

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'LIVE! At CancerCon: Transitioning to Primary Care'

Description:

Please join us for this special episode live from CancerCon®, a young adult cancer conference presented by Stupid Cancer®.

Following a cancer diagnosis and treatment, oncologists often become the default primary care for patients. Transitioning away from the oncologist to a primary care provider for general healthcare may be challenging at times for patients but may have tremendous benefits. In this episode, we ask young adults with cancer about their experiences transitioning to primary care during or after treatment.

Be sure to stay tuned for the next episode from CancerCon, where we will be hearing from experts who presented on cancer “ghosting”, rediscovering yourself after cancer and mental health.

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 Austin, Texas, and is attended by nearly 250 young adult cancer patients, survivors, caregivers, as well as nonprofit 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 transitions in survivorship. There can be many different types of transitions that a cancer patient may have after their diagnosis. One in particular is the transition away from their oncologist to a primary care provider. Oncologists often become a default primary

care provider. However, a provider in internal or family medicine can give the patient a point person for all aspects of their healthcare, addressing issues related to or not related to their cancer treatment.

While we will be interviewing young adults in this episode, a transition to primary care 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 transition from diagnosis through survivorship. So, let's get started.

Olivia

Olivia: Hi, my name is Olivia. I am 28 years old. I was diagnosed with Stage 4B Hodgkin's lymphoma in 2022, and I'm currently two years NED (no evidence of disease).

Elissa: I like to hear that. So, do you have a primary care physician outside of your oncologist?

Olivia: I do.

Elissa: Was that the same one that you had prior to your diagnosis?

Olivia: It is not.

Elissa: Oh, okay. So, you had one prior to your diagnosis, and now you have a different one? What happened?

Olivia: So, my journey to diagnosis was long and tiresome; and it took almost a full year to be diagnosed. I had gone to my primary care physician, I think, 10 or 11 times in total, and I was, frankly, dismissed. Even when I had presented with some pretty concerning symptoms, including tumors that were protruding from my chest, which she had mentioned was probably just a muscle that I should get a massage for, and I had some lumps in my neck which she said were probably just from the COVID vaccine, and a couple of lumps under my armpit, which she also dismissed. So, this

was really quite a long journey, and I had gotten to the point where I forcefully asked for a scan because at that point, she hadn't done any sort of blood tests or any scans. And I was just really not feeling great.

And, she had finally given me the scan. It had come back. There were tumors all throughout my chest, and it was metastasizing into some of my organs as well. At that point, I had decided that I no longer wanted to see that PCP; so, I had gone through treatment with my oncologist. But when I had finished treatment, I had wanted to establish care with a new PCP. So, I did some Googling around. It took a while to establish care. I think it was a four-month waitlist. And then I had gotten in with her. She's a little bit younger, and she really listened to me. We sat down. We did quite a long intake together, and I've been with her for about two years now.

Elissa: So, what made you want to reestablish care with a primary care physician when you were still going to your oncologist?

Olivia: So, my oncology center is about 4-1/2 hours away. It's quite a commute, so I really wanted to have a doctor that I could go and see for, every day concerns, especially in the winter months with any sort of like colds or a flu or strep throat, anything that I needed kind of immediate assistance that wasn't an ER (emergency room) or an urgent care, just so I could ensure follow-up care and that everything was documented in my chart and in one place. So, that was the reason I wanted to establish a PCP.

Elissa: Yeah, do you feel like having a primary care health provider is important and being established with somebody?

Olivia: Yes. I definitely do. For example, prior to my two-year scan, about three months earlier I had felt something in my armpit; and it was a little lump that I hadn't felt before. And that kind of sent me spiraling, and I called my oncologist, and she said, "It can be just residual disease. It can be a normal lymph node. It could be



allergies.” But if you’re really concerned about it, why don’t you go see your PCP, and she can check it out.”

