

Interview Transcript: Jen

Jen lives and works in Richmond, BC. Since her diagnosis she has become a strong advocate around better care for young adults with cancer and is involved with Callanish and Young Adult Cancer Canada.

Location: Richmond, BC Type of cancer: Endodermal sinus, a rare form of ovarian cancer Age at diagnosis: 29 Year of diagnosis: 2006 Treatment: Surgery and chemotherapy

Even though I had a fantastic prognosis — the type of cancer I had has a 90% cure rate, cure rate! — but for me to have heard that word "cancer," my nana had passed away from breast cancer two years prior to that, and I saw what my mom had gone through and I saw what she had gone through, so to hear that word automatically meant a death sentence to me.

I'm Jen Luce, I'm a three-year ovarian cancer survivor. I had a rare form of ovarian cancer, which was an endodermal sinus tumour, a germ cell tumour, which generally affects young women up to the age of 29. I was 26 when I was diagnosed — no, pardon me, I was not 26 when I was diagnosed, I was 29 when I was diagnosed. I'm 32 right now.

Diagnosis and treatment

Within three weeks I was in for surgery and the mass was removed. And I remember being on the operating table and saying to her, "if you don't have to take both, please don't; I would still like to have children." So this mass was removed and it was about that big, attached to my right ovary. They removed that and the fallopian tube. They did a peritoneal wash to make sure that everything was clean in the area and everything was, which was good. So to me it was like, "OK, this is it, that's all it was, it was a mass and I'm OK now."

So two weeks went by and I went into the cancer centre, got myself registered in with that, sat down with an oncology nurse, sat down with the oncologist, sat down with another oncologist, and they said I had to start chemo. And I didn't want to do chemo, I didn't want to have to go through that, and the first thing I remember saying was, "I can't, I'm starting school next week and I've got this going on and I'm planning this and this and this," and she's like, "no, this was a fast growing cancer and we have to make sure that this doesn't come back and we have to plummet you with treatment." Two days later I started and it was such a blast of overwhelming...I don't know what you would call it, it was too much, it was way too much to deal with, and I had no choice on waiting a week or what about preservation of my eggs or what about any of this and they're like, "no, we can't wait, we have to get you in there as soon as possible."

Dependent once again

A ton of people came out of the woodwork that I had no idea really existed. Friends and family, from people at work, people who had been affected by cancer in different ways, all came out to help support, but I wasn't open to it, I wasn't open to receiving the help. So that support was there but I wasn't accepting of it, and all I wanted was my boyfriend to look after me. This was someone who I had been with for three years and we were talking about getting married, so to have that diagnosis and to say, "I don't want my mom, I want you here, you are my main support person," because I had the most intimate connection with him. Looking back at it, it wasn't really the best thing for me to have done because he wasn't able to provide that care for me. He had his own issues to deal with, he had his own history of cancer in his family and whenever that can happen a lot of times we hold ourselves back and we're afraid of the possibilities of what can happen. He was scared of losing me so he retreated to some degree.

So I had to call my mom, I had to have her fly out, she lived in my apartment on a pullout in my living room for a week or two at a time during my treatments and that was really hard for me, to have to let go, for her to do — I was very selfsufficient and very vivacious and doing all my own things since quite a young age. Having to depend on her was weird. I was like, "I've come all this way to get past that, I've come through my life so I don't have to depend on her." This was not a place I want to go back to.

Finding support

I went to a support group for ovarian cancer and they were all 60splus, talking about who had just died, who was coming up, and it was so not my thing — it made me retreat even further. So then I was searching for support networks and came across one called Callanish, which was my godsend, they are this incredible group of people. So through Callanish I went on a youngadult retreat and it was the first retreat they had had, and that is where I began my healing process. I met other people similar to myself and they are still a part of my community.

Returning to work

Initially I was petrified of going back to work, not being able to remember the name of a pencil, like how am I supposed to be able to function in this capacity, in my previous capacity, how I am now? So after a lot of time and deliberation between my psychiatrist, my oncologist, my general practitioner, we all came up with a gradual returntowork program, once I felt comfortable even going back. And that took a long time.

Work, thankfully, was quite open with the gradual return to work and they were very flexible with my hours. I would kind of go all over the place, I would do maybe once a week for two or three hours at a time and that would continue for a month or two because that was all I could physically handle. I was exhausted just from having to think for two hours, it was too much, it was too much overload. So I would increase my hours and then it was too much and I would decrease, and then I would increase again. And then it just started to gradually increase and I felt more comfortable, so to move into that but to be welcome, and my workplace was OK with the fact, was really big. I can't imagine if they were forcing me to go back to work. They were really just allowing me to ease into it as I felt comfortable, and I would push myself through things to some degree to get myself back to a state where I felt like I was functioning before.

I've been back to work since April of '08 so it's not even really been that long, it's not even been two years yet, and I would say until I felt comfortable was probably seven or eight months after I started back at work. So it was like learning a whole brand new job again, to some extent.

Looking forward

I'm on nutritional supplements and I'm on antiinflammatory, natural medication that apparently does not contradict for anything else, and all medically that I'm on drugwise is an antidepressant. It came to the point of me having to say, "OK, this is something I need to be on for a while" and being OK with that, coming to a point finally when the cloud lifted from the whole hormonal issues that I was having postmenopause. I was in menopause for about eight months and then my period started back up again, but it took about a year for my hormones to settle down, where I wasn't crying every two minutes. Again, that was a factor why I wasn't working, why I wasn't social, why a lot of things weren't happening.

So it's really been a lot about me advocating for myself and being open and honest to others about my experience. So when cancer came and went and through the process of the healing I think somehow I managed to disassociate myself from that label. Though I'm a survivor and though I've had cancer, cancer is not who I am.