while I felt angry that my body -- and my breast particularly -- betrayed me. But somewhere by the time the surgery came around, I began to feel -- not literally, just as a way of looking at it -- that I had been invaded by horrible little aliens or monsters or something. I felt like they were stomping around wreaking havoc in my breast and it horrified me. About five days after my surgery I realized they were **GONE!** Evicted! An enormous sense of relief overcame me. Now my vision is that if there are any remaining cancer cells in me, they are like tiny Gollums only without the potential to redeem themselves. Horrible creeping sneaky little creatures. It occurs to me just now at this moment that this could be a good meditation/visualization tool... if you combine that thought with the one where you fill yourself with white light? Well wouldn't Gollum just HATE to be hit with white light?*

Anyway, my anger is at what is being done to me, not at myself, and that is where the difference seems to lie. Please don't be angry at yourself. You didn't do anything wrong. Bad things happen to good people. It happens. It happened to all of us. Do you think [another of my chemo girlfriends] is a freak for getting cancer? Of course not. Neither are you.

Chemo and Reconstruction 'How I'm doing' update January 6, 2009

Yesterday's chemo was held up not only by the hour long wait in the waiting room but also by the fact that my bloodwork on Friday showed my platelet count too low to go with. So they did a quick draw and ran it over to the lab. Results came back still lower than "normal" range but high enough for chemo, so finally we got started. When I was finally done I was the last patient there and probably 75% of the staff was gone too. Yeesh. Other than all that, it was business as usual. I'm going to try to remember to ask if I can't come in for that extra blood draw before my scheduled chemo if my counts come out low again for next cycle. Just so I don't have to add in all that extra time when I'm not expecting it. And hey, next cycle is my LAST CYCLE!!! Now *that's* something to be happy about.

Today was the weekly seroma drain. I tried to guess in advance what the results would be. I felt puffy, but thanks to being on Morphine 24/7 I'm not in *constant* pain from this anymore. My guess was that it wouldn't be as much fluid as last week, but wouldn't be less than what was previously considered usual. The reality turned out to sort of split the difference, at 250 ML. Disappointing, but I would have been more let down if it had been as high as last week's. I can only guess that chemo isn't doing me any good as far as getting this thing healed.

I've actually enjoyed several days now of feeling fairly good. Relatively speaking. Not what I'd have called good before all this started, but compared to the several weeks that preceded this period, quite well, actually! I'll probably start that downward slide tomorrow afternoon. Possibly sleeping for 12 hours last night will give me a few more hours of feeling decent.

Chemo 'How I'm doing' update, with reflections... January 12, 2009

Well that was a bit of radio silence, I guess.

I continued to feel good through Wednesday, although I was starting to feel more tired by then. Friday rolled around and I felt truly crappy. I'd say that was my worst day. The whole weekend was on the poor side, though. I've been taking Compazine around the clock, though I haven't thrown up, thankfully. My taste buds are totally out this time around, which hasn't happened to this extent since Round 1. Weird. So I've been eating a lot of ramen and cream-cheese-and-jam-sammiches. Texture and some flavor comes through that's okay. Other things have no flavor or don't taste like they are supposed to. I knew better, but I tried to eat some tortilla chips and jalapeno cheddar dip last night. I knew my tummy wouldn't like it and it wouldn't taste like it should and I was right on both counts. I had just been staring at the stuff for days and wanted it so bad. =(Turned out that the tortilla chips by themselves weren't too bad, so I munched on a few of those.

I also have started developing neuropathy. This is a tingling/pain in my hands though it will probably spread to my feet as well. My feet actually have a tiny bit of tingling already but it's not at all painful and it's only on the tops of the feet, thank goodness. This is a side effect of the taxotere, and isn't considered a really big deal unless it really is driving you mad. Otherwise you just deal with it and move along. I guess they try to medicate it with neurontin or the like if it is too bad, but I tell you what, if I can get through this without taking another pill, I'm going to do my damndest to do that. So hopefully this won't get too bad. I keep telling myself: I only have one more of these to get through. I keep hoping it can't get much worse than this, or than I've already lived through. I'm not making any assumptions to tempt fate with, though. There's still a lot of things that could go wrong. I'm choosing to believe I can get through this without quite having any of those bad things happen to me. It's a tenuous optimism, I admit, but I'm doing my best.

My elderly neighbor got taken away in an ambulance over the weekend. She is in treatment for cancer, but we don't know what kind of cancer or what kind of treatment. We were bummed to see this happen, but told each other that there are a lot of things in chemo that are considered emergencies that are also immediately and relatively easily fixable, such as a need for IV antibiotics, or even just fluids sometimes. Or even if it's a transfusion. It doesn't mean she really is on death's door. This is some of what we've learned about being a cancer patient, and it's a strange way of looking at things when compared to how I might have before. I guess somewhere along the way, my definition of "emergency" has changed just a little. It still means "do it now" but it doesn't seem to mean "panic" or "doom" as much as it used to. In fact, there are circumstances in which I could simultaneously consider something an emergency and a damn nuisance now. =P

Over at YSC once you've posted a brazilian times you are allowed to change the words above your name from "advanced member" to whatever phrase you like. I changed mine to "I didn't need cancer to appreciate my life." So many people talk about how cancer made them realize how important their loved ones were to them, made them change their priorities about how they wanted to spend their time, etc. Well, cancer didn't do that for me, I'd already figured that out on my own, thank you very much. But cancer does change you. It's important to have a goal in mind for how you want to end up after going through the treatment process and being released back into the wild... but still I think you are changed in ways you can't control. I don't know what all these are yet.

Chemo, etc. 'How I'm doing' update January 14, 2009

Yesterday morning I had my second EKG (or MUGA as they are sometimes called, though I've totally forgotten what the initials stand for). This will be compared to my pre-chemo/Herceptin EKG to see how well my heart is tolerating the treatments. I've noticed that my heartrate has been elevated since I started treatment, but when I mentioned that to the technician, she said she didn't know anything about that as far as being an effect of Herceptin. She stipulated that it could be, or it could be chemo. I haven't noticed anything else that could be heart-related. I am hoping like hell that I don't ever end up with bad news from an EKG, because I'm really banking on being able to use Herceptin. It drastically improves my chances. I meet with Dr. C next Tuesday and he'll tell me how it went.

Later that same morning I went for my weekly seroma aspiration. 230 ML. So I'm still above what used to be normal, but still below that one record high week. Current theory is that with my counts suffering more as time goes on, healing is suffering even more. Dr. W said repeatedly how he couldn't wait for me to be done with chemo. I repeatedly responded "YOU can't?!" =P I know he is sympathizing with me and also just wants to not have this issue going on with one of his patients, but really! Nobody could want this over for me as much as I do. I asked him if he was going to be the one to put the drain in after I was done with chemo or if he'd be wanting Dr.M to do it and he said he figured that if it had to be done he'd rather have his name on it. Which makes sense. On the one hand, I would be more comfortable if this were a procedure he was more familiar with, but on the other hand – after my expander-puncturing experience with Dr. Not-Ready – I suppose I'd rather not let anyone but Dr. W anywhere near my expander! Dr. W thinks that the procedure is a simple one. He's more concerned about infection from basically turning the situation into one with an open wound than about the procedure itself. I am not so worried about that, since we'll be waiting for my counts to come back up before we do this anyway. I did a little calculating, though, and realized we'll be into late February before my counts are good enough. And then who knows how long it will take for the seroma to resolve? And then *that* will have to demonstrate itself totally healed before they'll do the exchange surgery for my real implants. Oh well. At this point I'm hoping to just be recovered from that surgery by the time our anniversary comes around. And heck, I'll even have a little hair by then! Not much, but a little.

The neuropathy in my hands has gotten worse. They are pretty painful now. When I read about this condition, I didn't realize how much it feels like the problem is in the skin. I imagined it would feel more like it was in the muscles or something I guess. But it really feels more than anything else like my hands are severely chapped. Rubbing them against anything hurts a LOT. Sleeping last night, with the pain in my hands and the pain from the aspiration was rather a drag. I took norco before bed, but when I'm all sleepy it doesn't seem to occur to me to get up and take more in the middle of the night. Even if it did, I might decide to try to do without because 1) I take so many damn pills; and 2) I am really trying to not take too much norco when I'm already taking all this Morphine.

On the plus side, my feet are holding out okay. The tingling hasn't gotten noticeably worse and there's just a tiny bit of pain if I bonk my heel the wrong way, said wrong way fortunately not including the way I walk.

No more appointments this week, but of the four I have next week, three are on the same day. D'oh!

Even in theory only one of those could have been put on another day, but that one would have had to have been scheduled weeks ago when I didn't realize that one of the other two had to be that day (due to MLK day being the day before and the infusion center being closed that day) and, if memory serves, that week was hard to schedule even at the time. * sigh * So that will be a busy and tiring day for me.

Another positive note: I still haven't (knock on wood) thrown up this cycle. I'll probably get this whole thing figured out just about the time I'm done. =P

Chemo 'How I'm doing' update January 16, 2009

Well it turns out that part of the reason my skin felt particularly sensitive with the neuropathy is that I have a taxotere induced rash as well. Go me! The rash looks and feels like a chemical burn. He "prescribed" topical hydrocortisone. Thank goodness for it not being another pill! Also I am to avoid hot or cold water, particularly soaking. I am to wear gloves to shower. Yes, it's painful and yes, it's a hassle, but you know, whatever. One more bump in the road. I can handle this. My new mantra: I'm almost done!

I still haven't thrown up this cycle, but I've been so tired. Just totally pooping out around 9:30, even though I've been staying up later than that. But that's when my eyes start to close. Probably this is partly because I haven't been able to do much napping. The extra pain in my hands has been motivating me to take more Morphine boosts, and I can't nap if I've had one of those in the recent past.

Okay, this is total paranoia, but I have a spot of pain in my back, on the back side of my ribcage up near the shoulder blade that's been there for a while, maybe a couple of weeks. It's not intense at all, but it feels different from my usual tight muscle pain; it feels like it's part of the bone. Which it probably isn't, but is, of course, what is spawning the paranoia. I'm only even giving the paranoia this much voice so if it keeps up or gets worse or something I can at least begin to narrow down when I noticed it. The idea that I could be having bone mets while I'm in chemo is pretty far-fetched. And this, boys and girls, is why you don't want to have bipolar and cancer at the same time! =)

Chemo 'How I'm doing' update January 19, 2009

The topical hydrocortisone helped a lot. I still have the neuropathy, but not so much of the skin issues – I don't have as much pain pulling clothes or gloves over my hands, so that's good. The pain in my hands is kind of bad. I say "kind of" because on the one hand (if you'll excuse my phraseology) if it were this bad in my feet I wouldn't be able to walk, so that's bad. On the other hand, there's something kind of bearable about aching fingers for me. I'm glad it's not for the rest of my life, but it's actually less... I dunno, less pitiful feeling than some of my other pain. So yeah, it hurts, but I can still type, so that's good. I have to have help opening a soda and it's tricky to operate buttons and zippers, but I'll

live. I'm almost done! ;)

Tomorrow I have, as I mentioned in an earlier entry, three appointments. So I imagine I'll have a long report to make. Actually, two are fairly routine: Herceptin infusion and seroma drain. The other is my last meeting with Dr. C before the end of chemo, and I have a lot of questions for him.

Chemo etc. 'How I'm doing' update January 20, 2009

One of the first things Dr. C said to me today is “Have you been tired?” Well, gee, doc, maybe a little! Turns out that the blood-count-to-be-concerned-about-du-jour is my hemoglobin. Apparently my numbers last cycle weren't that far out of needing to be in the hospital. I feel obliged to mention, though, that when I glanced at my report on the computer screen *all* the blood values were red-flagged as low. Then again, maybe that means the hemoglobin was *really* low. Anyway, he ordered bloodwork for during my infusion later and recommended a transfusion around the time of my next chemo. That would give me a boost of good cells of all kinds, and I think the tremendous number of positives that can come from this vastly outnumber the negligible risk. Basically the only cost to me is more time in the infusion chair, and I'm completely okay with that. If I were unwilling to do the transfusion I would probably be forced to postpone my final chemo and I really really want to finish!

He was more concerned about the neuropathy than I expected. I guess the chance that it can be permanent is a little higher than I had thought. More likely than permanent is long term, meaning 6-12 months. Certainly not a good thing all by itself. He basically told me it was my call about whether or not I wanted to reduce the taxotere dosage and that I could tell him up to the last second before infusion, but that if my symptoms don't improve quite a bit it would be his recommendation to reduce the dosage. The carboplatinum dosage would remain the same.

When we were getting to the “any more questions” stage I mentioned that I had been intending to ask about managing the nausea the boosts cause but that I had pretty much figured it out. However, as we discussed it, he didn't really agree that being able to just manage two doses without throwing up in a day isn't that huge an accomplishment. He told me to take more Norco. He told me to intersperse the Norco and the boosts in whatever way made sense for my nausea and rest needs. Makes sense, but I guess I needed the extra nudge to feel okay about taking the Norco during the day as well. Dr. C is not the kind of guy who thinks “suffer” should be one of the options, and that makes him almost 100% different from almost every doctor in my experience.

I asked him what sorts of scans and tests would be done when I was done with chemo and he said that all the same things would be done that were done before I started, for a “secondary baseline”. A good term, as if all is well the pictures should look pretty much the same. Dr. C actually put on his serious face during this part of the meeting and said that if anything showed up during these scans it would mean very bad things for my prognosis. I just said “I know.” No need to dwell on it then and there. He went on to say that it is extremely unusual for someone to have something show up in scans done the moment they've finished chemo.

So I got the confirmation: After chemo is done I will start having the Herceptin infusions only every

three weeks. Woohoo! I won't be spending all my damn time at the infusion center!

This afternoon I had a Herceptin infusion and the blood draw ordered this morning by Dr.C. It's a good thing I asked about the latter, as it hadn't gotten into my folder. But they got my blood and did the test. I love my port.

After that was my weekly stab'n'drain. 245 ML this week. I'd felt rather puffy, and was curious about what the number would be. I've been quite bad about my guesses. I was pretty spot on this week though, in a non-specific way heehee. My thought was that I had a little more than last week, but not much. Exactly true, as it turns out. I had an active weekend, but only relative to the complete sloth of the two weeks leading up to it. I went walking down by the river on Saturday and to the Crocker museum and walking around Old Town Sacramento on Sunday. I don't really think that qualifies as vigorous exercise.

Nothing now until more bloodwork on Friday.

Chemo etc. 'How I'm doing' update January 28, 2009

My counts didn't end up indicating a transfusion. I was almost disappointed by this, because it wouldn't be just my hemoglobin that would be helped by the transfusion, I'd also have all these grown up white cells and platelets and such that are running low with me. But all my counts were good enough for chemo, though all of them were below normal for a healthy person.

At infusion, I went with Dr. C's recommendation and since the neuropathy hadn't entirely dissipated, I asked for the reduced dose. The nurse said the order was for a 20% reduction, but I guess they round that to the packaged doses and whereas 20% would have taken me down to 96ML, the dose was 105ML... which isn't much more than 10%. Oh well, bad news for my hands is also bad news for any last remaining cancer cells I guess. I'll just have to hope for the best.

I met Dr. L yesterday, the cancer center's psychiatrist. I really liked him. And I just remembered I gave him this link. Hi, Dr. L! =) Anyway, more on that when I have a bit more mental energy, but I'll be meeting with him frequently and I think he'll be able to help me with the anxiety and image issues that have come up. My appointments with him will be on Thursdays so as not to conflict with my appointments with Dr. W.

Speaking of which, yesterday afternoon was stab'n'drain time again, and it was back up to 280 ML. For no apparent reason. I tried to get an idea of when/how the drain would be placed, but somehow got side-tracked. I figure with the way my counts have been behaving that it will be at least four weeks before my counts are in normal range, and I feel pretty sure that Dr.W isn't going to go ahead on just "okay for chemo" numbers. I did go ahead and schedule the next three appointments for stab'n'drain. I might as well know exactly when, since I know I have to go, anyway! Until the seroma thing is resolved, I'm still going to be a fairly busy person, as far as appointments go, I just won't be spending quite as much time in the infusion center.

So the *drama* for this round well it's too tiresome to repeat it all, but suffice to say that I ended up having to do the nuelasta shot without trained medical help. I did have untrained loving help from Olav, though! And very helpful help it was, I feel like I would have needed three hands... well I *did* need three hands and one of them was his. I'd seen the nurse administer it to me twice, but it took a bit of nerve to stab myself in the tummy like that. It didn't hurt at all, though, just like when the nurse did it! Stung a bit, afterwards, though. I might have pushed the medication in faster than she does, though I tried to go slowly. Anyway, Olav and I survived the experience. ;)

Chemo etc. 'How I'm doing' update February 4th, 2009

Well let's start with the awesome news! I only had 70 ML to drain today! That is a new low by quite a bit!! If it is the start of a trend, I could end up being able to skip the drain and go straight to scheduling the exchange surgery! I would be soooooo happy about that! That would put everything weeks or even a month ahead of where I thought it was going to be. That would be so fantastic. So I'm hoping!!

Basic updates...

Tolerating this round of chemo okay. Low energy, some queasiness that is pretty well controlled by Compazine. I never once puked during my fifth cycle, that was a first! If I can make it to the 15th without puking, I'll consider this round puke free as well. But just because I more or less finally got the hang of this doesn't mean that I wanted it to go on any longer! Hell no! Very ready to be moving on.

The reduced dose of taxotere is having some effect on my hands, I think. I also have been paying a lot of attention and when they start to pink up, I'm all over them with the hydrocortizone. So I don't think I'll be burning and peeling quite so much this time around. I do have the interior feelings, and if memory serves that may continue to worsen for a few days and then slowly improve. But I have hopes that it will be just fine. I did have to put my wedding ring around my neck again, because my fingers swelled up somewhat. This too shall pass.

I've started having more dreams about 'what's next'. Some of them are just dreams about my hair growing back. Other dreams are bad ones about having scans come back with bad results on them.

Much like this time last round, I have a tiny bit of spaz energy -- which is not the same as useful energy -- going on and a bit of trouble sleeping. Possibly due to the steroids they give me to prevent nausea. I'm taking extra Seroquel to help me sleep at night and if this follows last cycle's pattern, I'll crash out when I stop taking the steroids in a few days. Just another thing to get through.

