

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'LIVE! At CancerCon: The Roadmap of Survivorship'

Description:

Please join us for this special episode live from CancerCon®, a young adult cancer conference presented by Stupid Cancer®. In this episode, we'll be speaking with patients and survivors about where they are along the road of survivorship.

In the exhibit hall, we displayed a roadmap of survivorship, which had many detours and pit stops along the way towards long-term survivorship. The responses from young adult patients and survivors varied and each person had different milestones or points along the road that they found significant.

We encourage our listeners to view the roadmap on the episode page. To our patients and survivors, where do YOU fit along the road? Be sure to share in the comments or discuss in the PodClub in our Subscriber Lounge.

Be sure to stay tuned for the next episode from CancerCon, where we will be hearing from experts who presented on various ways to cope with a cancer diagnosis and treatment.

Transcript:

Elissa: Welcome to *The Bloodline* with LLS. My name is Elissa and today we are podcasting live from CancerCon®, a young adult cancer conference put on by Stupid Cancer®. This year the conference is taking place in Atlanta, Georgia and is attended by several hundred adult cancer patients, survivors, caregivers, and healthcare professionals.

LLS is a proud sponsor of this annual event which is attended by people affected by all cancers. However, blood cancer patients and survivors often represent around 40% of the total attendees each year.



The LLS theme at this year's conference is the Roadmap of Survivorship. The term survivorship is defined by the National Cancer Institute (NCI) as the health and well-being of a person with cancer from the time of diagnosis until the end of life. This includes the physical, mental, emotional, social, and financial effects of cancer that begin at diagnosis and continue through treatment and beyond.

Patients and survivors can be at all different points along the survivorship road as progress and healing are not linear. In the Exhibit Hall, we have made up a diagram of what a road may look like having many detours and pitstops along the way towards long-term survivorship.

On the Episode page, we will have a picture of the roadmap that we had at the conference. I encourage everybody to go take a look and see what the patients and survivors were taking a look at. There are all different points along the road – diagnosis, insurance, treatment, work, school, family planning, relapse, and then long-term remission.

So, we wanted to hear from the young adults with blood cancer on where they are along the road. Did they feel stuck somewhere? Have they revisited some places along the road? Do they ever feel like they're moving backwards instead of forwards?

While they will be interviewing young adults in this episode, survivorship is a topic that is relevant to all ages. We encourage you to stay tuned and find connection as all patients and survivors of cancer move along the long windy road of survivorship.

So, let's get started.

Drew: My name is Drew. I'm 31 years old, and I have been cancer-free for over 5 years, coming up on 6 years later this year.

Elissa: And what kind of cancer?

Drew: I had Stage II Hodgkin's lymphoma.

Elissa: Okay. So, I want you to take a look at the Roadmap of Survivorship. Where do you feel like you fit along the road right now?

Drew: It feels like I'm very far down the road, in regards to long-term remission.

Drew: It is interesting because I did just notice the survivor's guilt and I do think that's something that I've absolutely experienced.

Elissa: Yeah.

Drew: It's something that I think is real and especially for me in Hodgkin's lymphoma, which is a very treatable form of cancer.

I don't think most people understand. They just hear cancer and they correlate cancer to struggling and maybe even potentially death, whereas Hodgkin's lymphoma's a very treatable form of it.

And I had a relatively smooth treatment process. So, I definitely dealt with this guilt where people were defining me and labeling me as something that I didn't really feel like I was for much of my process.

Elissa: Right. Yeah, absolutely. Does anything else jump out at you on that road?

Drew: Oh, man. I think I noticed fear of relapse. I think my attention caught that. It's something that I've thought of at times, when like a bloodwork might be a little bit weird. It's hard not to let your mind go there, but I think I have a pretty good relationship with that. And I do think that self-esteem and emotional and physical effects, I do feel like I'm better in those places than ever. I've really focused on my lifestyle, my overall holistic health since my cancer diagnosis, and I'm very much all into healthy lifestyle and living.

Elissa: Yeah, absolutely. So, you mentioned fear of relapse with the blood tests. Are you still getting tests or scans?

Drew: So, I'm still doing bloodwork at least once a year, if not multiple times because I have my oncologist as well as my primary care doctor.

Yeah, I think that I'm aware of potential relapse, but also of long-term side effects as well. That's something that I'm interested in.

