

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'Making Your Mark: A Transgender Cancer Patient Story'

Description:

Join us as we speak with Chelsea Brickham, a transgender model, actress, and professional cosplayer who was diagnosed with Stage II Hodgkin lymphoma in 2013. In this episode, Chelsea shares with us what it was like to go through cancer as a transgender female, the reaction from her family and friends, and how she maintained her femininity during treatment. Since her treatment, she has been active in spreading awareness of LGBTQ+ issues at comic conventions and on social media.

Transcript:

Elissa: Welcome to *The Bloodline with LLS*. I'm Elissa.

Edith: I'm Edith.

Lizette: And I'm Lizette. Thank you so much for joining us on this episode.

Elissa: Today we will be speaking to Chelsea Brickham. Chelsea is a transgender model, actress, and professional cosplayer who was diagnosed with Stage II Hodgkin lymphoma in 2013. She is active on social media and brings awareness of LGBTQ+ issues to ComicCon panels and small group presentations.

Welcome Chelsea.

Chelsea Brickham: Hi, thank you.

Elissa: So, let's start with your diagnosis of Hodgkin lymphoma. What were the signs and symptoms that led you to being diagnosed?

Chelsea: So initially I dismissed some of the key symptoms as being side effects of other things that I had been doing. Maybe using a different type of soap. When I was feeling itchy, I kind of justified that. And there were night sweats as well, and it was

very textbook. I didn't realize that at the time, but I assumed that it was just because I was leaving my heater on overnight or something and living up in Boston, it gets pretty cold at night.

Those were some of my symptoms and then also I noticed an asymmetrical swelling in my neck lymph nodes, mostly on the right side. I was even telling jokes at work and saying, like, you know, "Well maybe I should get this checked out again. Maybe I need another sick day." And when I went to my primary care physician, who is usually very jovial and smiling, he took a look at that and he was very serious. And he said, "I think I'm going to need to refer you a specialist, ear, nose, and throat specialist."

And those were kind of some of my symptoms in the path toward diagnosis. And it wasn't until my biopsy that it was finally official that I had been diagnosed with Stage II Hodgkin's lymphoma. It was quite the road, and I was really in denial about it, about having cancer. You know, it's just something that I didn't foresee as part of my life. You know, I'm Chelsea Brickham, I don't get cancer.

Elissa: Yeah. How old were you when you got diagnosed?

Chelsea: I was 31 years old. Yeah. And I turned 32 during chemotherapy.

Elissa: And it's just kind of right in the heart of your career too when you're getting this diagnosis that all of a sudden you have cancer.

Chelsea: True. Yeah. I was working as an electrical engineer for the DOD (Department of Defense) at the time at a shipyard and this was eight or nine years into my employment there suddenly I had a cancer diagnosis. I didn't know how to react to it. I didn't know if it was okay to tell people in the workplace or if I wanted to even be known as the cancer kid, young adult with cancer in the workplace in such a stressful work environment as the DOD or US Navy. So that was another thing that I kind of had to navigate as well.

Lizette: Usually at that age and if you're otherwise healthy, they're not looking for a cancer diagnosis, so you probably weren't expecting that when you went to the doctor.

Chelsea: Absolutely not, yeah. That's the part of the reason I was kind of still joking about it, like, "Obviously, it's an infection of some kind. I don't have any other symptoms like sneezing or coughing or anything, but, obviously, it's some kind of bacterial infection. Just give me some antibiotics and I'll be on my way." And so, yeah, I was totally in denial, absolutely.

Lizette: And what treatment did you receive? Did you start treatment right away?

Chelsea: So, I did my biopsy in early November 2013, and then I started chemotherapy. Actually, I went to Bermuda for a week just to get away from everything, just to not do anything. They were, like - "We want to, we want to cut you open next week." And I was, like, "I will be in Bermuda, and I'm not cancelling that trip." But, obviously, leaving Bermuda was very difficult because I knew what I was coming back to and as soon as I got back, I was pretty much scheduled for surgery the following week and chemotherapy the week before Thanksgiving. Yeah. So it was a pretty quick turnaround.

Lizette: I'm glad that you and your doctors were able to schedule that in. It really shows the open communication you have with your treatment team, that you are part of deciding your treatment.

