

Personal Info

My name is Jill Maxwell and I am a bad-ass 3 and a half-year survivor of stage 4 serous epithelial OC with 41 chemo sessions under my belt! I have 3 grown children ages 26, 30 and 31. I have been working throughout my diagnosis and treatment since I do not have anyone else to support me or to provide my medical insurance.

2015

In July of 2015 at age 54, when I went to my regular gynecologic visit, I had no symptoms. From my pap smear results, my doctor noticed that I was shedding cells. She scheduled an in-office biopsy because she was concerned about this. The biopsy showed cancer and she referred me to a gynecologic oncologist.

I saw a gyn onc who diagnosed me with HGSOE and scheduled a robotic hysterectomy the following week. He told me that this cancer was serious (serous is serious) and aggressive. He explained the advantages of robotic vs. traditional hysterectomy. He did not do any scanning or testing before surgery – not even CA125 which is the common blood test for OC.

While the surgery was easy in terms of recovery, I needed a second surgery because the cancer was not confined to my reproductive organs. I had cancer in my liver and spleen. This doctor was remiss in doing surgery before scanning. Even carpenters know to measure twice and cut once!

The gyn onc recommended port placement so I had both a chest port and an IP port placed once I was healed from the hysterectomy. He then referred me to a cancer treatment center close to my home with no plans to continue to work with me – I think he was either regretful about his treatment of me to that point or he did not like my odds or maybe both. There was no specialist (gynecologic oncologist) on staff at the recommended treatment center. The medical oncologist tested my CA125 for the first time and it was 850. She also did a CT scan after asking me 3 times if one had already been done! When the results of the scan came back, it showed nodules in my liver and spleen. The med onc told me “We might not be talking about a cure.”

While I understand that there is no cure for my condition – I also knew that this was not the right doctor for me. She seemed daunted and discouraged about treating me. My situation was clearly outside of her comfort zone. I decided to seek different care. I didn't want to work with a doctor who was afraid of my condition.

I looked on the clinicaltrials.gov web site and found a trial that was being conducted at the local university hospital. I called them first thing in the morning and got an appointment for the next day. When they saw my CT scans, they scheduled surgery for the following week (September 23, 2015). I recovered well from my liver resection and splenectomy with a transfusion of a unit of blood and a 5-day hospital stay.

In October, 2015, after I recovered from the 2nd surgery, I started a phase 3 clinical trial with Taxol, Cisplatin, a parp inhibitor known as ABT-888 and Bevacizumab (Avastin). I had 6 cycles of 21 days with IV chemo on day 1 and IP chemo on days 2 and 8. My CA125 dropped below 10 after the first cycle and CT scans showed good response.

2016

The chemo stretched through the end of February of 2016. It was especially difficult between cycles 5 and 6 because the cumulative effects of Taxol hit me hard. I had my IP port removed in March – it had caused me a lot of pain and I was really happy to get it out! I stayed on Avastin only every 3 weeks for 12 more months and my CA125 stayed low throughout treatment.

2017

My last Avastin only treatment was in March of 2017. At my first 3 month visit, my CA125 was 8. Three months later it was 24 and the following month it was 72. A CT scan in October showed new nodules. I started treatment on a phase 3 clinical trial for my 1st recurrence. I had 8 cycles of 28 days with Carbo/Doxil. This treatment was difficult to tolerate because it put me on the couch for the first 3 days of treatment and caused extreme fatigue for much of the rest of the month. I was able to arrange to work hourly even though I am a salaried employee and that made it possible for me to take time off to recover.

2018

In May of 2018, I developed a deep vein or portal vein thrombosis and started injectable blood thinners. I have since switched to oral blood thinners which are much easier to manage.

I continued on Doxil until June. While I had good response during treatment, my CA125 increased as soon as treatment stopped.

6 weeks after the last Carbo/Doxil my CA 125 started to rise again (20, 46, 109 up to 785). Two months after that, I had bowel obstruction that was caused by tumor growth. I was hospitalized for a week with an NG tub and no food. The obstruction resolved with lots of walking and my refusal to take pain medication (why oh why did they offer medication that caused constipation?). This was one of the most difficult parts of my ovarian cancer experience to date. The NG tube is painful beyond words - especially insertion – and waiting for bowel activity is very tedious. I would have preferred the major surgery of another splenectomy to the bowel obstruction!

Since the obstruction was caused by a recurrence, we needed to treat the tumor and prevent further bowel issues.

Treatment for my 2nd recurrence started at the beginning of November 2018. I completed 5 cycles of weekly Taxol with Avastin every 3 weeks. I asked for a week off between cycles since I am working, and it helps to have time to recover more completely than weekly Taxol requires.

I requested to eliminate Benadryl and Dexamethasone from my infusions because I had quicker recovery without them. This is common practice with ovarian cancer patients in other parts of the US though it was unusual in Denver. I also stopped taking Compazine or Zofran because I prefer nausea to constipation (post-bowel obstruction syndrome?).

I am now on Avastin every 3 weeks but my CA125 has been rising again so I need to think about chemo treatment in the next few weeks.

Recovery from chemo is ongoing and I still have some chemo brain but I am planning social activities and travel – something that isn't possible during chemo treatment.

I have great confidence in and respect for my care team and the treatment I receive. I also appreciate the many OC and other cancer patients who have gone before me and helped treatment improve with side-effect reducing medications. I am excited that there are potential new treatments and I look forward to the time when chemotherapy is looked upon the way we view leeches in medical care today. I feel confident that there are better methods of treating cancer than sickening the host and I look forward to participating in the research to move us in that direction!

In the meantime, I must keep working to maintain insurance coverage. I do have the option of going on SSDI and purchasing insurance on the exchange. Doing so would greatly diminish my standard of living so it is not an option I am likely to choose unless I become unable to do my daily job. I can elect to go on short term disability which is limited to 12 weeks per calendar year. On short term disability, I earn less than my regular pay but can maintain my lifestyle.

I don't qualify for long term disability for my condition because of the pre-existing condition clauses in most LTD plans. This clause says I can only claim for a condition that I have not been treated for in the prior 12 months (from the time of a claim). It is unlikely that I will ever go a year without seeing my doctors since they will want to monitor me more frequently.

So here I am in a wait to see what's next phase. I can't really make plans for travel or social activities since I might be in treatment in the next few weeks. I'm not sure how long my employer will keep working with me in my dramatically reduced capabilities. So I take each day as it comes at me. If I had guaranteed health insurance (ie. if I was a member of congress or if we had a socialized medical system), it would be such an amazing relief and a big weight off my shoulders. As it is, I must balance my ability to earn a living with my medical needs and this is very difficult.