Elissa: Right.

Drew: But, I do think that I am in a comfortable and confident place, that I'm doing everything that I can, and that there is a certain aspect of things that are outside of our control that I am not worrying too much about.

Elissa: So, you've mentioned that you felt like things were pretty easy. Just looking at the whole road, how do you feel like that journey along the road has gone for you in general?

Drew: I think before cancer, I was a little bit lost in life; and I was doing things that I thought I was supposed to be doing. I had a good high-paying job, but I wasn't necessarily happy and fulfilled with that job. And the shock that was the diagnosis and going through chemotherapy and scaring myself and people around me of just being told I have cancer. It was a big shock.

Elissa: Yeah.

Drew: But, like I said, the treatment was relatively smooth. But what that shock gave me was this curiosity to explore a little bit. So post-cancer, when I was healthy enough to travel, I started traveling in South America-

Elissa: That's good.

Drew: -and I never stopped. So, I live in Spain now, after five years on the road. And I'm living what feels like a very energized, purpose-filled life which I credit to this time period. From that diagnosis to the process and all the things that came up during

it, to creating and initiating the spark of wanting to live and explore inside of me. That hasn't gone out quite yet.

So, it still feels like it's raging strong, the fire of adventure and exploration; and I don't imagine that that will be leaving me anytime soon.

Elissa: Oh, that's awesome. I love it. That is quite the change after a cancer diagnosis.

Drew: Yes.

Elissa: Now, we have quite a lot of milestones on that road. Does anything particularly connect with you, any milestone on there?

Drew: Well, there's the work/career. That's the one that stands out the most. I just totally changed everything and changed my focus, and I think that I had known at a deeper level that money was not the source of happiness; but I think I wanted to actually take action on that after going through a cancer process. Not just talk about it but put it into action.

Elissa: Right, absolutely.

Drew: Yeah.

Elissa: All right, Drew, our last question today. On our patient podcast home page, we have a quote that says, "After diagnosis comes hope." Based on your cancer experience, how would you complete that sentence? After diagnosis comes-?

Drew: After diagnosis comes freedom, opportunity.

Elissa: All right, what does that mean to you?

Drew: It means a different perspective, a different way of looking at the world, a heightened sense of gratitude and appreciation, and a sense of going for it and not



waiting. Doing the things that you've always wanted to do. Doing the things that energize you and excite you-

Elissa: Yeah.

Drew: -and not waiting. There's no better time than now.

Elissa: That's awesome. Well, thank you so much, Drew, for taking the time to talk to me today; and I hope you have a great rest of the time at CancerCon.

Drew: Thank you very much.

James: James. I'm 36 years old. Diagnosed with acute lymphoblastic leukemia, so B-cell ALL. And right now I'm in long-term survivorship.

Elissa: Okay. So, I want you to take a look at that Roadmap of Survivorship. Where do you feel like you fit along that road, right now?

James: I'm probably somewhere in this bend of long-term remission, where there's like still some emotional effects and physical effects to keep sifting through, I would think.

Elissa: Yeah, yeah. So, getting closer to long-term remission; but still not quite there?

James: Yeah.

Elissa: How do you feel like this journey along the road has gone for you?

James: I think in the beginning I was very much like, "Oh, I'm just going to push through and power through," and I had a great support system, was really honored by the amount of love. I was diagnosed in high school, and so I felt like I was going to be moving through all these phases really fast.

I had a big hard moment about one month in. People who have leukemia treatment will know that first month is usually called induction; and I was not really educated about what would be coming after that. And so, I thought at the end of induction, maybe I had a little bit more, and I'd be done. But then I got hit with that day, "Okay, your disease is looking good at the end of induction. Now, here's the next 2-1/2 years."

Elissa: Yeah.

James: And so, that was really hard, and I've heard that in other people's stories. So that was a big struggle or tough time.

Maintenance had its ups and downs. I had a diagnosis of pneumocystis pneumonia (PCP), the night that I graduated from high school. And that was actually the scariest moment.

But since then, it's just been a rollercoaster of remembering and honoring my past, but not dwelling on it. Just now, in the last year or two, even though I work in the cancer healthcare space, realizing that I haven't really processed a lot of what I went through. So now I'm kind of learning, "Okay, it would be good to talk this out with a professional counselor and process some of the things instead of just burying them,".

