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THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'LIVE! At CancerCon: A Journey Through 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 what the word, "*survivorship*" means to them.

We found the responses to this question can vary from patient to patient and even change once treatment ends. We hope that through their words, listeners will find a sense of connection and evaluate their own meaning of survivorship.

Be sure to stay tuned for the next episode from CancerCon, where we will be hearing from experts who presented on various aspects of survivorship, such as the growth mindset, creating a survivorship plan, and imposter syndrome.

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 Minneapolis, Minnesota, and is attended by around 200 young 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 Survivorship. The term survivorship is defined by the National Cancer Institute 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."

But we want to hear what survivorship means to current patients and those who have finished treatment. While we 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 we hear how the term survivorship varies from patient to patient and also how it might change as you move through and past treatment. So, let's get started.

Veronika: So, my name is Veronika. I am a non-Hodgkin's lymphoma (NHL) survivor. I am 33, and I am currently post-treatment, NED (No Evidence of Disease) for the last eight years.

Elissa: Okay, what does survivorship mean to you?

Veronika: So, survivorship to me means living with cancer and how I live with it every day. It really means for me how I find my joy in my life and deal with cancer, you know, that little bug that sits on your shoulder that never leaves and how I live my best days.

And the other part of survivorship for me is definitely my legacy. I worry about what I leave behind; and I want to build programs and things that once I'm gone, that they'll be here serving others. So that's an important part of my survivorship as well.

Elissa: So, has the idea of survivorship changed for you since you ended treatment or since you had a break in treatment?

Veronika: So, for me, I think when I was first done with treatment, I thought I was done with cancer. I thought I never had to think about it again. I heard about, oh, once a year and that would be great. So, eight years out, I finally got a once-a-year appointment. Then I've had over the last eight years so many different things that weren't cancer related, but because we've had cancer and because poison and chemo has gone through our bodies, our bodies just aren't the same anymore. And so, kidney stones are a little worse. Autoimmune disorders are a little worse. Constantly getting that bloodwork and my veins are so bad.

So, for me, today survivorship means getting to tomorrow. It's still an every day. The cancer isn't active, but it has warped my body in such a way that, I can't think that the cancer is gone because that makes me anxious or fretting about it coming back or the next new thing. I just have to be in the present and survive till tomorrow. That's all we can do.

Elissa: Yeah. There is definitely that misconception out there that once you're done with treatment, you're done. Everything's good and that doesn't seem to be the case with you.

Veronika: No, I had also two recurrent scares as well. Actually, that was the worst part, the thought that I had done everything right, that I had followed all the directions. I had suffered through it and still having it happen twice, that's where getting to the next day was so important because I didn't know if I had a next day. And still, it's always in the back of your mind; but I just go with the flow now, and I feel so much better to just accept that the cancer potentially could impact tomorrow. But that today I'm going to be happy; and I'm going to do things that make me happy.

Elissa: Yeah. Now what do you wish your healthcare team would have told you about survivorship and what that all means?

Veronika: I think I'm still waiting for that conversation. Eight years later I'm still looking for that survivorship talk. I'm still looking for those long-term side effects. I mean we can do our research, and we have a good understanding that our bodies are forever changed, and things are going to happen. But it would be great if my oncologist would give me a little bit more insight into what to expect. But I know that new things are going to happen; and it was kind of anticlimactic. It was, "I'll see you in a year."

Elissa: Yeah.

Veronika: Dot, dot, dot. Have any questions? Great.

Elissa: Yeah, we hear that a lot that you finish treatment and it's like, "Okay, bye. We'll see you in a year or a few months."

Veronika: "Get that bloodwork every other month. I'll let you know if there's a problem."

Elissa: Yeah.

Veronika: That's the epitome of our talks. But unfortunately, we have to do our own research. We have to know what to expect, and we have to be able to advocate for ourselves in the moment.

Elissa: Yes, definitely. Now 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?