Chelsea: Yeah. I got first and second opinions for both the specialist and then later for also the chemotherapy approach as well.

Elissa: How long did your treatment end up going for?

Chelsea: I did every other Thursday starting the Thursday before Thanksgiving through the end of April 2014.

Edith: As you mentioned, you were in your early 30s when you were diagnosed. Many young adults struggle with the financial aspect of a cancer diagnosis. Did you have insurance through your employer at that time?

Chelsea: I did, yes. Government employee health insurance is pretty robust, so I was fortunate to have some decent health insurance through my workplace. And I definitely hit my out-of-pocket maximums for both 2013 and 2014 pretty quickly into my diagnosis. So, yeah, fortunately, I was in a good position. I understand not everyone is and I do what I can to try to help, but in my situation, I had some excellent health insurance.

When I was dealing with insurance and things like that, I was somewhat concerned about the cost, before I knew the true cost, I was worried about how I was going to pay for some of these bills and things like that. So, some of my friends suggested crowdfunding or raising money somehow through different websites and things like that. And I didn't end up using any of those options myself, but, my out-of-pocket maximum, was reasonable enough that I was able to balance it myself. But I know a lot of people turn toward crowdfunding and things like that to really help with those costs.

Elissa: Yeah. Between the deductible and the out-of-pocket cost, that can be overwhelming for people. I think my out-of-pocket cost was \$4,000, and I hit that basically on the first day at the hospital after diagnostic testing. But I was lucky that my parents stepped in and helped with that because I would've had to pull that out of savings, which I was going to have to use over the next few months of not working. And so that can be really hard. And it's kind of sad to know that in our healthcare system, people have to crowdfund for support.

Chelsea: Yeah. That shouldn't be the case. I was worried about my job. I took a bunch of time off, like four or five days at a time for each chemotherapy. I chose Thursdays because I had Friday, Saturday, Sunday off already. So just taking

Thursday off with the option of taking Monday off was adequate enough for me to recover from each of my chemotherapies. So, I actually did end up working completely through my chemotherapy but, but that's not always the case, certainly.

Elissa: Yeah, that's tough. And we have an advocacy arm at LLS, and we really try to push policies that are making it so that patients can get quality care and they can afford quality care without making that decision of possibly going bankrupt at some point in the future just to be able to live.

Chelsea: Yeah.

Elissa: Now you went through treatment then as a transgender female. Before we get into the details, would you define both transgender and LGBTQ+ for our listeners?

Chelsea: Absolutely. LGBTQ+ is the umbrella community that covers all of lesbian, gay, bisexual, transgender, and questioning individuals. So generally sexual identity and sexual orientation is the kind of group that we all fall under. And we celebrate in June, and we kind of enjoy being whoever we want to be and loving whoever we want to love. And it's a nice time in June to kind of demonstrate that. So, I frequently join pride parades and things like that, and I talk about GLBT or issues at ComicCons and things of that nature.

But to me transgender typically means you feel very strongly or identify very strongly with a different gender than you were assigned at birth. So, if you feel that the two don't quite match up, there's a lot of individuals like myself who were assigned male at birth but identify as female throughout life and then eventually, do surgery and hormones to kind of ease the body into congruency with the mind. But there's also nonbinary people that prefer they/them pronouns and things like that, so they are included in the transgender umbrella as well. It runs a full spectrum of generally people who don't fully relate to the body they were given.

Elissa: Now if our listeners don't know, how would you define nonbinary?

Chelsea: Nonbinary typically doesn't relate to either gender extreme, so its somewhere in the middle between the different genders and generally they just like to not really identify with either side. So that's either, emotionally sometimes they'll change their appearance to be kind of androgynous or just kind of gender fluid, and that's perfectly fine as well.

Elissa: Now do you remember being a particular age when you felt like you identified more with being female?

Chelsea: Yeah. I have plenty of photos from my childhood age three and four when I was seriously asking my mom to take me dress shopping because all the girls are wearing dresses and I want to be like them. I feel like I'm like them and I want to be one of them.

I didn't understand, why I didn't get a Sweet 16. I didn't understand why girls could wear both skirts and dresses and pants where I was only relegated to pants and shorts. And, yeah as a young person didn't understand why I was being so rigorously controlled by my parents.