Elissa: Yeah, absolutely. Are there any milestones on this map that particularly jump out at you?

James: One thing that's on here is insurance. The thing that's been interesting for me, it's probably different than the way most people would think of it is, I had health insurance through my parents at the time. And now I don't have a coverage issue. I have a good job.

But life insurance is this new thing I'm running into with now having a child of my own, a wife, and owning a home and the struggle of figuring out how to get a larger policy that makes my family feel secure if something was to happen to me that doesn't cost

us an arm and a leg because of my cancer history. And that's just something that we still have a lot of grounds to gain in how to improve that situation for survivors of cancer, I think.

Elissa: Absolutely. Some insurance companies, yes, you can get it after a certain amount of years in remission. But that does not mean it's going to be affordable.

James: Exactly.

Elissa: So, our last question, on our patient podcast home page, we have a quote that says, "After diagnosis comes hope." Based on your cancer experience, how would you complete that sentence? After diagnosis comes-

James: After diagnosis, comes shock; but then, luckily for me, support in the midst of that shock. So, while I was a typical teenage guy and I kind of shut down and was shocked for several days, I had a great community that did surround me and support me and love me and that made all the difference.

Elissa: Yeah, that's great.

Well thank you so much for talking with us today. We really appreciate it, and I really hope you enjoy the rest of your time at CancerCon.

James: Of course, thanks, Elissa.

Elissa: Thank you.

Flavia: I'm Flavia. I'm 36 years old now. I was diagnosed with Hodgkin's when I was 23.

Elissa: So, take a look at that Roadmap of Survivorship. Where do you feel like you fit along that road?

Flavia: Right now, I think I'm in the long-term remission.

Elissa: Yeah, just right there at the end where we have an ellipsis right there where, who knows what's going to happen.

Flavia: Yeah.

Elissa: And you build this story of your life. So, how do you feel like the journey along that whole road has gone for you?

Flavia: Actually, for me, when I was diagnosed, I felt really lonely, like I was the only girl facing cancer in the world.

Elissa: Yes.

Flavia: And, when I had the relapse of the cancer two years later, I decided to change it. So, I started a blog to share my story.

Elissa: Okay.

Flavia: And from the blog, I became working with cancer patients. And now I'm the President of an institute in Brazil that helps cancer patients of any type of cancer.

So for me, it was really important to keep on moving, even though I had cancer because I stayed under treatment for like three years. I never knew how much longer I would live, but we actually never know.

Elissa: Yeah.

Flavia: So, it's something that I had to deal with. And now, this year is my 10th anniversary-

Elissa: Yay!

Flavia: -of bone marrow transplant.

Elissa: Okay.

Flavia: So, I'm really happy to see how far I came. But I only came so far because I was not afraid to make the next step without knowing how long I walk.

Elissa: Right. Now, do you feel like there are any milestones there that jump out at you?

Flavia: I think first treatment was really tough.

Elissa: Yeah, how so?

Flavia: Because it's like you have to go back to normal life, but life's never normal again.

Elissa: Right.

Flavia: It's never the same after the diagnosis. So for me, it was challenging because I felt like I needed to do something with my life. I needed to do something meaningful for me and for others. But, somehow when you're young, people expect it's like you're rehearsing your life, you know?

Elissa: Yes.

Flavia: Like, it's not your real life. Your real life will start when you have kids, when you graduate, when you get married. And so. It was really hard for me to understand that I had to live what I could and not what people expect me to do.

Elissa: Yes, live your own life.

Flavia: Yeah.

Elissa: I like that. So, our final question. On our patient podcast home page, we have a quote that says, "After diagnosis comes hope." Based on your cancer experience, how would you complete that sentence? After diagnosis comes-?

Flavia: Courage.

Elissa: Courage, what does that mean to you?

Flavia: I mean you have to be really brave to keep on living in spite of cancer and understand that we will never know what's going to happen next.

Elissa: Right.

Flavia: So, life is always surprising for us, especially when you have cancer this young. It's like you have to just be brave enough to go ahead.

Elissa: I love that. Well, thank you so much for joining us today, and I really hope that you enjoy the rest of your time at CancerCon.

Flavia: Thank you. Thank you so much.

