

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'Cancer and a Pandemic – A Non-Hodgkin Lymphoma Story'

Description:

Join us as we speak to Nikki Steltenkamp, a young adult, non-Hodgkin lymphoma survivor. Nikki, an engineer, was 24 years old when she was diagnosed with primary mediastinal B-cell lymphoma. In this episode, we hear about her intense treatments that finished up just as the world was entering a global pandemic. She also shares her experiences with mental health, fertility preservation and her podcast, *That 6-Letter Word*.

Transcript:

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

Edith: I'm Edith.

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

Elissa: Today we will be speaking with Nikki Steltenkamp, a young adult, non-Hodgkin lymphoma survivor. Nikki is an engineer and was 24 years old when she learned about a softball-sized tumor in her chest cavity which was soon diagnosed as primary mediastinal B-cell lymphoma. She underwent six rounds of intense inpatient chemotherapy, finishing treatment in April 2020 as the world had just been locked down in a global pandemic.

She is now passionate about sharing her story and connecting with other young adult cancer patients about their unique experiences. Nikki does this primarily through a podcast she started called, *That Six-Letter Word*, where she and her cohost, Emily, not only share their own cancer stories but those of young adult survivors. Welcome, Nikki.

Nikki Steltenkamp: Hi, thank you so much for having me.

Elissa: You were diagnosed with primary mediastinal B-cell lymphoma, a type of non-Hodgkin lymphoma. Could you tell us what that is?

Nikki: Yes. So, the little bit of the backstory. I thought that I had a respiratory infection, so I was coughing. I had kind of some weird pains. I couldn't really figure out what was going on. And ultimately, I ended up with some pain in my shoulder and my neck, and so I went to the hospital; and what they found was a tumor in my chest. And the first conversation was, "You know, here's this tumor. We're not sure what it is, but it's pretty big, and it's pressing on the veins that leave your heart.

So, there were blood clots, and what we came to understand was that basically this tumor was a manifestation of this B-cell lymphoma. So primary mediastinal refers to where that mass was; mediastinal is kind of the chest area. B-cell lymphoma is the type of white blood cells that were cancerous. Lymphoma, obviously, is blood cancer. So, my B-cells were the ones that were cancerous, and basically in trying to fight something that wasn't there, they created this mass in my chest. So that was the kind of initial diagnosis process.

Edith: So, how did this all start? What signs and symptoms led you to go into the hospital?

Nikki: Yeah, so I was actually on a trip with my friends. I was hiking the Grand Canyon, and like I said, I thought that I maybe had a respiratory infection. I wasn't sure what was going on. I had been coughing. There had been a couple of weird aches and pains.

When I hiked the Grand Canyon, I actually threw up in the middle of our hike, which was very uncommon. I was in shape and active, so I was concerned something was up. And then within about a day, I had a lot of swelling and pain in my neck and in my shoulder; and that's when I went to the hospital because my shoulder kind of felt like a sausage, my arm. And so, I went to the hospital and said, "Some sort of weird

swelling is happening." I thought maybe I got bit by a spider in Arizona. I wasn't sure what was happening.

They put me on fluids, and they started with a CT scan and a chest x-ray. The chest x-ray didn't show much, but the CT scan showed an opacity is what they called it, kind of just a big area in my chest that looked opaque. And then ultimately a PET scan revealed kind of how big the tumor was, where it was sitting. It did reveal that it was pressing on the veins leaving my heart, which is what led to the urgency of starting treatment really quickly because there were huge blood clots in my neck and my shoulder. So I had to go on blood thinners immediately, and then ultimately chemo melted the tumor, for lack of better terms, and also killed the cancerous blood cells in the blood.

Elissa: Oh wow. So, you were only 24 years old when you were told you had cancer.

Nikki: Yes.

Elissa: When many of us have symptoms of anything, we tend to go to *WebMD* where there is a running joke that it will always tell you that it's cancer. We don't really think that at the end of the day. What was your first thought that went through your head when the doctors told you that you had lymphoma?

Nikki: It was a lot, obviously. I remember really vividly my mom was in the hospital with me. My parents had both come. Fortunately, I live pretty close to them; so, they both had come to the hospital as soon as I said like, "Hey, I think I'll be here for more than a couple hours. Something's going on." My dad had gone home to sleep, and so my mom and I were like spooning in the hospital bed because it's so tiny; and we were just trying to sleep. It was like 3 in the morning.