And I called my PCP. I got in with her within 24 hours. She checked it out, and she said, “You know what, I think it’s just a normal lymph node; but knowing your history, let’s get you in to do an ultrasound.” So, she got me in within 12 hours to get an ultrasound. And it ended up being just a normal lymph node that I could feel because I’d lost a bit of weight. But just having that reassurance and someone that was able to act quickly and get me answers quickly without having to make an appointment with my oncologist really just gave me peace of mind, and it also was really reassuring how serious she took it and how quickly she acted, and I just really appreciated that as well.

Elissa: Absolutely. And that is awesome to have somebody available that will do these things so quickly for you versus oncologists can sometimes only be in clinic one or two days a week, and it’s a little harder to get in with them. So, I’m glad that you got established with somebody.

Our final question for 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-

Olivia: Community. I think, everybody says it, but cancer is the family that you never wanted but the best family you’ll ever have. The worst club but the best members. I think, I say all the time that this community saved my life. These are people that understand what you’re going through, even if not completely. Everybody’s journey is different. But whenever I am getting into a spiral or whenever something good happens to me, it’s always my “Lymphoma Ladies” group chat that I reach out to first. And I think this community is just full of really beautiful people, and one of my commitments in survivorship is to help as many survivors or people going through it



currently as I can. So, I'm just really committed to the community, which is why I'm here at CancerCon as well.

Elissa: I love it. This is a perfect place to be to find community. So, thank you so much, Olivia. I really appreciate you talking with us today.

Olivia: Thank you.

Ashley

Ashley: Hi, my name is Ashley. I'm 38. My diagnosis was acute myeloid leukemia (AML). I did have an allogeneic stem cell transplant four months out from diagnosis in 2021. And I am rebirthed, three years old.

Elissa: Wonderful. Having the rebirthday. So, do you have a primary care physician currently outside of your oncologist?

Ashley: So, I just graduated oncology a week or two ago. I do have a primary care physician, but I haven't seen them yet.

Elissa: Okay. Well, it's good to get established with one, definitely. Did you have a primary care prior to your diagnosis?

Ashley: I did.

Elissa: Okay, so why did you not continue with that person?

Ashley: I felt more at ease with my oncology care team, and I feel like I need more specialized care now.

Elissa: Yeah.

Ashley: Even this far out from transplant.

Elissa: Yeah, I think that is very, very common to feel so comfortable with your treatment team that it's like, "I don't want to go anywhere else." Right?

Ashley: Yeah.

Elissa: So since you wanted more specialized care, who did you go with for your primary care physician? Is it an internal medicine physician? An onco-primary?

Ashley: I'm figuring that out. I do have a primary care physician. She is not specialized, but she's aware of my history. I have become friends with other AYA cancer survivors, and they've told me about some options where I could do like a survivorship clinic or something. But, I haven't looked into that. I'm kind of fresh out of graduation.

Elissa: Yes, yes. Just left your oncologist.

Ashley: Yeah.

Elissa: That's often very scary.

Ashley: It is.

Elissa: Yes. But having primary care is also nice because I think that you have somebody to go to. What do you feel like the benefits of primary care are?

Ashley: Just to check in. Something that's been really hard postdiagnosis and post-transplant is getting grounded in what my body's telling me. Like what's a major concern, what's a small concern? That concerns can exist that aren't cancer related, which is hard.

Elissa: Yeah, absolutely. It is nice to have somebody to go to for those things that are not cancer-related, right?

Ashley: Yeah.

Elissa: And not have to potentially schedule it out for weeks to get to your oncologist.

Ashley: Yes, yeah.

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-

Ashley: After diagnosis comes a new you. Diagnosis is really scary, but as a person, you inherently change, or I inherently changed. And even though cancer is terrible, that change doesn't have to be a bad thing.

Elissa: Yeah, fully agree.

Well, thank you so much, Ashley, for talking with us today. And I hope you enjoy the rest of your time at CancerCon.

Ashley: Thank you.

David

David: My name is David. I'm 27 years old. My diagnosis is acute myeloid leukemia, and I'm almost ten years out of treatment.