Veronika: Well for me it's joy, which I've said a couple times. It's love, it's loving life and loving me. And I think it, for me also it's control. It's getting the control back in my life and making decisions that aren't cancer related is super important to me, to be able to make healthy decisions, do the best that I can, and not be stressed out about all the things that I can't control and can't change.

Elissa: Yeah.

Veronika: But living up every moment and being here at CancerCon is definitely in that direction. Being with friends.

Elissa: A lot of joy.

Veronika: A lot of joy, a lot of friends, and definitely, the social, emotional. We need that in our lives. We need people who understand us and can be able to see our experiences through that cancer lens as well; and that makes the good times better.

Elissa: Yes.

Veronika: And the bad times, it's a little rough because we had so many poor experiences.

Elissa: Yeah. Well thank you so much, Veronika, for talking with me today; and I hope you enjoy the rest of CancerCon.

Veronika: You too, thank you.

Alique: My name is Alique, and I am a two-time acute myeloid leukemia (AML) survivor. I was diagnosed for the first time at 4 years old and then went 22 years in remission and was diagnosed again at 27 in 2021.

Elissa: Wow, that's a lot. What does survivorship mean to you with, both of these diagnoses that you've had?

Alique: I think survivorship has changed throughout my life course in both of my diagnoses. So, having cancer so young the first time, I grew up being a survivor. I grew up knowing I was a survivor and survivor already being part of my identity.

I started my work in the cancer community speaking for the first time at five years old for the Armenian Bone Marrow Donor Registry, which my family and I actually helped to form after we had so many people test to be a bone marrow match for me that did not work. However, we turned it into a registry for others.

And I think that my survivorship and growing up a survivor was just such a crucial part of my identity that I almost even took it for granted. I was active in the cancer community. I shared my story. I wanted to help as many people as possible. But as I got older, it was almost like the thought of being a survivor started to wear off.

And then I still have long-term effects. I still had to go to the doctor all the time. I still dealt with being scared of recurrence until one day recurrence actually happened. And after my recurrence, I think survivorship changed for me. It changed from being part of my identity, which it still is, but it turned into this next-level type motivator where I had to share my story. I had to figure out how to advocate. I had to work in this realm where I had to use my education, my PhD to help people like myself and figure out how I can improve the realm of oncology and the cancer world for others.

Elissa: So, it sounds like you moved from having being a cancer survivor be your identity when you were so young and growing up to it becoming kind of a purpose for you.

Alique: Exactly. And I knew I always wanted to work in cancer, and I got my Master's in Public Health, I got my PhD in health promotion education, and I started working on my first cancer grant. And I turn it in, and two weeks later I got diagnosed.

And it was just this surreal experience of feeling like I was finally starting to do the work I had always wanted to do, and then it all came crashing down again.

Elissa: Right.

Alique: But that time, it made me take the time to become an expert in this field. I used my diagnosis to do every single kind of psychosocial service available to me so that I could use it in the future to help others.

Elissa: That's great. Now what do you wish your healthcare team would have told you about survivorship?

Alique: I wish that my healthcare team wouldn't have been so dismissive. I was told a couple of years ago that I was so far out from my cancer diagnosis that I barely counted as a survivor anymore. It was almost as if my cancer never happened.

In August of 2020 I was told that my cancer would never come back and that I didn't need any more follow-up care. And then in March of 2021, that same doctor is the one who had to give me my diagnosis. And I just wish that my doctor never would have said never. And that's something that I've been trying to advocate for when I've been working with physicians, when I've been working with medical trainees and nurses is taking that "never" out of the language that people use because the truth is we don't really know what can happen.

Elissa: Right.

Alique: The generation of the 90s pediatric survivors are pretty much the first generation of long-term survivors of 20, 30 plus-year survivors. Nobody really knows what effect those treatments are going to have. Nobody really knows what the long-term effects are going to be or how relapse can work. I'm the first ever person to relapse after 22 years, and I think hearing "never" almost made my diagnosis harder.