And so, yeah, receiving that information, obviously, was really scary. So, my mom and I were laying there. Obviously, we were given this information; and we both turned to each other and basically said, "WTF, what is going on?" Like it was mostly just how

the heck can this happen? So, it's a lot of fear. Obviously, you're so young, you almost can't process it.

I think what was almost more scary is that the blood clotting was so serious that the initial information from the doctor said that you might need surgery to remove these blood clots; and because I had just gotten the CT scan that night, they thought that the cancer was growing on my heart and lungs. And so, the initial information I received was a much worse diagnosis than what ultimately was going on.

So, it was just a lot of fear and a lot of like "this doesn't make sense" given not just how young I was but I'm a pretty healthy person. I had just hiked the Grand Canyon. I had run a half marathon like less than a month before. Like it just didn't make sense for a person who's been active my whole life. Fear and confusion I would say were the raining feelings.

And then once we got more information, kind of the blessing in disguise was that the prognosis got better as we learned more from that initial emergency information from the doctor. We were mentally prepped for the worst; and then as information came out, it was a little bit more manageable, which I think, obviously, wasn't fun but helped us a little bit in the long run.

Lizette: Sure. I know that sometimes our blood cancer patients don't get diagnosed right away; and a lot of our patients are told that they have something else like mono or just something else that is more prevalent, right, so you're not really looking for cancer, especially in a young adult that is in great shape. It's usually not the first thing that they look for.

So, they told you, you had cancer first before they used the term lymphoma?

Nikki: Well, yeah, it was an odd one. So that first night they said, "There's a tumor. We think it's growing on your lung and your heart. It's causing these clots," and they said, "You'll see the oncology team tomorrow." They didn't say we think it's cancer,

but they said, "There's a tumor, and you're going to see the oncology team." And I said, "Okay, we can put two and two together."

I met my oncologist the next day for the first time and got my first PET scan, which is when she basically came back and said, "There's two or three types of lymphoma. We believe it is a lymphoma." So that was pretty clear within about a day.

What was challenging was that I actually had to do three different biopsies to make it clear. So, I actually had about three weeks before I had a full diagnosis. So, we pretty much knew what it was, but it was a process. Each of the biopsies just took time. They were needle biopsies. They went in really right in the center of my chest. The first one they took two, three, four samples which is kind of standard. And because so much of the mass had already lived and died, they basically got inactive cells; and so, they couldn't make a diagnosis with inactive cells.

So, they did the first one. A week later we did the second one. Took eight, nine, ten samples, which is a lot for a needle biopsy. Still could not find active cells. But the doctors kind of knew, like we know there's something in there. We have to figure it out. We can't just say that the whole thing's a dead tumor.

So, I went in for a third biopsy. They took like 17 or 18 samples. It was a really long one, two different spots in the tumor. And ultimately, that's what delivered a diagnosis. So, it was kind of a slow process, but like I said, the ER doctor gave us the shock factor of, "It's a tumor. Go see your oncologist." My oncologist then kind of honed us in on a couple of options, and it did take a few weeks to get a complete diagnosis.

Lizette: So, during these few weeks, were you on treatment or were they still trying to figure things out as to which treatment to provide to you? And were you getting other information like any discussions about fertility or any discussions about how much time you would be in the hospital?

Nikki: Yes. So, that first conversation with my oncologist, I remember it was a Saturday when she said, "We think it's one of these two or three types of lymphoma," and she explained that there were basically two or three different chemo treatments that would be coming. But she wanted to understand exactly what it was before we administered those.

In the next breath, she basically said that fertility would be a big topic since I was so young and said, "You know, whatever chemo we give you runs a risk of hurting your fertility in the future. We don't have a good way of predicting that, and if you want to freeze your eggs, you have to start today because as soon as we figure out which type this is, we will start treatment the next day." She basically said like we're on a tight timeline, so go see your GYN today.

Fortunately, my GYN practice works out of the same hospital that I was at, so I was able to see one of the doctors that day. They referred me to a fertility doctor close by, and the day I got out of the hospital, I went straight to the fertility doctor and started that treatment or, rather, started the conversation. The next day, the fertility treatment started.

So, what was really interesting was those three weeks of waiting for a diagnosis, I was also doing the egg freezing, which, I think, was kind of a healthy distraction. Like it was something positive that we could do.

Lizette: Sure.

Nikki: Like it's such an insane thing to wait around for these diagnoses, and so many phone calls and just kind of waiting periods that to go into a different doctor every day, they had kind of the overarching positive association in that like, okay, there's hope. Here's this thing to prep us for the future that I'm going to have. That was a really, I think, valuable distraction for us.