I have no more appointments this week, wacky. Next week I have Herceptin, stab'n'drain (hopefully numbers as good as this week!!) bloodwork, Dr. C and Dr. L. Things might actually start to get moving again after next week, if my drainage is low and my CBC looks good! I'd be so happy about that.

??? 'How I'm doing' update February 10th, 2009

I hardly know how to describe the last few days in any way that will make sense.

Friday I noticed that my left hand and wrist were swollen. If it had been the right side I would have immediately thought 'lymphedema' but it wasn't. There wasn't any pain involved at the time and not much discomfort even, so I mentally tagged it with a 'wait and watch' thinking it possibly had something to do with a reaction to taxotere, since my fingers swelled up from that anyway. Not much of a change on Saturday. Sunday, however, the swelling was all the way up my arm and had gotten painful and I thought that a phone call to the docs was warranted. I *almost* wish I had waited, though it probably wasn't in the best interest of my health to do so... but the events that followed were such a mess.

Anyway, the doc on call said that it sounded very like I probably had a blood clot and I should go to the ER. Not really the way I wanted to spend my Sunday, but off we went. If I were to try to give you a play by play we would both only get confused, so I'll try to sum it up as best as I can.

An ultrasound was done and multiple clots were found that were apparently just shy of being deep vein thrombosis, although that was the diagnosis written up for me. I was admitted to the hospital. The only good care I received while I was there was adequate pain management. The rest was a mess of lack of communication or, when communication happened, conflicting communication. I was released with the information that I would be called by Interventional Radiation about removing and/or replacing my port, which hadn't even been mentioned since before I was admitted, for instance. And my medication instructions were changed between discharge and the pharmacy and now I have no idea of what I'm really supposed to be doing. It's pretty much my understanding that clots are life-threatening and I'd really like to know exactly what I'm supposed to be doing to save my life here. =(

As usual, I couldn't sleep in the hospital, so I was feeling pretty awful by the time they let me go. In fact, I was about 5 minutes from simply leaving without permission. I was so fed up. Other than all this crap, though, I'm doing okay. Unfortunately, this is a bit "that". Hopefully I'll get some answers today.

Blood Clot 'How I'm doing' update February 10th, 2009

I called the cancer center this morning and spoke with the nurse, leaving a detailed message about what had happened – to my understanding – and how confused and upset I was. I got a call back a bit later asking me to come by later in the afternoon, after my appointment with Dr. W.

To touch on *that* quickly, Dr. W. thought that it didn't look like I had any more seroma than last week and he was extremely reluctant to stick a needle in me while I'm on blood thinners. I'm not in any particular discomfort on that side right now because my left side hurts so much that only the hideous headache I got this afternoon could compete with it. So I told him fine, let's let it lie for this week and I'll come back in a week and we can see what we want to do then. I guess it's going to be a balancing

act; if the seroma doesn't go down, he'll *have* to drain it, even if I might bleed a little. I'm not afraid of a little blood, but maybe I'm underestimating the problem.

Anyway, onto seeing Dr. C. Actually it was his NP who explained most of it to me, but Dr. C came in at the end basically to reinforce and reassure me.

The clot is apparently pretty obviously caused by the port. They want the port out ASAP, marked urgent. and one of the questions they ask you before they schedule you is are you on blood thinners. Well, yeah! that's sort of the point! So what am I supposed to do? I left the problem in their lap, told them I'd see them in the morning, when I have my 6 month follow-up with my Dr. M. Figure it out, tell me when you do, whatever! As we were leaving, the nurse who deals with drug approvals said she got the mail order thing straightened out -- took her that long! Not ragging on her, it was just a mess. I went from there to the pharmacy where I could now actually get my Warfarin, but NOT the two more shots I need to carry me through until the mail order gets here, because my insurance won't approve them until tomorrow. *rolls eyes* Luckily (ha!) I'm going to be down there tomorrow anyway for the aforementioned follow-up appointment AND the Warfarin clinic (where they educate me, take my blood and who the hell knows what). One good thing, I guess, is that this took care of my appointment that I was going to have with Dr. C on Thursday. I'll see him again in two weeks, and in the meantime, I'll have my CT scan on the 19th. I'm supposed to see my therapist on Thursday, but I know Dr. C is hoping I'll be in surgery that day. We'll see, I guess.

And if that sounds like a scheduling nightmare -- and I hope it does, because it is -- let me just add that going on Warfarin means that I will be going in weekly at first and then probably every other week to have them test my blood to make sure the right amount of the drug is in my system. So I've traded weekly chemo/Herceptin visits for another kind of weekly visit. At least these will be much shorter. And it's just a finger prick, is my understanding. I guess I'll learn about that tomorrow, although I think they are actually drawing blood tomorrow.

I am so incredibly over this. This is one thing too many. The seroma thing, I was just like, okay, this is a PITA and it makes me take a lot of pills, but hey, it's my cross to bear and fine, no biggie. Aggravating, but I figure, this is my glitch, right? Apparently it wasn't a big enough glitch. And I know I have to just suck it up, but I'm just a little angry right now.

(mostly) Blood Clot 'How I'm doing' update February 12th, 2009

Yesterday morning I had an appointment for my 6 month post-surgery check up with Dr. M, although it was actually his NP that I saw. Nothing really interesting to report from that, no signs of cancer from a physical examination. I did show both the nurse and the NP the blister I got from the 45 seconds I had a bit of steri-strip on my skin in the hospital. I didn't mention that here before. When I was checked into the ER they put a red wrist band on me, indicating an allergy, but the doctor didn't bother to look up what my allergy was and when she was fixing the IV to me she put some tape on me that looked awfully suspicious and I said "is that steri-strips?" and she said yes and I told her I was allergic to it and she took it off and replaced it. I have one sizable blister from those few moments as well as a couple other tiny ones and some redness here and there. I'm so glad I recognized it, since it didn't look

exactly like the kind that actually took my skin off the time I learned of my allergy; it was much wider, but it had the tell-tale lengthwise threads in it. I have no idea why that particular kind of steri-strip is so bad for me, when another variety – a brown sort of stretchy kind – is perfectly fine.

From there I had to scoot quickly to the Warfarin clinic. There were three other people there too. We had to fill out privacy forms, forms saying we'd be good little patients and get our blood tested when told to and inform the clinic of any changes to diet, medication, lifestyle (seriously!) shoes (okay, not that heehee) etc. They had us watch the same video that I had been made to watch in the hospital, so that was boring. Then they pricked our fingers for the "INR" test. I don't know what the letters stand for, nor the numbers involved, but my target numbers while on Warfarin are between 2 and 3 and I was a .8. I have to get my blood tested again Friday, which was supposed to be my only day off this week from appointments. To my dismay I was told that none of the labs have the finger-prick readers except the clinic itself and you have to make an appointment for that, *and* they have limited time slots. But I'm totally willing to work with their schedule if it means giving my veins a break. I mean, holy cow, pierce my veins for one drop of blood? How ridiculous! So I made my appointment for the clinic there.

After that I went to the hospital pharmacy to pick up more Fragmin shots. I had been told it would just take a moment and though I thought I didn't really believe it I was still horribly disappointed when it took 20 minutes. How friggin difficult is it to count to two? The idea behind just getting two was that the rest of the supply would be coming from a mail-order company. This idea was wholly that of my insurance company. So I get home and a little while later I get a phone call from that pharmacy and the guy says "Guess what?" I said "What." in a really flat voice. There was no way I was going to like anything that followed and I knew it. He told me that the mail order company was not going to send me the shots. Would not? Could not? Who knows. Anyway, new plan was that I would get the rest of my shots from the hospital pharmacy and I could pick them up any time, no problem. Why does everybody keep telling me that things won't be a problem? It only ends up being more frustrating that way. I suppose I'll try to pick them up today in case there's a problem of large proportions; it will give them time to figure it out, since I'll be going back down there Friday anyway.

Olav had this fabulous idea that maybe since my seroma issue seems to finally be resolving itself I could have my exchange surgery at the same time as my port removal. That would be sooooo awesome. So I called Dr. W's nurse, Rebecca, and she said that that had been done in the past but she couldn't say if it could be done in my case, but she transferred me to his surgery scheduling gal... who was on the phone so I got her VM. She did not return my call yesterday, so I suppose I'll call her again today. Dr. W is so timid about things outside his own area that I can totally see him wanting to wait out this blood clot thing rather than go through the trouble of putting it on hold for a week at some point... and I do *not* want to wait the 3-6 months I'm supposed to be on Warfarin to have my exchange.

This business is really destroying me. Every difficulty, set-back, confusion, fark-up, whatever, has me in tears. I feel like mama nature is trying to kill me. Or trying to suck the joy out of a life that but for all this should be heartfillingly wonderful.

Today I have to pick up a Morphine refill (for some reason the FDA has decided that a paper prescription is more secure than an electronic one so I have to handle it personally), see Dr. L (the shrink), and, as mentioned above, go by the pharmacy and see if I really *can* pick up the rest of my Fragmin shots. Seriously I don't know how people who work do it.

Blood Clot 'How I'm doing' update February 14th, 2009

Well unfortunately Olav's great idea about combining the surgeries isn't going to work out. Dr. W can't do the surgery as soon as the port needs to come out. Very disappointing. In theory I could ignore medical advice and do it that way anyway, but I think that would be stupid. As much as I would like to minimize the number of surgeries, as much as I want to get these damn expanders out of me, I still have to put my health first.

Before I got the word that waiting 3-4 weeks would be too long, the folks at IR (Intervention Radiology) called me to try to set up a surgery date. The woman was incredibly, breathtakingly rude to me. She refused to believe me that the two surgeries could be combined (that they can be has been confirmed by two of Dr. W's staff). She called me back and got my VM (I think because I was in the basement of a building) and said she'd spoken to Dr. W, but if so he would have had to answer a page from the OR... so there's an extremely good chance she was lying. If so, I do believe I'm going to try to get her an introduction to the bad economy. I called IR and left a message saying that I would discuss scheduling the surgery with anyone but her, but that she was too rude to me for me to deal with her. I also mentioned how impressed I was with what an important person she must be for Dr. W to return her page from the OR. Nobody called me back... I have this picture in my mind of her listening to that message and wondering how the heck she can explain that someone else needs to do her job.... that's okay, sweetie, I'll tell them for you.

My INR was a 1 yesterday and I go back on Tuesday for another finger stick.

The swelling started to go down, but doesn't seem any better today than it was yesterday.

I seem to be doing something wrong the last couple of nights giving myself my Fragmin shots – I've actually felt the needle going in. It's bad enough that it stings for about five minutes afterwards. I really don't look forward to that part of my day. I do the Fragmin shot and take the Warfarin pill around the same time in the evening and a little while after that I tend to feel a bit dizzy for a little while. Just a little. Since I do them both at the same time – and worse, I'm *supposed* to do them more or less at the same time; in the evening anyway – I don't know which of them is responsible. I actually have a suspicion that it's the Warfarin, because I don't recall having that sensation of dizziness before I started the Warfarin. But it's mild enough that I could be mistaken. Maybe I can offset them by an hour or so tonight and see if I can isolate the issue. I don't think it's anything to worry about, though.

It's very frustrating knowing I'm going through all this ramping up on the Warfarin only to have to do it again very shortly after the surgery.

Blood Clot 'How I'm doing' update February 17th, 2009

First on the agenda today was Dr. W for a stab'n'drain. He agreed with me that I was pretty puffy and I

told him I was in quite a bit of discomfort, but he didn't want to stab me unless he knew what my INR was, because if it was too high I could bleed into the seroma pocket which could potentially lead to an infection. He told me that if I was at a 1.5 or less he would do it. I had an appointment for an INR scheduled for 10:30 and he said I could just come right back from that if the number was good, so I went on over there and arrived at about 9:40, but they were able to take me back about five minutes later, which was awesome. For better *and* for worse, my INR was still at 1. This was good because it meant that Dr. W could go ahead, but bad because it meant that the Warfarin wasn't doing anything. Also good for another reason to be revealed later in this post. They directed me to take half again as much Warfarin tonight and tomorrow and see them again on Thursday. Well, I'll see them again on Thursday, but for the rest, read on.

So I went back to Dr. W and he did the stab'n'drain. 235 ML. Which for two weeks isn't too bad, but I have to admit I was hoping for something more like 140. At any rate, I was glad that he did it. It hurts, as usual, but at least I'm not puffy anymore.

After I got home I got a phone call from Dr. C's office saying that IR had told them they were unable to schedule with me. I explained the situation and the gal said 'so if someone else calls you this afternoon you can schedule the surgery?' and I said 'absolutely!' A little while later Pat from Dr. C's office calls and tells me that they've scheduled the surgery for this Friday. Those ridiculous cowards – or possibly just this one woman – wouldn't even get on the phone with me, they actually made the appointment without me! And this is where that other 'for better' comes in. If my INR weren't at 1, I wouldn't be able to do the surgery in three days. It takes at least 5 days off Warfarin, generally speaking, to get to a 1. I have no evidence that anyone checked my INR before scheduling the surgery. But they might have, it's a simple thing for anyone in the medical group to access. Funny, looking back, that Dr. W just took my word for it. Although the information may not have been in the computer at that point, it's only a ten minute drive from one place to the other, tops. So anyway, no more Warfarin before the surgery, and unless I hear otherwise from them, I won't take anymore Fragmin after tonight until after the surgery. I'll have to find out from then when after the surgery to start all that back up again.

So here I am this evening, in less pain than last week, but still enough to go 'round the clock with the breakthrough meds. If it weren't for the surgery I'd predict that I'd be off of 'round-the-clock by Friday, but there goes that idea.

Port removal and general 'How I'm doing' update February 21st, 2009

I had my CT scan on Thursday. Though I'd had one before, I couldn't remember how they went. I've had so many scans and procedures. As it turns out, they put the IV cath in before they put you on the machine's table and then right as they are ready to scan you they squirt saline and then some radioactive stuff into your veins through the IV. They warned me about sixty-*l*even possible side effects I might feel, but I only felt some cold when it went in and then a sort of hot flash. No biggie. The scan didn't take long at all, only a couple of minutes I think. As I said a little while back, I think the results will be ready by the time I have my appointment with Dr. C on Tuesday.

My INR was .9 Thursday morning, and Jason, the big guy at the Warfarin clinic, said that the cancer

center didn't have access to their computers -- which I find extremely odd -- so I carried the results over to the cancer center by hand. I'm to start the Fragmin and Warfarin back up again tonight and go for another finger stick on Monday. Although it isn't entirely in my best interests I'm kind of hoping that my INR won't have gotten above a 1.5 by then so that Dr. W will drain me Tuesday. For some reason I already feel puffy. Possibly that is paranoid thinking.

Anyway, on to the main event.

Rather to my surprise, the port removal surgery went pretty smoothly. There was a glitch, which I will get to, but over all, not too bad.

Had to be there at 6:45 which is a time when I like to be telling the alarm clock it's got to be kidding, but we made it there only a couple of minutes late and didn't have to wait too long. This time they let Olav tag along, thank goodness.

The nurse who prepped me was absolutely flummoxed by the problem of me having the surgery in the arm that I was allowed to have IVs in and was afraid she'd have to put the IV in my foot. The supervising nurse told her it was fine to go in my hand, they could work around that. I figured that would be the case, since they did it that way when they put the darn thing in!

They got me in the OR and onto the operating table and gave me the nighty-night juice in the IV and then all of a sudden I was awake on the operating table looking at the surgeon about to slice into me. I was like 'Hold it!' I don't remember my actual words because though I was awake, I was still pretty drugged up. I know I threatened to punch someone if they didn't get it right on the second try. They later claimed this had *nothing* to do with them tying down my right arm hahahaha! At any rate, they *did* get it right on the second try. While we were waiting for it to take effect the doctor said something like 'you probably don't want to hear about this, but I'm going to go in through the same incision'. I don't know if it came out, but I know I intended to reply 'I don't really want to hear about it, no, but that's good.' That's the last thing I remember before waking up again back in the staging area. I was under approximately an hour and a half, though I'm not sure how the business with the second try comes into that. The first thing I remember of waking up is Olav's face. A distinct improvement over that of the surgeon.

They let me go pretty promptly. They *were* going to make me eat some crackers to demonstrate that I could fail to puke, but they changed their minds about that for some reason. Maybe Olav convinced them while I was in the bathroom. Over all not too terrible an experience.

For the rest of the day I was very sleepy and rather loopy. I would fall asleep for 15 seconds and start to talk out of my dream and confuse the hell out of Olav. Or I would do something like get myself a fresh coke and totally forget that I did. I mean, have no memory of doing it. For that one I did manage to come up with one detail about it after straining my brain, which I did because I hate blank spots in my memory. I suspect there are quite a few in yesterday, but if I don't know about them they won't bother me. I took a big nap and also went to bed early. Consequently I got up really early for a weekend today. I changed my bandage this morning. The tape stuck alarmingly to my skin but not where the wound was -- that bit was covered with bandage -- it was just that the tape was very sticky. I'm supposed to leave the superglue stuff they put on the wound alone, so I can't really see how good a job he did putting me back together. Doesn't matter too much, it is what it is, and the scar isn't in a terribly visible place... which was part of my plan when I chose that spot for my port in the first place.

The pain is not horrible. I'm taking boost pain meds by the clock to make sure nothing gets too bad, but the pain level is about what I expected. And to give some perspective, the blood clot pain was worse. Certainly the axillary dissection was, but I'm sure that's not a surprise. Anyway, the pain is livable and I don't think it will take too long to heal. I hope it heals quickly, since I'm not supposed to lift heavy things or reach with the other arm either!

'How I'm doing' update February 23rd, 2009

The arm really isn't doing that badly. It certainly isn't as bruised as it was last time, oddly enough. I've been taking 'round the clock pain meds and it's been very manageable. I'm not ready to have 'em slap a blood pressure cuff on there *just* yet, but I think it's healing up just fine.

I had my INR finger-stick this afternoon and it was a .9. The good thing about that is that I'll be able to show those results to Dr. W tomorrow and get drained. I'm feeling distinctly puffy today. The bad thing, of course, is that I'm nowhere near the target 2-3. Not that I expected to be after only being back on the medication for 2 days.

Of course my stab'n'drain and my appointment with Dr. C aren't close enough together for me to make it one trip. Oh well. I'll report back tomorrow. The point of the Dr. C appointment is blood clot health management – an area where we haven't actually gained much ground over the last two weeks – but the reason I'm *really* looking forward to it is because it is my hope that my CT scan results will be in and I can be told I have no evidence of disease. This is what I really really want to hear tomorrow. I put some champagne in the fridge to celebrate when we get home. I'll still be in treatment until October, but I can be declared at least apparently free of cancer and I am certainly undeniably done with chemo. I think that's cause for a wee toast. =)

'How I'm doing' update February 24th, 2009

Really sleepy here, so I'll try to keep it short. I can't keep my eyes open!

