



Interview Transcript: Laurie

Laurie is a school teacher in Ottawa.

Location: Ottawa Ontario

Type of Cancer: Colon cancer, stage 3

Age at Diagnosis: 28

Year of Diagnosis: 2004

Treatment: Surgery, Chemotherapy

My name is Laurie Hinsperger. I was diagnosed with colon cancer, Stage 3, in 2004 at the age of 28, and it's been six years since diagnosis.

I had the surgery and they had removed my large intestine and a portion of my small intestine, but had noticed that there were lymph nodes around that were infected so basically when my surgery was over I was told "you're going to have to do chemotherapy, six months of chemotherapy," so pretty aggressive. He said because it has spread, it's metastasizing, so we need to get rid of all of it.

Chemo

It's interesting, there's actually more side effects from the chemo than there are from the cancer. People don't realize that the chemo, it's a poison, you're basically poisoning yourself and it's poisoning your bad cells and your good cells, so getting out of it with no side effects is highly unlikely. As young adult cancer survivors we all talk about the chemo brain too, like just our memory is not where it used to be, our short-term memory, it just... Like I have lists of list of lists because if I don't write it down right away I forget it. Even as a 34-year-old. It's like, "I'm not supposed to be having issues like that until I'm 70 or 80 years old" when that's something that happens at that age. It's not something you expect to happen right now.

Other challenges

It's going to be very difficult for me to have a child. It's not impossible but it's going to be extremely difficult. And then they're like, "the good thing is once it actually happens, smooth sailing," but all of those... I find that being a young adult, trying to juggle all of those things is just... like as a young child it's mom and dad, you have mom and dad to do it for you, and as an older adult you've had your job, you have your cottage, you've had your kids, whereas the young adult, you're kind of in that space where you're transitioning. Just the juggling itself is just "ahhh!"

Timing

I had just accepted my first teaching position ever and as a teacher once you get your foot in the door it's not something you can really say no to, so I completed my surgery, I went home

and about a week later I started teaching kindergarten full time, knowing at the end of that month that I would start chemo treatments. So yeah, I was teaching kindergarten full time, doing chemo treatments at night and amongst all of that, in hindsight again, I was paying student loans and one of my loans when into default so I was not only working full time and getting chemo treatments, I was being harassed on the phone every day by the collection agency and you know, they didn't care that I was trying to survive, they just wanted money.

So dealing with all those things and losing my hair and side effects and things like that, just crazy. Honestly, thinking about it now... I did, after everything, after the chemo was done and everything like that, I did have a little bit of a break where, driving along, I had to pull over and it just kind of poured out. I was like, "oh my goodness." Everything I had gone through, I was just like, "wow, I actually did all of that." I think I didn't really have the chance to, because I was working and I needed money and it was chemo and then all of that stuff, I don't really think I had the chance to digest everything. Which is interesting because I don't have a digestive system at this point (laughs).

Talking about colon cancer

That in itself, for me, was a really hard topic 'cause it's a taboo subject. I do the (makes an X with her fingers), because you don't talk about stuff down there and how it works and... So I mean, that in itself, there's a big stigma around that. So I find even down to what it actually was, that that was difficult to talk about. Like for me, people actually asking, "so what do you have left in there?" and I'm like, "well, I do have an anus." I try to make a joke out of it but I kind of get the "what's going on here?" But I think the most important thing is to have a sense of humour about it. I think people sometimes don't understand the sense of humour part, but I think a sense of humour is what really gets us through things.

Advocate

I made the time to do my own research because of the fact I was misdiagnosed, so I really didn't have a lot of faith in the medical system or doctors, and then kind of getting a little backlash as well, because I didn't mean to say to the doctor, "well, this is what I found," I didn't mean to back-talk him, but I was kind of like, "well, I found this" and I kind of got a bit of a negative tone. I said to him, "I'm not — you've got to come from my point of view, I was misdiagnosed by your system and I honestly don't really have faith in the system right now. And you have to see it from that point of view. It has nothing against you, it's just, this is what I found."

And that starts to... the line between doctor/patient is getting skewed because where am I a patient and where am I doing what the doctor should be doing? Is the doctor supposed to do that? And yeah, that's becoming the issue now. Where do I stop being a patient and where do they stop being a doctor? What's the overall picture? The overall picture is for Laurie to get better and be able to transition back into a somewhat normal life. But then, the roles and responsibilities you come to, where, ok, as a doctor how are you going to do that? As a patient, how am I going to do that?

What if it comes back?

Having blood tests done, every week, every month, I knew where my blood was at. And then when my treatments were done, it was like, "now you have to wait three months to get your

next test.” I’m thinking, every couple of weeks I know where everything is and now you’re saying I have to wait three months? In hindsight I was very happy, no more chemo, but on the other side, I’m like, “what if something happens in that three months?” So then that three month goes by and you get to that point where you have the blood test and you don’t sleep the week before and you don’t... The particular test I had took nine days to come back — it was a special CA test, an enzyme test — and so you don’t sleep until you get the test results back. And it’s like, man, what if it comes back, how am I going to deal with it? And I don’t really know how I got through it the last time. All those things running through your head, it’s hard not to say, “no, stop it.” It’s like mind over matter. But I think I had the opposite... Now I’m at my six-year point, I actually forgot it was my six-year point, which I guess is a good thing for me, last week it was. But I think I still... it always once and a while pops into my brain: “wow, what if?” I don’t know what I would do.

Normal

Being normal? What is that for me right now? Before I was diagnosed to right now, I’m a completely different person, inside and out. Literally. So just trying to get back into a somewhat normal life and then having to deal with these things cropping up about having trouble having children and with my ankle. It’s tiresome. And I know for my partner, he doesn’t say it, he’s very supportive and everything, but it’s tiresome for him as well because he’s been through the whole process. It’s tiresome for him to see me be put through more issues related to my cancer. So yeah, just trying to get back in there, get back to that “ok, we don’t want to see you for another three years,” like everybody else. That’s the struggle right now.