I was also really lucky to be able to do fertility preservation because, obviously, it's wicked expensive; and my insurance covered zero dollars. So, I went through Livestrong Fertility, which is an organization that you basically can get a grant for some of the medication, so I didn't have to pay as much out of pocket, which I'm really grateful for because I think that could have been prohibitive had it worked out differently.

So, it moved very quickly. I was lucky to be able to do it, but it was kind of the healthy distraction while they waited for a diagnosis. And then I got a diagnosis Friday, exactly three weeks after I had initially gone to the hospital; and I started chemo the following Monday.

Lizette: Wow. I am glad though to hear that your doctor spoke to you about fertility. We hear more and more young adults saying that the conversation was started by someone else, even someone in their family telling them. And then having a more acute or aggressive type of diagnosis. Just like you said, it's kind of very quick. You have to think about it and actually go through the fertility preservation, man or woman, to actually have it done prior to treatment starting. And that's something that people should know that this has to be done prior to your treatment starting.

Nikki: Right. Yeah, it was definitely something where I remember, I have come to love my doctor so much. But the first time I met her, you know, she walks in and says, "We think it's lymphoma. Also, freeze your eggs." And I was angry at her because I was like, "Can you please give me one thing at a time to worry about?" And I was also 24 and just at a point in my life where it hadn't even occurred to me to worry about having kids yet. Like just where I was at, I was building my career and doing other things; and so, I was mad, clearly at the situation but also at how quickly it was brought up. But ultimately, I'm so grateful that we had that conversation that day because I was able to get in the next day and complete the whole process kind of right in time to start treatment.

And that was really good because she did kind of say, if you don't start it tomorrow, it'll be your life on the line; and we're going to start chemo, and that might be the reality. So, it worked out well but definitely is a tough one.

Elissa: Yeah

Edith: So, what was it like, and how long did the six rounds take to complete?

Nikki: So, it was basically one week on and two weeks off. So, I did a chemo regimen called DA-R-EPOCH. The DA stands for dose adjusted, so every round they increased the doses I was receiving. R is Rituxan; it's like a pre-drug, and then EPOCH is the chemo itself.

So, I would go in Monday morning. My very first round I went in at like 7 AM Monday to get my port put in, underwent the procedure, and then they accessed it and started treatment that day. The first day, Monday, would be that Rituxan, some other premeds to kind of prep, and then I would start the chemo that afternoon. And it was basically four days of 24/7 infusions. So, I'd start it sometime Monday afternoon, and it would basically continually run until Friday.

My first round, I was able to do outpatient, so I would wear a little fanny pack that had the chemo in it. I was attached to it all the time. I had to sleep snuggling my fanny pack. It was a whole thing. I was glad to be able to do that because I live close enough to my office where it was kind of nice to be able to sleep at home. But starting Round 2, they were all inpatient because they just wanted to monitor symptoms and things.

So, starting Round 2, I would go in Monday morning, stay till Saturday morning basically in the hospital, getting treatment the whole time. I was always hooked up to the IV, and then I'd take two weeks off at home and then go back. So, it took just under five months start to finish, and I was in the hospital. Most of it was okay because my mom's retired and was able to be there with me all the time, my dad

would come pretty much every night for dinner. Friends were in and out, so I felt really lucky to have kind of mobility and also energy to interact with people in the hospital.

The last round was the worst because it was COVID, so I had zero visitors. I was just in solitary confinement basically for a full week, which I wouldn't wish on my enemies. And, yeah, that was kind of the whole treatment process. I was really fortunate to not have a ton of side effects, so I felt pretty good the whole time. I really didn't have nausea, and I wasn't particularly tired, so I walked a lot in the hospital and tried to keep busy as often as possible.

Elissa: Oh, that's good. How long did that all take? Was it several months?

Nikki: Yeah, it was about six months start to finish. So, I went to the hospital on November 15, 2019. I started treatment on December 9, a few weeks later. And then I finished treatment on April 4, 2020. So, it was about five to six months total.

Lizette: Wow

Elissa: Yeah, that's a lot. So as many of our listeners know very well, there are both financial and emotional impacts of cancer. Let's start with financial. As a young adult, were you still on your parents' insurance? Were you able to be fully covered through your treatment? I know you had mentioned not being covered with fertility, but what about the rest?

Nikki: Yes, so it's funny. I was actually off of my parents' insurance right before that. I'd been in my full-time job. I started it right after college and decided I was independent and had my own plan. And so, I was on my own insurance. I was really fortunate that my company was able to give me a disability leave, so I was off of work for those full six months. And I received my paycheck the whole time and maintained my health insurance, which was really, really lucky.