Well my nice low INR number didn't do me a lot of good with Dr. W. Seems that the expander has moved around again, this time towards my armpit, the area with the seroma problem. Dr. W doesn't think there is much seroma left, but that it is the expander itself that is hurting me. He also seemed to imply that he might drain at higher numbers, even though he specifically said he would do no such thing last week, so I don't know what to make of that. He put in an order for an ultrasound to see how well the seroma pocket is healing.

Later that same afternoon Olav and I met with Dr. C and his NP. We did a basic review of the blood clot treatment so far, and also spent a good deal of time discussing my chemo fatigue. He said it could

take a few months for me to feel like myself again, but that it will help if I start trying to exercise again. For the moment I'm stuck with walking, but I can and should start doing that again. We agreed that my next Herceptin would be next Monday, as planned.

But the best part was the CT scan results! I can hardly believe I'm being allowed to write these words. There is no evidence of disease. I can, in the parlance, call myself NED. ;) For me this marks a turning point. I may still be a cancer patient, and I may still be in treatment for cancer, but even though most doctors would never say I'm *cured*, I still feel like I no longer need to say I *have* cancer. It may be too immediate for me to jump right in and go straight to 'I *had* cancer.' But I don't really have cancer anymore! How wild is that?

I puked, just out of nostalgia tonight. Hahaha! Actually it was most likely the order in which I took my pain meds in combination with the tremendous rollercoaster today was, emotionally speaking.

But before that, at dinner, I realized... I'm going to live to fight these dumbass battles that are still in front of me. The blood clot and the seroma and the expanders and the PT I'm going to need for my arms after my exchange surgery... I'm going to actually be *alive* to have all these problems! A living person can do this. I'll find my strength.

'How I'm doing' update March 1st, 2009

My INR was a whopping 1 on Thursday, so they raised my dose to 10mg and my next INR is on Monday. 10Mg is the biggest dosage they make the pills in, so I'm kind of wondering if my body is just not responding properly to the drug or what. Despite hoping for a drain next Thursday, I'm worried enough that I hope I see significant improvement tomorrow. I'm not sure what my options are if I don't respond to the Warfarin.

I'm having a very disappointing amount of pain on the seroma side. Because of the last appointment with Dr. W I don't know if it is from seroma buildup or from the expander moving or both. Probably both at this point. On the 'good news' side, the surgery arm is doing well. No pain when I move the arm, just a bit if I actually poke the area. The surgeon was a little sloppy when he applied the superglue stuff, getting a bunch a blood mixed in, so it's more or less impossible for me to tell how healed the incision is, so I'm continuing to keep it out of the water when I take a bath, but not bothering to try to keep the bandage dry in the shower.

I had my third meeting with Dr. L on Thursday as well. I really like him. I'm sort of spacing on what I was supposed to think about for my next appointment, but that's three weeks away, so hopefully it will come to mind before then. In the meantime, I think I can work more on some of the things we discussed in the past, as there is plenty of use to get out of that still. He is helping me think constructively about moving forward. Some of the concepts are a little hard for me to grasp – as far as applying them to myself – but I know he will help me. He said, wisely, that there is no point in working against my nature to try to accomplish my goals.

I have a Herceptin infusion in the morning, and they are going to take my INR sample from me there so

I don't have to make a separate trip for that.

So far I only have three appointments on my calendar for next week and one of them is just a finger stick. 'Only' three? Well considering that I had *nineteen* appointments (and I'm counting the hospital admission as an appointment) in February, three seems like a light week. I had 8 appointments the second week of February, ugh. Here's hoping March will be a bit lighter on the schedule. Especially with my girls in town for most of the month!

'How I'm doing' update and wee introspective interlude March 2nd, 2009

Getting the IV placed for this morning's Herceptin infusion brought on strong unpleasant memories of my last hospital stay. I'll say no more, because I'm trying to not hold on to that mental association. Other than that and the fact that they were running behind, I suppose the infusion went just fine. I was very antsy for some reason, though. I just couldn't wait for it to be done. They took blood for who-knows-what and also my INR.

I got a call from the Warfarin clinic about the INR results this afternoon, and the number was 1.9, so we finally made some progress. I'm to take 10mg again tonight and then go back down to 7.5 for tue and wed. and then have another finger stick on Thursday. My only other appointment this week is also on Thursday... three hours later. Not exactly convenient. Does it make it better or worse that the second appointment is probably going to accomplish nothing at all? That's the one with Dr. W and since my INR will be in therapeutic range, he won't be enthusiastic about sticking a needle in me, to say the least. Oh well, I need information from him, regardless of whether or not he can do anything about the pain I'm in. I need to know if I'm just going to be allowed to blow up like a balloon while I'm on blood thinners or what. I need to know if allowing more build-up of seroma is slowing down the healing of the seroma pocket. I need to know when I can have my exchange surgery. It's all so tangled and complicated.

Here's when we get to the introspective part.

It's really weird trying to talk about how I'm doing right now and about what is up with my treatment. Most people *really* want to stop listening at 'I'm done with chemo'. They want that to be all there is. But it's not! It's not even that I'm still recovering from chemo – still suffering from extreme fatigue and still bald – but that I'm going through all this other stuff that you, my readers, are all too familiar with. I can't even cram it into a nutshell, because it's confusing!! People think they want more than just 'okay' as an answer for how I'm doing, but they just aren't prepared for the complexity which is my current situation. I'm not sure how to handle it, really.

Oh, speaking of introspection. When I was with my shrink last week I told him about the emotional yardstick idea I wrote about in my first introspective interlude, December 14th, and he liked the idea so much he said he was going to use it. =) I can't be doing it *all* wrong if my shrink wants to use some of my ideas!

'How I'm doing' update March 5th, 2009

First on the agenda this morning was the INR. It dropped back down to 1.2, so the worry about it overshooting the goal was obviously unfounded. We're back to 10 mg and another finger-stick appointment for Monday. The gal there today said it looked like I'd eventually end up taking 10 mg five days a week and 7.5 mg two days a week. But first we have to hit the target range.

From there I went to IR. I got a call yesterday telling me that I had an appointment for Friday (news to me!) for a post-op check-up, but that, in looking at my calendar, perhaps it would be easier for me to drop by at my convenience before or after one of my Thursday appointments. It would only take a few minutes, I was told. Ha! Well, the exam, such as it was, only took a few minutes, but I waited at least a half hour, and I wasn't pleased about it. Those morons also had written down that I was there to be checked for just having had a port installed on my chest. That's almost exactly the opposite of why I was there. It took me mentioning this three times before it sunk in to the nurse, who then basically had no idea what she was looking at and just said that the incision looked like it was healing well. I coulda told them that. After all, I'd just let her take my blood pressure on that arm, that says quite a lot right there. What a waste of my time.

Then this afternoon was my appointment with Dr. W. I waited about an hour and twenty minutes. He examined me and thought I didn't have much seroma and that the expander might have moved more. Since there was very little obvious seroma, he wasn't willing to risk puncturing the expander. In other words, just like last week. We realized nobody had called me regarding the ultrasound order; I've got to keep that in mind so that I follow up on it if nobody calls me this time. One thing Dr. W mentioned that nobody had yet was that the large doses I'm requiring of Warfarin mean that my liver is healthy. He said little old ladies needed 1 mg. So that's *one* piece of good news, I guess. So Dr. W decided to not have me in again for two weeks.

Meanwhile he said that with luck the seroma is resolving itself, but that we need to keep an eye on the moving expander. It has to be settled into place before he'll do the exchange surgery. Oh freaking yay, another thing to *wait* for. I didn't even dare ask him how long we have to wait. He'd just gotten through telling me how it can take a year for squishies to settle into final position after exchange surgery, so I just didn't have the strength to hear bad news. Maybe I will in two weeks – well two and a half – when I see him again. Meanwhile I am just going to suffer, I guess, since he can't do anything to help me. Just keep chugging the painkillers, I guess. So I suppose I got some answers, I just didn't like them very much. Dr. W said that this was like a journey and his patients should enjoy the scenery instead of focusing so much on the destination. I told him the scenery sucks. =P

'How I'm doing' update March 9th, 2009

Unless something goes wrong, all I have this week is INR checks. Wow!

First one was this afternoon, and I'm finally in range, though just barely. 2.0. I'm to take 10mg of Warfarin tonight, 7.5 tomorrow, and 10 again on Wednesday. A careful recipe. Another fingerstick on Thursday. Anyway, this means I can stop giving myself the Fragmin shots, woohoo! Those things are pretty painful, relative to the general run of injections. The stab itself isn't usually any big thing, but the spot, an area about the size of a silver dollar, stings for 5-10 minutes afterwards and I won't miss that! I'll have to do them again if I go off the Warfarin to have the exchange surgery... and as much of a pain in the butt (and tummy!) as that would be, I'll still be hoping for it. However, the seroma thing and the moving expander thing will have to resolve themselves first. * sigh *.

Speaking of all that... I feel puffy, but who knows, maybe it's just the expander. Either way it's not a good thing. Painful and annoying.

I seem to be pretty much healed on the port-removal side. So at least I have that arm at my disposal again.

I feel like I have a little more energy than I did a couple of weeks ago. I'm still inclined to sleep as many hours as I'm awake, but I can work at chores for longer stretches without a rest.

I don't however, seem to have any more damn hair!! I can't remember if I mentioned this recently, but I heard back before I started chemo that Herceptin can retard hair growth and now I believe it! Some of the other girls in my chemo group who finished around the same time I did have $\frac{1}{4}$ to a $\frac{1}{2}$ inch of hair already! I barely have the hint of scratchiness where stubble will be. I know my hair will grow back, but I'm really impatient now. I think I handled my loss of hair with grace and good humor, but I'm tired of being bald. I've been through a lot and I think I deserve some hair!

'How I'm doing' update March 13th, 2009

I had another INR check yesterday, and my number had climbed to 2.7. That's more or less a good thing, but the concern now is that the number will overshoot. This business is made more difficult by the fact that the effects of the drug have a few days of lag time, so with INR checks so close together it's hard to tell what the true effects of the current dosage are. So we're continuing with interspersing 10mg and 7.5mg, only this time heavier on the 7.5mg. The gal who did my INR seemed hopeful that I might be able to go to once-a-week checks if the numbers go as expected at my next check. Which is Monday.

On the general topic of blood clot recovery, I don't have any more swelling, but my veins are still more visible in my chest and shoulder on that side. It's kind of creepy. It's not as dramatic as it was, though.

The only other thing *currently* on my calendar is my shrink on Thursday. This month is turning out to have fewer appointments after all. Primarily due to not seeing Dr. W as much. I surely wish I *was* getting drained, but I guess he wouldn't be doing it even if I had the appointments.

My right arm is slightly swollen, which I feel pretty sure is lymphedema, rather than another blood clot.

I also theorize that I'm having this problem right now because my expander is trying to crawl into my armpit. I imagine it might be squishing the remaining lymph nodes. Also, I'm a little alarmed and confused by the theory behind letting the expander move the way it is. Dr. W said he wants it to stabilize before the exchange surgery or the implant will just keep traveling in that direction, but is the whole pocket moving? Am I going to end up with a boob in my armpit? Isn't there another way here? I just put a call into his nurse's VM mentioning these concerns and saying I could use a little reassurance if my concerns are baseless. My pain seems to not be a relevant factor in all this. It is to *me*, but apparently I have to just suck it up. And take handfuls of painkillers.

Again on the energy topic, I feel like my energy is very slowly returning. According to Dr. C it will be a long time coming, but it's nice to see some improvement, no matter how slight. It's certainly nice to not have my energy level plummeting every three weeks now, though. I tell you what, there's nothing I miss about chemo. I might feel differently when I have to start shaving my legs again!

Update: Rebecca (Dr. W's nurse) returned my call and suggested I call Dr. C about the lymphedema thing, but as far as the expander movement, she suggested that I come in next Tuesday instead of the following Tuesday so he could take a look at it. So we scheduled that. Despite myself, I can't help but hope that he can do something to alleviate the pain. She said she would let Dr. W know about my lymphedema concerns, but that he's in surgery today and may not be able to get back to me until Monday. However, to sum up, I didn't really get the reassurance I was hoping for, but at least I know that I won't have to wait as long as I might have.

'How I'm doing' update March 16th, 2009

INR day, this time 3.0, so we're a bit concerned about it overshooting. We're going to do 7.5 for a whole week until my next fingerstick! Not much else to report right this second. I see Dr. W tomorrow morning, though I don't have a lot of hope that it will be a fruitful appointment. I'll report back anyway.

This month is ending up having fewer appointments after all! Maybe as few as 12, which would even be lower than back in the bad ol' chemo days, which I usually had 14 or 15. Last month was just stupid.

'How I'm doing' update March 17th, 2009

As I had feared, the appointment with Dr. W didn't do anything to make me feel better. It does seem like the seroma isn't being produced at nearly the rates it used to be, but we won't really know what's going on until I have that ultrasound.

The bad news is that at the rate things are going he thinks I won't be able to have the exchange surgery until June or July. I cried right there in the exam room. Three more months of pain? And it's not like

implants are perfect when you first get them. They have to settle in and get softer. I just want this to be *done*. I'm so tired of it all. It's hard to keep my chin up. It's hard to have this wonderful attitude that everyone says I have. That's BS, I'm impatient and sad. Cancer has absolutely ruined my last nine months and it looks like it's going to keep pounding at me for many more. I am not okay with this, even though I know there is nothing to be done about it. It would help if *something* could go right.

'How I'm doing' update March 26th, 2009

It's been a little bit, I've been busy with the kids and with a house guest. However, it has been something of a relatively slow month, appointment-wise. I've only had four appointments, and one of those was just a Herceptin appointment, and another was just an INR.

First, though, was my appointment with Dr. L. One of the main things we ended up talking about was my pain, actually. I've been taking my breakthrough meds around the clock and he pointed out that that makes them baseline meds. He told me I had to tell Dr. C about that, and we talked about doctors and addiction and related matters. I talked a lot about my frustration about feeling like I didn't know when all this was going to end. When I was in chemo I had a date to look forward to and I really thought that when that day came I would be almost done with everything and just be getting better. But almost immediately I got stuck in a limbo with no guide book. No way to know when it was going to end. Vague notions, nothing I could put on the calendar and be optimistic about.

The INR was supposed to be drawn with the Herceptin, actually, but they didn't manage to get a big enough sample from me. When I go to the Warfarin clinic for a finger stick they literally only need a drop of blood for their little machine. The other labs, however, don't have these machines, and they need a bit more, like half a vial. So the clinic called me to tell me that the test had failed and asked me to come by after my appointment with Dr. C in the morning. I forgot to do that, of course, so I ended up finally making it over there this morning. My INR was a 2.0. That's an acceptable number, but they're concerned that it might drop further down, so I'm back there in a week. Even if it does I probably won't have more than one 10mg dose a week.

I enjoyed my appointment with Dr. C of course. I always do. He told me that I would be off the Warfarin no later than August 8th, and probably could go off of it when Dr. W was ready for my exchange surgery in June/July. So now I know what I'm looking for, I have an end date, something to count down to. I feel better. That was just what I needed to hear, some idea of when this all will end.

Then we discussed my pain. He immediately agreed with Dr. L's statement about the breakthrough meds becoming baseline meds. His solution was to change my Morphine dose from 30mg twice a day to 60mg twice a day, but telling me that maybe three times a day would work better.

I also mentioned that I have been having night sweats, and the basic conclusion of that conversation was that if they got intolerable then we would try to treat it, but not before.

Speaking of that made me ask the question of when I might expect to recover my cycles, if I should be so lucky. I said as I asked that I knew he couldn't really tell me. However, he did say that almost

everybody that got them back did so by six months post-chemo. Which is more of an answer than I expected.

Dr. C was on Tuesday and I started the 60mg regimen that night. Yesterday I did okay for the morning, but as the day went on I got more pain, and then some nausea. After I took the next dose I got even more queasy but the pain didn't seem to get any better at all. I had a very bad night. I was so groggy that it never occurred to me to get up and get some norco, I would just wake up and moan and go back to sleep. This morning I wasn't queasy, but again, the pain didn't seem to be helped at all. I finally took some norco and got some relief. In the afternoon I called and left a message for Dr. C. When he called back I told him about the situation – not the play by play, but the gist – and after verifying that I had sufficient quantities of various medications, he recommended that I try going to 30mgs three times a day and see if my body liked that balance better, since it clearly wasn't tolerating the higher dosage properly. He said that if this didn't work we'd have to go to another drug entirely, but reminded me that I wasn't to stop taking the Morphine abruptly because I would go into withdrawal. Yes, doc, I know. I don't *feel* addicted, but I'm not going to risk putting myself through that. The whole medical center is closed for a three day weekend, but Dr. C told me that he could be reached if there was an emergency. It's my thinking that the Morphine is going to have to go, and I am not pleased by this. I hope I'm wrong, in fact. But as long as I can get through the weekend, it will all be okay.

The other possibility in all this is that the painful area may be being significantly more painful right now for some reason. How the hell can I tell at this point? I've been in pain from one level to another for months now, and taking painkillers for it the whole time too. It's virtually impossible for me to tell right now if I'm hurting more because the painkillers are working less or if I'm hurting more because something is hurting me more. I *think* it's the painkillers, just based on things like being able to feel the regular aches and pains of living. Ah the existential questions of cancer treatment.

how I'm doing' update March 29th, 2009

I've now spent the cancer center's "three day weekend" on the 30mg-three-times-a-day experiment and it's been okay. A hell of a lot better than the 60 mg twice a day. I don't know how that dosage completely failed to kill my pain and yet made me so tired and queasy. But that was a no win there. This weekend I've probably been taking about half as much breakthrough medication as before the switch, so it's an improvement, but I'm not sure I'm satisfied with it. Ideally I would like to have breakthrough pain to only occur badly enough to need to be medicated maybe a few days a week? Certainly not every day. Certainly not hours on end. However, there is a lot involved in changing from Morphine to another agent, and that's not to be undertaken lightly. I'm going to talk to Dr. C and see if I should regard this as an acceptable compromise, or if the best thing to do is to undertake that change. One thing that I probably ought to do before I talk to him is see how I tolerate a dose of the liquid Morphine breakthrough medication at this dose of baseline Morphine. I don't want to be 100% reliant on norco for breakthrough pain. Not ideally. Argh, it's so complicated.

