

Yeah, I know it's been a long while between posts, but here we are again. I have several things to report on the cancer treatment front, and some musings about ending one phase of the process while also looking ahead to the next.

First and most exciting to report is that I had my final chemo treatment last week. While it's still going to be about another week or so until I'm fully recovered from the not-so-fun collection of chemo side effects (including spaciness and fatigue, both of which make it hard to blog), I must say that reaching the end of this chemo phase makes me super happy. To celebrate, I brought along some tiny bubble wands (with pink hearts on top!) and got my mom and Josh to blow them with me down in the Meditation Room (the overprotective nurses at the infusion center didn't want me to blow them there—fine, be that way). Now I get to look forward to my hair and eyebrows growing back, which will hopefully start sometime in the next month or two. It's not unreasonable to expect that by the end of summer I'll have an actual hairstyle and can say goodbye to the crazy colored wig extravaganza. It's been entertaining to be pink- and purple- and blue- and green-haired, but I'd way rather have my dark hair with sparkles back.

Now that the chemo phase is over, though, it's time to turn my (and my team's) attention back to the surgical phase of treatment. Therefore, the day after my last chemo treatment last week (while I was still feeling reasonably energetic from the steroids they gave me the day before), I went back to UCSF to meet with my breast surgeon, Dr. Ewing, and my plastic surgeon, Dr. Foster, and talk about next steps. When we had last left Our Heroine, these two docs had already successfully performed on me a lumpectomy and sentinel lymph node removal, along with a "nipple-saving" breast reduction, in preparation for the upcoming double mastectomy and reconstruction surgeries. We put those other surgeries on hold while I completed chemo, but now it was time to get that ball rolling again.

Also, I had had a chance to do some more thinking during the months of chemo about what kind of reconstruction (and ultimately, what kind of long-term outcome) I wanted, and had had a change of heart that I wanted to discuss with the surgeons. Basically there are two choices when it comes to reconstruction: you can reconstruct with implants, or you can reconstruct with your own tissue (there are several different ways to use your own tissue, but the most popular one these days is called a DIEP flap, which involves taking fat, tissue, and veins from your abdomen and moving them to your chest). Originally I had been planning on implants, because I didn't like the idea of adding an additional surgical site or the more difficult recovery time involved in the donor-tissue option. But over the last month or so, prompted by a brief discussion last month with my medical oncologist where she urged me to think about the DIEP option, I did a lot of reading and thinking about final results and I changed my mind. What it basically came down to was me wanting to feel like at least my boobs would still be made of

flesh (and more importantly, my own flesh) rather than plastic, so that there would still be a texture, warmth and jiggle that was familiar even if the rest of it was numb and different. But I also had some concerns, and wanted to make sure that I was a good candidate for the DIEP and find out how the process would change with this new direction. Would they be able to condense the two remaining surgeries into one, and do both the mastectomy and the DIEP reconstruction at the same time? Some of the people I'd read about had done just that, and while it would make for a long and major surgery, I liked the idea of fewer surgeries overall.

So all that being said, how'd the meeting go? First up was Dr. Ewing. She was really quick to remind me, in no uncertain terms, that just because I'd changed my mind about using donor tissue instead of implants for the reconstruction, that didn't change the number of surgeries I would have. (Dang.) There would still be three total (two more to go), and the next one would still be as we had already planned, the "nipple saving" double mastectomy plus the placement of expanders (which would be partly filled up with sterile saline at the time of the surgery so at least I won't wake up flat). She examined me, and seemed pleased with the way everything had healed up from the last surgery. She also said we could use the same scars to go back in for the mastectomy, so that's good. Then we talked about when the first upcoming surgery date could be, and settled tentatively on April 26th. She seemed totally fine with "only" a month off after chemo (Dr. Majure had been fine with this too when I asked her the day before). Then Dr. Foster came in, and Dr. Ewing left to talk to the desk folks about scheduling while we talked to him. He too examined me, said the scars looked good but that "we could clean them up some" (whatever that means). We talked some about the DIEP, although it turns out that it's not him who does the DIEP surgeries, it's his colleague Dr. Sbitany (who "went to an extra year of medical school just to learn how to do these kinds of surgeries". Well okay then, he sounds like our man). I asked both Dr. Ewing and Dr. Foster about whether or not there would be any issue with all the radiation my skin had undergone 23 years ago, but they didn't seem to think it was going to be an issue (though of course they, like everyone else, said the equivalent of "we won't really know til we try"). Dr. Foster felt my abdomen too and said it seemed soft and not a problem, but added that we really didn't have any data about the effects of abdominal radiation on abdominal surgical procedures like we do about radiation to the breasts and surgery (this is where it sort of sucks being the special snowflake 2-cancers person that I am). Dr. Foster was very patient with my scattered-brain, repetitive question asking, and reasonably reassuring also. He said that we'd be able to ask more questions later on after the second surgery, when I'd meet with Dr. Sbitany to discuss and finalize the third surgery. I am eager to set up that meeting but will likely wait until after the second one is over to do so, since there's plenty of time in between.