Elissa: Yeah. Now, speaking of dresses, you made the decision to wear formal dresses during your treatments. Can you tell us about that?

Chelsea: Absolutely. Yeah, I have quite the dress collection I guess maybe as a side effect of not having them as a child. So, I have a beautiful, wonderful dress collection, and I decided to wear beautiful dresses to each of my chemotherapies as almost like an individual celebration or reclamation of my femininity that I'm losing. It took me a lot of effort to maintain my feminine appearance, which, obviously, includes having nice hair and manicured eyebrows and things like that a lot of which gets stripped away when you enter a chemotherapy program.

So, in the absence of that, I decided to celebrate my own individual femininity by wearing formal dresses to my chemotherapies, which I asked beforehand if it was okay

if I do that. And they said, "As long as that you have access to your chemotherapy port, then it should be fine."

Elissa: That's good that your doctors were so supportive of that, and your nurses. What was the reaction of your family or friends to you wearing dresses?

Chelsea: My family did not respond well to it. My parents have always been very strict and controlling, as I touched on, and they're both former military and very conservative. And they kind of viewed it as a disrespectful act toward them, which, obviously, it wasn't, but they no longer came to my chemotherapies as a result of me doing that. But my friends came out in droves when they found out that my family was not stepping up very well during that time. So I am eternally grateful to my many close friends that I had in my Greater Boston Area who came and saw me and sat with me during infusions and things like that. It's important to have that support structure whether it is family or friends certainly.

Elissa: That's good. That must've been so hard to have your parents kind of break away at the point when you needed them.

Chelsea: Yeah, it was difficult. But I mean I'm not surprised because they had pulled similar things in the past with not being supportive of the transgender issues even though it's something they always knew was part of my life from an early age. So, I replaced them with friends instead.

Lizette: That's something I think we've been hearing a lot more that a lot of people's friends really become their support during their cancer journey and not everyone will have family there, but a lot of our guests have said that their friends were there for them, they became their family and that was something that did lift them up through treatment.

Chelsea: Yeah. I like to refer to them as chosen family because it feels like they're nonblood family and it definitely made a difference.

Elissa: With all that going on with your family, then your friends stepping up, but then losing your hair and losing that almost crucial part of femininity for women, for people that identify as female. What was that like just that emotional impact for you of cancer and treatment?

Chelsea: It was hard and one stressful thing that actually made it easier for me was coming out as transgender in the workplace. Before that time, I had not because it didn't seem that important to me to be openly trans in the workplace, and I decided to come out as transgender because I would be losing my hair and I didn't want to be seen as a bald guy in the DOD. So I came out as transgender and actually got a really nice wig. So, the weekend I shaved off my hair for the treatments, I styled a wig nicely and that's what I came into work on Monday wearing. So, they didn't see much of a change, but there is definitely, definitely a huge change.

Elissa: Were your coworkers supportive of you through your cancer, through coming out as transgender?

Chelsea: It was mostly well received. Switched bathrooms the following week and didn't have any issues. There had been isolated incidents where a person that transitioned from male to female, because we have a very engineering, scientific workplace, and so it occasionally comes up, but it was pretty well received. I didn't even tell my coworkers I had cancer. I just went about my day as a female instead.

Lizette: Now you were undergoing hormone therapy at the time of your diagnosis. Was there any concern about continuing that during your treatment or did it have any effect on your chemotherapy?

Chelsea: By that time, I had been on testosterone blockers and estrogen for about ten years, and I continued it through treatment with the advice of my primary care physician and my oncologist. So, I wanted to make sure that it wasn't going to interfere with anything, and it didn't so I continued with my estrogen supplements and things like that.

Lizette: That's good.

Elissa: We've heard from other patients that their doctors weren't sure if they would've gone for a bone marrow or stem cell transplant if that would've affected that or they would've had to delay it. Did they talk to you at all about the possibilities of needing a bone marrow or stem cell transplant and how the hormone therapy might affect that?

Chelsea: They did not touch on that. I had Stage IIb Hodgkin's lymphoma, and it responded very well to chemo. And by the end of my fourth treatment, early January 2014, I was already in remission.

Elissa: That's wonderful.