Anyway, I made it through the weekend in good shape.

'How I'm doing' update April 7th, 2009

Things really have been slowing down. Hanging in limbo. I only had 11 appointments in March, down from 19 in February. Since my last update, all that I've had was an INR and an appointment with Dr. L, both on the same day. Nothing particularly profound came of the Dr. L appointment, but he is helping to keep me focused on the future.

My INR last Thursday was 1.9 so they told me to take 10mg that day and 7.5 for the rest of the week. I go back this Thursday to see how that worked. If we can ever get this stabilized I can go to checking this every other week.

The new Morphine regimen actually continued to improve. I'm down to taking breakthrough meds usually only once a day. While that isn't as good as only a couple/few times a week, it's good enough for me. It seems like the times that I need to take a second dose of breakthrough meds is more related to how tired I am than to how active I've been, though I'm not entirely certain about that.

Between the less frequent appointments, the decrease in pain and the amount of other stuff I've had to do in my life I haven't been nearly as focused on cancer stuff. Thus the longer gaps between updates.

how I'm doing' update May 4th, 2009

It's certainly been a long time, but little has happened really. I've been going weekly for INR checks and only last week finally was allowed to go to a two week interval. I've seen Dr. L a couple of times, but nothing much to report of that. I'm glad I'm seeing him, he helps keep me looking forward, but there isn't a lot to say about the visits. I've had two Herceptin infusions, but other than my hatred of IVs, there is nothing of interest there either. I go, they happen. A few things of note happened and I will discuss them below.

Dr. W finally gave me a surgery date for my exchange. In the horribly distant future of July 10th. Since it is so far from now anyway, I'm considering pushing it back one more week so I can go on my friend's annual river rafting party on the 11th.

When I saw Dr. C I finally asked him about whether or not CT scans did bones as well. I'd been meaning to ask him that for a couple of months. I have this spot of pain in my back that I really can't tell if is in the bone or in the muscles or what, so I wondered if the CT ruled out the bone possibility. As it turns out, it doesn't. CT is more for soft tissue and will only find bone mets if they are pretty advanced. I told him where the pain was and he pulled up the CT scan and it happens that just about there there is an area that is a tiny bit questionable. He thinks the likelihood that it's cancer is very very small, but he told me to try ibuprofen (since it's the only painkiller I haven't tried) and to keep an eye on it and if it didn't go away we'd do a bone scan. I've since wondered if an x-ray could straight-up rule

it out, so I'm going to ask about that... might as well go for the cheap option, even if it means that a potentially inconclusive result means I end up getting the bone scan anyway. I'm trying not to stress about it, it could be so many other things. For the record, the ibuprofen hasn't helped, but I didn't expect it to. Not because I think this is cancer – honestly, that does seem unlikely – but because ibuprofen has never done a damn thing for me before and I didn't expect it to start now.

My main problem right now is hating my body. Well the boobs in particular. seems like every time I take a shower and half the time I take a bath I end up sobbing. Yesterday I did fine until I was oiling up before toweling off and I started remembering how my PS was talking about how the expanders looked great, really symmetrical, he didn't think he was going to have to do a lot of extra work to make the implants look good or have to go back in to make corrections. He and his nurse stood there looking appraisingly at my chest, nodding encouragingly at me as I swallowed hard, keeping the tears inside until they left the room. They come back pretty much every time I think about that. I know I should be glad, all of that should have made me feel better, but I felt like it was pity. poor girl, we're going to do our best and she's still going to be a freak. My shrink said that some people feel better about the loss of their breasts by improving the rest of their body (working out, he meant, not more plastic surgery) but while I intend to exercise more and be healthier, I know that having great legs or a great butt would only make my loss that much worse to me.

I finally did have an ultrasound on that area that is hurting me so much, for all the good it's going to do me. I don't know, maybe Dr. W will look at it and decide I need to have my exchange surgery sooner hahahaha. Not bloody likely. The tech suggested it was hurting me because the seroma pocket was like having another expander in there, but if that was all it was you'd think it would be a skin thing and my skin would have long since gotten over it. This is definitely different. Oh well. Just have to live with the pain until July, I guess.

So that's pretty much it. 10 appointments in April, but half of those were INR or Herceptin. Things are moving really slowly now, and not in a good way. Not winding down, just waiting waiting waiting.

How I'm doing' update May 16th, 2009

I swear I was *not* complaining about being bored. Just about things going slowly. I wouldn't temp fate like that, I know better. Nonetheless, interesting things found me.

When I went for my INR check on Tuesday the 12th, I had a feeling that the number might have gone down a little bit. I was actually feeling a little smug, because I felt like if they had asked me I would have told them that, based on how I'd responded to the Warfarin thus far. So imagine my surprise when the machine said my INR was a 7.8. I said 'That *can't* be right'. And the gal (a pharmacist this time, the students who had been rotating through were all on their way to graduating) said that that's what they did, another stick test and then a vein draw if necessary for a third opinion. So we stuck another finger and the machine said 8.0. I started crying hysterically. I said (well sobbed really) that it had been three of the three to six months I had been given and I wanted to stop now. I said "I can't do this, I can't do this I can't do this" over and over. She told me that at least I wouldn't be expected to take any Warfarin that night, but was to have my blood drawn in the on-site lab and pick up a vitamin-K tablet which I

was supposed to take half of if the lab test showed the same high number. The lab actually came back with a 7.6 but that is still waaayyy too high, so I was told to take half the tablet of Vitamin K and come back in the morning for another finger stick. This all devastated me so much. It broke me. One thing too many. The blood clot in the first place was too horrible to believe in, and the hassle of all the appointments to get the numbers correct were insult to injury. To have it not even work out properly was just too much, too much.

When I went back on Wednesday, the vitamin K had lowered the INR to a 4.something and I was told to not take anymore of it or of the Warfarin. I told them I had no intention of ever taking the Warfarin ever again. Meanwhile they were trying to get in contact with the doctor who had referred me to the anti-coagulation clinic, and it became clear that said doctor was not a specialist; certainly he was not a doctor I knew anything about. They asked if they could contact my primary care doctor and I said sure, I loved her, but I didn't see how it could help since she was a GP. They also told me come back the next day for another finger stick.

Thursday my INR was 1.3 which is *below* what they want it to be. They wanted me to start taking the Warfarin again. I said no. We argued. Finally I agreed to take the Warfarin if Dr. C could convince me it was in my best interest, even though *she* thought I was agreeing to take it no matter what. Nuh-uh. No way, pharmacist (she says in a voice dripping with contempt). Only a doctor I know and trust can make me take this bane-of-my-existence medication again. So eventually I get ahold of Dr. C and he says it's totally up to me, but it wouldn't really hurt me to take that small a dose (5 mg) until Monday when the head of the clinic comes back. He also ordered an ultrasound so that we could see what was going on in the area the clot was in. So I'm going back to the clinic on Monday at which point I will tell them that I won't take any more pills until I see this doctor who is the head of the clinic. They need to treat this as an emergency if they want me to take this drug. I reminded them that while my file describes me as a compliant patient, but that I had no intention of being compliant on this matter. I wasn't just going to do what I was told, I was going to have to be convinced that there was a medical necessity. *Convinced*. Because right now I don't believe it at all. Right now I believe this whole business is actually a danger to my health and certainly a danger to my overall well-being.

I saw Dr. L on Thursday and in addition to crying about all of the above I also talked about the pain I am dealing with. The subject came up because my reaction on Tuesday was that I decided that I wanted one day – one flipping day – without pain, so I took breakthrough meds all day at about triple the prescribed dosage. I described my pain by saying that with the baseline pain meds, I feel like I have a table knife stuck in my chest at all times, breakthrough pain was like having a hunting knife stuck in me, and that breakthrough meds brought the pain levels back down to table knife. He told me that that's not how it's supposed to be. I didn't know that, I thought I was just supposed to be living with this, as tiring and awful as it is. He told me I needed to tell Dr. C about the knife description of the pain levels. So I did, and he said to double the amount of baseline meds I'm taking. This will actually put me at *more* than what made me sick before, but I'm hopeful. I was queasy after the first dose, but haven't been since then. But lordy have I been sleepy and groggy! It's been ridiculous! That part should pass and isn't important if the killing-the-pain-part actually works. It seems better, but I'm not sure yet. You'd think I would be, wouldn't you? But we'll see. It's only been a day and a half.

Wish me luck, I want to be *done* with this part of my treatment.

How I'm doing' update May 20th, 2009

EDIT FROM 6/12/09: I have no idea what's up with the this entry and the next one [Editorial Note: the post referred to is the previous post, but I've rearranged this version to be in chronological order]... I think I forgot I'd written the week before and then got my time-line messed up. A lot of the stuff in this entry is copied and pasted from my posts at youngsurvival.org and slightly edited for different jargon and the like. Upon reading this entry and the next one, I've decided to leave them both in, because there is a little bit of different perspective in each, a little different wording. The "today" in this entry was the 20th, but the "Wednesday" referred to the 13th, and the "Tuesday" to the 12th. I know it's a bit confusing, but, as I said, I'm going to leave it be. Back to the originally posted entry:

Well this week was eventful!

Today:

I've been having a hard time with depression. These disappointments have taken a simple normal situational depression and made it bigger and more of an issue in and of itself. But for some reason, I don't *feel* like it's another issue – in the sense of 'would I add it to a list of the calamities that have befallen me?', no I wouldn't – so I guess that's a good thing.

I got a call at 8:30 yesterday morning telling me I had an ultrasound at 10. As I was getting ready to go, Dr. C's NP called to tell me that he'd found a sort of replacement for my liquid Morphine break through meds until the factory gets its act together or whatever the issue is. I told him that I was leaving one minute ago for the u/s and would go by the cancer center after that.

The ultrasound wasn't as good as it could be. The tech found I do still have a clot. It's in my collarbone area and is obviously responding to the Warfarin, but, dammit, it's not gone. I can't see the cumadin doc saying that it was okay to go off the Warfarin with that information in front of him. And I guess, sadly, that he would probably be right. However, I'm calling the damn shots. We're not going to be so freaking out about exact numbers this time. I'll get the fingers stuck once a week and we'll try to keep it under control, but I refuse to have panic reactions to deal with. I can't handle that kind of stress; stress is not good for people wanting to not have remissions. Well it's not particularly good for anyone. That annoying little bitch kept saying 'I know' when I was telling her how I felt and such and I just looked her full in the eyes and said 'I don't think you do'. Oh well, I'm glad I had the u/s done prior to that appointment done... hopefully that cuts down on the total number of tears I'll have in that appointment.

Photography really is my best therapy. I get a bad phone call and out comes the camera and I'm looking for a spider to shoot. I'm really starting to feel ownership of my 'new' camera and I love it!

Gods I hate chemo brain. It IS getting better, but still... a friend called me Monday morning and it took me almost 24 hours to remember what the hell our conversation was about!

My readers: has anyone heard about vision being affected by chemo? I feel like mine was. I can't tell if it has improved enough and I need new frames and lenses for my regular lenses and just lenses for my sunglasses. I'm feeling very impatient about this, but don't see the point of getting a prescription that's going to be moot in two months.

Wednesday:

My INR number this morning was 4.7 which certainly was an improvement. The lady was not successful in contacting the doctor that referred me to the Warfarin clinic and the only thing we know for sure about him is that he's not the head of the Warfarin department. I doubt contacting him is going to be fruitful. The head of the clinic is out until next week. I told them I wasn't going to take any more Warfarin until someone resembling an expert was handling this. I told them that somewhere in my file was a note that I was a compliant patient but that I wasn't going to be on this issue if it came right down to it. They asked me about contacting my primary doctor and I said I didn't have a problem with that, that I love her, but I didn't see the point as it wasn't her field; she's a GP. Anyway, they want me to come back again tomorrow and see if yesterday's dose of vitamin K brings down my levels any more and aren't asking me to take anymore Warfarin in the meantime (as if I would). I did cry at this appointment, but at least it wasn't hysterical crying like yesterday and at least that woman didn't try to hug me. Personally I don't like strangers within reaching distance. This whole treatment thing has been one violation of that after another, and yesterday, when I was already so upset, made me want to punch her. I'm totally cool with friends and loved ones being close to me -- I can even be a totally snuggly person -- but I prefer strangers where I can't reach them. I just have a large personal space. It comes from being too sensitive to people. For instance: today while I was waiting to check in at the clinic, a lady came up to the receptionist and handed her a map and said it was to the 'thing tomorrow night'. The receptionist thanked her and the woman left the room. After I was checked in, I leaned closer and said 'you aren't going to that thing the map is for, are you?' She looked really surprised and said 'I made other plans, I totally forgot about it'. I said 'I could just tell. Don't worry, I don't think she could.' And she just laughed sort of nervously. She might have been blushing but it's hard for me to tell when really dark skinned people blush. Okay, end of random digression.

My response to yesterday's blow to my sensibilities was that I wanted to have one day, just *one* flipping day, where I didn't hurt. Usually the baseline meds just cut the pain down to a dull roar except for breakthrough, when it's sharp... then I take the breakthrough meds which put me back down to that dull roar. So I tripled the prescribed dosage of breakthrough meds all day long and actually was pain free (except for a twinge here and there) but it did make me a little loopy (which I *never* get from my current dosages, even if I add a little extra), my coordination suffered (I wouldn't have driven) and it exhausted me. Obviously I can't do that every day. But man I just needed it, one day without pain, for the first time in 8 months.

Tuesday:

Had my INR this morning and on the drive over there I was thinking that my number might have gone down, that maybe I'd need to take just a teensy bit more each week to hit the spot, based on my history. So I get there and the machine says 7.8. I'll remind you my target range is 2-3. I just said 'that can't be right, do it again' she told me that if it again gave me a high reading they would want me to go to the lab and have my vein punctured for the other kind of INR test. So we prick a different finger and it says 8.0. I lost it. I just started crying hysterically. I said 'I don't want to do this anymore. I was told 3-6 months and it's been three months and I want to stop now, I want to stop, I can't do this, I can't do this, I can't do this, I can't do this'. She made me promise to go to the lab for the other test and to go by the pharmacy for some vitamin K, and I did so after I left. She kept putting her hands on mine and hugging me but this was the first time we'd met and I just want to scream 'don't *touch* me! I *hate* you!' but I had enough awareness to know that it wasn't her fault, so I held my tongue and let her be kind. I wanted to break her tiny skinny body into bits. But again, not her fault. I even apologized for freaking out, aren't I

so polite. The lab results came back in about an hour -- I had gone home, the gal called me to tell me -- and they said something like 7.6, which still sucks. She wants to see me tomorrow, for all the good that will do. I was told previously that five days is the least amount of time to process Warfarin's effects on the body. Whatever. I have to wonder, though, what my cancer team would do if I really did refuse to continue this treatment. They can't actually make me. But I know Olav would 'make' me even if it meant going to all the appointments with me again. But this is breaking me people. Cracks are running all through me and something, anything, could shatter me.

How I'm doing' update May 26th, 2009

Not too much happened between the last entry and today, medically speaking. I had a very busy memorial day weekend. Too busy for my taste, but nothing to be done about it, one time opportunities, that sort of thing. We did absolutely nothing Monday to make up for the rest of the weekend.

This morning I was nervous anticipating my appointment with Dr. White. I didn't know what sort of fellow he was, so I didn't know if he would be understanding of why I was so distressed. I actually wrote out a little timeline for the last 11 months that would probably stress someone out just reading it. As it turned out, I didn't show it to him. He was a great guy! And I'm not just saying that because he told me I didn't have to take the Warfarin anymore. Heeheehee. I say that because he carefully explained everything he talked to me about, drawing diagrams and such. Really, the only thing I cared about was that he said that I didn't need to take the Warfarin anymore; the 'clot' the tech saw was, he says, essentially scar tissue, not something that is going to break off and cause me problems. I was so happy to hear the news, though, that I told him I loved him! Hahaha.

With this behind me, I'll have a lot less to worry about schedule-wise. Health-wise, too, I suppose, but honestly as soon as it stopped hurting it became a pain in my ass rather than anything I was concerned about. I'll have racked up 10 appointments for May, but it's entirely possible that I'll only have three in June. Three. Holy Cow that sounds blissful. Of course, I "get" to be hospitalized again in July, but hey, I can sort of enjoy June, right?

How I'm doing' update June 10th, 2009

I tell you whut, being freed from the Warfarin changed my life. Not in some grand earth shaking way, but nonetheless it did. My depression is definitely lifting. That one-to-two less pill(s) to take, all those appointments I don't have to go to, all that stress I don't have to deal with.

Also lifting my spirits is the date of my exchange surgery coming nearer and nearer.

I have made my own efforts as well, by refusing to dwell on the bad thoughts. For a while I was

allowing myself a few private pity-parties (I hate others feeling sorry for me, but feeling sorry for myself in my own head when nobody's around isn't an absolute no-no... in moderation), because I thought it would help me process my feelings rather than repressing them. Well I think I took it too far. So I put a nix on the pity-parties, just refused to cater to the bad thoughts, and have spent a good deal more time not feeling bad.

Reasons for feeling bad have a connection with the only medical appointment since my last entry. That was with Dr. C, yesterday. On May 4th I mentioned that I had spoken with him about the spot of pain on my shoulder blade. Yesterday we spoke of it again. I told him that I know that it is almost certainly something *other* than bone mets – there are several things it could be – but that not knowing was really bothering me and I'd like to have the scan, so he ordered it. But *then* he brought up something he hadn't mentioned before... I don't know if he didn't know it or just didn't think to look, but he said my alkaline phosphatase (ALP) levels were high which can be an indicator of bone mets. Well *that* was reassuring. (not!) When I got home I tried to find a copy of my most recent labs, but the most recent I could find with the ALP measured was in March, and I can't find any test until back in September that measures that particular thing. This report was 7 pages long, whereas most of them are 2, so I guess it was a more comprehensive test. It would be helpful to know if there was a measurable rise in that number over time or if perhaps that was an aberration, a one-off sort of error. The number in September was well within normal range. The range is 35-115. In September my number was 76. Smack dab in the middle. In March the number was 125. I really really really want to know what it is today. I did a lot of searching in the Internet today about this stuff. I found out that elevated ALP levels can indicate a number of different things, including dietary things. I could not find anything that says whether being 10 units (for lack of a better word) over normal range was a little or a lot. I also researched the symptoms for bone mets and found that I have a couple more, but again, those could easily be explained by very valid other things. I really do vacillate between thinking this is all complete and ridiculous paranoia and thinking that I'm going to get under that bone scan and light up like a Christmas tree. Obviously I hope for the former. The prognosis once you have bone mets is not good at all.