Sarah: My name is Sarah. I am 35, and my diagnoses have been neuroblastoma and acute myeloid leukemia, as well as having a bone marrow transplant.

Elissa: And where are you at after your transplant?

Sarah: I am in remission right now.

Elissa: Wonderful. So, I want you to take a look at the Roadmap of Survivorship. Where do you feel like you fit along the road right now?

Sarah: Long-term remission.

Elissa: That's great.

Sarah: I am seven years out from my transplant-

Elissa: Okay, I love to hear it. Now, how do you feel like the journey along the road has gone for you?

Sarah: It has been extremely bumpy and definitely a lot of hills on that road.

Elissa: Yes. Are there any milestones that jump out at you in particular?

Sarah: I would say chronic care has been the biggest. I've had a lot of complications that were unexpected and getting over those have been the hardest part.

Elissa: Yeah, that's tough. And, physically it's been a difficulty for you too, right?

Sarah: Oh, yeah. I ended up with a very uncommon complication. I ended up with a brain parasite called toxoplasmosis-

Elissa: Oh, goodness.

Sarah: -after my transplant; and it caused a cognitive injury. It caused some intestinal pancreatitis, and recovering from that has been just as hard compared to the bone marrow transplant as well. That's taken a huge toll and learning to recover from that has definitely been a journey in itself.

Elissa: So, our final question today, on our patient podcast home page, we have a quote that says, "After diagnosis comes hope." Based on your cancer experience, how would you complete that sentence? After diagnosis comes-?

Sarah: I would have to say struggle, but then once you find your footing, you just find a way to move forward. And there are people who are there to help you. When you find your people, you learn how to get there.

Elissa: Absolutely.

Sarah: And you sometimes just are lucky enough to meet the friends who help carry you through it as well.

Elissa: Yes, find that support.

Sarah: Exactly. And that's essential.

Elissa: Well, thank you so much for joining us today on the podcast. I hope you enjoyed CancerCon. I know it's been a few years since you've been able to come. So, welcome back; and I hope you enjoy the rest of it.

Sarah: Thank you. I've had a wonderful time here.

John: My name is John. I'm 32 years old. My diagnosis is Hodgkin lymphoma, and I was diagnosed with it back in 2018.

Elissa: And where are you at with your treatment now?

John: Five years in remission.

Elissa: Awesome. So, I want you to take a look at that Roadmap of Survivorship. Where do you feel right now that you fit along that road?

John: I would say probably long term in remission.

Elissa: Now, how do you feel like the journey along the road has gone for you?

John: Um, been kind of rough-

Elissa: Yeah.

John: -and it was a little bit a dark place but kind of got out of it.

Elissa: That's good. I'm glad you were able to get out of it. We know that healing is not linear.

John: No.

Elissa: It tends to be a very squiggly road, just like that picture right there.

John: Yeah.

Elissa: Now, are there any milestones on there that you feel like jump out at you on that roadmap?

John: Probably the school because that's where I got diagnosed with my lymphoma my sophomore year. I thought I was with infections and then when doctor told me, "Hey, you've got cancer," I was so upset and felt bad. And I had to go back from school to home to do my chemo treatments. So, it was very hard, very rough.

Elissa: Yeah, I'm glad that things seem to be going better now; and you feel like you're really on that road to long-term remission.

That feel better now?

John: Yeah. It feels a whole lot better.

Elissa: It is hard to look back at those times though.

John: Yeah.

Elissa: So, our final question, on our patient podcast home page, we have a quote that says, "After diagnosis comes hope." So based on your cancer experience, how would you complete that sentence? After diagnosis comes-?

John: After diagnosis comes, hmm. That's a hard one.

Elissa: I know. You always want to just say hope.

John: Yeah, just hope and good luck and good life, yeah.

Elissa: Well thank you so much, John, for joining us today; and I hope that you have a great rest of your time at CancerCon. Is this your first one?

John: Yes, this is my first one.

Elissa: Wonderful. What are you thinking so far?



John: It's great. This has been really great. I got to meet people that were diagnosed like I am, and this is really, really awesome to be around with good, positive people. I've been around some negativity before-

Elissa: Yes.

John: And this is a big change for me, and being around-

Elissa: Yeah, and they just understand you.

John: Yeah, they understand where I'm coming from.

Elissa: Yeah, that's wonderful. Well thank you so much, John. Appreciate it.