Elissa: Yeah. I think that's the very reason why we have started our children's initiative, now called "Dare to Dream" that looks at targeted treatments because we really don't know how pediatric patients are going to react to these harsh treatments, 20, 30, 40 years down the line. Your case is the exact reason why we are doing this.

Now on our patient podcast home page, we have a quote that says, "After diagnosis comes hope." Based on your cancer experience, both as a child and recently, how would you complete that sentence? After diagnosis comes?

Alique: I think after diagnosis comes rebirth.

Elissa: Love it.

Alique: I changed so much after my diagnosis. It really ripped me down to my core through treatment, through research of what was going to happen, through the loss of everything that I knew, and then trying to put back all of the pieces. But I feel like it freed me to be the most authentic version of myself. And I think that I'm more comfortable with myself and more proud of the person that I've become than I ever had been in my past. And I think it's because cancer forced me to accept myself for who I am without any of the bells and whistles. It's just really me for me.

Elissa: Yeah, I love it. Rebirth.

Alique: Yes.

Elissa: That's great. Well thank you so much, Alique, for talking with us today. We wish you the best with your continued treatment.

Alique: Thank you.

Fabian: So, I am Fabian. I'm currently 26. I was diagnosed with acute lymphoblastic leukemia (ALL) at age 17.

Elissa: So, what does survivorship mean to you?

Fabian: Survivorship, in my own experience post-treatment, is the acceptance and the confrontation of reality of my diagnosis and my treatment and an acceptance of life that I am still here and have the ability to share my story and help others.

Introspective position that I've had through my treatment, I realize that facing my own mortality at 17 years old is not an everyday occurrence. And it took my years to accept it and to be able to move on and to be able to thrive in my life.

Elissa: Now do you feel like that idea of survivorship has changed since treatment ended?

Fabian: The term survivorship implies an end. However, the number one cause of cancer is a previous cancer. And it seems that since I had it at 17 years old, such a young age, I've accepted the fact that I will most likely have another cancer with the next 50 or 60 years. Therefore, survivorship is an odd topic. It's more of this pause. I've heard the term "no evidence of disease," and it's this long dance with NED. Even though I might not have anything today, doesn't mean I'm in the clear for 50 years from now.

And I've seen that shift of survivorship where, when I started treatment at 17, it was a lot of, "You'll survive. You'll live a long life." And as I've gotten older, as I've gone through college, I have realized that the survivorship is the continuation of life.

For example, I got my motorcycle license. I moved countries. I moved home, different states. I tried new things just because I was diagnosed with cancer and almost died doesn't mean I'm going to stop living. In fact, it offers a new hindsight in life.

And survivorship is not just surviving, and you're done, continue as you were before. It's more of this progression of where do I go now and the new opportunities I'm able to see.

Elissa: Now what do you wish your healthcare team would have told you about survivorship?

Fabian: I had an amazing team. I was treated at City of Hope in the pediatrics floor, and they covered everything. I believe the only thing that would have helped me as a 17-year-old, which I realize now as a 26-year-old, even in survivorship, I was never explicitly told that it's okay to not be okay.

Elissa: Yeah, that's great advice that is needed.

Fabian: Yes, so I tell people, there's always the "Stay positive." There's the "Oh, you lived. You're a survivor now," they're trying to be positive. However, I've noticed that when someone tells you to be positive or, "Oh, you're a survivor so you should be happy" or there's expectations of you, it almost invalidates the other emotions you're going through in survivorship.

Therefore, the one thing I kind of wish someone else would told me, whereas I realized later on in life, is that even in survivorship, it's okay to not be okay.

Elissa: Yeah. So that leads to our next question, so on our patient podcast home page, we have a quote that says, "After diagnosis comes hope."

Fabian: I feel bad because the first thing that came, depression.

Elissa: That's okay.

Fabian: Again, you think about hope. You think about the positivity, but the truth is there's fear. There's frustration. There's a struggle. And that's the truth. I think shying away from the truth kind of hinders because if someone doesn't feel hope after their diagnosis, it seems that they might be depressed, might be suffering. And saying that you should be joy, should be hope, that's invalidating the feelings people are going through.