Moving on, though...

A couple of the gals in my chemo group have been saying how sick of all this they are, sick of thinking about it, sick of seeing reminders everywhere... one gal said that in a way this was the worst part, trying to climb out of treatment and find normal. And it got me thinking...

This is sort of like parenting, only without the rewards lol. Each stage or phase has its own challenges.

As parents we have first to deal with constant diapers and wondering what the heck the baby is crying for *this* time. Then they start to be a little more independent and suddenly you have to worry about them falling down, or getting into the garbage or the knife drawer or drawing on your important paperwork. Then the terrible twos when their favorite word is no and tantrums and whining are the name of the game. To jump forward a little, they become teenagers and you have to worry about sex and driving and smoking and drinking. And then they leave the house for college or just to live with someone else...!

Why didn't I mention the first smile, the first laugh, the first I love you, the first time your parenting is praised?

Because none of that applies to cancer. The stages we go through... Fear when we find the lump.

Waiting for the biopsy results. Choosing a treatment. Starting surgery or chemo and then doing the other, depending. Then rads if you have to. Herceptin or tomosifin, or whatever. Scanzxiety. NED. Trying to find 'normal'. Doubts about possible mets symptoms, more scanxieties and more waiting. No, instead of tickles and giggles we get blood tests and infusions. And every step of the way is different but doesn't actually seem to really be easier. Just different, just like I always tell new parents.

I know, that's maybe one of the blackest ways to look at it. I'm having a bit of scanxiety, you see...

But on the whole, I'm doing a *lot* better, emotionally speaking. I'm feeling optimistic. I have things to be scared about, nervous about and paranoid about, but right now I'm still feeling pretty positive.

how I'm doing' update June 12th, 2009

I've done a little more research on the ALP thing and one thing I found out is that the numbers can be affected by narcotics usage. I also went through my lab reports (the ones I have at home, which is only most of them) and found a couple more ALP tests. What it adds up to is that the numbers can totally be explained by my narcotics usage. Again, I'd very much like to see what the number is today, because it would help me to correlate between March and now, knowing what I know about my Morphine intake. On the other hand, maybe the results wouldn't make sense and then I'd just worry more. Anyway I feel a bit more relaxed to know that the numbers could all be due to the enormous amount of Morphine I'm on. Blood tests are so hit and miss as far as indicating cancer anyway, or they'd do it all the time. While perusing my lab results I came across a tumor marker test (there are a few different kinds) ordered by Dr. M right before my mastectomy. According to my MRI at that point I had tumors 'too numerous to count' and yet the results of that test came out at the absolute bottom of the range. The range was 1-5 and my result was " <1 " So much for blood tests!! I mean, really, how much cancer would you have to have to make that number show up?! In the end imaging is pretty reliable, especially the more detailed you get, but for an absolute final answer you need a biopsy. Hands on, so to speak, is the only way for an unquestionable answer. Although it's my understanding that a lot of mets aren't or can't be biopsied. I guess they take the imaging's word for it based on the patient's history, possibly with other kinds of imaging and other symptoms as well.

So anyway, I'm feeling better.

Oh, about number of appointments. I actually had NO appointments the first week of June. None at all. I haven't had a week without appointments since August. I'll be ending up with seven for June, in total. Just to give you a perspective on the lightest month since August, they are: two appointments with my oncologist, one with my therapist (would have been two, but scheduling didn't work out), one Herceptin infusion, one routine follow-up with my cancer surgeon, one bone scan and the pre-op appointment with my reconstructive surgeon's team. From October through February my appointments numbered in the teens. For laughs (or tears) I counted all my appointments from my first panic appointment to the anniversary of that date: **128**. I counted INRs as appointments: they were very short, but they did require at least 40 minutes of driving time etc, etc. And I only counted hospital stays as one appointment, no matter how long or short or what they did to me. I have on my calendar 11 more

appointments this year, but what is not yet on there are any follow-up appointments for the exchange surgery; any additional surgery(s) needed to perfect the exchange; any continued appointments with Dr. C; my twice monthly appointments with Dr. L; my routine follow-ups with Dr. M; or any imaging. Just counting for the rest of 2009 that's 24 more on the very optimistic side.

how I'm doing' update June 18th, 2009

It would be too tiresome to do the play-by-play, so I'll just leave it at: Dr. C's nurse Pat is on vacation and nobody has been following up on scheduling my bone scan but me. Which means I've had to think about it every day which has made something that I've tried hard not to be stressed about into something I can't help but stress out about. If it were just scheduled, I could put it on a shelf in my mind and not think about it. But no. As things stand, the scan is scheduled for the day after Dr. C wants to see me. Ugh. So I'm working on it, but dammit, I shouldn't be the one working on it. If it isn't fixed tomorrow morning, I'm sicking Dr. L on all of them.

So since I've been stressing about all of this, I guess I should admit that I've kind of been downplaying some of this. There's the one spot I've mentioned repeatedly in my right shoulder blade, and if pressed I will hastily and dismissively mention the other places. I don't think anyone has made note of them, so I thought I'd make note of them here. Not that that does my health care team any good. So... right shoulder blade, as mentioned. Also, rib under right boob and I think two separate spots on my spine. At least one, I'm not sure about the other. I can't get my hand there, it's one of those 'can't reach' places. It's just sore. It's extremely hard for me to take a sore back seriously, but my paranoia can't help but remember every instance I've read of people with bone mets who've said that they just thought it was a sore back. I wish I could have been left in peace about this, left to not think about it. It's a terrible thing to contemplate. I'm not spending too much time actively fearing it, but I get these attacks of anxiety that don't come along with words or concepts, but I still know why I'm having them. And any little thing can remind me of the little pains. I can't wait for this damn scan so I can put paranoia in its place.

how I'm doing' update June 19th, 2009

Actually, I *am* going to give you the play-by-play. This is my phone log for trying to get my bone scan scheduled. My appointment with Dr. C was on the 9th, and I let them be until that Friday when I was told they were waiting for insurance approval. Here's the rest of the story:

6/15; no news in my file, they took a msg to have someone call me back. =/

6/16 – no call, nobody told me (I had to call and ask) but appointment for 7/6, changed to it 7/1,

on advice of Outpatient Radiation, told cancer center to pressure it for before 6/30.

6/18 called and found that nothing at all had been done. Pat is on vacation. Pam is covering. Pam said she would call Outpatient Radiation, but she sounded unenthusiastic.

6/19 called the cancer center (because I left home without the OR #) and found that somehow my bone scan was now on the schedule for the 6th. wtf? The lady (she didn't give her name) said that the scan order was tagged as urgent and all I had to do was call OR and tell them that and if they didn't schedule it right, ask for a supervisor. I reminded them that OR had said *they* had to call, but this lady said, no, this would work. Right. So. I got the number, and she nuff the gal says she can't change it, only a supervisor could, I said I was told that and could I talk to a supervisor and she said that the supervisor would need to have that conversation with the cancer center. I wailed "but nobody there will HELP me!" and she agreed to transfer me to her supervisor, but said person was on the phone. Said she'd have her call me back. 20 minutes later, I called back (at this point I have no faith in my calls being returned) and the supervisor managed to get me to the 30th, which I pointed out was still not *before* the 30th. Also it was revealed that I was never scheduled with Dr. C. Lovely. She said she'd talk to the magic person on Monday morning and maybe they could move the date up appropriately. If I don't hear from her by late morning I'll call her. Once I talk to her, I'll call the cancer center and tell them I WILL be seeing Dr. C on the 30th, because he wants to see me then, and figuring out how to make it happen is their problem.

I'm keeping this record so I can tell Dr. C alllll about it. He's never going to let Pat go on vacation again once he sees that nobody else in the office can handle his patients. This is pathetic. I am doing *all* the work here.

how I'm doing' update June 23rd, 2009

The supervisor talked to her "magic person" and got my scan scheduled for this Friday morning, woohoo! And it turned out to be no problem to get the appointment straightened out with Dr. C, though not at the time I had originally had it on my calendar. I may have to scurry to get there from my pre-op appointment, but I'll make it. It might all be moot if the scan comes back with mets... docs tend to call you in right away when you have bad news. So here's hoping it isn't moot! My pain in these areas didn't really worsen appreciably between say January and April so I think the fact that it seems to have worsened over the last few weeks is all in my head. Anyway, I'm still freaked out a bit, but much more relaxed now that I'm not having to stress about getting the dern things scheduled.

I wanted to talk about something a bit tangential. This actually happened several weeks ago, but I remembered it last night when I got queasy and felt so sleepy I could hardly keep my eyes open, yet I still wanted to be able to put my kids to bed rather than go to bed first and have Olav do it. Which I managed, by the way; go me! (and go Compazine!) What happened was that a now ex-friend said I was 'too wrapped up in whatever's going on in [my] life'. I guess he thought that now that I was done with chemo, that I should be totally 100% back to where I was before. I guess it was too much trouble to read my blog and see that chemo was in no way the end of my troubles. I composed an email to him in

a friendly voice trying to catch him up on what else is going on aside from the blog, with a gentle reminder that he could go there to keep up on my health, but I never sent it. In the end I felt like I didn't need to get into any drama with someone who was apparently too wrapped up in *their* own life to think about what might be slowing me down. I know I'm a bit obsessed with all this, but it interferes with my life on a daily basis. I'm trying to start to look forward and move on, but I'm still physically handicapped, still in pain nearly constantly, still chronically fatigued... Chemo is a big deal, but it isn't like a cancer patient is miraculously ready to resume life as it was before the day they are done with it. Especially if there were complications like I've had. This is something that a lot of women at youngsurvival.org complain about. It hadn't really happened to me before, but now it has, and now I know their sadness.

how I'm doing' update June 26th, 2009

Well either way I'd be doing better if the results were in.

I went in at 8 this morning for an IV shot of radioactive sugar. Cancer likes sugar straight in the blood stream there, so it tries to grab it as it zooms through the circulatory system. It's a messy eater and gets radioactive goo all over its face after it eats, and this is how the scans can find the cancer. If any. So that was no biggie at all, the guy was great with a needle and I told him I'd see him in a few hours. A few hours later I was back to the waiting room and had not even got my book open before he was poking his head into the waiting room for me. He had me lie down on this narrow table, trussed me up so my arms and legs wouldn't fall off if I fell asleep and so I'd stay reasonably still, started the machine and I promptly fell asleep. I slept through the whole thing, though I woke several times opening half an eye to see where in the machine I was. Finally I was awakened by him ripping the blankets off of me – brr! I think it took a little less than an hour.

I needed him to show me the way out, but also needed to pee, so I went to the restroom and then back to the scan room and he wasn't there, so I went to the computer and my file was up, but I couldn't make heads nor tails of it. Nor did his demeanor give me any hints as to what had been found. He might have been a bit more subdued, but he wasn't exactly spastic to start out with. And I might have imagined it. Either way it wasn't enough to make me feel like it was significant.

So we came home and I tried to call Pat but she was on the phone, so I left a msg. Then I went to take a nap. She still hadn't called by 4:00, so I got up to call her again and she answered the phone herself that time. She looked in my file and all it said was that I had a report pending. She told me that the nuclear medicine guys usually took their work home on weekends so it should be done Monday morning, and she'd call me then. She clearly understood how hard it is to wait and not know, but she couldn't help me today.

The idea of getting through the weekend not knowing is dreadful. The idea that someone knows, but I can't know for three days, is horrible. I just want to sleep for three days now.

how I'm doing' update June 28th, 2009

Well I've gotten through the largest part of the weekend without freaking out. Or at least not much. A couple a leaky moments, but no hysterics. Not even very heavy Ativan usage and while I took two naps on Friday I only took one yesterday. So not too bad. I slept poorly last night, but that was because I forgot to take my bedtime meds. I slept just well enough to not realize why I wasn't sleeping well. When I realized it at 7:30, I gave up. I only took the absolutely necessary med, not the sleepy pill, though! So a bit more nappage might be in order today.

I sure do hope Pat was right and that the results will have been entered over the weekend. While I'm sure it would still upset me very much, I have tried to mentally prepare myself for the possibility that they won't be ready until Tuesday. The more I read about bone mets the less I want them in my life, as if I wanted more cancer loose in my body in the first place. Not that I suppose cancer to an organ would be preferable. Goodness no!

But when (trying to say "when" not "if") that scan comes out clear, I think I'm going to need a serious massage therapist. The way to manage to afford that (in other word, with insurance) is to find the physical therapist that believes that massage is what constitutes therapy. I had one like that after a car accident in '95. I had to stop going there because the location was so inconvenient, and I was disappointed to find that normal PT's make you want to do stretches and exercises and stuff! Heehee

Well soon enough I'll be through my exchange surgery and I can start PT then. The limitations placed on the movement and strength of my right arm is my first guess as the culprit to all the mysterious pains. I'm off balance. Once I can get my limbs equally strong and equally used again, I'll feel a lot better.

Gosh, so many things are going to get better after my exchange! Less than two weeks, now, I can hardly believe it. I wouldn't say that time flew, as silly people said it would. But it has passed, and here we are.

Here's my little plan. Exchange surgery. Six weeks of recovery. Then PT, hopefully as part of a treatment-recovery exercise program but if not, then that program will follow. There I'll get my balance back, some or all of the pain gone, and an idea of my new strengths and limitations (which I hope won't be too different from the old ones, but it's going to take work). After that I will contact this group that sets breast cancer survivors up with free yoga. In perpetuity, is my understanding. I've been wanting to do yoga for more than a year now, but cancer got in my way. Cancer will be getting out of my way so I can do yoga. Nice little plan, no?

how I'm doing' update June 29th, 2009

Pat called me at 7:58 – talk about first thing in the morning – and told me... **THE SCAN IS CLEAR!!!** Once off the phone with her I started sobbing with relief.

No need to say any more this morning. Tomorrow I see the surgery team for my exchange and Dr. C.

how I'm doing' update June 30th, 2009

I got to enjoy bliss for about 26.5 hours.

Then came my pre-op appointment. Dr. W was running late, so his nurse went through all the paper work with me and then I said “To kill some time, why don't you show me the kind of implant he's planning on using on me?” She gave me a sort of blank stare as if I were nuts and said “He only uses saline.” My eyes just about popped out of my head. How had I missed this? Olav was with me, and HE didn't remember anything of the sort either. I said, “Well that isn't going to work,” and started to cry “I guess we're done here”. And she said “Dr. S does silicon”. And she walked out of the room. I thought she was going to talk to him, or see when he could talk to me or check his schedule or something, but whatever, I just broke down sobbing. This man that I have built up all this trust with, who I had decided I didn't want anyone else touching my foobs, etc, I was going to have to replace 10 days before my supposed surgery date. Who knows when my surgery is going to be? It's going to be with someone who is basically a stranger to me, etc.... I wanted to have a tantrum so badly. I don't know when the last time I so much as threw a pillow on the floor, but I wanted to trash the place. I actually had Olav move the little rolling table away from me, so I wouldn't pick up anything on it and throw it. I just cried and cried.

After a while I wondered what had happened to the nurse. So I stuck my head out of the door and said. “Are you coming back or are you just waiting for us to leave?” She looked surprised and said. “Well the doctor is coming and I thought you might want to talk to him.” I said, “I don't see the point,” and went back and got my purse and coffee cup and Olav and we left. On our way out she suggested I make an appointment with Dr. S, and I said I'd phone. I didn't say, but I was on my way to see Dr. C, and I wanted to see if he would recommend Dr. S or someone else.

Dr. C gave Dr. S the thumbs up so I called for an appointment with Dr. S; it's on the 10th, the day I would have had my surgery.

I'm absolutely heartbroken that I have to wait longer for my exchange.

My appointment with Dr. C went much better. He showed me the images from the bone scan, explaining each bit. Certainly a relief. We discussed again how the pain likely had my expander issues as the cause, and would improve once the exchange had occurred.

That was a good segue into how his nurse had given me a smaller refill of norco on Friday than I've

been getting. She was concerned about the Tylenol intake. Dr. C figures that since the amount of norco/Tylenol has increased slowly over time my liver has had time to learn to cope with it, and he's not too worried about it. He said it's fine if I want to keep on the same painkiller regimen that I'm already on. He offered to increase the Morphine again in an effort to need less norco, but I really don't want to do that... plus I really am not sure how well the Morphine is working for me anyway. I see no point in getting more addicted to something that isn't helping me all that much. I didn't mention that part because I didn't want to get him started on a discussion about how difficult it would be to change to another drug, since I have no intention of putting myself through that. And hopefully, despite yet another fucking delay in my exchange surgery, this won't be going on too much longer.

Most of the rest of the talk was about what we can expect over the next year or so. I'm going back to see him in about 6 weeks which we all sincerely hope will be *after* the exchange surgery.

how I'm doing' update July 6th, 2009

This is not a 'whatever' journal, it's about my health, so I won't go into *why* my holiday weekend had so much drama and stress in it, but in a way it might have actually done me a favor. It was so over the top (but not related to my cancer at all) that it practically paralyzed me. I couldn't think about anything else, I couldn't really do anything, focus on anything. Realizing that this was not going to work for me, I meditated on it, for lack of a better word. I'm not much of a meditator – never really picked up the knack of it – but I actually pulled something really good out of this one. I told myself – and more importantly I listened to myself – that any of 'yesterday's' problems were over and any future problems hadn't happened yet and I would deal with them when they happened and then *they* would be done too! It didn't relax me 100%, but probably about 95%. And I've been hanging on to it. When I feel myself starting to hang on to something that's already past or worrying about what's coming next, I take a few breaths and remind myself of these things. It really is working! It's a little trickier when I think of something like my exchange surgery issue... but I tell myself 'there is nothing I can do about this right now, let it go. Deal with it when there *is* something I can do about it.' I'm sure this isn't a complete cure-all for stress, but it's really helped me and I'm feeling tremendously better for it. Really really. =)

how I'm doing' update July 10th, 2009

Well, I was supposed to have my exchange today, as we all know, but instead I met with my new reconstructive surgeon, Dr. S. Dr. C had warned me that some people didn't like his office demeanor, but said that his work was good, but I didn't find anything wrong with him. He seemed very nice! We talked about why I wanted silicone and he did a physical examination. Then he said they'd have to re-run the insurance approval and then we could schedule the surgery and another pre-op. I don't see why it should take very long to get approval for something that was already approved, so I imagine I'll be scheduled shortly. Olav completely tripped Dr. S's circuits by telling him that he was trying to persuade me to get smilies in place of nipple tattoos. He just now said “putting the fun back in the fun-bags”

hahahahaha!