John: It's no problem.

Elissa: So we've heard from a few patients and survivors already and, wow, what incredible stories and journeys along the road of survivorship. We're hearing different experiences, but we're also hearing some similarities, so let's take a listen to a few more.

Adrian: My name is Adrian. I'm in remission right now. 27.

I've been in remission for 16 years now, and I'm a childhood leukemia survivor.

Elissa: Okay. What kind of leukemia?

Adrian: It was a combination of AML and ALL. Now I can't remember which was which, but it was like 85% of one and 15% of the other.

Elissa: Wow!

Adrian: Yeah.

Elissa: So, I want you to take a look at the Roadmap of Survivorship. Where do you feel like you fit along that road right now?

Adrian: I think, thank God, it's safe to say at the long-term remission.

Elissa: I love it. Okay.

Adrian: Yes.

Elissa: So, how do you feel like that journey along the whole road has gone for you?

Adrian: I just talked about this in one of the sessions we're in, but I think it's been one long discovery process of myself.

Elissa: Yes.

Adrian: Other than the physical hardships I had when I was going through treatment, I think for me being a kid, it was this thing you experience and then you go back into the real world. And then, over that time I've been kind of coming back to then. I feel like this whole event here I'm linking those two things together to that kid, when I was sick when I was younger.

Elissa: Yeah, definitely. So, are there any milestones along the map that jump out at you?

Adrian: Yeah. I would say diagnosis. I still have a vivid memory of that—

Elissa: Oh do you?

Adrian: -when I had that, yes.

Elissa: How old were you?

Adrian: I was nine years old.

Elissa: Okay.

Adrian: There was no symptoms leading up to it. I was at public school at the time in Brooklyn. I remember just having this really sharp pain in my leg.

Elissa: Right.

Adrian: And I literally couldn't walk down the stairs. All of a sudden somebody had to help me down the stairs, and I couldn't make it up the block and just everything happening so fast. To this day, I thank my grandma who passed away a couple years ago because she recommended a specialist, and I'm here today because of that.

Elissa: That's good.

Adrian: I still firmly believe that.

Elissa: Wonderful. Our final question today. On our patient podcast home page, we have a quote that says, "After diagnosis comes hope." Based on your cancer experience, how would you complete that sentence? After diagnosis comes-?

Adrian: I'm going to say, insight; insight that nobody else really has. And I'm going to say to everybody listening to this to follow that insight. Don't try and fit back into where you think you were or where you were going to be before life with cancer.

Cancer's a part of you for the rest of your life mentally, where you set yourself up, your support group, so stay with it. Don't forget about it. That's my biggest thing.

Elissa: That's great advice.

Adrian: Yes.

Elissa: Well, thank you so much, Adrian, for joining us today. We really appreciate you. And I hope you have a good time at the rest of CancerCon.

Adrian: Thank you. Pleasure to be here. Thank you.

Elissa: Thank you.

Crystal: I'm Crystal. Age at diagnosis was 32 and the stage was 4B Hodgkin's.



Elissa: Okay. How old are you now?

Crystal: I am 38 now.

Elissa: Okay. So, I want you to take a look at the Roadmap of Survivorship. Where do you feel like you fit along that road right now?

Crystal: Probably long-term remission. I've been out of treatment with no recurrence for five years now, so probably there.

Elissa: Awesome!

Crystal: Yeah.

Elissa: So, how do you feel like the journey along the road has gone for you?

Crystal: It's been ups and downs-

Elissa: Yeah.

Crystal: -you know. Treatment itself is tough. It's a lot. I was living in Las Vegas and my mom came out to help me with treatment, and the first treatment just completely kicked my butt.

Elissa: Yeah.

Crystal: And, I realized pretty quickly that my friend group out in Las Vegas was not equipped to really help me. They were all wage workers, where they were just barely making it, very young and couldn't take off if I had an emergency.

Elissa: Yes, you need a caregiver.

Crystal: Yeah. Yeah. So, I made the decision after that first treatment, and I saw how hard it was to move back home to North Carolina. So, I lost my job, I lost my town, I lost my community, I lost my independence that I had built up-

Elissa: Yeah.