Elissa: Right.

Fabian: I hesitated. My first immediate thought was after diagnosis comes depression; that's not the best thing. But it's real. We have to acknowledge the bad. Then eventually hopefully leads to the good, but it's a rough path.

Elissa: Yeah.

Fabian: After diagnosis comes struggle, comes pain, comes suffering. And at the end of the tunnel, it's uncertainty.

Elissa: Yes, absolutely. Well thank you so much, Fabian, for talking with us today. Really appreciate your time, and I hope that you enjoy CancerCon and the rest of the weekend.

Fabian: All right, thank you.

Corina: My name is Corina. I was diagnosed when I was 27, and I'm now 30. And my diagnosis was acute myeloid leukemia (AML). And then right now I currently hit my two-year mark for post-BMT [Bone Marrow Transplant] on June 5, 2020, so I'm two-year, I like to say cancer free, remission. Currently, I see my oncologist every two months.

Elissa: That's wonderful. So, what does survivorship mean to you?

Corina: So, for me survivorship just means that I completed treatment, as in chemotherapy, radiation, all of that stuff. I would say kind of back to normal, but not really.

Elissa: Not quite.

Corina: Yes, but that I was able to overcome, and I survived this deadly disease.

Elissa: Has the idea of survivorship changed for you since your treatment ended?

Corina: It changed a little bit just because sometimes I kind of forget that I went through all of this. And I'm like, "Oh, I'm actually in survivorship mode, and I have to just remember that I have to be like a little bit cautious in certain things."

Elissa: Definitely. What do you wish your healthcare team would have told you about survivorship?

Corina: That it would be best if I had a survivorship plan. This is the first time I'm hearing about it. I really had no idea that there was even a survivorship plan.

Elissa: Now 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?

Corina: After diagnosis comes a light at the end of the tunnel.

Elissa: Love it. That's great. Thank you so much, Corina, for talking with me today. I appreciate you sharing your story and talking to us about what you feel about survivorship. I hope you enjoy the rest of CancerCon and have a great time.

Corina: Thank you so much.

Stephanie: My name is Stephanie. I had non-Hodgkin's lymphoma (NHL). I had two bone marrow transplants and treatment. I am past treatment, but I'm still in active treatment for consequences from the bone marrow transplant.

Elissa: So, being in active treatment for side effects and complications of the transplant, what does survivorship mean to you right now?

Stephanie: Survivorship meaning is exactly that, surviving day by day, going through each treatment. So, they say cancer survivor, but to me it's two different things. One's cancer and then I think it's surviving. And for me cancer was the easy part. Surviving is the difficult part.

Elissa: Yeah, it's very different once you finish treatment.

Stephanie: Yes.

Elissa: And then kind of try to find life again.

Stephanie: Yes.

Elissa: So, do you feel like that idea of survivorship has changed since you finished treatment?

Stephanie: Yes.

In the beginning, because you think of survivorship, you think, oh, once I'm done with cancer treatment, I'm done.

Elissa: Yeah, go on and live a happy life, right?

Stephanie: Yes, it's done. You're over with. You're never going to hear this again. Everything's perfect now, and it's not. It's all about the survivorship. Like I said, going day by day. Every day is something different. Every day is something new. And once you think you're done with one thing, something else pops up. So it's the survivorship that's the difficult part.

Elissa: Yeah. What do you wish your healthcare team would have told you about survivorship?

Stephanie: The honest truth that survivorship is the difficult part.

Elissa: Yeah.

Stephanie: That cancer treatment's one thing. The cancer's one thing, but surviving, it's going to need a whole lot of more of a medical team, more of mental stability, things like that, more than treatment itself.

Elissa: Yeah, definitely. Now 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?

Stephanie: Despair.

Elissa: Despair, yeah. What does that mean to you?

Stephanie: It's difficult. It's just very difficult. After cancer, you've been painted this pretty picture that everything's going to be well afterwards, and it's not.

Elissa: Yeah, it's not always like that.