He described the procedure and said I'd be going home the same day as the surgery – which scares me a little, but I hate the hospital, so I'm good with that. He also said there would be no drains! WOOHOO! I am fearing this less and less....

Today while we were in the waiting room Cassie said "I'm afraid about you dying" and I said "the doctors have looked and can't find any cancer in me; there's no reason right now to think I won't live as long as any other mommy". I can't lie to my kids and promise I'll live to be 80, I can't promise that, who can? But it felt good to be able to say that much.

I can't find the quote, but I once read: you become a cancer survivor the day you get your diagnosis and decide to live. Since breast cancer -- like many cancers -- can't ever really be said to be 'cured', but only "no evidence of disease", that definition of survivorhood has the most resonance for me of any I've heard. Thus, today is my first Cancerversary. A year ago today I got the bad news. And I'm still kicking.

I saw Dr. L yesterday and he was terribly impressed by my epiphany about managing my stress. Really, so am I. Not so much that I had it, it's hardly original, but because it worked and is *still* working.

Life is actually pretty good right now.

how I'm doing' update July 17th, 2009

Well I had quite the emotional rollercoaster around 1:30 today!

I called to see how the insurance and scheduling thing was going for the exchange, first time talking with this gal. She said she hadn't gotten the message from the other gal (whom I called on Wednesday mistakenly thinking she did all the scheduling for that office), which I am slightly skeptical about, especially based on how things went after that. Then she said that she said the insurance wasn't going to be a problem, she was going to submit it today. I about choked and said something about why wasn't it done a week ago (that being when I had the appointment and, I'm quite sure, when she was given the task) while she went on to say that the doc was going on vacation for the first two weeks of August. I went from zero to tears with no stops on the way, which totally shocked her. I apologized for my sobbing, explaining that I had just been delayed so many times already. I'm not even sure what else was said in that call except that she told me she wouldn't delay my surgery. After I got off the phone it hit me that it was possible with the doc going out of town that the surgery might not be before September at this rate and that wouldn't do, as our insurance is changing for the worse on September 1st. So I called her back -- without crying -- and told her that it was really important to me to have the surgery scheduled before the end of August, and why. She put me on hold for quite some time and then got back on and said that there had been a cancellation for July 27th, but she'd have to ask the doc if he was okay to put me in that slot, so she'd call me back in 15-20 minutes. It probably wasn't more than 15, and she asked me if I was free the 27th and I told her I didn't care whether I was or not, put me down! hahaha In point of fact I actually do have a scheduling conflict -- Herceptin -- but that will just have to change. I was quite serious that I didn't care what was on my calendar. So she put me down for surgery

and scheduled the pre-op for next week and the follow-up visit for the day after the surgery. Wham bam thank you ma'am! Kat's famous combo of pathetic and sincere works again! heehee

how I'm doing' update July 21st, 2009

I had my pre-op appointment today. Dejavu. Well, not really, because this one went a bit more smoothly and didn't end in sobbing. Not completely smoothly... the scheduling gal – whom I'm less impressed with all the time – didn't actually get my pre-op appointment into the calendar so they were very surprised to see me there this morning! But they ran with it and we weren't there much longer than we would have been if it had been done right. I did, however, make sure that the surgery and the follow up were on the calendars as they should be. They were, thank goodness. Whew! *That* was scary! But the rest of it was paperwork, making sure we were all on the same page with what was going to happen and that I understood the risks involved in the procedure, signing things to that effect, that sort of thing. I totally forgot to ask how long it would be until I could drive, but a little research says 'about a week'. The whole thing sounds considerably less traumatic than the mastectomy, not least because it's outpatient. Merely being able to discard the fear of the hospital itself is a relaxing thing! I'm still nervous, but I can't *wait* for it to be over with. The resident who works with the doc (I would have seen the doc himself, but he was a tad busy seeing as how I wasn't on the schedule!) told me that all of these things would be gone over with me the night before the surgery (actually probably the Friday before, since my surgery is on a Monday), again when I got to the hospital and yet again shortly before the procedure itself. Somehow both maddening and reassuring. That time between waking up on the day of surgery and being put under is the worst. Too much nervous excitement. But still... can't wait!

Been sleeping quite poorly for a few days. While I'm not consciously worrying about all this stuff I have no trouble swallowing the idea that I am worrying about it in the back of my mind. Going to try more drastic measures (meaning up my sleepy drugs) tonight to see if that helps. Don't need to go out of my tree right before surgery just because I'm not sleeping well! Usually a “hard re-set” does it for me and I don't need a second night of higher dosages.

I had to reschedule my next Herceptin for this. It, too, was supposed to be Monday, but I knew which one would be easier to reschedule!! So now that will be on Wednesday morning. Too bad they can't just drip it in while I'm under the knife. That would be convenient... heehee

My friends want to throw me a 'new boobies' party after the surgery. A few weeks after the surgery of course. I think it's a funny idea, and I'm for it. If nothing else it will point out that we're more than ready to get back in the social swing of things... a point we've been trying to make for a few months now, I might add. Well, whatever it takes, I guess! Still, a fun and funny idea.

Pre-Surgery how I'm doing' update July 24th, 2009

Much to my relief, I did indeed get the call with the time of my surgery this afternoon. After that business with the pre-op not being on the schedule, I couldn't quite shake the worry. Sadly it's at 2:00 in the afternoon, which means I'm going to be *starving* once the anesthesia nausea wears off. 8:00 A.M. would have been perfect, but I'd have taken 6:00 A.M. over 2:00! However, I'm just grateful to be on the flipping schedule at all. I managed to not catch, during the pre-op, that the procedure is not being done in the hospital, but in a surgery center elsewhere on the UCD campus. I've had outpatient surgery in the main hospital twice, so I wasn't expecting that. Oh well, as long as they DO it, I don't care if it's in a damn McDonald's. Well, maybe, but I think my point is made.

Having made my point that I'm eager, anxious, even mayhap rabid about getting this surgery accomplished, I have to admit that I'm also nervous on a number of fronts, no pun intended. I'm only a little nervous about the very slight risk of death. Likewise the much greater risk of infection, at least immediately; somewhat more so further down the road, though I can't say why. So, in my typical rambling fashion, I shall commence to babble about what actually *is* making me nervous.

Not the main issue, but I am somewhat concerned about the pain management. I'm surprised I didn't mention this the other day, but when the resident looked at my current pain medications he decided he couldn't give me any more and they would be sufficient. I think that's totally cockbrained. I gave myself a sore thumb playing Mario Kart today through all that Morphine and a hefty dose of norco taken because my pain levels are high today. And surgery, methinks, will be a bit more painful than a video game. Just a guess. I put in a call to Dr. C's office today to tell them about this, um, *interesting* idea of theirs, and said I was going to give it a go, but that they might be hearing from me. I met with Dr. L yesterday and he thinks having Dr. C manage the pain meds is probably a good idea too, since he's the one that is familiar with my med history, etc. I'm just glad the surgery isn't on a Friday where I'd be high and dry over the weekend, or at least be made to jump through a lot of hoops – possibly even in the form of going to the ER – to get help.

My main concern is for the mental and emotional transition to the squishies. It's not like I like the expanders, don't get me wrong. I hate them! But I've been waiting for sooooo long (and been in pain for every day of it) and while I don't like the way I look, I have sort of (and I mean “sort of” literally, not as an introduction to the idea) gotten used to the way I look with them in. The implants are going to be different, which is a *good* thing, but it's something, well, *different!* Also it can take up to four months or even more (but four is pretty sufficient) for the implants to settle into their final place, shape and feel. In so many ways it's going to be a great thing, but I'm still a bit scared. What if I don't like them any better? I comfort myself by saying that they'll be tremendously more comfortable at least. And then there's the matter of the scar healing starting all over again. Boy you can sure tell the difference between incisions closed by a plastic surgeon and ones not, but time helps a whole lot as well. Not too huge a deal, the scars don't show in a swim suit, they're actually even hard for *me* to see without a mirror. And I'm nervous about further loss of sensation. I've gotten back more sensation than I expected to by this time, though I still want a lot more, and I don't want to lose any that I've regained.

Also on my mind is the recovery period. Some pain, though I'm not expecting it to be too bad or last too long (this relative to the mastectomy). Some weakness. And a general prohibition from certain things like lifting anything heavy or reaching above my head. I have been handicapped since November when Dr.Dumbass punctured my right expander and this will just make everything worse, though not by much. More than that it will be an inconvenience, not only for me, but for Olav, because I won't be able to do most of the chores that are my job for a little while. Again, none of this will be as extreme as it was for the mastectomy.

So there's all that... In no way does any of this mean that I don't want the surgery. I want it very very very much! It's just that it's not a simple thing.

Recovering from cancer is not a simple thing, not any part of it. It's not just “get chemo and get on with your life” (and “get new boobs” for breast cancer patients). There's so much more going on in the heads of survivors. And it doesn't boil down to a few easy words to say to a stranger or even a close friend... it's a long journey to “well” and “normal”. But I've got my hiking boots on, and I'm on my way.

Post-Surgery 'How I'm doing' update July 27th, 2009

I'm writing this from the living room recliner, a place I expect to spend a great deal of time in over the next few days, recovering from surgery. At this precise moment, 8:40 P.M. I am really really out of it and probably not up to the task. So for now I'll say that I survived -- obviously -- and am hopeful. That sentence took an hour to write from beginning to end. That one threatened to; I'm just really out of it. Not on anything unusual pain-wise and that story is for a more awake time. It's just that general anesthesia does that to you. Can't focus on anything for very long, fall asleep at the drop of a hat. At least today's mini-dreams have been pleasant and amusing as opposed to some days, when they are obnoxious and/or depressing. So, yeah, I'm thinking this is about it for right now and I'll fill in the play-by-play when I can be counted on to be able to finish a sentence in less than half an hour.

Post-Surgery 'How I'm doing' update July 28th, 2009

I was so out of it last night that I only just now posted the previous entry to the web. D'oh! I thought, though, that I'd get it out there now, while I started on the play-by-play. And then I'll probably write more again after my follow-up appointment, though presumably there will be less to tell about that.

Since the surgery was at 2:00 we took our time waking up yesterday... me with no coffee. I think the nurse said I could have coffee as long as I didn't put any dairy in it... but I no longer care for black coffee, so I declined. Then, about two hours before we were to leave, we went to the park to take a few pix for our photo contest next week (not this week, for which I currently have maybe one picture?). The theme was a stupid one -- set your timer on your camera and then run away from the camera so it takes a picture of you running away -- but I might not be that able to run (or rollerskate, as I opted to do in one of the pix) by next Wednesday. What dedication to do that two hours before I was supposed to be at the Surgery Center!! heehee.

Just before we left, I had Olav take a couple of my foobs in their last day with the expanders.

We walked in the door of the surgery center at, I believe, 2:01. They were, apparently, already getting anxious for our arrival, but then didn't seem to be scurrying to get me going. I suppose it was more like three that they rolled me away. Three people – a nurse, a doctor and the anesthesiologist – came and asked me the same questions about when did I last eat, do I have heart disease, that sort of thing. I fudged a little bit because I had misremembered that I wasn't supposed to drink any water after noon, so I said I had only had a couple of sips, but it was HOT yesterday and in any case, I have something to drink by my side 24/7, my body would NOT be pleased if I told it it wasn't getting any liquids for 2 hours. Also I made a mid-night – well 3 AM – snack of an ice-cream bar and I didn't tell them that either, as that was 12 hours before surgery and they say the same thing to people having surgery at 8:00.

Getting the IV in was not too bad, because the nurse pricked me with some numbing injection that didn't hurt as much as an IV placement. It worked fast and well; I didn't feel the IV go in at all. They put it in my hand, which I would not have allowed for anything but outpatient.

Eventually they gave me the relaxy stuff they give you preparatory to the real anesthesia. They had to give it to me twice as I felt nothing different after the first try. Damn drug tolerance. I'd even taken 3 Ativan over the last 3 hours, too!

Then they finally wheeled me off. That second shot had done the job because I don't remember what the OR room looked like or anything. Well, I remember the transfer between beds, but that's all. Olav says I was under about two and a half hours.

I was definitely on the grumpy side when I woke up. My throat hurt from the tube they stuck down it during surgery and they had an oxygen mask on me and they were asking me questions about my surgery pain. It was damn hard to answer loudly enough for them hear me under those circumstances! I demanded they get Olav for me. And they tilted the bed up for me and took the damn mask off and I got some IV pain meds and stopped feeling so grumpy. Still, I really wanted something to drink, but they were not having that, in case I threw up, but I wasn't feeling queasy. (the resident at my pre-op had prescribed me an anti-nausea patch to stick behind my ear – either it worked or something they gave me intravenously helped.) They got ice chips and Olav fed them to me. Hardly adequate, but an improvement.

I couldn't wait to get out of there; my general reaction to being in a hospital, even if it *is* an outpatient hospital. Eventually I was allowed to dress and leave. Well, they wheeled me out, which probably wasn't too bad an idea, since I was still pretty out of it. And home we went.

The release instructions said to start me off on clear broth to see if I could hold it down before moving on to more solid foods. Since I wasn't remotely queasy, I compromised and had chicken and rice soup... and mostly ate the rice and veggies, spilling some of the broth on myself and just not being interested in slurping down the broth in the bowl after I'd eaten the actual food. Later it was back to the irresistible ice-cream bars. I'll be kind of glad when they're all eaten; I can't be eating that many calories *every day!* Heehee

Oh yes, the pain issue... the surgery center people played along with the dumbass idea that I already had enough painkillers, as if surgery might not be a bit more painful still. I take a boatload of Morphine daily and norco is one of my breakthrough meds ordinarily, but at the moment I'm taking the norco on a schedule. With this kind of injury, it works tremendously better that way than to try to take it in response to a spike in pain. I'm still tossing around the idea of calling Dr. C for short term additional

help. The pain is so much less than with the mastectomy that I may actually beat this without anything else if you don't count me taking a greater number of norco at a time. Which my doc might.

My bandage this time is, I think, what my bandage was supposed to be last time. They were/are both halter bra type designs but whereas the previous one had just hung loose on me as if its only function were to partially conceal my scars, this one is quite snug and I can't remotely peek or even had a feeling for the size and shape I am now! We are supposed to go buy me a special kind of sports bra to wear to keep the jostling down while the healing continues... we have to do it today on the way to see Dr. S in case he cuts the bandage off – which I think is part of the point of the appointment – though I know my earlier bandages were on for nearly a week. An excruciatingly itchy week. This one is just starting to tickle me, but knows how it would be tomorrow? Oh we'll find out at the post-op follow up this afternoon.

I also really want a copy of the surgery transcription, but I doubt it's ready yet. Probably tomorrow, because I'm sure the folks who do the transcriptions didn't get it until this morning. I have Herceptin then, so maybe I can get a print-out then. They have access to my whole file from there.

Later that same day:

The doc took off my bandage – which I appreciated – and told me not to soak the area (like swimming or hot-tubbing) but do anything else I felt up to doing; let my body tell me what to do. Sounds fair enough. Interesting to me was that they didn't need to reopen the whole mastectomy incision. I'm going to have Olav take another picture to compare with the picture I had him take yesterday morning to see how different they look. At the moment they don't look a whole lot different to me, but some. And they are almost as hard. But it will be weeks before they are in their final resting place and up to four months before we can be sure that it's time to say yes or no to revisions. I sort of blew off the topic of pain to them because I knew they didn't have anything useful to say and I'm hanging in there with the meds I have after all. Yeah I'm in more pain and no I don't like it, but it's not intolerable and is actually noticeably a little improved already.

They had me get a front open bra with no underwire – not an easy task in my size apparently! That sort of thing seems to be relegated to the 40d and up sizes, which I am not. But we found one which I can wear if I absolutely have to, but I don't think I'll be running any marathons for the next few days, so I intend to be braless around the house, at any rate. I intend to find out how important it is to wear a bra at all and if it is ever okay to wear an underwire bra with implants, because if I have to go around wearing a bra I'm going to have to do better than the one I got today! I'd like to be able to wear my old bras, but they have underwires. Oh well, research to do during my convalescence.

I guess that's about it!

Post-Surgery 'How I'm doing' update July 29th, 2009

It has been brought to my attention that maybe my anticipation of this particular surgery has been going on so long that I just assumed everyone knew what it was exactly and I might have used some verbal

shorthand. So for just a little background....

Back when I had my bilateral mastectomy in September, my cancer surgeon (Dr. M) was there to take the cancer out of me and at the same time a reconstructive surgeon (Dr. W, at the time) put in tissue expanders. From October through November Dr. W gradually filled the tissue expanders with saline to stretch my skin so that it would fit around a normal implant that would approximate the size I was before the mastectomy. Once fully expanded, one can make the switch from expanders to implants, but I had to wait for two things in theory and more in reality. First I had to wait until I was done with chemo, because you just don't do surgery during chemo unless it's an emergency. Second, plastic surgeons like to give the area time to get used to that size before they cut you open and put in the real implant. Additionally, of course, I had that seroma issue, and Dr. W wasn't going to operate on me until that was resolved. It really looked like we might come close to the original time to do the "exchange surgery" as it's called because the seroma wasn't needing to be drained any more, but then I got the blood clot and had to wait out my time on blood thinners before going under the knife again. Then Dr. W had this conference to schedule around. When he got back, and only then, did we all discover we weren't on the same page as far as the *kind* of implant I wanted and the last delay went into place as I switched doctors and waited to get onto *his* surgery schedule.

So that's what this is, I've gotten those terrible expanders out of me and have my implants. It's funny, I always felt like the expanders were invaders or at least unwelcome houseguests, but the implants are *mine*. I feel ownership of them and protective of them. I don't look much different yet because of swelling and things not falling into place yet and those things will take weeks to resolve, but I feel connected to them like I never did to the expanders.

