

## THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

### ***Episode: 'Cancer & Caregiving: Navigating My Young Adult's Cancer - Diagnosis'***

#### **Description:**

Join us for our special series where we focus on parent caregivers of young adults with cancer. In this series we will be listening in on a conversation between a social worker and parent caregiver as they navigate the various stages of the young adult cancer journey – diagnosis, treatment, post-treatment survivorship, and the young adult moving back home.

In the first episode of this series, Sage Bolte, PhD, LCSW, CST, will talk with parent caregiver, Lisa Dominisse about the experience of caregiving for her young adult son, Will, through the diagnosis stage of Acute Lymphoblastic Leukemia (ALL).

#### **Transcript:**

**Elissa:** Welcome to *The Bloodline with LLS*. I'm Elissa from the Patient Education Team at The Leukemia & Lymphoma Society. Today's episode is part of a special series for parent caregivers of young adults with cancer. In this series we will be listening in on a conversation between a social worker and parent caregiver as they navigate the various stages of the young adult cancer journey – diagnosis, treatment, post-treatment survivorship, and the young adult moving back home.

At LLS, we recognize the unique challenges that come with caregiving of a young adult with cancer and that these challenges may vary during the different stages of cancer. We invite you to hear about these challenges, learn from the social worker's perspective, and find connection as a caregiver.

For today's episode, we will be hearing from Sage Bolte and Lisa Dominisse about caregiving during the diagnosis stage of young adult cancer. Sage Bolte is the Chief Philanthropy Officer and President of the Inova Health Foundation. She has a

doctorate in social work and was an oncology counselor for 15 years at Inova prior to moving into her current role. Sage is known nationally for her work in sexual health and cancer and as a respected leader in the field of oncology social work.

Lisa Dominisse is the mother of William, a 23-year-old survivor of acute lymphoblastic leukemia or ALL. She is also the President and CEO of Family Service Society in Indiana, a nonprofit organization that provides mental health and family-focused services to the marginalized populations in their community. Lisa was the primary caregiver for William from the time he was diagnosed through post-treatment. His cancer journey included multiple treatments, two relapses, and finally a successful stem cell transplant in early 2020. You can hear more of this story from William himself on our podcast episode, "I Will Survive: A Viral Tik Tok Star's Journey Through Acute Lymphoblastic Leukemia." Welcome Sage and Lisa.

**Lisa Dominisse:** Hi, thanks Elissa.

**Sage Bolte:** Hi, thank you.

**Elissa:** Lisa, in our introduction, we mentioned that William was diagnosed with ALL when he was 20 years old. After he went to the hospital, he was diagnosed with mono. How did you feel when you received a phone call that William had a cancer diagnosis?

**Lisa:** Oh, that's a great question. So, Will had called me and told me he wasn't feeling well, and I said, "Go to the Urgent Care and find out, what's going on." So, he did, and he called me back. He said, "Mom, I've got mono. There's nothing they can do. They gave me some mouthwash to numb my throat, and I just have to gut it out." I'm like, "Okay." I said, "Well, let me know how you're doing in a few days."

And a couple of days later his roommate called me. It was like 10:30 at night, and he said, "Lisa, I have Will in my car. I'm taking him to the emergency room. He's just acting kind of weird, and it's one of the things they tell you to look out for on the sheet

about mono. So, I just feel like I want to go get him checked out. Probably just dehydration, but I just want to give you a head's up. I'll call you later and let you know."

And he calls me later and just says, "Hey, the doctors are running a bunch of tests; and they're going to call you." And so, the emergency room physician called me and tells me at midnight, "Hey, Lisa, I need to let you know that Will has leukemia." And I'm like, "Okay, you let me know what his white count was." And it was not one they can really measure because it was too high, and so when they tell you that, you're like, "All right. We'll be on our way within an hour. It's a 10-hour drive to get there. So, he's like, "All right, come straight to Sibley in DC," and I'm like, "All right."

So, in the meantime, I call my husband, we're making the plan. My husband immediately comes home from work. We're on the road driving before 1 AM and all packed and ready to go with no idea what's on the other end for us. And then all night long the emergency room is calling us and just checking in and making sure that we know the status.