So, I had good insurance. I mean I paid my deductible every year, which was about three grand. So, I paid that out of pocket for each calendar year, which is money, but was not prohibitive, just because of what I was making and the family that I had around me.

And yeah, the fertility treatment was kind of additional cost that I got some help with from my parents and my grandparents; otherwise, my insurance covered everything, which I was really lucky to do because the insane sticker shock when I go into my health insurance account and see how much I have incurred in that time, it's disgusting how much was paid – not by me fortunately – to take care of me. It's really surprising.

Elissa: Yeah, I think a lot of cancer patients have definitely seen the benefit of good insurance to be able to pay as much as possible so that you have less out of pocket, especially if you're not working, if you're not able to get on disability, whether Social Security or through your company. It can be very, very expensive.

Nikki: Yes, definitely. I felt really lucky that I was covered the whole time because it would have been a lot of debt to take on that I was not ready to take on at all. So, it worked out well. I felt really lucky that I was at such a big company that had a lot of kind of structures in place to take good care of me.

Elissa: That's great. So now let's go to the emotional impact of cancer.

So, when I was diagnosed with AML, one of the best nuggets of knowledge that was given to me was that your body can handle a lot. It's the emotional impact that will be the biggest challenge. The emotional part, however, can hit at different times.

Sometimes it's in the beginning when you're diagnosed, and it feels like the whole world is crashing down around you. And then often it's, after one has finished their treatment, and it finally leaves that space to reflect and process those emotions, what was that all like for you? Did you end up choosing to go to therapy?

Nikki: Yes, I did. And also, I absolutely identify with just that topic, that the emotional is worse. And it's something that no one really had told me. I think that I came in ready to just handle it, and I am kind of an upbeat person. I have been my entire life.

And so, the initial diagnosis, and really through most of the treatment, I found it pretty easy to be optimistic. I think part of it was that I just had this very deep core feeling that like my body will pull through. It never hasn't, and I've been an athlete, I've been challenged in other ways that I felt really okay, even being challenged physically, which sounds a little odd. But I think that I just kind of knew that things would be okay from that perspective.

And for me, getting from day to day during treatment, all I had to do was show up for the next appointment, and then go to bed and wake up and show up again. There was a goal to reach, and I felt prepared to reach it because my only job was to wake up and show up and do the things.

And that was good. I was like, "Yeah, I can totally do this." It was after, and so I really identify with that feeling. It was after when it was much harder for me.

And I think COVID, obviously, plays a huge role in that because I finished treatment right as COVID was happening. So, it wasn't just that I had been through something crazy. It was that I emerged into a world where I couldn't reintegrate myself into my old life. I couldn't be with people that I'm close to, aside from a couple family members. And obviously, coming out of treatment, your immune system is so challenged that on top of COVID, you really can't see anybody. We weren't even sneaking around and seeing any relatives. It was my parents and I locked in a house for about three months. I didn't go in the grocery store. I would drive my mom and sit in the car. I was really, really isolated, and so that was, I think, a big factor as well.

But yeah, the emotional impact of trying to reemerge into a world after having changed yourself and after having the world change while you were gone was really

tough for me. It was just difficult to connect with my friends because they hadn't been through it, which I'll get to because I did have one friend who had, so that helped me a lot.

It's also just difficult to go back to work. I mean I went back to work when we were remote, and so I didn't have the chance to really have real conversations with people. I got back on meetings, and people said, "Hey, glad you're back. Okay, so about that thing we were working on," and it was like, "Guys, I was gone for six months. Like ask me how I'm doing. What is going on?" So that was really challenging for me, just trying to navigate kind of how to interact with other people after so much time alone and also just going through such a hard thing. It's like a weird line to draw because people don't want to ask you the wrong thing, but you also want them to ask about how you're doing. That was a big challenge for me.

Elissa: Definitely. Yeah, it is hard to finish in itself and then, even if you're positive through the whole thing, you're like, "Whoa, what just happened? I haven't dealt with any of these emotions whatsoever from the time of my diagnosis." And then it just kind of hits you like a brick.

But then you're finishing treatment, and the world has completely locked down around you. I feel like that would just add such an extra burden and emotions on top of that to then be finished and, people who finish treatment, they're like, "Yes! I'm ready to go out into the world. I'm done. Let's do this!" And then you're like, "Wait, okay, so now I have to continue isolation?"

Nikki: Right.

Elissa: And not only that, there's a virus that is a huge threat to blood cancer patients like yourself-

Nikki: Yeah.