On a totally different note, I got a call from Dr. S today saying that the seroma he sent to the lab from my surgery had bacteria in it so he's putting me on antibiotics for a week and they'll be doing further tests on the bacteria to see if the med he's prescribing is the best one; if not it will be changed. Obviously I don't want an infection there right now. On the other hand, I've probably been walking around with it for several months. I find that slightly amusing and quite irritating all at once. It always did puzzle me that the docs didn't do more to figure out why I was in so much pain, and I'm betting this is a big part of it. Oh well, still kicking here, and possibly this business means I'll be returning to no pain faster than I'd even hoped. Of course, it also means *more effing pills* for at least a week*. I bet you could fill our hot tub with all the pills I've taken throughout this. Well at least the bathtub!!

*A glance at the bottle reveals that it is a 10 day course. * sigh *

Post-Surgery 'How I'm doing' update July 30th, 2009

Healing is going great so far. The infection thing is a drag, but I don't feel sick. I'm just bummed about the 6 additional pills I'm taking (four are antibiotics and 2 are acidophilus, which stops the antibiotics from visiting various horrible side effects on me) on top of the greater number of painkillers I'm taking at the moment. Other than that, I am starting to lower my amount of painkiller already. I'm still not healed enough for a nice big hug, though, and until I can be, I figure I can mostly coddle myself.

I am still feeling wondrously pleased at my feeling of ownership of my implants. I always knew I'd be glad to be rid of the hated expanders, but I didn't at all expect to actually feel a wee bit of fondness towards my implants. Which is not to say that if they can't produce the result I want I won't feel free to revise them out of the picture. I want the best outcome I can get, since I have to go through this.

Post-Surgery 'How I'm doing' update August 6th, 2009

I'm pretty much mostly well at the moment.

On the down side is mainly anxiety. The stupid doctor who was supposed to call me Tuesday with the culture results didn't. I called yesterday to follow up on that and he's not at my doc's office anymore this week, but the nurse said she'd pass on my message to someone who could get my answer. But nobody has called me yet. So I *still* don't know if I've been taking the right antibiotics for the last nine days. What I *do* know is that the right side is still swollen and hard whereas the left side is nice and squishy. The right side is also giving me pain in the same old area... but! It's not as bad because I don't have that horrible hard unnaturally shaped expander in there. So, less painful, but more scary. I sooooo don't want my body to decide that my implant is the problem and reject it. I can't begin to emphasize that sufficiently. So I'm a buzzing giant ball of anxiety, and it's immensely uncomfortable. Just when I run out of Ativan! So now I have to hope my doc calls me back tomorrow or this is going to be a miserable weekend.

On the plus side we have a few things. The pain is really very minimal at this point. I mean, I'm still taking all that Morphine, but honestly I don't think it's killing any pain. Really. I've been taking it long enough that I just doubt it. And if I can have headaches like I do (from the anxiety) through that, then that headache would just plain kill me without it. So I think it just isn't doing anything but waiting to make me miserable when I try to stop taking it. But I digress. Very little pain relative to pre-surgery or the first couple of days after. And, the very best part of all, I can sleep on both sides again!! I think I might even be able to sleep on my tummy soon, we'll see. I'm just happy for the improvements so far. To sleep comfortably on my right side is soooooo awesome. Also, I can reach across my body for the first time in 9 months as well. Basically it adds up to a lot more comfort and I'm not knocking that. So you can see how answering "how are you?" is not so easy right now.

Post-Surgery 'How I'm doing' update August 9th, 2009

Turns out that doc *did* call me, but I missed the call entirely. It came a day and a half after I was expecting it and I didn't find the VM until Friday afternoon. I had been stressing out so much because Dr. S had been under the impression that the bacteria in me was some tough cookie that was very resistant to most antibiotics out there, and that I might have to take yet another kind when they figured out exactly what we were looking at. Turns out, though, that the bacteria in there was a total pushover susceptible to almost every antibiotic in the book, so I just had to finish the pills I'd already been given

and worry no more. Whew!

Also Friday I got the second worst migraine of my life, it was just brutal. So I put in a second call to my GP and while the receptionist was taking down the somewhat complicated message, she returned my call, so I switched over and talked to her. Turns out that she hates my migraine medicine, because it has a reputation for causing rebound migraines. Well, it's not done that to *me* in the 10 years I've been using it, and it's the only migraine medicine I've tried that works. However, we came to an agreement that I would try the medicine *she* liked and she would, in turn, prescribe some of the stuff *I* like in case this other stuff didn't work for me. Except she didn't. My migraine eventually went away, some time around Saturday evening, but whether that was from taking more and more of the medicine or just from the passage of time I couldn't say. The stuff gave me about 1000 hot flashes though, so I'm no fan. Needed a fan, maybe.... And *then* she does some bizarre 180 about my Ativan. She's been prescribing it for a year and all of a sudden is "concerned that it's going to lose it's efficacy" if I take it daily and that I might have an anxiety disorder. I don't think that it's all that likely that it's going to poop out on me after all this time and anxiety disorders are pretty much defined by there being nothing specific or reasonable to be anxious about. I think I have had some extremely valid things to be stressed about about over the last year and it ain't over yet. So she's cutting herself off as my supplier. It was plain weird, though, I tell you what. And rather offensive on a number of levels. It's not like I've ever asked for an early refill or an increase in dosage. Meh, whatever. But it's made me sadly consider that I might want a different GP. Erratic and uncompassionate behavior is not something I want in a doctor. Not to mention the cruelty of not prescribing the Fioricet like she said she would, leaving me to the mercy of hot-flash-apolooza. Wtf was that about? Up until I got to the pharmacy I thought we'd had a civilized agreement, but apparently she was just tricking me.

Niiiiice.

On the better news front, I stopped taking the norco as of Friday. I'm just not in enough pain to need to. Just the occasional twinge or moment of tenderness. I'm still taking the Morphine because I can't stop that without being under a doctor's supervision. That program will start Tuesday, I believe, when I have my appointment with Dr. C. I honestly don't believe it's doing a damn thing for me, but that doesn't mean my body isn't attached to it. Hm... I wonder if that's another valid thing to be stressed about about, doc? Jesus tap-dancing Christ on a cracker.

Oh, another thing about my doc's crack-brained idea of me having an anxiety disorder and suggestion that I get on a med to prevent anxiety? She admitted to me in our first meeting that she doesn't know jack about bipolar and that sure shows it. You don't go messing with a bipolar's psych med cocktail unless something is *really really* wrong. Adding a new drug could make things *worse*. What I need, and *all* I need, is to get out the other side of this, and I'll be fine. I spent 18 months as a psychiatric guinea pig, trying a list of drugs as long as my arm to find the right combination to make me functional. Not too up, not too down, with no intolerable side-effects. I have no intentions of messing with that just because I'm stressed out. That's monumentally stupid and she can be stupid like that if she wants, but I'm not gonna play dat. Nope.

So to sum up, I'm less stressed now that I don't have to worry about the infection, but I'd feel a lot better if the right side would calm down and match the left side. And the pain is as good as gone, especially relative to the last 10 months. Friday was a horrible day and my GP kicked me while I was down, but that's in the past and it's time to try to be patient with my healing.

Post-Surgery 'How I'm doing' update August 11th, 2009

I saw Dr. C today for a sort of basic “how ya hanging in there” meeting and we discussed many things.

I told him that for all intents and purposes I wasn't in pain any more. We started marking drugs off my list of current medications. THAT was fun! Really! So nice to see that number get smaller. Then we talked about ramping down off of the Morphine, because it's time, at last. I am currently taking 6 30 mg pills a day. The idea is to drop a pill out every three or four days, but to understand that when I start getting down to the end there I might want to stretch the intervals a little more if I'm having troubles. I failed to ask what form those troubles might take. He said there's no way to predict how it will go, I might have no problems at all.

Then I told Dr. C about my GP's strange trip-out over the Ativan and he said “Oh good grief” and told me I'd be getting my Ativan from him from now on. And that was that. He muttered to himself “Oh Bernadette” and said more loudly “she must have been having a bad day.”

At my next Herceptin, he's going to have blood drawn for my vitamin D levels (the latest craze in cancer prevention) and also going to check my hormone levels to see if they are consistent with menopause.

I asked about a certain clinical trial, but it's only for our metastatic sisters, which I thankfully am not one of at this time.

He told me I should be able to go in a hot-tub or immerse my incisions in a bath now if I wish, and then he examined me. He told me that my results were going to be great. Apparently the two most difficult bits to do are a natural looking undercurve of the breast and a symmetrical and natural looking cleavage area. I've got the underneath part, and he thinks the cleavage will be a lock too. I hope so! I see him again in two months. Which will probably be after my last Herceptin. What a concept!

Post-Surgery and Morphine withdrawal 'How I'm doing' update August 26th, 2009

I was supposed to have another post-op with Dr. S on Friday, but that morning I got the news that a dear friend had been killed in a car crash the night before and I didn't think about much else until late that evening. I keep forgetting to reschedule, but I must do that soon. Basically I haven't made a lot of progress in the last couple of weeks. The left side is pretty good... it could be squishier, but it's a heck of a lot more squishy than the expander was! And more the correct shape. The right side is a little less swollen, but still clearly bigger than the left when unclothed and definitely not as squishy. Also, it's still somewhat in my armpit, making sleeping on that side less comfortable. It's much more comfortable than it was when the expander was in there, but improvement is still called for. Pain in that area – other than from a bad sleeping position – is very unusual at this point.

Getting off the Morphine hasn't been toooooo bad. The first three pills were nothing more than a mild nuisance. Side effects were loss of appetite, occasional mild nausea (once intense enough to cause me to almost puke, but I managed to avoid it), insomnia and the resulting fatigue. Losing that fourth pill seemed at first to be more of the same until last night. Then: OW!! Little by little, my whole body started to hurt. Sort of like the achiness you get with a fever, but not on the skin, inside. And worse. I took a long bath and came out not feeling any better. At that point all I wanted to do was escape into sleep. As I was taking my nighty-night pills I realized that since one of them was Morphine, I probably wouldn't be having the pain problem much longer and would be able to sleep with the added sleepy meds. I still slept somewhat restlessly, but it was okay. As I type, the pain is creeping up on me – two+ hours until I can take the next pill. Hopefully tomorrow will be better. At this point I'm not looking forward to going down to one pill. And at that point I think I'm going to ask Dr. C for maybe 5 days of 15s, just so I don't have to go from 30s to nothing. I haven't had any craving for the drug, though. Not even knowing that it would take care of all these problems. I can wait them out, the pills don't interest me, it's not like I ever got a high from them or anything that would call to me like that. Clearly no psychological addiction. Just this illusory pain that feels all too real. I'll live. And after all, there are a lot of withdrawal symptoms that have, at least so far, passed me by.

Post-Surgery and Morphine withdrawal 'How I'm doing' update September 9th, 2009

Well I've been totally slacking and not calling any of my doctors. So I'm stuck at two 30 mg Morphine pills a day. When I eventually call I'll be asking for the 15s. And I still have to have that second post-op with Dr. S. I guess I've been taking a little vacation from receptionists. I really really hate to call those people. But nothing has changed. I'm mostly comfortable and doing okay. Thinking more of the future and the present where the present involves a lot less medical stuff. Today I had what was either my second to last or my third to last Herceptin. I'll be so glad when that's over. Not only because it means the end of my cancer treatment – which deserves a party right there – but because it will mean the end of regular IVs. My veins are fine for blood draws, but not so much for getting that catheter in there, as it turns out. File that under “things I wish I never needed to know”. The only nurse who could do it on the first try retired. So yeah, I'll be more than glad to be done with that. Soon! I meant to get a print out of my last bloodwork when I was there today, but I forgot. Maybe Dr. L can do that for me tomorrow; I don't know if he has access to that part of my records. Not that there will be anything earth shaking in there, I'm just curious.

Yesterday was the anniversary of my mastectomy. Weird. A whole year it's been since I lost my nipples. I tell myself to think of it as a whole year since I sent cancer packing, but it's a little harder since I'm still in treatment...

Post-Surgery and Morphine withdrawal 'How I'm doing' update September 28th, 2009

Nothing much has happened since last time I wrote. I *think* I have my last Herceptin on Wednesday, but I'm not sure. The person who tried to look it up for me may not have been looking in the right place. It will be so exciting to be through with treatment, but sort of annoying that I didn't manage to get off the Morphine yet! Once I get those 15s, it will be a week or so, I think. Not very long, anyway.

Dr. C and I have played a little phone tag over the Morphine dosage size, but at this point it looks like I'll be waiting until Wednesday to talk to him.

I finally did reschedule my appointment with Dr. S, and that's in a couple of weeks. Still lop-sided but it still looks like swelling, so I'm not sure I need to worry about it just yet.

Never did get copies of all those lab reports, but maybe I'll remember on Wednesday.

Post-Surgery and Morphine withdrawal 'How I'm doing' update October 1st, 2009

At some point after I posted the below, Dr. C actually called me and told me that my prescription would be waiting for me in the morning. At that point, I figured that since I'd be down there for my Herceptin the next day I might as well wait. What's one more day? So that's what I did.

Yesterday's Herceptin was *not*, in fact, my last one. I have one more, October 21st. It makes sense to me, though, because I *started* my chemo in mid-October and was told that I would have a year of Herceptin treatments. I forgot *again* to ask for the results of my latest testing. Luckily I did *not* forget to pick up my Morphine prescription or request an Ativan refill. I've been having generalized anxiety attacks that are below the level of a panic attack, but having Ativan around is a good thing. Also they help me sleep. I don't necessarily take them every day, but somehow it always seems to work out that I need the refill on time, give or take a day.

So anyway, I picked up the 15 mg Morphine (MS-Contin) pills and took one as my "morning" dose, wasting no time. I'll do this for two or three days and then switch my night-time dose to 15. As soon as that's all good, I'll drop the morning pill altogether, and so on. Dr. C gave me 20 pills, which will be plenty. I honestly expect this to take only about a week. I have forgotten to take that morning pill for hours once altogether without feeling any ill effects – or for that matter feeling any better for taking it after taking it late. I wouldn't be surprised if the last pill gave me a day or so of discomfort, but I really don't expect any problems before then. I'll just have to live with it. After all I've been through, it's not exactly a big deal. I can't believe I spent so much worry on this. To deploy my favorite quote: "Perspective: Use it or lose it."

Post-Surgery and Morphine withdrawal 'How I'm doing' update October 16th, 2009

This week almost felt like old times: three appointments in one week! In two days, no less!

First was with Dr. C and the first and most time consuming subject was my Morphine withdrawal. I'd taken my last 15mg MS-Contin on Monday night and spent Wednesday afternoon and evening throwing up. Compazine and a little Roxanol (the liquid Morphine) helped a little, but not enough. I had lost track of the date so I didn't realize I could refill my Ativan the next day or I would have tried adding that in the mix as well. Anyway, most unpleasant. All I'd had in terms of side-effects before was pain. Anyway, We discussed nausea management as well as options for the gentlest way to ramp off the Morphine. He said there wasn't anything wrong with my plan of using the Roxanol. With the Roxanol I can take the dosage down to a truly miniscule amount, whereas if I tried something like taking the MS-Contin pills every other day I feel like I'd just be putting off the inevitable because you can't chop those up; they're time release. And while we were on the subject of Ativan, I had him change the prescription he was refilling. He had been refilling the last one my GP had filled, which was a half-month's supply with one refill, causing more trips to the pharmacy for me, and more calls to the doctor for me or the pharmacy one way or the other. So he changed it back to the full month and, I assume, the 6 months of refills, but I guess I'll see when it's time to get the next prescription.

We also discussed various test results. My blood levels as a whole are normal. There are a few things that came out higher or lower, but he says that in the light of the other information in the test they aren't statistically significant. He had also tested my blood for the presence of estrogen, which came out negative. This doesn't literally mean I have no estrogen! But it does mean that my ovaries are not working, so either I'm really in menopause or my ovaries are still stunned. Dr. C said at my age he still wouldn't want to place bets. Personally at this point I don't want to go through menopause again, so I'd be just as happy to be done with it. For the first few months after chemo I felt differently, but that was then.

I also had him test for Vitamin D, because there is a growing amount of research suggesting that an appropriate amount of vitamin D in a woman can help prevent and fight off breast cancer tumors. Apparently it is more or less the rule rather than the exception to be Vitamin D deficient. I, however, am not. I'm on the low end (but not falling off) of "good", but I'm good. I was told I must eat really well, which I don't really think is the case. I mean, I don't eat like shit, but I am certainly not the best eater in the world. But I guess, whatever I'm doing, it has enough Vitamin D!

My last echo-cardiogram came out fine, as I figured since nobody said anything. They'll do another one a couple months after my last Herceptin. More likely it will end up being scheduled after my next appointment with Dr. C which is in three months.

To digress from appointments, let me say that yesterday was much better than Wednesday as far as the withdrawal goes. For one thing, I slept through the night on Tuesday night. For another I didn't have a migraine. I took a Compazine prophylactically at around 2 and another around 8 and only got one wave of really feeling bad around 11, whereupon, with some trepidation due to the late hour, I took a small quantity of Roxanol. I've been exceptionally stupid and clumsy all week, though. In my last update I was obviously speaking too soon. Yeah a lot of the getting off the Morphine *was* easier than I thought, but watch that last step, it's a doozy!

Moving on. I *had* an appointment with Dr. M this morning, but they changed it and somewhere between there and here there was a data drop out (possibly because they never ever call me, but I'm willing to posit a mysterious breakdown of communication lines) and not only was the staff in general in a meeting but the doc himself was in another state. This, of course, I found out while already at the

cancer center. * sigh *

This afternoon I saw Dr. S, quickly. It's weird, I don't get the feeling that he's rushing me, but after he leaves, I always feel like "what just happened there? I had questions, why didn't I think of them? Zoooooom!" Anyway, he said that he thought it was a little odd that the right side was still bigger than the left, but to give it two more months and then look at it again. If at that point it still looks bigger, we can start thinking about revision. We'll be thinking about an ultrasound before that, doc. I want you to know what you're getting into. o_O

I *did* manage to get release forms from both Dr. S and Dr. C for the exercise and physical therapy programs, so now I just have to find the right one and get my time slot and go for it! I know it's going to be hard work, but I'm looking forward to it. Once I've had my PT, I can take golf lessons and do yoga!

Post-Surgery and Morphine withdrawal 'How I'm doing' update October 18th, 2009

I went about 46 hours with no Morphine of any kind and only a little pain and/or nausea. But a great deal of fatigue. Today I got hit with the pain again, so I took a smaller amount of the Roxanol. We'll see how long I go until next time. My plan is to go longer and/or take smaller doses until I'm down to a really teensy dose and then stop that... and probably have a yucky day two or three days later, but then it will be OVER.