Crystal: -and then moved back home. And, after treatment, it wasn't wonderful either. You're starting to deal with your body is still different and it's slowly, getting back up to snuff but some things just aren't ever going to be the same again because that's just how things are. It took about a year for me to figure out what I wanted to do in terms of work and stuff. Fortunately, my family really supported me, and I got into doing voiceover work, and I've been able, because my family supported me, to really pursue the arts. And that has been good, and it's been good finding other people within that community, who also have physical disabilities. I didn't know there were so many people.

Elissa: Yes.

Crystal: So, I found community there. I found community, because of the cancer community. And so, things have been rough, but they've also been good at the same time.

Elissa: Very good. Love to hear that.

Crystal: Yeah.

Elissa: Are there any milestones along that road that particularly jump out at you?

Crystal: I don't know. Insurance.

Elissa: Insurance.

Crystal: Yes, learning how to navigate insurance was rough. One of the other charities that we have here that is actually to help people navigate things like FMLA and insurance stuff and all that jazz because that was such a maze to me. When I was going through my diagnosis and getting set up on disability insurance and stuff like that, I had no idea how any of that worked.

Elissa: Yes. I totally understand that.

Crystal: Of course.

Elissa: Yes. All right. So, on our patient podcast home page, we have a quote that says, "After diagnosis comes hope." Based on your cancer experience, how would you complete that sentence? After diagnosis comes-?

Crystal: For me, that thing about after diagnosis comes hope was true. I knew I was really, really sick. I knew in my bones that I was dying. So, when I got my diagnosis, it was like, "Oh my God I know what's wrong with me now." And when I found out it was Hodgkin specifically, it was like, "Okay, I'm probably going to actually get better." I was no longer in a state of actively dying.

Elissa: Right.

Crystal: It was like, "I might actually survive this. I have a pretty good chance of surviving this." I tell people my diagnosis day was like my vindication day, because I had friends telling me it was all in my head even as I was losing weight, unable to eat, going through all of these symptoms. So it was a good day. My diagnosis-

Elissa: Good.

Crystal: -day was a good day.

Elissa: Good. It is nice to finally get that diagnosis.

Crystal: Yeah.

Elissa: Well, thank you so much, Crystal, for joining us today. And I hope that you have just such a wonderful time at CancerCon.

Crystal: Yeah, it's been great!

Alexander: My name is Alexander. I am 17 years old, a senior in high school, and I was diagnosed about a year ago with Stage IV Hodgkin's lymphoma.

Elissa: Okay. So, take a look at the Roadmap of Survivorship. Where do you feel like you fit along the road right now?

Alexander: Yeah. It's a convoluted path and it's rarely a linear one, but I would say I'm post-treatment, I'm in remission. And I'm navigating life as a survivor and reconciling my six months of treatment with my identity as a highschooler.

Elissa: Right. So how do you feel like the journey along that road has gone for you?

Alexander: If you were to ask me the day before I was diagnosed to imagine what it would be like, I would never have told you because there are so many clichés and narratives that we expect, that we model our notion of cancer after. But as a patient, I noticed that I did not fit into any clichés. When I was diagnosed, I expected I would experience some profound existential revelation, I would cry, I would feel something; but I just stared at the doctor and asked him if I was going to lose my hair.

Elissa: Aw.

Alexander: I didn't feel anything. So, I went to school every day when I wasn't in the hospital; and I actually did very, very well, which I never would've expected I could do. And when I finished treatment, I didn't feel as if I had won a battle; I felt as if I just survived and I just existed because cancer is inherently senseless in that it's a soulless product of random mutations. It doesn't have any meaning-

Elissa: Yeah.

Alexander: -which I think like mainstream narrative's kind of obscure. They phrase as like a grand battle, a journey of warriors, but I didn't feel that. I didn't feel that my fight started until I was in remission—

Elissa: Right.



Alexander: -at which point I kind of felt both an intrinsic obligation, and just a like a sense of purpose and fun and advocacy and volunteering in cancer-related work.

Elissa: Yeah, sometimes you do feel like you're not doing anything necessarily, right-

Alexander: Yeah. I-

Elissa: -to get better.

Alexander: Right.

Elissa: You're just doing what you're told. And then you just survive.