Elissa: -to worry about on top of that. So, I mean really that had to have just been so much more difficult to come out of treatment and be faced with that and we're still facing it over a year later.

Nikki: Yeah, it definitely is a challenge; and, I mean, I am an extrovert through and through, and so I did not enjoy being alone all the time. When you're waking up and getting to the next day, it's like very easy to see the light at the end of the tunnel and you stay positive and you're like, "All right, I'll beat it. And then when I beat it, I'll be good." And then you beat it, and you're like, "Oh God, there's like so much more to do; and I can't see my friends while I do it because that's dangerous. And I can't even go walk around outside because that might be dangerous too."

And so, then it's like, okay, I did it, and now I'm back living with my parents, which isn't my home. I live separate from them, but I had a roommate who I couldn't be around, because it was unsafe. And so, it was just a lot of like I didn't get to go back to normal. I had to find a new normal that was not helpful to me. And it was like I had such big plans, like you said. You finish treatment and you're like, "I'm going to go do fun things with my friends."

And even the example is like I had planned to do a big brunch with my grandma, a couple aunts and uncles, my two best friends. We were all going to go out for brunch the day I left the hospital. And the idea was everyone make sure you don't have a cold. We're going to go out in public and celebrate this thing, and then I really wanted to go on a trip the month after I finished, right before I went back to work.

I was going to go to Ireland and do a whole thing, and then obviously COVID hit like two weeks prior to my final treatment, and everything got canceled. So you looked forward to this big ending; and then it's like this prolonged quarantine. I joke that my quarantine started six months before everyone else's, so now I'm like two years locked down basically.

Elissa: Yeah.

Nikki: So yeah, it's definitely an odd challenge. I will say kind of to the therapy point, I finished treatment, was home with my parents, kind of assumed that I would work my way through it, which ultimately, I did, right? It was just the challenge of day to day, trying to figure out how to interact with people, how to go back to work, all these things.

I didn't actually end up seeking therapy until late last year when I was about six months post-treatment because that's when it kind of started to hit that it's like, okay, this isn't just a prolonged quarantine. This is the new normal, and it will continue to be. And so, without being able to see my friends and not really knowing where things were headed was the point where I was like, "It would be good to talk to someone, just because we're in this waiting game, right? And I've been in the waiting game even longer than people who have been in quarantine." And so that was the big challenge for me.

Now that we're vaccinated, there's definitely a light at the end of the tunnel. I've had the chance to see some friends, and I've been able to visit my brother, which is really exciting because he's lived in California for two years; and I haven't been there because I was sick. So things are starting to kind of brighten up, and it's helped a lot. But, yeah, it was certainly just a challenge to sit through all of it.

Elissa: Yeah, therapy's definitely important. Did you get recommended therapy by a doctor or social worker, or did you just kind of figure that out on your own that, hey, I need to talk to somebody?

Nikki: Yeah, it was actually on my own. We had a really great social worker who was on the oncology floor, but I only ever saw her when I was in the hospital. And so, she'd walk by the room and say, "How are you doing?" And I'm like in the middle of a Scrabble game with my mom, and I'm like, "Oh, great. What do you mean?" "I had a quesadilla for dinner, got Sprite, my mom's here, like I'm good. Thanks for asking."

You know, I didn't really see the big picture. So, I ended up seeking it out sort kind of on my own months later.

Yeah, I do think that doctors probably should push it a little bit more on a lot of people. I think it would have been good for me to be pushed into it a little bit harder early on, but I think that it worked out okay.

Lizette: And prior to getting therapy, what do you feel helped you the most during your treatment?

Nikki: Definitely my family being around. I feel really lucky that my parents live 20 minutes from me, and the hospital that I was at was kind of dead between the two of our houses, so I really had the opportunity to have my family there.

And also, I think, it sounds silly, but keeping my close friends. I've made this comment before, especially when you're a young adult cancer patient. Having close friends who remember who you are before being a patient is what helped keep me the most sane because people who didn't know me as well kind of treated me as fragile, which I think is common because cancer patients are fragile to some degree. But, you know, if a friend would call and say, "Oh, well I don't want to bother you with my problems because it's nothing compared to yours," and you're like, "No, the only way for me to get through this is to feel like a person who still lives in my world."

And so, it really helped me. I have kind of three best friends who lived in the area who would visit me in the hospital and like be able to joke with me or be able to tell me about their problems and their relationships or whatever was going on. And it helped to make me feel like a person throughout, which I think really kept me moving through it. I didn't melt into the cancer patient cave that I think I could have if I was more isolated from the world.