Chelsea: Yeah. So, it responded very well. At that point, they said, "You can stop chemo and do radiation or you can continue with the full 12 chemotherapies to maintain the statistics of the chemotherapy drugs." And I chose the short-term side effect chemotherapy over the long-term side effects of radiation. At the time, I was working in Southern Maine and driving down to Boston at Dana-Farber and radiation would've been like an everyday thing. It would've been a little bit more difficult to do that every day rather than every other Thursday for chemotherapy. It was easier for my schedule and I think it was a better choice for my body as well.

Edith: As a transgender patient, do you feel like you faced any discrimination during your treatment?

Chelsea: Not really. Boston is really good about including LGBT individuals in their medical guidelines and things like that so, for the most part, I felt included and respected in medical spaces. Obviously, the one exception to that would've been the very first chemo when my dad came along, and he threw a fit when I told the doctor I prefer female pronouns. But other than that, everything went smoothly.

Elissa: That's good. That's always good to hear when you are treated like every other patient and still as a valued individual. So it's really good to hear that you did well within the healthcare system.

Chelsea: It depends a lot on the mentality of the state. Massachusetts, and Boston in particular, is pretty liberal when it comes to including LGBT. Even their state insurance will cover a lot of transgender, what would otherwise, be considered cosmetic procedures like facial feminization surgeries and even breast implants and things like that, for transgender diagnosed patients. They'll cover all those expenses so it's quite nice there.

Elissa: Now you have been very open about your cancer story. How would you say that cancer has changed your life?

Chelsea: Oh wow! Prior to cancer, I kind of just had dreams and aspirations. And after cancer, it really kind of pushed me to start achieving those goals. I bought a small camper that connects to my truck and I parked it at the beach. And that was really something I always wanted to do, and I did it.

Elissa: That sounds like a lot of fun.

Lizette: It does.

Chelsea: It's parked in the driveway. I own a house now, but at the time, I was renting and after a few years of renting, I decided to live in it for a period of time. Yeah. So that was also pretty adventurous, but I own this little house now and it's parked here.

Elissa: And that got you in a good place because you're technically retired from the electrical engineering, correct?

Chelsea: At the time, I wasn't. I was still working full time. This is a couple years after I completed chemotherapy, so I was still going to Boston for annual checkups.

And when I was living in the camper, I would park it outside the workplace Monday through Thursday, do all my working, and then be a weekend warrior after that, off adventuring at ComicCons for the weekends and other weekend festivities and festivals and things like that.

Lizette: That's a great commute. Park it right outside!

Chelsea: Absolutely.

Lizette: I love that!

Chelsea: No traffic. You can sleep in. You could, you get the best parking right across the street.

Lizette: Wow! Yes, you're very adventurous. I love it. Love it.

Chelsea: And I'm an engineer so I upgraded a lot of the systems. I put solar panels on it. I put a heating element inside-

Lizette: Wow!

Chelsea: -the bed. I put Wi-Fi in it. So, yeah. I had all my streaming services ready to go on the TV, you know.

Lizette: It's more like glamping, right?

Chelsea: It really is, yeah. Less surviving-

Lizette: I like that too.

Chelsea: -and more thriving, yeah.

Lizette: Very good.

Elissa: So, we talked a little bit in the introduction about you really advocating and spreading awareness for the LGBTQ+ community, and you did this at CancerCon,

sorry, ComicCon and social media. Could you, tell us more about this? And what is ComicCon for our listeners who don't know?

Chelsea: First of all, that was a great slip because I actually have been to CancerCon as well, and I wore my Supergirl uniform that I wear-

Elissa: Oh yeah?

Chelsea: -to ComicCon also at CancerCon. But anyway, ComicCon is kind of like an amalgamation of comic books and TV and pop culture and movies and everything that has a fandom around it, like *Star Trek*, *Star Wars*, a huge following. You can go meet celebrities. You can go attend panels from those celebrities where they take questions and a lot of cons will have 24-hour movie shows going on in one of the conference rooms or sometimes they'll have, like, a gaming room where you can just go retro game as long as you want on any number of systems with friends. And, they have informational workshops where they teach you how to work with certain materials or just talk about a fandom from its origins through its modern-day thing. So, it's a lot of presentations.

Elissa: Right.