Elissa: That's amazing, ten years! Okay, so do you have a primary care physician outside of your oncologist?

David: No.

Elissa: Did you have one prior to diagnosis?

David: I got diagnosed when I was 17, so I-

Elissa: Okay, so you had your pediatrician.

David: Yeah, my pediatrician.

Elissa: Have you thought at all since your diagnosis, since you're ten years out, about getting primary care?

David: I was in the survivorship clinic for a little bit, and then I went to graduate school. And when I went to graduate school, I just stopped. I didn't transition over because I moved.

Elissa: Right, yeah. Do you know what benefits there may be from having a primary care physician?

David: Yeah, I think so. Like they'd know what different cancer-related things to appoint, especially with someone who's had a bone marrow transplant. They know like what test to give.

Elissa: Yeah, or things that aren't related to cancer, right? So, if you have an illness or an ankle sprain or something like that, that you'd be able to go to, rather than urgent care.

David: That's true, yeah. I think it is somewhat like an inconvenience in a sense. That's not the only reason why I haven't sought out like all the tests that someone would get with a bone marrow transplant just because I think sometimes, they have a hard time working around your schedule.

Elissa: Yeah, that's certainly the harder part about going to see your oncologist for something that may not be cancer related. It's hard to work around their schedule versus having somebody that you can just call up and hopefully go to within a few days.

David: Yeah.

Elissa: Do you still live in the same area as your oncologist, or are you seeing an oncologist at all?

David: I don't see my oncologist anymore. I do live in the same area, but I just go for physicals; and it's with a random doctor every year.

Elissa: But it would be nice, you know, potentially to have the same person each time, right?

David: Yeah, yeah, build that rapport, yeah.

Elissa: Well, good. So, do you think you're going to go home and potentially look into primary care?

David: Yeah, I hope so. I've been in graduate school, so that's really the barrier of everything because I work full time and I'm getting my graduate degree in child life. I just finished my thesis, so I'm about to graduate. So, I'm obviously going to have a lot more time to like research who I want to be my primary physician, but I guess choosing a random doctor is like, it's just basically out of convenience. And sometimes I don't even tell them that I've had cancer, just because-

Elissa: Wow.

David: -I'm not going to see the person anymore. It's been two years like that, so.

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-

David: I'd say community. I'd say that's what makes hope, in my opinion. When I meet survivors or events like this, I feel understood. They validate how I feel, especially that cancer is like a lifelong journey. You go through different stages as a survivor, and to me, events like this make me feel so whole and happy really.

Elissa: That's awesome. That is definitely the benefit of events like this. So, excited you're here and I hope you are enjoying CancerCon.

David: I am, thank you.

Elissa: Great. Thanks so much, David.

Mari

Mari: Hi, everyone. My name is Mari. I am 25 years old. I had post-transplant lymphoproliferative disorder, Stage III after a bone marrow transplant for a different illness. I am in remission for about four years now.

Elissa: Yay, that's so good. I love hearing people in remission. So, we are talking about primary care today. Do you have a primary care physician outside of your oncologist?

Mari: So, that's a fun question. I live in a big city. I live in DFW (Dallas-Fort Worth), so in theory healthcare is everywhere. And I do technically have a primary care physician, but with the state of healthcare right now, it's really hard to get an appointment; and I kind of just don't go to a doctor anymore.

Elissa: Okay. So, are you still seeing your oncologist at all and checking in?

Mari: I'm not able to do that. My clinic shut down.

Elissa: Oh, no. Oh, my goodness. So, you do have a primary care physician, but it's difficult to get an appointment?

Mari: Yes. It's difficult to get an appointment. Things have kind of changed in the last few years, and it's packed all the time. Basically for anything, you have to schedule months in advance, or you won't be seen for several months.

Elissa: Oh, wow. Is that with all primary care in your area?