Stephanie: Yes.

Elissa: We just have to find a way to survive the day by day, just like you said.

Stephanie: Yes.

Elissa: Well, thank you so much for talking with us today. Really appreciate your time in sharing your story, and I hope you have a great time at the rest of CancerCon and are able to learn things and hopefully grow in survivorship.

Stephanie: Thank you.

Elissa: As you can hear, we're hearing quite a few different definitions of what it means to be a survivor and also the language surrounding that. There's positivity, negativity. There are so many different ways to feel about the experience of cancer survivorship. So, let's hear a little bit more.

Barrett: My name is Barrett. I'm 28-years-old. My diagnosis is Hodgkin's lymphoma (HL). Initially diagnosed Stage 2, and I'm posttreatment about three months or so now.

Elissa: Great! Now what does survivorship mean to you?

Barrett: I think for me it really has to do with perspective. Sort of going through this experience, the unexpectedness of the experience, the surprises, the highs and lows, really can give you a bit of insight, not only about who you are but what you want to do in life, how you want to interact with people; what you'd like to do moving forward. And just being able to reflect on that, some people say is sort of a gift. Certainly, it's not, but I am thankful for what I feel I've gained out of survivorship or what really it does mean to me.

Elissa: Yeah. And that brings up a good point because not everybody considers themselves a survivor, not everybody is still in that patient realm, some want to be called thrivers or warriors or things like that; so it's kind of different for everybody, right?

Barrett: Absolutely, yeah. And certainly, everyone has their own journey and their own perspective and sort of how they'd like to interact with the world and along with those labels as well.

Elissa: Definitely. Now since your treatment ended not that long ago, has your idea of survivorship changed since the beginning of treatment, what you thought that might look like to what it looks like now?

Barrett: Absolutely. It is a week-to-week thing if not a day-to-day thing.

Elissa: Yeah.

Barrett: Your thoughts about everything from maybe initial crumbling of everything you thought you knew to be true and building that up through treatment. What does the future look like, what does it look like for me, what am I expecting to do in the future. All that really has evolved over time. I'd say time has been healing, time has been helpful. Certainly, I might be a little more positive about everything looking forward now than I was, but there's just so many unknowns along the journey.

Elissa: Right.

Barrett: I think that's just part of growing through your own experience as well.

Elissa: Definitely. Now what do you wish your healthcare team would've told you about survivorship?

Barrett: That's a good question. I had sort of an interesting journey. It was just kind of rocky up and down. I got passed from provider to provider as circumstances changed. And the communication really was there throughout most of my journey, but I don't know if I was sort of presented with a lot of resources. I was one of the only people in maybe this circle kind of going through this and I wasn't sure who to reach out to. I felt very isolated at certain points, so, certainly learning more now, and having time to research different things, but I just wish certain things were presented to me that I didn't know I was looking for.

I know that's hard looking back I'm saying, "Oh well now I can see that it was X or Y or Z." That's tough for them to do. I'm certainly understanding of that, but just being aware of some of the resources that I wasn't aware of at the time.

Elissa: Yeah. And I think that's why, things like CancerCon, where you are presented with not only resources, but people who've been through the same thing and you can meet people that are 5, 10 years out and see what they have gone through post-survivorship where you're pretty new into kind of the survivorship/ posttreatment realm. And it is so important. Now 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"?

Barrett: Wow! I mean it kind of goes back to this enriching quality about the entire experience, you know? Being able to put things in perspective. I think hope for me is taking each day and trying to make the most of it and then also hoping to give back.

Elissa: Yes.

Barrett: Just sort of the idea that, wow, I went through this and who knew I was going through this? What could anyone else be going through at any given moment, cancer related or not, and being able to capitalize that. Not to have this like great "love everybody" message, but it really is that. Being able to look at people and appreciate time with people.

Elissa: Absolutely. Well thank you so much, Barrett, for talking with me today. I really hope you enjoy the rest of the weekend and enjoy your first CancerCon and find ways to grow in your survivorship as the years go on. So, thank you so much.