So really the plan is the same as it's ever been, with the three surgeries, but the difference is that instead of putting in implants for the third surgery, I have decided to make it more complicated in the short term in hopes of a better long term result (specifically, one I'm happier with) and use my own abdominal tissue instead of implants. That third surgery, with its two different surgical sites, will be the hardest to heal from, not the second one (though the second

one will be no picnic). They guesstimate 6-8 weeks, with the first month or so being the hardest. I guess it's sort of a silver lining that I'll also wind up with a much flatter tummy in the long run, because of all the tissue that will be removed. What's a little weird to me is that I'll wind up with a totally resculpted top half, with smaller boobs and flatter tummy, but my bottom will still remain the same, with big jiggy thighs and butt. I will for sure be a pear, not an hourglass. I've been also joking that what I'll look like when all is said and done is a centaur—with a svelte human top and a big horsey bottom. And yeah, a shit ton of scars. The abdominal one will be horizontal from hip to hip (making sort of a cross with the vertical one I already have from the abdominal surgery I had during the first cancer go-round), and there will also be one around my belly button. I'm not that fussy about smooth skin and I know from past experience that scars fade and get less noticeable, but yikes.

It's taken me almost a week to get my head around all this information and my feelings about the whole thing, even though a lot of it was information I already knew. The truth is, all of this surgical stuff is still at least somewhat scary to me. I am confident that I can handle the pain part, and that I can hold my focus on the temporary nature of the restrictions in movement and ability that will be a part of the recovery—but there's still definitely fear and anxiety going on inside me as this surgery stuff gets closer. What's that about? Let me indulge in some "keeping it 100" navel-gazing for a minute (you know, while I still have an untouched navel.)

Well, for one thing, I'm sure I'm scared because I remember and am still somewhat traumatized by the first major abdominal surgery I ever had (the staging laparotomy/splenectomy from the Hodgkins Lymphoma). That was a hard experience both physically and mentally (it was my first experience of major debilitating pain and the restrictions that come with it, plus I woke up missing an organ and with a bunch of other stuff rearranged). The recovery from it took a long time, and I'm definitely not looking forward to doing that again. No matter how brave and optimistic I try to stay, there is still a part of me that wants to "just say no" and run away and hide so I won't have to go through this. I am afraid of what it will do to my psyche and my sense of self and safety, when the sanctity of my body, my familiar fleshly container, is once again violated—repeatedly!—by outside forces, violently, painfully, and certainly without my full, enthusiastic consent. And that fear seems pretty reasonable, despite all the reassurances that after a period of transition, there will be a new normal, and eventually I will get so used to it that I won't even think about what happened to me most of the time.

For another thing, I'm scared and anxious because I am still struggling with the idea that my body is going to be so radically rearranged and modified, both from what it once was, and from what other humans have. My new boobs will feel like flesh, yes, but they will be just a weird sculpted facsimile of ideal boobs made out of belly fat, and not like the original complex, sensitive, imperfect milk-making structures that accompanied me for the last 35 years. Some days when I think about it deeply, the idea that we can just pull flesh from one place (or person)

and put it in another seems wrong and horrible (I mean literally horror-inducing, like in a scary movie), like a perversion of the natural order and design of our embodied human experience.

There isn't a lot I can do to calm these fears and anxieties down except to acknowledge them and try to give myself complementary or alternate narratives to focus on. For example, as a long time science-fiction fan, I am also trying to see if I can shift the narrative here to something more futuristic and change-positive: modified humans are cool! Look what we humans have learned to do to hack and improve the original design of our physical selves! We do not have to be not bound by our bodies, we can fix things that break and change what we want so that we can focus on our inner lives, on our passions and desires, on what gives life meaning. We are closer now to being able to do whatever we want or imagine, without the constraints of the flesh or the random genetic and environmental challenges that trip us up. Humanity is evolving, and this is one way we are doing it. All of humanity will eventually be modified in one way or another—heck, many of us already are, if you think about things like dental work or exercise programs. I'm just a frontrunner, ahead of my time (as an Aquarius, that kind of excites me).

So that's where we're at for now. Over the next few weeks I'm going to try to focus on healing up and strengthening my immune system with all the good self-care stuff, and to distract myself by making flags and setting up all my plans for Maker Faire and Wiscon, so that I can look forward to participating in those events once I'm done with the next surgery. Just keep swimming, just keep swimming...