



Interview Transcript: Lindsay

Lindsay was training to be a nurse when she became sick. She now works for the Leukemia Lymphoma society with outreach programs and support services.

Location: Calgary, Alberta

Type of cancer: Acute Lymphoblastic Leukemia

Age at diagnosis: 29

Year of diagnosis: 2006

Treatment: Chemotherapy, stem cell transplant, full body radiation and spinal tap radiation

I don't really like the word "can't" sometimes. We don't live the whole "can't" word in our cancer world. I didn't. And then it was always "I can, I will." Afterwards, something creeps in your mind where you can't do this, and that's where I would say to myself, "where did this word can't come from? Never used it in my whole entire treatment and it's coming out now? Got to get rid of it. How do I step over the barrier of these limitations?"

I'm Lindsay Lenny and I was diagnosed when I was 29 with acute lymphoblastic leukemia. So I had two rounds of chemotherapy, stem cell transplant, full-body radiation and then I had spinal-tap radiation as well.

The hospital

I was diagnosed in April, so three months in the hospital. The isolation started right away. I felt completely alone because I'm by myself, scary, you don't know what's happening, all you know is that you've got cancer, you're close to death and trying to focus on that. And then it was moving to the new ward, being isolated from everybody, your door is shut, people come in with gloves and masks on. So you have the physical barriers too that you can't really interact, so you're feeling like this creature or the ETs. So it was a little bit difficult.

We weren't allowed to associate or talk with other patients on the wards. Because we're so sick, one person can carry an infection and another one can't. And because we have no immune system, they wipe your immune system so you can't fight even a common cold. But I just...I could not help myself, I'm such a social person and my family made contact and built relationships with other families on the ward. So that kind of helped me; they were like, "OK, this person's here, they're this kind of an age." So I met one of them and we became really good friends. We were able just to kind of connect and say, "oh, I'm glad you're feeling this, this is what I'm doing, doesn't this suck?" Kind of just bring some humour around it and just be able to sit with each other and understand that we didn't even have to talk, just being with somebody else was so much better than not having anybody there.

Friends

I lost a lot of friends. They've got to move on with their lives, so they were there in the beginning, "oh well, this is awful, this is happening, here's your get-well card," and then it was just no contact after that. And sometimes the people you — the people I thought would stick around didn't and the ones that I hadn't talked to before or for a long time came forward and really stepped up and were there for me, that I could totally count on, that I'd least expected. So that was a bit of a surprise. I think it really brought out an understanding that yeah, people are real, a lot of people can't handle some of the things that I'm going through or watching their friends do that, and that was OK.

It was still hard for me to lose a few friends. I had one who was completely honest with me who said, "I can't come and see you. I can't handle the fact that you are sick. I don't know how to talk to you and I just can't do it," and I didn't talk to her for almost over a year. And she's like, "I'm sorry that I had..." I'm like, "you know what? That's OK." The big thing was like people saying to me, "I don't know, we don't know what to talk to you about." Well just talk to me normally, what's going on in your life? I want the gossip, give me the goods, I'm stuck in here, I know life is continuing on out there. Give me something to focus on or talk about. It doesn't have to be about my cancer all the time. This is just where I'm at right now.

Returning to the world

People are going to look at you no matter what. I just had to make sure you know who you are, this is the journey, they have no idea of the fight you've just gone through. Be proud of you being here, standing here, and showing yourself. Be proud that I fought this battle. I fought this cancer so hard, I deserve to be here; look at me all you want to. It's been a little bit hard now with the way my hair is. This is with four-year growth. It's so much finer, it's little baby hair. I joke around a lot: "Oh I just love your hair," or I see other people who have gone through the same thing and their hair is thick and beautiful: "Oh, I'm so jealous, I love your hair." That's just who I am. I just have to keep plugging along. Self-image is always something you've got to work on. I've got to accept me for me.

New normal

Getting back into the workforce, getting back into a normal life or trying to find that new normal — I didn't know what was going to happen. I was such a professional, always-wanting-to-work type of person, liked my own independence, having my own career goal set, that future was still in my mind but my body and cancer diagnosis wouldn't let me go forward with it. So there was a lot of, like, losses, it's a lot of losses that you don't think about that you have to grieve through each one. So getting to that point and then going, "OK, getting stir crazy at home, I'm getting better, I'm getting out in the world, maybe I can think about doing some things."

And then I found out about the Leukemia Lymphoma Society, so then I just started volunteering and they had no support groups set up yet. They were just starting. So I worked with their patient service manager and helped her start and then the ambassador of the support group, the leukemia group, and then they have more now. So that was — I just started going, volunteering with them, working as much as I could in the office because that was what I could do, at least I could volunteer and feel like I'm contributing.

What if it comes back

For me I think it's always there. And maybe because they're like, "you've got to hit the five-

year mark,” and I haven’t hit the five-year mark, and even if after, it can still reoccur. So I think it’s always in the back of my mind, I’m always extra cautious. Always the thoughts of, “OK, what if I relapse? What will I do for treatment?” The choice of do I do treatment again or do I not? Do I really want to go through it all over again? I don’t know.

So end of life has been a big issue. I prepared myself for that. I don’t want the burden of that to be on my family so I’ve planned and I’ve paid for my funeral costs. Have my will done. So that it’s just taken care of for them. I know for me I’m not afraid of the dying, I’m afraid of saying goodbye and I would rather them pick up the phone, have the nurses do it and it’s just taken care of. That’s a reality, unfortunately, but that’s just a reality that I had to make...that I thought about. And I know now that if I relapse or if anything happens, that stuff is taken care of. So those logistics, that’s the little part about control, right? Because you lose so much control, these are the little things that you can take control of. And just kind of having an attitude of I’ve gone, I’ve done it, I’m still fighting and I’m going to continue to fight; whatever comes up next comes up next.

Finding a balance

People are like, “you know Lindsay, you’ve got too much cancer stuff going on, it’s all around you.” And then I think but no, that’s who I am. That’s really defined who I am. This is maybe why I’ve gotten this cancer. There’s the big huge question of why. But I know I have to turn them into “this is what’s happened, this is my experience, how can I help others?” And that means in the future, bring awareness, like helping other people, knowing that they’re not alone in their experience. Being able to say “I’ve been there, I’ve done it, I’m here.” Giving that hope to other people. So I don’t think I could ever now pull myself out of that whole cancer world. It is who I am. I have totally accepted that. And now it’s just incorporating it into my life in a healthy way.