And I had a friend who was in DC doing some work for the United Way, visiting some legislators out there. I called her at like 5 in the morning, and I said, "Hey, I'm on my way to DC. My son is at Sibley in the emergency room, and the gentleman that's with him needs to leave because he has an office to run, and would you please go there?" And so she went and actually stayed at the emergency room with my son and fed him breakfast and made sure that she could ask and answer questions. And I gave them permission to give her information, and we just went from there. So a shoutout to my friend Alicia Hazelwood, who just happened to be in DC at the perfect time-

**Sage:** Wow.

**Lisa:** -and spent the morning there with him. So that was great. It was just the weirdest, most surreal thing; and the 10-hour ride was almost bizarre because if I were

to tell you that my husband and I had fun on that ride, seems a little bizarre. But we had-

**Sage:** Like back to college tripping days?

**Lisa:** Yeah, we had to compartmentalize the cancer and just be like, "Can you believe it's 3:00 in the morning or it's 4:00 in the morning? We're in Pennsylvania." It was just strange, you know, really bizarre.

**Sage:** Yeah. And when you think about hearing, okay, he has mono to he has leukemia, to then getting there and upon your arrival, I'm sure once you got your eyes laid on him, there must have been so many other things swirling through your head. Talk a little bit about how you even began to process what this meant for him.

**Lisa:** That's heavy. I knew that it was going to be life-altering for him if not life-ending for him. And so, if it was going to be just life-altering for him, which is hopefully the better plan, what did that mean for him? What did that mean for him to having a family? He was so ill that we didn't have the opportunity initially to do.

**Sage:** Sperm banking.

**Lisa:** Yeah, fertility preservation. We did get that opportunity after CAR T. We did get that opportunity during a phase before he was on any other medications. And so he was lucky in that regard.

But yeah, so there's all these things you're thinking that wow, the what-ifs and the maybe nevers, and all that is just kind of swirling around. And then you sort of just hunker down in the moment, and it becomes just the moment. And then all that just sort of fades away. The initial was all about, okay, wait a minute, I don't have Power of Health. I don't have Power of Attorney. I don't have the legal right to make these decisions for him. What am I going to do if he becomes unconscious, and we knew he had a high likelihood of being intubated; and so, we had to work as quickly as possible to get him prior to that because that was going to put him in a state where he

wouldn't have been able to sign and even the signatures that he gave were pretty rough actually.

**Sage:** I can imagine, just chicken scratch, and barely there. Yeah, yeah. And I know you had said in your workplace and just who you are as a person, it's kind of the what do we have ahead? What's the project? I can manage. Let's pull up my boots and let's go. Was there feelings that went with that? Was there a sense of disbelief and numbness? Was there sadness? Was there a moment where it felt really overwhelming? What were the feelings? And all of those can be happening at once too, right. So, what were the feelings that came up for you?

**Lisa:** The overwhelm and the fear came actually about a week later because the touch and go part was very in the moment, and the focus was very high. I was sleeping in the hospital. I was showering at the hospital. I mean like I wasn't leaving the hospital. So, for nine days, that was my whole life. And then it ended up being extended, once we got out of the ICU, then we moved up to the floor. And then I was able to like take a breath for a minute.

I think that was also close to the time when my husband had to go back home because we did have children at home, and other people were helping take care of them; and it was just one of those things. Luckily my oldest daughter was home and very capable, but still not the same. She's not used to running a household, so it's just different.

**Sage:** Sure.

**Lisa:** I think it was really at that point when I realized, okay, it's me and him. That was my point at which I felt all the things.

**Sage:** Yeah, yeah.

**Lisa:** And I had the big ugly cry in a conference room on the phone with my therapist friend, Ed.

**Sage:** And that was that tidal wave that just hit, yeah.

**Lisa:** Oh, yes. And it was a tidal wave. It was a total tsunami for sure.

**Sage:** Yeah.

**Lisa:** And then I remember just hanging up the phone and going, "Suck it up, girl. Suck it up."

**Sage:** It's a good pep talk, get over it women. You got this. Get in there and do my job.

**Lisa:** Do my power poses.

**Sage:** That's right.

**Lisa:** You know, my Wonder Woman poses.

**Sage:** Right, Super Woman pose.

**Lisa:** Power pose a little bit, yeah, yeah.

**Sage:** And I think, you know, that leads into another question about how you've transitioned so quickly. So, you go from mom to now immediately over to full time eyes on caregiver because you were the eyes and ears for his medical team for many months until he could be his own eyes and ears. And so, did you kind of move into an autopilot? Like just learn what you can and go? How did you continually keep the pace that you had to keep, even when days felt probably super long? It still is so much going on, especially in those first few months when there's so much happening at once.

