

By Way of Explanation

I discovered this piece of writing on Susan's computer desktop a couple of weeks after she passed away. It appears that she wrote this sometime in the early summer of 2014, in the middle of recurrence 4. Her typically excellent writing is on display here. Also on display is her singular courage and grace in the face of the horror she was experiencing. I have not edited or altered this in format or content, in any way.

I'm Dying Here

Said usually in jest, but in my case, I really am dying.

Thirty months ago I had a little operation to rule out cancer, only in my case the opposite happened. I expected a short nap in the OR followed by some good drugs and then by some pampering over the Christmas holiday, after which I expected to get back to my real life. The surgery took about nine hours. It did not go as I had planned. While in the recovery room I heard a loud voice call my name and order me to "breathe." I took a deep breath and it was so refreshing! I wondered even at the time "How is it that I can forget to breathe, but I can still follow directions?"

I am a big fan of neuroscience, and it amused me to think that my language skills, a fairly high level brain function, remained intact, but my central nervous system was out of it. I thought it was funny, even in my delirium. Eventually the recovery room staff figured out that Dilaudid was not controlling my post-surgical pain and they put me on morphine, with a patient-administer button I could push periodically. I had been opened from my solar plexus to my pubic bone and I was held together with metal staples inside and with steri-strips on my skin. I had been "optimally debulked" by a highly respected oncologist. While I was on the table to have a suspicious ovary removed and sent to the pathology lab for biopsy it was ascertained that I was full of metastatic ovarian cancer, stage 3-C.

My gynecologic oncologist cleaned me out as well as possible, but the cancer was already in my lymph nodes, the highway to the rest of my otherwise very healthy body. I still am really healthy, except for cancer. My oldest sister, Avra, was waiting with my husband, Matt. When the doctor came out to tell them the news Avra asked the hard question, "Prognosis?" Dr. Johnston told them that I had a 50% chance of surviving five years. Later she told me that 75% of her patients are like me. Advanced stage ovarian cancer. A 50/50 death sentence within five years.

As I write this I am halfway to that marker. I am also in my third recurrence. I have been on chemotherapy of one type or another for almost the entire time since initial diagnosis. I recently read on the internet that people with ovarian cancer live an average of 12-32 months after their first recurrence. And that recurrences of ovarian cancer happen closer and closer together. They call the time between, "Progression Free Interval." Those PFIs get shorter and shorter. Last treatment I was on for only two months before it stopped working (that was Gemcitabine.) Before that I was on Doxil for eight cycles and off for two months before cancer reappeared.

This is the fourth time I am undergoing chemotherapy. This time I am on Paclitaxel (Taxol) on a schedule of three weeks on and one week off. The doctor told me she plans to increase the dose every week. I asked her, "Till I say 'uncle'?" and she said yes. Until my side effects become intolerable. "Then we'll hold it at that level." She rubbed her fingers with her thumb in the universal sign for "money" but I think she was trying to indicate something to do with peripheral neuropathy, the tingling, stabbing or numbness that can occur in the hands and feet. That's only one side effect, of course. There's the baldness, the burned and damaged stomach lining, mouth

sores, bone marrow suppression, constipation, diarrhea, acne, bone and muscle pain... I'm sure there's more but that's the gist of it.

The thing to note is that until last month I never felt any symptoms from the cancer. I suffered plenty from the side effects of chemotherapy, but the cancer wasn't causing me any pain until very recently.

When I was coming out of anesthesia Dr. Johnston hovered over me and said, "This is the news you don't want to hear. You have ovary cancer." I nodded my head to indicate I heard her, but I knew she got it wrong. I knew she had me confused with some other patient. I tried to believe all the doctors that came to see me over the next five days I was in the hospital. One of her partners told me, "It's hard work. But you can do it," as he was describing the chemotherapy regimen. Okay. Maybe I can tough it out for the next five months. I was to start with a combination of Taxol and Carboplatin administered into a chest port every three weeks. I was also going to have cisplatin delivered directly into my abdomen through a port in my belly. This combination would clear up any small bits of cancer that got left behind. The whole picture sounded so barbaric, especially on top of the gutted-like-a-fish surgery I'd just had. But it also sounded like it should work. I started out healthy, as I said, and I was only 59 years old. My mom lived to 86 and was only ill for a very short time before she died. None of us die of cancer in my family. It's heart disease all the way.

Now I wake up thinking, "I'm gonna miss me when I'm gone." But at least I'm waking up. I'm still here to complain. This has been a terrible stressful period in my life. It's hard to know what to say about it. I know it's been brutal on my husband and on my children, too. I am so lucky to have them. On my list of side effects above I forgot to mention insomnia and fatigue. I've had to quit work. Matt takes care of everything now. All the shopping, cooking, laundry. He helps me manage my symptoms, keeping track of the million medications and helping me figure out what to take when for the best results.

Right now this minute I'm sitting on the front porch listening to the leaves rustle in the trees. I hear birds, the occasional car going by. A random dog-walker. It's a perfect day, crystal clear and sparkling green with temperature in the low 70's. Sunny with a chance of mourning doves. Perfect.

At this point in my disease treatment is considered "palliative." That means we're not looking to cure it, but to give more "quality of life." I was going for quantity, but I suppose I will have to settle for quality. When I ask the doctor, "what should I be doing?" She says, "Go have fun." It sounds a little too much like a "Make-A-Wish" answer, go have fun. Like what, a trip to Disneyland? What's fun for me is to spend time with my children. They don't live near me but they all live in interesting places. Yes, I can go have some fun by visiting them! We're lucky this year that our son is getting married in Hawaii. That will be one of the "fun" events coming up soon (less than four months away now!) Before then we're going to visit our daughter out in Spokane, and if all goes well, also a visit to Brooklyn, NY to see our oldest son & his wife and our grandtwins. Having something to look forward to helps me tremendously. How could it not?

I'd like to say that making art heals me, but I can't say that. I'm an art therapist and I have spent the last 20 years bringing art-making to people in need of non-verbal ways to express themselves. Having this disease put me in the perfect position to experience art therapy as a patient. I've made a lot of art since my diagnosis. Enough to fill a book, if only there were a way to get published. Books of art are hard to bring to press. It's unfortunate, because it's the way I tell a story best.