Mari: From what I've heard from other people, yes. I don't think it's specific just to me because of my health concerns. People in my family have had trouble when they

need to get a viral swab when they get sick or if they have a health problem that is not cancer related. So, it's kind of something that I feel like has been going on for a while in DFW at least, for a variety of people.

Elissa: And that's Dallas? Dallas-Ft. Worth.

Mari: Yes, Dallas.

Elissa: Okay, wow. So, when people get sick or they get injuries or things like that, do they end up in urgent care or emergency room then?

Mari: Yes, urgent care is like a staple for us. The emergency room, especially on weekends, it's inconvenient; and I know it's not the way the system was designed, but it's kind of the best we can do right now.

Elissa: Yeah. Oh, wow. So, do you feel like having a primary care physician is important, particularly if you can get in a little bit easier?

Mari: I think it is important. I think that all of the things that I've listed are very helpful, and they should, in theory, be used correctly. So, I would like to be able to go to a primary care physician if I don't need to go to urgent care or the emergency department.

Elissa: Yeah. Are there any solutions for you in your area to be able to potentially find somebody, do you think?

Mari: I'm exploring it. Part of my issue was time because I'm very fortunate to have financial resources to go outside my area, but I don't have the time. So, now I'm trying to do some research, see if there's anybody that I might have missed that might be able to make some time in their schedule for me during like business hours where I can be in DFW because I do think it's important.

My primary care physician is the one who caught everything that's ever happened to me. She has been very aware, very attentive. She has the ability to be a little bit

more personal with me, more than an urgent care, an emergency department doctor is able to as great as they are at their jobs. So, I am making a huge effort now that I kind of have more time in my schedule to explore and see like please, I hope there's someone in DFW that's able to see me.

Elissa: Yes, absolutely. It is nice to have somebody who knows you and has seen you before and knows of what you've been through, particularly with cancer.

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-

Mari: After diagnosis comes learning. It can feel like a lot sometimes and like a burden. It's not fair that I have to relearn or learn new things after getting sick. But I also think there's room for a lot of positive learning. I feel like I'm learning about a new body, about a new life that I didn't really have planned, and that can be sad sometimes. It can be happy at other times. But, I think learning is neutral inherently. There's going to be a lot of learning, and I hope that people can think about that a little bit. I didn't expect it when I was in treatment, so I was like this is a lot of work. But, I encourage people to lean into it and to reach out for help if they can because learning is more fun with friends, I think.

Elissa: Absolutely, fully agree. Well, thank you so much, Mari. I really appreciate you talking with us today, and I hope you enjoy your first time at CancerCon.

Mari: I'm having a blast so far, so I think I'll keep enjoying it.

Elissa: I love to hear it.

Mari: Thank you so much.

Rachael

Rachael: So, my name's Rachael. I'm 29. I was diagnosed with Hodgkin's lymphoma, and I'm about six months out of active treatment.

Elissa: Okay, great. Now, since you're fairly close to treatment, do you have a primary care physician?

Rachael: I do.

Elissa: Okay, did you have one prior to your diagnosis?

Rachael: Yes, I did.

Elissa: How did that go with having a primary care going through your diagnosis?

Rachael: I think through my diagnosis, it took some time to get all the pieces together. Some of my first symptoms started about six months prior to my diagnosis; and so, it took a little bit of finagling to get everything to come together when I finally saw my PCP about how things were going. Yes.

Elissa: Good. Are you still seeing your primary care?

Rachael: Yeah, I am.

Elissa: Okay, good. Do you feel like having a primary care physician is important?

Rachael: I think so because I think they, do have an overview of things in your health and if you're sick with a cold and want to see your doctor, maybe like other specialties are not the best choice for that.

Elissa: Right, yeah. It is nice to have somebody else that you can go see with you know, minor things or everyday things, right?

Rachael: Yeah, exactly or to keep up with you, on an annual basis too. She helped me get started with who to see, what to do, with some referrals. And then I ended up

going to a different hospital system nearby, so she could see my treatment and how things were going but she wasn't really an active participant in that.