Barrett: Absolutely. Thank you. I appreciate it.

Sabrina: My name is Sabrina, age 36, ALL leukemia (acute lymphoblastic leukemia), and I just finished up with my treatment. I had CAR T-cell clinical trial, and I'm just going for checkups right now.

Elissa: So, what does survivorship mean to you?

Sabrina: It's just focusing on my quality of life after treatment and just trying to get back to a sense of normalcy and seeing what I need to do to get my body back to where it was pretreatment.

Elissa: Yeah. Has the idea of survivorship changed for you since you finished treatment?

Sabrina: It's pretty much stayed the same. I mean I've learned in this session that I just went to at CancerCon with LLS about all the different variables that encompass survivorship, about all the team of people that need to be aware and help me get my body back to where it was and how to take care of it in the future. So, definitely after today's session, it has shown me what survivorship really is and what other steps I need to take to be able to do better and be better in the future.

Elissa: That's great. Now what do you wish your healthcare team would've told you about survivorship?

Sabrina: I wish they would've told me that it was an actual thing. I heard about it from different conferences that I've been to, but I didn't actually really know that it was a actual thing that you can write out and there's actually a team of people that are supposed to be a part of your survivorship plan.

Elissa: Yeah. And you're meaning the survivorship care plan?

Sabrina: Oh yes. I had no idea about that because my team of doctors never mentioned it or mentioned that it was a thing that should be a part of my life.

Elissa: Yes. There's a lot of aspects that go into survivorship care and just survivorship in general, right, with potential late term effects.

Sabrina: Oh yeah.

Elissa: Side effects that may last for a while, fertility issues, career, things like that.

Sabrina: Right.

Elissa: Those things really need to be addressed and it's important.

Sabrina: And it was never mentioned, never talked about, and I pretty much just heard about it going to different conferences.

Elissa: Now 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"?

Sabrina: Possibilities. Initially when you have a cancer diagnosis, it's the worse news that you could possibly get. And then after you go through it and get through treatments, you realize how much you can actually handle and how much you can actually do and get through. And so, it definitely develops resilience, and it helps you put things into perspective more so than before.

Elissa: Yeah, absolutely. Well thank you so much for talking to us today. I hope you really enjoy the rest of the weekend at CancerCon, and we appreciate you sharing your story.

Sabrina: Thank you.

Theresa: My name is Theresa. I'm 33 years old, and I'm a Hodgkin's lymphoma (HL) survivor.

Elissa: So, what does survivorship mean to you?

Theresa: Survivorship means a step closer to normalization of my life and learning and growing with what I went through in the past and looking forward to what happens in the future.

Elissa: Yeah, yeah. Looking towards the future is really good. Now are you still in treatment or how far out are you?

Theresa: I've been in remission since 2018, but I get tests and I still have my port because they're still like, "Well, you know, we'll just keep check of you" because I had around 13 masses in my chest and the biggest one was six inches, and it got smaller, but they still want to make sure that none of them act up.

Elissa: Right. Oh, my goodness! Now has the idea of survivorship changed since you ended treatment?

Theresa: Yeah. I thought that once I ended treatment that I would go back to normal in a sense because I'm a college student.

Elissa: Right.

Theresa: And so I would go to school and have fun and do things. But then I had to think about it and go, "Well, I don't know is this the right step for me right now? Should I take a break for the semester? Should I go back? Is this the right degree for me?"

Elissa: Now what do you wish your healthcare team would've told you about survivorship?

Theresa: I wish that they gave me better expectations because they said, "You'll be feeling better. You'll be back to normal in like six months, and your treatment wasn't as bad as some other people, and you should be all right." And it wasn't like that.

Elissa: Yeah. That wasn't the case. So it didn't really kind of leave you with a feeling like, this is what should be happening.

Theresa: Right.

Elissa: Yeah. Now 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"?

Theresa: A new adventure.

Elissa: I like it! What does that mean to you?

