

Interview Transcript: Julie

Influenced by her own experience with cancer, Julie returned to school and is now doing a PHD, focusing on the social and psychological issues related to cancer and survivorship.

Location: Fredericton, New Brunswick

Type of Cancer: Hodgkin's Lymphoma

Age at diagnosis: 23

Treatment: Surgery, chemotherapy and radiation

I had to kind of almost learn to be sick. Which sounds funny but I had to learn that OK, things have changed, and to kind of embrace that, but also when I finished treatments I had to learn to be well again, so that was another journey after.

My name is Julie. I'm from Fredericton, New Brunswick, and I was diagnosed with Hodgkin's lymphoma 10 years ago, when I was 23. I went through chemo and radiation and I'm happy to be cancer free right now. And have learned to use the experience to focus my future on positive things.

Diagnosis

At the time I was kind of at an in-between stage anyway. I hadn't quite figured out exactly how I was going to progress in my career plans or school plans and I was just at that point of deciding whether I should go to grad school or what I was going to do with my life. And so I guess in some ways that was a good time for it to happen but also it was really hard because at the end to try to regain normal when normal hadn't even been established yet. So for me the worst part was the waiting. And not knowing what it was because again up to that point I was invincible. There was nothing that could happen to me so it was a reality check that OK, it can happen and it did happen, and it caught me off guard. So a lot of where that first time period, when I was first diagnosed, was kind of coming to grips with my own mortality, I guess, with the fact that I wasn't invincible anymore.

Losing my hair

It's funny, when I was first diagnosed and they said, "well, you're going to have to have chemotherapy," I was pretty naïve as to what that entailed and the first thing I thought was, "oh my God, I'm going to lose my hair" instead of, "oh my God, I've got cancer and I'm going to die." And I'm not a vain person and wasn't at the time. The fact that that was the first thought that came to mind was really, really amazing to me, blew my mind that I would think that. But it was a huge concern. But what I learned from it was not to be afraid of that. That's not what — I guess before I had even curlier hair, before I was diagnosed, and I was always identified by my hair, but suddenly it was about finding a new identity where you strip away everything superficial and people were really seeing the strength that was coming out of me and seeing a

new side of me. That really taught me a lot about caring so much.

In between

What happened with me was I had nine dollars in my bank account when I was diagnosed. Really unfortunate. And I also was without health insurance, which was really, really tricky because I was in between jobs. My job had finished. I was working a contract that was finished. My partner had moved out West for a job and so I was deciding whether or not I would go with him or would I consider going to school elsewhere. So I was at this really in-between stage but again with zero money — well, nine dollars, I shouldn't say zero, nine dollars — and no health insurance. It was... that had a huge impact because when I was diagnosed and the realization that the chemo was covered by Medicare but not the anti-nausea drugs and all the extra drugs — and there are a lot and some of them costs \$25 a pill, or an injection to boost the white blood cells costs \$2,000 every two weeks. But you have to have it, so suddenly it was this huge debt load and to have zero resources to tap into, that I ended up having to go on social assistance.

But when you're sick and going through chemo and having to be the one that's trying to negotiate with the help of social workers in the oncology department, but a lot of it you had to do yourself because they had to talk to you personally. That was a huge struggle. Luckily I had my mother to fall back on. She was able to get a loan out and I had to get loans out and all my student loans had gone into repayment status so I had to work on getting interest relief and there was a lot of financial issues that were really, really challenging. And I was really grateful to be able to depend on my mother despite the fact that I was already living on my own and it was kind of a shift to have to rely on someone.

Friends

Some friends just disappeared and at the time I thought, "how could they do that?" But now that I'm 10 years passed that, I'm more reflective and a little more forgiving because they are at that point of growth that I've been at or been through to be able to handle things face on. I was kind of forced to learn how to do that. I kind of offered forgiveness in my mind for the people that weren't there and have opened a door to allow them back into my life and I don't hold it against them.

People handle things in different ways. But in hindsight, again it lessened the blow but at the time it was really difficult, especially when you're 23 and all your friends are seemingly out having fun and doing 23-year-old things and I felt like I wasn't fun anymore. That they didn't want to hang out or do anything, so I really did appreciate the people that came by, even if they were so uncomfortable — and they acknowledged that they were uncomfortable — that was better to me than not showing up at all. And it ended up being strengthening. A lot of relationships and a lot of people came out of the woodwork that I never thought would be my biggest supporters.

Soup

The hardest part for me, I have to say, about having had cancer was at the end of treatment, because when I was in treatment it was all about focusing in on the physical: how do I feel, am I feeling OK, OK I need to get through this, I have to set goals, I need to get through this chemo and the next one. You're counting down. But when I finished treatment it was like they handed me the rest of my life back and sent me on my way and again I was at a time period where nothing had been established yet. I was living with my mother, I had no money, no job and I

really struggled with “what am I going to do with my life that has as much meaning as what I’ve just been through?” I was kind of reeling... it set in what happened after I finished the treatment.

So the first thing I did was I bought a soup cookbook and every day would make a different kind of soup. And it was a simple task, a mindless task, but it was something and it was something that I learned to do well. I really make good soup now. I’ll brag a little bit about that but it was almost nourishing my soul as much as it was about doing something physical so that I had something to get up for that day. OK, next page, let’s try another soup. And I was really fatigued and tired and didn’t feel like myself. I felt like I lost all muscle mass. I basically slept for a good nine months, that’s what I felt like anyway. It was about also nourishing my body so it was a symbolic thing as well as a practical thing, and it was about just really, really evaluating what it was that I wanted to do with my life.

In the moment

I was so worried about the future, and in a sense having cancer kind of in one way — and kind of a negative way — made me a little bit afraid of the future. But from that I also recognize that I’m right here in the moment and from that experience have learned to live every single moment. So whereas going through cancer and even for the first couple of years, it was really about feeling, “oh my friends, I’ve felt really far behind from my friends and a little disconnected” and stuff like that to now, 10 years later, it’s a shift that I think for the friends that I can’t relate to, it’s really that they can’t relate to me because I’ve travelled, I’ve taken risks, I’ve tried new things and I guess use my experience as a motivation to really live every moment because that’s what we have, and recognizing that anything bad can happen at any given moment. But so can anything really great.

So it’s really that what I took away from the whole experience was that this is it right now. So the soup was the beginning of that and it was the beginning of “I’m going to be very present,” and “how do I feel right now?” and “what makes me happy right now in this moment,” and that’s what I’m going to focus on right now and not worry about what lies down the road because anything great can happen.