I mean I love my oncologist a lot, but, she was mostly focused on my lymphoma. Anything that was, related to that, making sure I didn't get sick and had other precautions during treatment. But I don't think she would be keeping up with me in other aspects of health.

Elissa: Right, absolutely.

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-

Rachael: I think I would complete that with after diagnosis comes perseverance, because there is hope; but also it's hard work. You have to keep going and even post-treatment, you have to keep persevering through things and through fears and anxieties and even what happens next or in a year. And I think after diagnosis there's a lot going on in your head and you have to keep on keeping yourself together a bit.

Elissa: Absolutely. Well, that is a good answer. Perseverance, I like it. Well, thank you so much, Rachael, for joining us today. We really appreciate it, and I hope you enjoy the rest of the time of CancerCon.

Rachael: I will. It's been great so far.

Elissa: Wonderful. I love to hear it.

Angelique

Angelique: Hi, everybody, my name is Angelique. I'm 26 years old, and I was diagnosed with ALL, and I just finished a CAR T (cell therapy) treatment which put me in remission.

Elissa: All right. So, do you currently have a primary care physician outside of your oncologist?

Angelique: No. So, after a bad experience with my pediatrician, I never even considered doing any type of primary care at all.

Elissa: How old were you when you got diagnosed?

Angelique: I was 17.

Elissa: Okay.

Angelique: So, I've been dealing with leukemia for the past eight years. I also don't really have any parental advice or things in my life. So, I kind of just go with the flow and nobody talks about primary care.

Elissa: Right. Was your bad experience with your pediatrician having to do with getting diagnosed?

Angelique: Yeah. So, I kept going to my pediatrician saying I am super tired. I don't know what's going on with me. I was very active and on the go, and so this tiredness was very weird. And, I got diagnosed with anemia and was put on iron pills. It turns out that I caught my cancer right on the dot versus them holding it off till I went to the emergency room.

Elissa: Oh wow, okay. So, since you don't have a primary care physician, have you thought about getting a primary care physician?

Angelique: Yeah, so that's exactly why I came to today's session is because I wanted to see exactly how to go about it because even though I'm 26, I'm like a child when it comes to looking this stuff up. So I figured, okay, this is the best way to get the information that I need to even start this journey of finding somebody.

Elissa: Well, I'm glad that this session has helped you to at least start thinking about the benefits of primary care. Now, from what you learned in the session, what do you feel like would be the benefits of finding a primary care physician?

Angelique: So recently I've been struggling with my doctor because I am going to him for everything.

Elissa: Yeah.

Angelique: And so, he doesn't always have the answers, and I just kind of brush it under the table. But I trust him so much that I only feel comfortable with him. So, now I'm hoping that I'll be able to be like, "Oh, okay, I have a runny nose. I need antibiotics." I'm not trying to make an appointment with my physician that's going to be two, three weeks out and it's too late now.

Elissa: Yes, exactly. That definitely is the benefit to find somebody fairly quickly when you have an illness or an injury or something like that and probably something that's not even related to your cancer.

Angelique: Like even basic referrals for women doctors, if you know what I mean and things like that. I found myself recently having that uncomfortable conversation, and it keeps getting put off and put off and put off, but I know I need it. And so, I feel like a primary care physician would be able to do that very quickly.

Elissa: That's good. So, do you have a plan when you get back home to start looking for a primary care physician?

Angelique: Oh, yeah, absolutely. And I got some good information to reach out to maybe somebody in the network. That way it's all connected still, and they know about my treatment. That's something I never even considered till I heard it.

Elissa: Absolutely, yeah. I fully agree. 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-

Angelique: Living.

Elissa: So, what does that mean to you?

Angelique: So, living is just going out, doing what you're supposed to do. As a cancer patient, you have such a different outlook on life. Time is so much shorter. Time is so much more valuable. And so, you may think of things and like, "Oh, I'm going to hold off on this" or "Oh, I'm too scared to even try this." And now it's more like, "No, I'm going to live in every moment. I'm going to do everything that I say I'm going to do. I'm going to do it to the fullest extent that I can and just keep going with that."