Oh, and a random fun fact. I just reflected that I was glad my ability to open a can of soda by myself had returned. Counting my blessings, however small. =)

Morphine withdrawal 'How I'm doing' update October 25th, 2009

Well, I've been lengthening the time between Roxanol doses and making the doses smaller at the same time. Interesting to me was that when I took the smallest dose to that date on Friday after 56 hours to boot, I got a buzz! I'd never gotten a buzz even on that one horrible day that I decided I wanted to be pain free for just one day and really took more medicine than maybe I should have. But even then it just barely did the job, it didn't give me a *buzz*. So I knew I was on the right track. Mind you, getting to 56 hours was no bed of roses, but I never threw up! Just had pain increasing over time and wanted to crawl out of my skin. And occasional minor nausea, but I've been taking Compazine prophylactically when I thought it might be needed and so far so good. So today I stretched it to 60 hours and boy did that hurt. I was watching the clock those last 5 or 6 hours. This time I gave myself a little less than half of what I'd given myself before. It took care of the pain and if I really looked for it I could see the edges of a buzz, but not like last time. I've decided to not take any more after tonight because I know I'll get worse feeling and probably vomit for several hours if not a couple of days when my brain figures out I'm just not giving it any more at all. I want to go through that hell before November 1st,

because I'm participating in NaNoWriMo this year. It's a challenge to try to write a 50 thousand word novel in 30 days. My outline is pretty damn good, I've gotten to know my characters pretty well, my plot holes have been clogged up and paved over. Best thing? Not about cancer. The word "cancer" will not be in my story. I've effing had enough of cancer. And Pink Month, too. Is October over yet? I wish I could just hibernate through the Morphine withdrawal, but somehow I don't think that wish will be granted. Oh well, it is what is is. I needed it when I needed it, and now it's got to go.

Morphine withdrawal 'How I'm doing' update October 29th, 2009

94 hours and I think I've turned the corner but this sucks. Don't get addicted to Morphine if you can avoid it, folks.

Morphine withdrawal 'How I'm doing' update November 2nd, 2009

Okay, I'm pretty much all better now. So now I can tell y'all what it was like. The worst part was that I felt like I wanted to jump out of my skin for almost a week. It started less than 48 hours after the last dose despite me stretching it to 60 hours on Sunday night. And it lasted until Friday night. Ugh. It made sleep really difficult. I only started ramping *down* on my Seroquel last night, actually, and despite the fact that it was 50mg less than the night before it was the first night I slept the night through. The first night in weeks, probably. I didn't have too much nausea this time, I had the runs instead. Which is preferable, actually, but I could still live without it. In addition to this was the pain. Constant annoying phantom pain. I also managed to hurt myself last Monday for real (being clumsy) so I had this real pain that I couldn't do anything for. I have four different strengths of Morphine in the house and can't take *any* of them. I suppose down the road when my body is very very sure we're done with this addiction thing I could take some for pain, but I'm not risking going through withdrawal again for one pill. That would suck so bad.

I was able to go out on Halloween and have a good time, though, which was very fun and just nice to be able to go out and *have* fun at all. I stayed up later than I wanted to, though, and got a late start on my NaNoWriMo writing. As far as that goes, though, I'm now two days ahead (in terms of word count average), so no biggie.

Anyway, feeling like a human being again, praise be.

Oh yeah... minor little detail... on October 21st,

I had my last Herceptin treatment!

I AM DONE!!!!!!

Well, a few cosmetic loose ends, but the cancer part – the important part – is done done de-done done!

Woo!

Random 'How I'm doing' update November 13th, 2009

Okay, so less than a month ago I reported that a blood test had showed my ovaries as shut down. Apparently they were faking. My period came back yesterday. And good grief is it serious about it. I've read many posts at the YSC site from women getting their first period after chemo, all saying how bad it was, so this isn't really a surprise to me. Actually it's still a little shocking, but at least it isn't alarming.

I really had resigned myself to not getting my cycles back. I was feeling like it was fine that I had already gone through menopause. I wasn't happy about being post-menopausal at my age, but I had accepted it. Now I have to readjust my thinking again. So I'm reminding myself that this will delay or at least slow some of the aging of my body. And trying not to think about going through menopause *again*.

Other than that, I'm fairly well. I've been pretty low energy lately, but that's partly due to the writing; it just drains my brain. I'm up to 27,345 words as of this update. => Hey, some people run marathons when cancer doesn't kill them, I'm writing a book. ;)

Random 'How I'm doing' update January 11th, 2010

Wow, two months? But I haven't had a doctor's appointment in all that time – until last week – and nothing really worth mentioning has been going on, health-wise.

I was successful at NaNoWriMo in November, getting to the goal of 50,000 words on the 25th. I wasn't done with the book, though, so I kept writing until December 2nd, for a total of a bit over 67,000 words. All that writing really aggravated an old repetitive stress injury of mine in my left elbow. Its origins are actually in holding books, but apparently typing 2000 or so words a day also bothers it. I'll be talking to my new doctor about it next week.

I was supposed to have that appointment last week, which makes a nice segue into another topic of minor interest. The reason I didn't go was because the appointment was supposed to include a GYN exam and my period came a day early. Third one since they started back up. The second one came 28 days after the first one, almost down to the hour. This one was a day and about 4 hours early. I called and rescheduled the appointment for the end of this week. I also want to mention my lack of migraine

medication when I'm there. This new doctor's first test will be whether or not she reads my file before she meets me. If my lack of nipples surprises her, I will think less of her. * sigh * I hate starting with a new doctor. I hope I like her. She's had really amazing availability, and this concerns me. I wonder what's wrong with her.

But I did make it to one appointment last week, with Dr. S. The disparity in size between the two boobs had not changed. The appointment pretty much consisted of me saying that and that I didn't like it. He replied "I don't like it either." I said, "Good." Then he asked which size I preferred and we had a conversation about size vs shape. I am very happy with the shape of the left one, the smaller one. The right one not so much, but the left one looks small next to it. Dr. S said that the different shape had to do with the amount of breast tissue that was removed from each breast and that neither side would be affected in shape by the size of the implant in it. So I told him to make the smaller one bigger. And I've been second guessing myself ever since. I still have some discomfort on the right side. Nothing like before I got rid of the expanders, but it worries me a little... It just makes me wonder if any of the size and shape going on on the right side could possibly still be swelling even after all this time. It also makes me worried that something isn't right in there. I'm not specifically or particularly worried in a cancer direction, but just in a general "things do go wrong" way. Things have gone wrong for me quite a lot during this whole thing, so I suppose my paranoia is pretty natural. My shrink says so, though I haven't seen him since October.

Anyway, the surgery hasn't even been scheduled yet and I have an appointment with Dr. C on the 21st and I plan to ask for his input.

Now that it's been almost a year since I finished chemo, I'm starting to really get to work on making this blog into a book as I've been encouraged to do. One of the women from my chemo group has undertaken the herculean task of putting together all of our posts and this will, I'm sure, prove to be an invaluable resource to me as I go on.

So I'm working on figuring out how to turn a blog into a useful book, working on editing my NaNoWriMo book (The Sunshine Line) and still pursuing photography. It all keeps my mind occupied and I'm hoping to keep this kind of creativity as part of my daily life.

Random 'How I'm doing' update February 11th, 2010

I failed to mention some things that went on in January out of sheer laziness, I admit it. On the 15th I had my annual Well Woman exam and liked my new doctor fairly well. We didn't talk in depth, but I felt comfortable with her, not rushed or intimidated, so I guess we're off to a good start. I hate having new doctors. Please can I keep this one for a while? I didn't even move to lose the last one, she up and quit doctoring!!

Anyway, my pap came back with abnormal cells so they scheduled me for a colposcopy for today. That word is a major pain to pronounce, so I renamed it the cooter-cam. I even told the doctors who saw me today. They cracked up and thought the idea had some merit. =D Anyway, they did horrible painful

things – okay, on the scale of 1-10 pain it was maybe a 2.8, but it's in a place you just don't ever want to hurt! – to me and showed it all to me on the monitor. They were looking, after painting my cervix with this and that, for white spots. There weren't any. So they did a sort of mini-biopsy, or glorified super-pap or something to send to the labs for further analysis, but it looks like I'll be put on paps every 6 months until I've had clean ones for 2 years or something like that. So, despite the doubling of the number of icky icky pap smears, it was indeed a good news day.

I should have heard by now from Dr. S about scheduling the revision surgery, but I haven't. I haven't bugged them because I'm starting to feel like I want a second opinion. I have no intention of having anyone else do the surgery, but I'd just like for someone uninvolved to verify or amplify on what I've already been told. Reassurance would be nice too, if available. Although I absolutely insist on matching – so the surgery *will* be done – I'm not in a big hurry. I don't think it's going to magically make me like my body again.

On a more positive note, I found more or less by accident that I've got some of my strength/wind back. Even after I thought I'd gotten most of my energy back after chemo, I would just die if hills were involved. Short and sharp or long and gentle, they just killed me. Then Sunday night we walked up a long slow slope and I felt just fine! I was pleased. After all, it's been more than a year.

Had a weird thing the other night. I was introduced thusly, “This is Kat. She's a cancer survivor.” I just looked at him – a guy in my circle, but not someone I'd say I'm super close with – and said, “Was that necessary?” I really was floored. Turns out his new girlfriend went through losing 210 pounds through gastric bypass and considers this experience akin to going through cancer treatment, so my friend was introducing me to her as someone with whom she might have things in common. I must admit that even after I came to understand the why of the introduction I was still a bit nonplussed by the whole situation.

I'm fighting a bit of depression. Very common for this time of year for me, diverse challenges notwithstanding. Other than that I'd say life is pretty good.

Random 'How I'm doing' update April 3rd, 2010

Okay, time to catch up again! Part of the reason this took so long is a complete failure on the part of my medical staff to actually call me. I had to call them.

First, my cooter-cam/biopsy came out with wholly completely normal cells. Whew! Now I have to do something like three consecutive 6 month apart clear paps and then I can go back to yearly.

Nobody ever called me about scheduling my revision surgery. I went and got a second opinion from a non-UCD doctor. Less of a second opinion than just greater information from someone who had nothing invested in it. After meeting with him – really nice guy – I decided that I was going to go with what I told Dr. S and have the smaller side brought up to the larger side.

So *then* I called Dr. S's office to talk to his surgery scheduler, who told me that according to my file

there had been no discussion of a revision surgery, just a note that I should come back in three months. Huh? I told the gal that that simply wasn't what happened, but since we were at about three months go ahead and schedule me. At this point I think I'm going to wait until after my wedding anniversary to actually have the procedure done. Might as well not be healing for that! Probably it's too late to schedule the procedure before then at this point anyway. Personally I doubt this gal's word. For the last surgery she didn't actually call my insurance company in the 9 business days before I got impatient. I really wonder what she is doing with her time... because it doesn't seem to be her job.

I got the flu in February, but was recovered (mostly) just in time to attend the 10th Annual Conference for Young Survivors of Breast Cancer. I got to meet a bunch of my chemo girls, as well as other friends from YSC. Also just an interesting conference. I also had PMS at the time, so I was leaking tears at frequent intervals, both happy and sad tears.

I also had, since I last wrote, a chest x-ray. You don't put implants in the boob-iron, so the casual method is the x-ray. I imagine they go to sonogram after that if anything suspicious shows up. But nothing did. Third cancer-free scan! Woohoo!

Random 'How I'm doing' update April 24th, 2010

Okay, little bit of news, but most of it is no news; in the no-news-is-good-news sense. I had routine follow-up appointments with both Dr. C and Dr. M last week. They essentially were the same. Same questions that if I had answered yes would have been concerning, but there hasn't been anything for even *my* paranoid mind to worry about. Then listen to me breathe, and finally poke and prod me in fifty-lleven places, looking for pain or lumps, neither of which I had. Dr. C told me to come back in four months – up from three -- and Dr. M said 6 months, which is how long it's been since the last time.

More pertinent was my appointment with Dr. S the week before. Basically it was a repeat of the appointment in January in every respect. How he came to write that I was supposed to come back instead of be scheduled for surgery nobody could figure out. Fortunately he got it right this time and his scheduler called me in less than a week. I'll have my revision surgery on May 17th. Hopefully that will be the last time I have to go under the knife. If Dr. S can't get it right on a second try, I might look elsewhere for a doctor, or wait until fall when we are considering changing our insurance to Kaiser. I'd be sad to leave Dr. C, but our current insurance is so freaking expensive and we're sort of hoping I won't really *need* an oncologist for anything more than poking and prodding a few times a year.

Revision 'How I'm doing' update May 17th, 2010

This entry is slightly loopy from the after effects of anesthesia...

Well I'm home from my revision surgery and in a moderate amount of pain. I don't expect it's going to get worse. I sorta lied to the nurse a little so she'd let me go home sooner than the end of time. I know that nurses won't let you go home until your pain is 4 or lower and you're not puking. Well in truth I wasn't the least bit queasy, but I lied about the pain. I know there are very good reasons for these rules/regulations... but understanding them as I do, I also know when I don't need to heed them. Their IV painkillers are very short lasting; I'd get into a stupid loop. And I would get more antsy and irritable as they kept me there, with the boredom and the beeping and the freaking IV in my arm. This would *not* help my pain issues. Stress makes pain worse, 'tis a known fact.

I know the freaking drill with hospitals. I know that the anesthesiologist really only needs to know that my heart and lungs are those of someone very physically active despite my fairly sedentary ways and that I don't have acid reflux. Anything else is information that might be used to determine said health... but I hardly need that, what with my low blood pressure, my blood oxygen level at 100, and a recent echo-cardiogram. It drives me insane to have 10 people asking me the same questions, especially when it's something like "hi, I'm the anesthesiologist and I need to ask you a few questions," and then five minutes later, "hi, I'm the assistant to the anesthesiologist, and I need to ask you a few questions." And they're writing this shit down! Seriously, save me the frustration and read the notes of the first nurse... Or maybe the notes from the pre-op, the first time I answered all those questions. Maddening.

So anyway, Dr. S sent me home in a silly-large bandage – like a bra made of bandage – but considering the location what else could he do? I see him tomorrow morning, and he'll cut off the big bandage then and leave the tape over the incision. I'll also be asking him for Norco instead of Vicodin... I just spaced it when he asked me about painkillers at my pre-op, but the amount of hydrocodone he prescribed is almost like taking nothing. Norco would at least have more hydrocodone in it. Or, if he prefers, I'll take percocet or dilaudid. All I know is that vicodin is inadequate – I took *four* about 45 minutes ago, and can barely feel any difference in the pain level. =(The pain isn't extreme... but it's certainly bad enough to want relief from it!

I'll report back tomorrow after my post-op appointment if anything interesting happens. If not, then when I can tell how the revision went. To say I hope he got it right would be a grievous understatement.

Revision 'How I'm doing' update May 29th, 2010

I didn't report back, but truthfully there wasn't anything interesting about the post-op appointment. Dr. S cut the bandage off and told me I could should limit heavy lifting, but otherwise do anything I felt up to doing, and he gave me a prescription for percocet. The pain was much improved by Thursday and then kinda stopped improving. In fact I still have a bit of annoying discomfort, but not enough to make it make sense to medicate. Mainly because it isn't constant, more than the pain level. If it were constant, I'd probably want something for it.

The surgery side is bigger now. Hopefully it's swelling. If it's not, I'm going to be very unhappy. It's as least as lop-sided as it was before. I'm actually sort of simmering with rage about it, but not letting myself boil over because it *could* be swelling and I *could* end up even. After all, I'm still in pain, so that could very well mean that I'm not at the final size. Some women don't have their final look for several

weeks, even a few months. I tell myself these things, but I know that after my exchange surgery I looked the same two weeks out as I did when I went in for my revision. I don't know what I'll do if I'm still uneven. Living with it is unacceptable. But I'm hesitant about having surgery again on the cancer side because I've had continual pain issues there even after the exchange. I think it's nerve damage and I'm not sure if a larger implant would exacerbate that problem. On the other hand, I'm reluctant to have a fourth surgery on the left side because there is some statistical evidence that the more surgeries you have the more likely you are to have a problem of some kind with the implant. And I know for a fact that unless I die first I'll have to have them replaced at some point, because implants break. They just do. They aren't guaranteed for life. Sooner or later they spring a leak and you have to replace them. This could be as soon as three years, it probably won't be more than 10. I also know that although my surgeons have been spectacular as far as the incisions and how I'm going to scar (which is shockingly not bad) but if you keep cutting through the same place it's going to develop some thickness to it. And it's not like I want him to pick a new place to cut!! So really, I'm in a world of sucky options. IF things don't change. So think good thoughts for me.

Afterword

That's it, that was the last post I made to the "blog". It's still up there, for anyone who has the address. People stopped asking, or I became strong enough to personally respond... It ended, and that was fine. But I can't leave it at that; you, my readers, deserve to have a few loose ends wrapped up.

I'm writing this "afterword" on March 29th, 2012. I can look at the passage of time in a lot of different ways. It's almost four years since I married Olav. A couple months shy of four years since my diagnosis. Three and a half years since I lost my nipples. A bit over two years since I finished treatment.

My health is pretty good. I had a chest x-ray not too long ago that had No Evidence of Disease. Still one of my favorite phrases.

I still have large portions of my skin that feel numb, but my scars look great, as far as such things go. It took a while for everything to settle into place, but I am content with the results of my reconstruction.

For the most part, it's all part of the past for me.

As I read through my blog I realized there were so many things I never talked about, like the damage the taxotere did to my finger and toenails that took several months to grow out. Or that the lemon-pepper Dr. C recommended was incredibly helpful after chemo did funky things to my taste buds. But I made a decision to leave it as written and I'm sticking with it.

There's one thing, though, that I feel I need to address: in the blog I discussed my pain management quite a bit. In retrospect I did it all wrong. I put up with a lot more pain than I should have. Withdrawal from morphine wouldn't have been any more awful if I had been taking twice as much or ten times as much. I have since been assured that the quantity of morphine I was on wasn't really that large. If I had to do it over, I would have communicated better with Dr. C about the pain.

Although I didn't need to get cancer to appreciate my life, it did change me. I'm still working out who exactly I am, now. But I'm alive to figure it all out, and with luck I'll have plenty of time.