Chelsea: It's a lot of, things you can do, people you can meet, hang out with friends. It's a really nice community that is very encouraging of anyone of any skill level to try your hand at cosplay. Cosplay is really just kind of honoring a character or something that you really enjoy or identify with and bringing it to life through costuming. So, you can make your own costume. You can buy a costume. You can modify an existing costume. It really allows so much creativity to just be poured into this work of passion to share with your friends and enter contests and hang out and things like that. It's a fantastic community. And from my experience, very inclusive and encouraging of anyone to really get involved and just enjoy your interests.

Elissa: Oh, that sounds fun. So, what have you been doing to really kind of spread awareness for the LGBTQ+ community there?

Chelsea: I have sat for panels at various ComicCons, both small and large, to talk about LGBT and cosplay. And most recently, one of my friends, because ComicCon's kind of got put on the back burner, obviously, with the COVID pandemic-

Elissa: Right.

Chelsea: -so one of my friends actually got the idea of having an online on *Twitch* and *Zoom* and a couple of the platforms together. So, they put a ComicCon that had different links to different workshops and stuff like that and I had the honor of presenting LGBT and pop culture to a small group of Zoomers that are attending that virtual con. It was called WebCon. One of my friends in Boston put it on even though it doesn't really matter where they were from because it's all virtual. But it was a lot of fun.

And I did that last summer during the pandemic. I actually got dressed up in my Poison Ivy cosplay and appeared on-

Elissa: Wow!

Chelsea: -camera and I gave a little presentation. And for those who are not aware, Poison Ivy is a very feminine and yet kind of bisexual character as well. So, I kind of introduced my, my presentation that day by talking about Poison Ivy and her attraction to male characters and female characters throughout the comic books and things like that. I do little things like that.

I do openly transgender. I have a Facebook page for my cosplays as well and there I talk about being transgender and the ability to play with gender. In fact, you can do like a gender swap of a character that is traditionally male in a female sort of way, or masculine of a female character as well. So, you can kind of play with gender.

And I also talk about how that can be personal. You can explore gender through cosplay, rather than coming out immediately as transgender. So, there's always an underlying ability to do that with cosplay.

Elissa: Oh, that's really interesting. Now you and I met at CancerCon at the last time it was in person in 2019. And how did you feel as a transgender cancer survivor with all of those patients and survivors and all the issues that we covered there? For our listeners who don't know, CancerCon is put on by Stupid Cancer. It's a young adult cancer conference where we have probably 400 to 500 cancer survivors from all over the country and a few outside of the country come in. So tell us about that and what that was like for you.

Chelsea: It was a lot of fun. That was my first one that I'd ever attended, and I would definitely go again. It's a wonderful cross-section of different types of people because cancer is so random and affects so many different young adults as well. And to see that many diverse individuals come together and really kind of have this common ground already, it was quite lovely to be part of. And I had a blast. I loved everything I was part of. I made some really good friends that I'm still close with even now. And it was really good.

And one thing that I enjoyed especially was at the CancerCon at the registration booth, they had little pins with pronouns on them. And I was like, "Wow, you get that many transgender people?" because that's, my life, that's my perspective, so, of course, I'm going to take the female pronoun. But, also cis women, who identify as female who have been female their whole life suddenly going through chemotherapy and, they don't have any of the characteristic feminine traits and some people call them masculine pronouns. And that was something that pronouns are kind of my eternal struggle. I never really thought that there would be a struggle for someone who is cis female as well. That was definitely eye-opening for me and I can understand why they had so many pronoun pins ready to be distributed. So, it's more than just the transgender stuff. It's definitely respecting humans in general.

I really had a good time at CancerCon. I thought it was very well organized and well attended. So it was definitely fun.

Elissa: That's great. Yeah. One of the things that I really appreciated at CancerCon was the pronouns but then also the different colored lanyards, so you could tell if there was another cancer survivor because they were wearing the red lanyard. And so, you could just go up and you'd know their pronouns right off the bat if they were wearing their pin and then also you could just say, "Hey, what kind of cancer do you have?" and just find that immediate way to connect with people.

Chelsea: Absolutely, yeah. You can connect over similar experiences with similar cancers or learn about someone with a completely different cancer or even a rare type of cancer and find out what their life experience has been in that situation.