Elissa: Well, thank you so much, Angelique, for joining us today on the podcast; and I hope you enjoy the rest of your time at CancerCon.

Angelique: Thank you.

Bree

Bree: My name is Bree. I'm 24 years old. I was diagnosed with acute myeloid leukemia, and I am five years off treatment.

Elissa: All right. And you're doing well?

Bree: Yes.

Elissa: Wonderful. Now, do you have a primary care physician outside of your oncologist?

Bree: I do as of last month.

Elissa: Last month, okay. So, let's talk about before your diagnosis for a second. Did you have a primary care prior to your diagnosis?

Bree: No. I had a primary care, and she went on maternity leave, so the practice closed. So, I didn't have a primary care doctor when I was sick.

Elissa: Okay. So, after you got diagnosed and you went with your oncologist, what made you want to get a primary care again recently?

Bree: I had seen some primary care doctors. I live in a rural area, and I was traveling about an hour to see primary care, so I wasn't going to primary care often. I avoided it if I could. But I did want to establish with primary care because I still deal with a lot of issues, and it's good to have that one person who kind of knows everything going on and can help you get those specialist referrals and figure out plans of treatments for those.

Elissa: You said you're rural, so how far away is your oncologist?

Bree: An hour and a half.

Elissa: Okay, yeah, that what makes it nice to have somebody a little more local for you, right?

Bree: Yes.

Elissa: Yeah. Do you feel like a primary care physician is important to have?

Bree: I think it is really important to have a primary care doctor, to have that person that follows you as a whole and can help you figure out next steps and just have someone to go for the smaller things that you wouldn't necessarily feel comfortable going to an oncologist for.

Elissa: Yeah. Have you had some issues following your treatment that you've had to follow up on with your primary care?

Bree: I've had a lot of different issues. I have hemochromatosis. That's actually the only reason why I see an oncologist.

Elissa: Can you explain what that is for our listeners who don't know?

Bree: I have excess load of iron from all the blood transfusions I had to have. So, the iron stayed in my liver and in my lungs. So, we have to make sure that we do phlebotomies every week to get the blood and the iron off of my organs.

Elissa: Yeah, and you definitely don't want to be driving an hour and a half-

Bree: No.

Elissa: -to get that done.

Bree: Well, I do.

Elissa: Oh, my goodness.

Bree: Yeah, because they're the only ones that will do it; and I say that they're my oncologist, my actual oncology team is a 4-1/2 hour drive.

Elissa: Okay, okay. So, it's a community cancer center that you go to for that?

Bree: It's a bigger cancer center but it's not a transplant center. And since I had transplant, I have to get my follow-up care from a transplant center and the closest is four hours away.

Elissa: Yes, there's certainly fewer transplant centers. Well, I'm so glad that you found a primary care that you're able to see.

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-

Bree: I'd say after diagnosis comes rediscovery.

I think a lot of times during treatment we're like thinking that we're waiting to get back to our old normal; and there's just none of that old normal. You have to kind of find yourself. It's not a bad thing because you've gone through this experience, and it's changed the way you are. It's changed your perspective. It's changed your circumstances, and you get to learn who you are under these new circumstances. And you learn new parts about yourself that you might not have understood before. You get to learn more about the people around you, you get to meet new people and be kind of a new person in some ways and just learn who you are in a different life.

Elissa: I love that. Well, thank you so much, Bree, for joining us today. And I hope you enjoy the rest of CancerCon.

Bree: Thank you so much.

Lauren

Lauren: So, hi. My name's Lauren. I'm 32 years old. I had Hodgkin's lymphoma, and I'm less than a year out of treatment, in remission right now.

Elissa: Okay, good to hear that you're in remission. So, do you have a primary care physician currently outside of your oncologist?

Lauren: I do.

Elissa: Yeah, did you have that before your diagnosis?

Lauren: I did. She actually helped get me diagnosed.