Lizette: Sure, it gave you some normalcy-

Nikki: Yes, exactly.

Lizette: -that you were probably looking for instead of, I know that everybody says the new normal afterwards. Then you have to create a whole other normal because going through this experience, you're not the same person.

Nikki: Right, exactly.

Edith: In your podcast, you said that you had just ended a relationship around the time of your diagnosis. Did you try to get back out there with the dating during COVID?

Nikki: Oh, I'm trying, but it's rough. A little bit, yeah. So, I guess that's another context. I was in a relationship heading into my diagnosis. Basically, within the week of being diagnosed, we broke up. That was mostly my decision, and there was already some issues. It wasn't like it was all because of the diagnosis, although it was a factor, obviously.

But, yeah, it's funny because that was another thing, I think for me is like so much of my reality changed with the diagnosis, which includes that relationship. And so, then I had said the whole way through, like, "Ooh, I'm so excited to get back out there. You know, as soon as it's done." I had this cute wig that I bought. I'm like ready to go. And then it's COVID, and so you don't have the opportunity to do that.

So, I have a little bit in the past few months as vaccinations have come through, and it's been a little bit safer. But it's a weird thing to date after having been through this, and the more distance I get, the more comfortable it gets.

This is a silly example, but the pictures on my dating profiles no longer look like me because my hair suddenly is much shorter. So, it's just funny things of like trying to navigate the normal; and then it's a decision of like do I tell this person who just met me that I've been through all of this trauma? Do I want to tell them about this today, or do I just pretend like I'm a normal person and tell them next week or whatever? So that's been kind of the challenge is just figuring out how to talk to people about the

experience mostly and about life up to this point. But it's been a little bit of an adventure, I would say. Nothing serious but I'm definitely attempting.

Elissa: Yeah, I think it's been certainly difficult for cancer patients to get into the dating world period, whether they finish treatment or they've kept going because then, you're not only worried about when do I tell them that I had cancer or if you're still going through it, but then it's, "Hey, we actually have to do Facetime or I still have to stay distanced from you or we still have to wear masks because I'm high risk." So then you almost kind of have to tell them anyway because you're high risk; and so that adds just such a bigger element.

We actually did a video webcast with Dr. Anne Katz recently about sexuality and young adult cancer, and she discussed dating during COVID. So for our listeners, we highly recommend that you listen to that. It's great information that really just talked all about body image and all of this stuff that we just talked about. But then adding onto it what has been going on with dating for blood cancer patients during this crazy, crazy year.

Nikki: Yes, absolutely. That's definitely a feeling that I'm glad has been validated, and I hope that anyone listening has validated too is like you want to get back out there; and part of it is just the emotional fear of talking to people about it. But part of it too is body image, at least as a young woman. It's like I used to have super cute long blond hair, and my hair's growing back curly; so, we're slowly getting back into something.

It's a difficult thing to be like, "Okay, I don't look like these pictures. Do I take new ones? Am I even comfortable with that person? You know, what if they ask?" It's just a weird thing to have to navigate. Also, I think it's really helpful that with every passing day, I feel a little bit more like myself. And I settle into what the new normal is; and I hope that that's the case for anyone kind of on their way out of that experience because it's a weird thing to be bald, obviously. It's not something you're

used to. You kind of get used to it, and then it grows back. And it's tough just being a woman dating who has some of your identity wrapped up in that. It's just a weird normal to try and figure out.

Elissa: And when you just don't look like you anymore and then you don't recognize the person in the mirror anymore. And yeah, with pictures, especially during COVID, what pictures do you take? Just selfies at home? I mean you can't go anywhere. You can't be around anybody and have those pictures with your friends or pictures out with drinks or things like that. So yeah, there's a lot of different things that come along with that.

Nikki: Definitely.

Elissa: So now let's talk about your podcast. What got that started?

Nikki: So, this is kind of the part of the story that I left out. One of my best friends in college, we lived in a house. There were five of us who lived together for three years in college, and they're spread all over the country. One of them, Emily is from Texas, and she moved back to Texas after college.

And in October of 2018, so almost exactly one year before I was diagnosed, she actually went to the doctor for migraines, went through a bunch of tests, and ultimately found a lesion in her brain. And so we received that news from afar, and they said, "It might be cancer. We don't know yet, but you do have to go into brain surgery. We're going to remove this, and then we'll figure it out."

She underwent surgery on her brain. They removed the lesion in her frontal lobe, and it was a very long recovery for her. She went through aphasia and some different things as she recovered from surgery. She had brain swelling, all of these things.