Alexander: Yeah. Everything was done in the passive mode. I was given chemotherapy. All this stuff was done onto me, but I was just a passenger. And I would show up for appointments, I would take my pills, and that was that. So, I think there isn't much to say about existing with cancer because that's really all it is you're existing in spite of cancer. And that's something that I realized that I was doing everything, I was succeeding, but I was doing these things only in spite of cancer and that I would never be the same as if I wasn't on cancer, I would always do better, but I was just striving to achieve what had once been normal.

Elissa: Right.

Alexander: Once the barrier of cancer went away and chemotherapy, my inertia really carried me through just to go above and beyond what I would ever expected before.

Elissa: Yeah. So, are there any milestones along this map that particularly jump out at you?

Alexander: Yeah. I think diagnosis has always been the most important milestone for me-

Elissa: Yeah.

Alexander: -because that's the only part at which I felt my life had changed and everything from there on, I was just kind of surviving. But when I was diagnosed, it wasn't necessarily that my life was shattered. I just kind of looked at everything differently. I don't know how I felt, but it wasn't what you'd expect.

Elissa: Kind of that break in time, where it's a before cancer and after cancer, right?

Alexander: Yeah. So, some people describe cancer as a sort of rebirth and that I think I didn't feel reborn though-

Elissa: Yeah.

Alexander: -until after treatment. I felt that, certainly there was a before cancer and after cancer, but, it's muddy. And because your brain doesn't readily adapt to being diagnosed with cancer.

Elissa: Yes.

Alexander: I mean, at least mine didn't. Some people's does. Some people go into shock. Some people, they experience all these emotions, but I didn't. I just felt like a teenager going into treatment. I just had been told I had cancer. So, diagnosis stands out to me because, well, on one hand, it's a large change in your life. It's a dramatic shift and now you're visions for the future just morph into something completely different.

Elissa: Yeah.

Alexander: But at the same time, you don't really change as a person. I think you just reveal underlying aspects of yourself. And in that, you're kind of the same. It wasn't until after treatment for me that I actually felt like I was starting to grow.

Elissa: Right. So, our final question. On our patient podcast home page, we have a quote that says, "After diagnosis comes hope." Based on your cancer experience, how would you complete that sentence? After diagnosis comes-?

Alexander: After diagnosis comes, for me, meaning. I think that's what it was about for me because, I mentioned this earlier, but cancer, especially in children, targets without discernible cause, it's senseless. And for me, my journey, if you will, after diagnosis was about assigning meaning, bringing my own meaning to cancer. So, I think that's sort of what everything has built up to is finding purpose and experience within cancer, which has no meaning on its own. And so, it's a very personal journey in-

Elissa: Right.

Alexander: -that it's about the meaning that you can bring to it. Some people will say that everything happens for a reason. Oh cancer, this is your sign, but that's not true. Cancer didn't teach me anything. Cancer is not a teacher. It's a killer. I didn't learn anything from cancer, but I learned things from myself in the way I processed it, and I had to teach myself these things. They didn't come to me.

Elissa: Yeah.

Alexander: But I think that's what life after treatment was about.

Elissa: Absolutely. Well, thank you so much, Alexander, for joining us today. I hope you have been enjoying your very first time at CancerCon. And, again, thank you so much for talking to us.

Alexander: Yeah, thank you. I appreciate it.

Jaisa: I'm Jaisa. I am 20 years old. I was diagnosed with lymphoepithelial carcinoma Stage II and Hodgkin lymphoma Stage I.

Elissa: Oh!



Jaisa: I currently finished radiation like three-ish weeks ago, so I'm post-treatment now.

Elissa: So I want you to take a look at the Roadmap of Survivorship. Where do you feel like you fit along that road right now?

Jaisa: I'd probably say in the school and work career. I am in nursing school at the University of New Mexico (UNM) and I currently work at UNM Hospital as well, so just getting my life back on track.

Elissa: Yes. Kind of stuck in that circle for a little while.

Jaisa: Yeah, yeah.

Elissa: Yeah. So how do you feel like the journey along this road has gone for you so far?

Jaisa: At first, I would say it was kind of slow. It took about six months from when I found my tumor to get my diagnosis and then after that, it progressed very rapidly. And so, I had my first diagnosis in January and second diagnosis in February, and then had chemo in March, April, May. Radiation June, July, and I just finished.

Elissa: And then lymphoma was your second diagnosis.

Jaisa: Yeah, the Hodgkin's lymphoma was my second diagnosis.