Elissa: Wonderful. How was that experience because it seems to be very different from AYA to AYA.

Lauren: It was a really positive experience for me because we had had a pretty good working relationship. I'd been having a variety of random symptoms that we couldn't really figure out. And she was very committed to helping me navigate them, even if she didn't know the answer. She would be really honest. Like, "I don't know, but, let's figure it out together. Let's try X, let's try Y." That kind of thing. And when things eventually progressed, she was the one that sent me for a scan that ultimately led to me getting the diagnosis.

Elissa: That is so good.

Lauren: Yeah, so I really feel like she saved my life, and I've told her that many times.

Elissa: Oh, that's so sweet.

Lauren: Yeah.

Elissa: So, what do you feel like are the benefits of having a primary care physician?

Lauren: Yeah, I feel like she's really helpful for me, even though I still see my oncologist since I'm early in my survivorship. Like when I need help with finding psychiatry or a mental health provider or like where I wasn't walking a lot, and so she helped me figure out finding an oncology-specific PT when my oncologist maybe wasn't aware of those resources.

I live in a rural area, so she was just like an added partner to like help look at things like in a more like whole person point of view.

Elissa: That's awesome. 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-

Lauren: After diagnosis comes change, a lot of change. The change comes at you fast, but I think sometimes change can feel scary, and sometimes our fear can point us

in the right direction of growth. If we decide to lean into some of our fear, sometimes that can be really beautiful.

Elissa: Absolutely. Fully agree. Well, thank you so much, Lauren, for joining us today and sharing all about your very good experiences with primary care. So, we really appreciate it.

Lauren: Yeah, thank you.

Rachel

Rachel: Hi, my name is Rachel. I'm 40 years old. I have multiple myeloma. I am Stage III, and I was diagnosed when I was 34 years old.

Elissa: So, do you have a primary care physician outside of your oncologist?

Rachel: I do. That's kind of a loaded question because I have bounced around. I've been trying to find the right primary care for me, hopefully currently working through it.

Elissa: Right. So, did you have a primary care physician prior to your diagnosis?

Rachel: I did not, no.

Elissa: So, what made you want to then get a primary care after you've been diagnosed?

Rachel: Really, my oncologist suggested it. I was dealing with high blood pressure after transplant and some of the aftereffects of menopause. Transplant put me into menopause, so there were just aspects of my health that he felt like was best suited for primary care to take over.

Elissa: Absolutely. And then what was that search like? It sounds like it's been a lot to find somebody who's just right for you.

Rachel: Yes, absolutely, because I do find physicians that are uncomfortable making decisions without my oncologist. Some of them are not exactly sure of what the cancer exactly is and maybe don't want to prescribe hormones. I've never been on hormones, but I've been in menopause for six years. So, that is something that I'm actively seeking now. But just trying to find the right doctor that feels comfortable enough to make those decisions without me having to go back and forth between my oncologist and them.

Elissa: Right. Have you looked for somebody within your hospital system, somebody who would be able to communicate easier with your oncologist?

Rachel: Yes, absolutely. I find that that's the easiest because a lot of the medical records now are electronic, so they can get online and read the notes. It's not so much of a back and forth because they can just get on the computer and see my last note from my oncologist. So that's been very helpful.

Elissa: Yeah. Now, I know your oncologist recommended you seeing a primary care. What are your general thoughts about having a primary care physician? Do you feel like that's important?

Rachel: I absolutely do. Sometimes I get a little bit frustrated with like, okay, you're the one that gave me menopause. You're the one that gave me high blood pressure. But at the end of the day, his job is to treat my cancer. And other physicians have their specialty. So, I do feel like it's best suited for me to see an endocrinologist or an OB/GYN or my primary care for some of these other conditions. Even though sometimes it can get frustrating to have to go to different doctors, I do see the value and the importance in it.