And when they did the biopsy on the lesion, they did find that it was cancerous, and it's something called oligodendroglioma. It's most common in middle aged men, so she was an odd case. So in the winter of 2018, one of my college roommates was



diagnosed with cancer. This was before I was diagnosed, and you know, all of us kind of said, "How the heck does this make sense? We're just fun college kids who studied engineering together but also went to the bar and had a great time as college students and she was diagnosed." And her prognosis is that she has to remain on tumor watch but doesn't have to do chemo and radiation just yet. They say that she'll probably have to in the future.

So that was where she was at in life, and then I was diagnosed almost exactly a year later. So out of our little group of five, two of us were diagnosed with cancer.

One thing that was really helpful was that she actually happened to be in town in Ann Arbor the weekend that I got diagnosed, and so she was visiting from Texas and had the chance to see me in the hospital like that first day, which was cool, just to see a friend.

But we got to talking and, I mean, the first thing was what are the odds? It makes no sense that the two of us out of five both received diagnoses, and then the next thing was our diagnoses, and our experiences are so different, but we're still really grateful to have each other to talk to because the fear and the confusion in all of these things, even the insurance, isn't a thing that your standard 25-year-old friend would understand. It's just not part of our conversations when you're that young typically.

So, we felt very lucky to have each other. And like I said, it was really valuable for us to acknowledge that we had different experiences from one another. She had a surgery and then was kind of living scan to scan. I had a scan and then was in treatment, and it was intense. She would call me and ask about chemo because she hasn't done it yet; and she wanted to know what it would be like. And she had frozen her eggs before I did, so I got to call her and ask questions; and this kind of led us to the idea of like why doesn't a platform exist for us to hear stories from people like us, especially who are young women who are otherwise living normal professional lives?

We couldn't really find that resource where the conversations were more candid. You know, it's like your doctor can talk to you about the science of it, and people recommend therapists who want to have really deep conversations. And we wanted to joke about the dating topics and that my leg hair didn't grow back for six months; and it's like a funny tidbit that in any other setting didn't make sense.

And so *That Six-Letter Word* was our attempt at kind of creating that community and just finding other people, and I think too for us is giving other people the chance to tell their story, like this platform too. There's so much, I think, that both of us experienced that we didn't say outright to our family and friends while it was happening, but we said to each other. And so then we were like, "Well, if we're thinking it but not saying it out loud, there's probably other people out there with similar thoughts who aren't really saying it out loud because it's weird. But maybe if there's a platform where they can, not only can we find each other and help each other out, but they can send it to their friends and family and say, 'Just listen to this, and don't ask me so many questions. Right, here's the questions that I didn't tell you that I was thinking.'"

So that's really what it was borne out of. So, it's been a lot of fun I mean for her and I to bond. She lives in Texas, so like we have scheduled dates now. We talk more now than we did right after college. And also, it's just an opportunity, like I said. We're excited to kind of build this small community and really let people tell their stories.

Lizette: Wow. And like you said, you and Emily have had different types of cancer, but you could still relate to each other. Can you always relate to your guests, even though the guests have different types of cancer? And even lymphoma, there's so many types, so even just another lymphoma patient that has a different type of lymphoma. Do you find that you can always relate to something in a cancer patient's story?

Nikki: Yeah, definitely. I mean that's what I think has been so interesting is that kind of the two things I've learned, and they're almost contradictory. But one is that just because they have *That Six-Letter Word* in common with you doesn't mean that you know anything about their story necessarily. That was kind of what it was borne out of is like our story, by the facts and figures, meaning mine and Emily's, are so different. And all we really share is the word cancer. But kind of beneath that, there's so many feelings and thoughts that we do share, even though the facts and figures are so different, and that's, I think, what has been cool is talking to patients, I mean from like sarcoma or colorectal cancer or breast cancer.

We talked to a woman who was pregnant when she was diagnosed. There's so many different plotlines let's say that we all kind of have; but underneath all of those, there really is this common thread of, you know, we're grateful to our friends and family and people who kept us normal. And there's certain habits that we either made during cancer and have kept or things that kept us sane and just the feelings of you feel very isolated because your body is the one going through it, no matter how many people you have around.

People are grateful that their family and friends were there to help them through it. Another common theme is that everyone says, "I'm way stronger than I thought, which sounds a little bit storybook lineish but is true. You kind of get this diagnosis and think like, well, that sucks. I'm going to die, and then you wake up every day and you survive it, and then you're able to look back and say, "Okay, well that was pretty awesome that I was able to make it through."