Theresa: Well, you might be on one path and then you veer off when you have cancer and going through cancer, but that doesn't mean that you can't continue on that and have a new adventure in that direction or it could split off again and you could go a whole different area, a whole different adventure in that.

Elissa: There's a real possibility for opportunity.

Theresa: Right.

Elissa: That's great. Well thank you so much, Theresa, for talking with us today. I hope you enjoy the rest of your first time at CancerCon and learn a lot and grow in survivorship.

Theresa: Thank you.

Ambreen: My name is Ambreen. I'm 30 years old. I'm about 11 years out of my diagnosis. I've been in remission for 10 years. I was diagnosed with Hodgkin's lymphoma (HL) when I was 19.

Elissa: So, what does survivorship mean to you?

Ambreen: Survivorship to me means just living. It means knowing all too well that life is finite and it's different than it is for people who are not in the cancer space but still just living life to the fullest anyway.

Elissa: I love that. Now has the idea of survivorship changed for you since you ended treatment, especially now that you're 11 years out?

Ambreen: Yes. I think when I was in treatment, I had this very idealized notion of what survivorship looks like. It looks like being strong and, this best version of yourself. And I realized quickly after ending treatment and going into remission and kind of being labeled as a survivor that it's not like that. It's really a roller coaster. It's an up and down process; sometimes you are worse, sometimes you're better, and sometimes you're just okay. And I kind of came to the understanding that I'm a work in progress and I always will be a work in progress, but that's okay.

Elissa: Yeah. That's very important I feel like for people to know that it is sometimes a work in progress. And sometimes you can have your bad days, sometimes you can have your good days, and it is what it is.

Ambreen: Exactly, yup.

Elissa: So, what do you wish your healthcare team would've told you about survivorship?

Ambreen: Well, when I entered survivorship, I feel like it was a very different landscape because this was 10 years ago, and since then, survivorship care plans have become a big thing. I was never offered one when I finished treatment because it wasn't really talked about as much, so I really didn’t know anything going into survivorship. All I knew was I would have to come back for my follow-ups. But other than that, I didn't know what to expect in terms of side effects, how to adjust. I was in college at the time, and I went right back to taking full-time classes right away as soon as I got the all clear because I was a nerd like that. And I had no idea what it would be like. I didn't know what support was available for me, and it was a whirlwind. I really had to do a lot of that research on my own. I felt like I was kind of thrown into it not knowing.

Elissa: Yeah. I think we hear that from a lot of patients and survivors that they just don't know what is ahead, and there's so much uncertainty, and they kind of have to figure it out for themselves.

Ambreen: Yeah.

Elissa: 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"?

Ambreen: Ah! That's a good question. I would say, "After diagnosis comes community."

Elissa: Community.

Ambreen: Yeah. I didn't even know that this whole world existed, that there's so many other cancer survivors and patients out there like me who've gone through the same thing. And my diagnosis allowed me to enter the cancer club, the club that no one wants to join, right? You always hear that. But I gained so many incredible friendships. And the friendships I've gained because of cancer, they're almost deeper and more insightful than the friendships that I have before cancer because these are people that have faced one of the most challenging experiences, I think we ever face as people. And they've learned so much, and we learn from each other, and we get this sense of support and sense of community that I don't think exists outside of the cancer space. I mean, I wouldn't wish it on anyone, but I'm truly grateful for the community.

Elissa: Absolutely. And that is such a benefit of what we get here at CancerCon, that community and friendships for life.

Ambreen: Definitely, yeah.

Elissa: Which is great. So, thank you so much for talking with us today and sharing your story and what survivorship means to you. I hope you've been enjoying CancerCon and I hope the rest of the weekend goes very well for you.

Ambreen: Thank you so much for having me. And, yeah, I hope CancerCon continues. It's so great to be in person and we talked about community just to be able to see people again in person.

Lucas: Hi, I'm Lucas. I'm 22 years old, and I was diagnosed at 19 years old with acute lymphoblastic T-cell lymphoma (T-ALL). I am in remission. I am done with treatment.

Elissa: Now what does survivorship mean to you?