Elissa: Right, that's good. Now, 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-

After diagnosis comes determination. I'm determined to get through any ailment that comes my way. I'm determined to find the answers. There's a lot that I am after diagnosis. But I definitely feel motivated to push forward, motivated to be an advocate for myself, motivated to see the best doctors, to provide the best health for myself.

Elissa: Well, thank you so much, Rachel, for talking to us today; and I hope you enjoy the rest of CancerCon.

Rachel: Thank you so much. Appreciate it.

Hailey

Hailey: My name is Hailey. I am 27 years old. My initial diagnosis was Hodgkin's lymphoma, Stage IIA, and I have also had atypical hyperplasia in my right breast. And as of right now, I'm just on surveillance and routine scans.

Elissa: All right, so do you have a primary care physician outside of your oncologist?

Hailey: I do, yes.

Elissa: Did you have that same person prior to your diagnosis?

Hailey: No, I did not because I moved states.

Elissa: Oh, okay, okay. Had you had a good experience with your previous one?

Hailey: Yes, I did. He was our family doctor. Loved him. Really wish I could have stayed with him, but yeah.

Elissa: So, were you with him when you got diagnosed?

Hailey: Actually, no, I wasn't. That was a different family doctor. He was also great, but I guess the more recent one I had following diagnosis, I felt like he really listens to

what I had to say and allowed me to be just an advocate in my own care, which is really important to me.

Elissa: So, after you moved, did you switch oncology then as well?

Hailey: I did somewhat. So, I did age out of the AYA program. Or I guess not age out, but I had been in remission for long enough to where I can get most of my scans through my primary physician.

Elissa: Okay, is that what made you just want to start with the new primary physician once you moved?

Hailey: Partially, yeah. I think it's just also needed for me for other things as well, just having a primary care physician and, thankfully, I have had private insurance through work. So, I've luckily had access to that as well.

Elissa: So, that's good. What are the benefits you see of having a primary physician versus going to your oncologist for everything?

Hailey: Yeah, I think having a primary physician, they're able to look, I guess the whole picture of your health. So, there's aspects of my health where maybe I might get anxious about cancer and I may be thinking about 10,000 other things that it could be, right, which can really, I guess, level set me and make me feel a little more comfortable and not as anxious about might be going on in my body, so.

Elissa: Yeah, absolutely. Well, I'm so glad that you have had a primary care physician and even when once you moved you got a new one and hopefully that is going really well for you.

So, Hailey, since I know you a little bit, as a member of the LGBTQ community, have you had any trouble with finding primary care?

Hailey: Yeah, I actually did. So, it was really important to me to find an affirming physician who I could talk to about things regarding my sex life and things and

changes with my body where it may be more affirming for me than would be expected. And I actually ended up with a primary care physician who is based an hour away from where I live. So, really not accessible within the city limits that I'm currently residing in.

And I think that is something that is not uncommon for my community in experiencing, and I'm really grateful to have an affirming physician and office. And I hope that we can continue on the path of more physicians really positioning themselves as somebody who's safe for the community.

Elissa: Yeah. It really is important to find somebody who you feel comfortable with and very safe with, right?

Hailey: Absolutely.

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-

Hailey: After diagnosis comes a lot of follow-up and a lot of change, and some of it's good, some of it's bad. And that's okay. And that's life.

Elissa: Yeah, you deal with it, you change, and you move forward, right?

Hailey: Yeah.

Elissa: Well, thank you so much, Hailey, for joining us today. And I hope you have enjoyed CancerCan.

Hailey: Yeah, thanks

Outro



Elissa: This concludes our first episode podcasting live from CancerCon 2024. 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.

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.

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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 on been affected by 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://www.lls.org/PatientSupport).

Young adults who are age 15 to 39 are encouraged to visit [LLS.org/YoungAdults](https://www.lls.org/YoungAdults) for all the resources that LLS has to address your unique needs. For more information on CancerCon and Stupid Cancer, please go to [StupidCancer.org](https://www.stupidcancer.org). All of these links will be in the show notes or at [TheBloodline.org](https://www.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.