And obviously, we have friends who didn't, so I don't want to discount those stories either. But it's really cool to have these conversations with people who are in treatment or have finished it to know that there's kind of a collective strength that you don't know that you're able to show up with. And then you do it, and that's been really cool to be able to talk to people and let them express that from their point of view, I think.

Elissa: It reminds me of some of the stuff and the wording that is said at CancerCon that's put on by Stupid Cancer, a young adult cancer conference, that says, "You're surrounded by people who get it, who have been through it, and they understand with very few words. And there's something there, no matter what type of cancer, that you've had that you will be able to relate to somebody on a level that people that haven't had cancer just might not really understand."

Nikki: Definitely. And it's something that, I mean we joked. It's frustrating because there's so many people when you get diagnosed that say like, "Oh, my grandpa had cancer. You should try XYZ remedy." And you're like, "Thank you for your input, but please stay out of it." Then you talk to another cancer patient, and you're like, "Oh, you get it. Don't tell me what to do. Let's just maybe share these experiences, and that's as far as we're going to get."

And so, it was cool to kind of have those conversations and poke a little bit of fun at some of the people who maybe made it uncomfortable for us because they thought they knew better. And then you're like, "No, listen, I'm good. I've got friends over here who actually get it." So it's cool to get to kind of find those communities for sure.

Elissa: Those cancer muggles.

Nikki: Oh, I know truly, said every word. We love them.

Elissa: Right? Now do you have a most memorable episode or guest?

Nikki: So, yeah. It's been so much fun to meet all of these people, so I do want to say, "Go check it out," and they're all different. They're all amazing to talk to.

I do think one of the most kind of inspirational stories we talked to was a woman named Alessandra, and she was diagnosed with inflammatory breast cancer during her like summer between her first and second trimester of her first pregnancy. And so, she was pregnant and excited and had waited until she was a little bit older. She was 35, 36 when she got married, a couple years later was pregnant, and so she was

excited because this had worked out; and she was thrilled and then, obviously, got this horrible news.

Almost every time that Emily and I record, the minute the guest leaves we like call each other to talk about it because we are so excited that we got to share the story. And she was the one who, it was just such a joy to talk to her because her perspective was really interesting of just how do you live through this knowing that you're bringing another person into the world, knowing that you may or may not be there to see them grow up? Like that's just such a scary situation to be in that I really can't even totally wrap my head around, but she had the chance to talk about it and just kind of share those feelings which I think was really valuable. And with like such grace and some humor but levity; it was really, really fun to talk to her.

What was really exciting about hers too is that she sent it to her doctor who deals with inflammatory breast cancer specifically, which tends to be pretty rare, as I have learned. And so, he was able to share it with other patients and some other doctors who dealt with that type of cancer. So that was a really fun one just to hear that more people were able to hear her story and I think just learn about that unique perspective of being a woman who's pregnant, going through treatment. She had a scheduled C section and then got back into chemo a week later.

She has a beautiful little boy whose name is Luca, so he's been born. But that was, I think, one of my favorites, just because it was a crazy story but told so beautifully and with such care. She's just really awesome, so yeah.

Elissa: I love it.

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

Nikki: After a diagnosis comes courage, and I think of that not just because of the courage that required me to get out of bed every day. That's almost less important, but I think that after going through something like this, especially when you're young, there's kind of just this renewed courage and determination to just like be yourself, so unapologetically because you have the awareness that life could be short. And so, while there are nice signs on everyone's walls that say, "Life is short" or whatever other phrases come to mind, I think that for me it's been kind of a cool, unique opportunity to really embody that and just make a decision that not only will I know that I have the courage to make it through that thing, but then for the rest of the days that I'm given, I will, you know, do everything to the *n*th degree because I can; and that's really exciting to me.

Elissa: I like it. Well thank you so much, Nikki, for being a guest on our podcast today and for sharing your story. And I know you've said it's so important for you to share your story and also get the stories out there of other cancer survivors. Just having that level of connection is so important and so helpful to our listeners, and we really appreciate you coming on today.

Nikki: Yeah, thank you so much for having me. It was so much fun to talk to you.

Elissa: And thank you to everyone listening today. *The Bloodline with LLS* is one part of the mission of The Leukemia & Lymphoma Society to improve the quality of lives of patients and their families. To help us 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](https://lls.org/PatientSupport). You can also find information specific to young adults at [LLS.org/YoungAdults](https://lls.org/YoungAdults). All of these links will be found in the show notes or at TheBloodline.org.

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