Elissa: Okay. Are there any milestones along that road that particularly jump out at you?

Jaisa: Treatment was a big one. I was stuck there for a while. I mean other people have had treatment for years and years.

Elissa: Yeah.

Jaisa: But I had to stop going to work and school. I was in the ICU for a little bit, and I just felt like I had to pause there for a long time. It wasn't like I could continue with school or work or anything. And I'm very grateful for my parents taking care of me and paying for everything, all of the necessities while I was not working. So, I felt like I was stuck at treatment for a while.

Elissa: Yeah. Definitely feel stuck.

Jaisa: Yeah.

Elissa: Our final question today. On our patient podcast home page, we have a quote that says, "After diagnosis comes hope." Based on your cancer experience, how would you complete that sentence? After diagnosis comes-?

Jaisa: I would say, after diagnosis comes acceptance. It took me a little bit to accept that I had cancer and it's hard to just like, "Oh, you know, I'll be fine; I'll get over it." But it's not something that you just get over. It's not really a bump in the road. It's a big mountain and you have to climb up. And then you get over it and you just have to accept the hair loss and the appetite, the weight loss, the scars. You just have to accept it because you can't change it. You can't get rid of it. It will never not be a part of your story.

Elissa: Right.

Jaisa: So you have to say, "Yup, I have cancer and that was that, but that doesn't define me and it is what it is."

Elissa: I love that. Well, thank you so much, Jaisa, for joining us today. We really appreciate it. And I hope you have a great time at the rest of CancerCon.

Jaisa: Thank you so much.

Elissa: Thank you.



Lucas: Hi, my name is Lucas. I'm freshly 24, and I had acute lymphoblastic lymphoma. And I am, as of August 9th of 2023, two years cancer free.

Elissa: So exciting! All right. So, I want you to take a look at that Roadmap of Survivorship. Where do you feel like you fit along that road right now?

Lucas: I would say near the end in the long-term remission. But, honestly, I don't see me on this map because I see the new version of me is a new and improved version. Not that the previous version prior to my cancer journey was bad by any means, but I think I've taken a lot, I've grown a lot, and there's so many positives to take away. So many beautiful experiences-

Elissa: That's great.

Lucas: -throughout the journey.

Elissa: So how do you feel like the journey along the road has gone for you this whole time?

Lucas: I'm an empath by default, and so I always try to find the optimism in everything and the silver linings. There were some negatives, some hard times for sure.

Elissa: Yeah.

Lucas: But there's always a way to spin it to frame it in a way that really makes you enjoy the moment and make everything as valuable as you can.

Elissa: Are there any milestones on that map that particularly jump out at you?

Lucas: I see the words family, the sex and intimacy part, survivor's guilt, for sure.

Elissa: Yeah.

Lucas: I consider it fortunate that I was able to be in the pediatric care, even as an older teenager when I was diagnosed. Being around all these younger kids, some people view it as negative, but for me, being like that big brother role was everything for me.

Elissa: That's great. So our final question. On our patient podcast home page, we have a quote that says, "After diagnosis comes hope." Based on your cancer experience, how would you finish that sentence? After diagnosis comes-?

Lucas: After diagnosis comes a new take on life.

Elissa: What does that mean to you?

Lucas: It means that anything is possible. There's no limitations. You can do anything and whatever you see fit for the rest of your life, make the most of it.

Elissa: Love it. Well, thank you so much, Lucas, for joining us today, and I hope you enjoy the rest of your second CancerCon.

Lucas: Thank you so much for having me.

Elissa: This concludes our first episode podcasting live from CancerCon 2023. Be sure to stay tuned for the next episode where we will be interviewing some of the presenters at CancerCon to hear the highlights of their presentations on the unique issues that affect young adults with cancer.

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.

Did you know that you can get more involved with *The Bloodline* podcast? Be sure to check out our Subscriber Lounge where you can gain access to exclusive content, discuss episodes with other listeners, make suggestions for future topics, or share your story to potentially be featured as a future guest. You will also receive an email



notification for each new episode. Join for free today at TheBloodline.org/SubscriberLounge.

In addition to the lounge, we could use your feedback to help us 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 or at TheBloodline.org. 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. However, if you would like to contact LLS staff, please email TheBloodline@lls.org.

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. You could find more information on programs for young adults at 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.