Elissa: How is it important to you to be able to spread awareness of transgender issues and LGBTQ+ issues to the general community?

Chelsea: I think it's very important because a lot of the sexuality issues kind of go unseen. And even though there's the same percentage of people that have always been LGBT, you're hearing more about it because it's a big part of who they are. And especially with sexuality issues so you don't really notice, but even more so with the transgender as well because a lot of people don't understand it, they don't relate to it. I find that it's much more important to be open and kind of give people the exposure, because the more exposure they have to LGBT, the more they understand it as being a prevalent characteristic of a certain percentage of people in society.

Elissa: What would you say to transgender patients going through treatment? And then after what you had experienced personally, what would you say to their family and friends?

Chelsea: Wow, that's a good question. I would say, "Be patient with yourself and try not to be too hard on yourself. It's going to be rough for a bit, but you can recover

and you can celebrate yourself, your individual identity in different ways. So, find something small that works for you that brings you joy and kind of figure out a way to center yourself." Meditation helped me quite a bit, but there are other ways to kind of relax and concentrate on right now rather than being overwhelmed by everything.

And I would tell their family just to try not to overwhelm the cancer patient. Don't do anything that will make the situation more difficult for them because cancer is something that'll change your life. That's trauma. And to emerge from that is going to require a lot of positivity and help from everyone involved. So, if you can't be that person, then I would try to find someone to talk to outside of your circle so that you can be that person.

Elissa: Now I do want to briefly mention on this podcast about our LLS community. If you haven't heard about it, we do have an LGBTQ+ group in there and that's where users are able to connect with other patients or caregivers in the blood cancer community.

We always want to make sure that all of our patients and caregivers can find that support from others going through the same thing. So, Chelsea, we hope that you will join if you haven't already. And to our listeners, you can go to [LLS.org/Community](https://lls.org/community) to join any group that fits your needs. So that can be LGBTQ, that can be diagnosis specific, young adults, caregivers. We have so many groups available so you can connect with other people kind of like we did at CancerCon with just connecting with other young adults going through cancer. And so, the link will be in the Show Notes, but, yeah, Chelsea, we would love to have you join and really just be able to connect with that community as well.

Chelsea: Yeah, that sounds like a blast. I'll definitely do that.

Edith: On our patient podcast home page, we have a quote that says, "After diagnosis comes hope." Based on your cancer journey and advocacy experience, what word would you choose to complete that sentence, "After diagnosis comes?"



Chelsea: I would say, "After diagnosis or after your cancer experience comes kind of an awakening of your existence." Life is fleeting so you want to really take advantage of all the time that you have to really make the mark you want to make on society. So, it's important to really just become your best version of yourself and move forward in your survivorship.

Elissa: I love that. Well thank you so very much, Chelsea, for joining us today and for really just sharing your experience of what it was like to go through cancer as a transgender patient, what it was like with your chosen family and all the experiences that you have, and how much you're just really spreading awareness of the issues that come with being a transgender patient and individual. And so, we really appreciate you sharing, and I know that some listeners are going to really be helped by this.

Chelsea: Excellent. I'm so glad.

Elissa: And thank you to everyone listening today. *The Bloodline with LLS* is one part of the mission of The Leukemia & Lymphoma Society to improve the quality of lives of patients and their families.

To help us to continue to provide the engaging content for all people affected by cancer, we would like to ask you to complete a brief survey that can be found in the Show Notes. This is your opportunity to provide feedback and suggested topics that will help so many people. We would also like to know about you and how we can serve you better. The survey is completely anonymous and no identifying information will be taken.

We hope this podcast helped you today. Stay tuned for more information on the resources that LLS has for you or your loved ones who have been affected by cancer.

Have you or a loved one been affected by a blood cancer? LLS has many resources available to you – financial support, peer-to-peer connection, nutritional support, and more. We encourage patients and caregivers to contact our Information Specialists at



1-800-955-4572 or go to [LLS.org/PatientSupport](https://lls.org/PatientSupport). You can find information specific to young adult cancer at [LLS.org/YoungAdults](https://lls.org/YoungAdults). All of these links will be found in the Show Notes or at TheBloodline.org.

Thank you again for listening. Be sure to subscribe to *The Bloodline* so you don't miss an episode. We look forward to having you join us next time.