Lucas: So, survivorship from an early point in my treatment, I knew that I wanted to pay it back in some way. In some regard, I wanted to make a difference for other people, especially because I was treated in the pediatric care. And being around all of the younger people and watching them go through, watching their families go through it, it really, affected me.

Elissa: Yeah. So, kind of felt like you wanted to make a purpose out of it.

Lucas: Yeah. Definitely, definitely.

Elissa: So, has that idea of survivorship changed since you ended treatment?

Lucas: A little bit. Specifically, since I've been able to sort of return back to my lifestyle a little bit. A theme that I had throughout was try to find the things that make you human. And during treatment, obviously, the lack thereof makes it easier to find. When you are returning and you're done with treatment, it can be a little difficult admittedly, but finding things, whether it's I've been playing sports my whole life, getting back into playing volleyball, just being around people again that definitely has helped.

Elissa: It's nice to kind of return to life and create somewhat of a new normal for you.

Lucas: Oh 100%. Like you said, the new normal. I don't think that I was necessarily opposed to who I was beforehand, but I think I've definitely taken as many positives, if not more, than the negatives throughout my treatment to who I am now.

Elissa: Now what do you wish your healthcare team would've told you about survivorship?

Lucas: So I wish they would've filled in more of the mental aspect of it that now that you've gone through this journey, this treatment where your life is dedicated to cancer and you're kind of going back into the real world, if you will, where not everyone has cancer, not everyone is aware of your story. Some people don't really have too much knowledge on cancer in general. The adjustment from the two different ways of life, it can be challenging.

Elissa: Yeah. Now 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"?

Lucas: After diagnosis comes a new opportunity.

Elissa: What does that mean to you?

Lucas: Whatever you desire to make of the rest of your journey, the rest of your life, that's what matters. It's your opportunity. You are able to mold and shape the rest of your life based off of the experiences that you have lived.

Elissa: Yeah. That’s a great outlook that you can just turn this into opportunity and purpose if you would like to and to set off on a new path.

So, thank you so very much for speaking with us today. We really appreciate it. I hope you enjoy your first time at CancerCon and learn a lot and grow in survivorship.

Lucas: Thank you so much for having me.

Word Cloud

Elissa: You've now heard from several of our blood cancer patients and survivors, but now we want to hear from other patients and caregivers at the conference. At the LLS exhibitor booth, we're encouraging attendees to write one or two words of what survivorship means to them. Let's hear what people are writing.

Speaker: So, I wrote, "Achieving my goals." And I decided very early on with my cancer diagnosis that I was going to try to live my life as normally as possible, and so for me that meant setting goals and trying to achieve them. So, I was diagnosed in the middle of my MBA program, and I was able to finish the program and go on to get a new job. I was promoted, and I also qualified for the New York City Marathon.

Speaker: Well I have metastatic Stage 4 breast cancer, so survivorship for me means living moment to moment and living in the moment, not thinking too far into the future.

Speaker: Taking life one day at a time because I was always someone who plans like five years out. I had carcinoid cancer on my appendix, and they caught it by accident. So, survivorship is just trying not to worry about if I'll have 12 more bad days in a row or whatever. It's just getting through this one day at a time, and it makes it so much easier.

Speaker: I wrote, "Going to Buffalo Bills games again is what survivorship means to me," because I'm the biggest Bills fan ever. And I want to be healthy enough for the upcoming season to make sure I can use my season tickets and be there at every game and some of the away games.

Speaker: I wrote, "Community" because I have been connected with such a great community, and I just want to keep giving back to it and helping newcomers to this club no one wants to be a part of learn the ropes and find out what's out there for them.

Elissa: This concludes our first episode podcasting live from CancerCon. Be sure to stay tuned to 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.

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 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. 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. Young adults who are aged 15 to 39 are encouraged to visit LLS.org/YoungAdults for all the resources that LLS has to address your unique needs. For more information on CancerCon and Stupid Cancer, go to StupidCancer.org. All of these links will be 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.