**Lisa:** This might sound super cheesy, but it is true. I created rituals out of my day, and to give an example, even when Will was bedridden, every night, and I slept at the hospital; and every night I would ask him, I want you to tell me three things that

you're grateful for from today. I don't care what they are. It can be the fact that you took a breath. It can be anything.

And he'd be in his bed, and I'd be laying on the couch, and we would just tell each other out loud what our three things were. And so that became our nightly ritual to keep us like connected to the good, and that was super, super helpful.

The other thing I did is I got up in the morning and I always walked a mile on the floor because one of the things with cancer patients, they're always wanting them to walk. Well, he wasn't capable at that time, but I was. So, I would just go walk a mile. And over the course of the day, I just made that like after I fed him lunch, then I would go walk a mile. Just to give myself a routine throughout the day.

Creating ritual and routine was really important. Like the ladies always knew what time I was coming for getting my coffee because I always came at the exact same time, and I always wanted two K-Cups every single time. Like it was never one, never three, always two. You know, it was just like this silly little, but those were the things that kept me sane because I was stuck there.

**Sage:** Yeah, I think that's so important to draw attention to of keeping some sense of normalcy, and rituals can help do that. And even days blur into days, right? We talk about Blursday during COVID. But when you're in the hospital, you forget what day it is. I mean days and without some of that daily structure of I get up, I shower, I feed, I go for a walk, right, and keeping some of that. Even though you're working remotely and have some distraction, I think the rituals of grounding and keeping some sense of normalcy in what you can "control," I've got everything in air quotes, then I think can be so important.

And I know in your journey, your specific family, you have you and your husband and then your ex-husband as well, this blended family to step in. And I know not everybody has multiple families to lean on in this process, but how as a blended family did you coordinate the care of someone who needed pretty intense care for a while?

**Lisa:** In the initial diagnosis phase, I know that for me, I wasn't really sure. I run a mental health organization in Indiana; and I didn't know how my board would feel about me working long term remotely, that kind of a thing. So initially my former husband and my current husband, put together sort of a rotation plan where I was there the first two weeks. Then my former husband would come for two weeks, and then my current husband would come, and, you know, that kind of thing.

And so that was what we initially did and then while I was home during my two-week time during that first part, my board chair and I had a really good discussion; and they were like, how can we say we're a family-serving organization and we put family first if we don't let you put your family first. And so, I said, "Well, let's try this, and let's see what happens. And if it isn't working well and things are falling apart and all the wheels come off, then we'll come up with a new plan. But if you're okay with it, I'm open to trying it." And they were.

And I have a really strong team, and while they didn't like me being gone, both for the reasons I was gone and also because we do have great connection and interaction here, they were very, very capable of keeping the wheels on. And so I got really lucky.

So, with my former husband, two things, and I think he would admit this. Well first, he didn't have the same flexibility. He works for a very large corporation, doesn't have that kind of flexibility. But the other thing is, and we discovered this very early on, he can't handle it; and he self-admits, he goes, "I really struggle. I really, really, really struggle. I don't want you to be angry with me." And I told him, I said, "You know what? If you can't, you can't."

**Sage:** So important to know that, right? It's so important to have that self-awareness and to say, "I'm out." Like "I'll be here present, emotional; but I am not the person that can do this for what he needs."

**Lisa:** And I think as the illness drug on over the years, that became a little bit harder for me I think because there was a part of me for a while that would be angry that, well, he and his wife are getting to go on vacations; they were getting to do all the normal things. And my husband and I are living separate lives but parallel, you know. And I did have a little bit of resentment; but ultimately, I'm very, very at peace with how we worked all that out.

We have always been really good friends, and the joke at the hospital was that normally when separate families come in and they're together when a kid is sick, like the whole ICU is just bristling because they're like, "Oh, my gosh, we're all waiting for a fight."

**Sage:** And they send a social worker into the room.

**Lisa:** They did all the time. It was so funny. Cindy was like, "Oh, they're fine. They all get along." Yeah, it was, we were very lucky in that way. But yeah, and he had to admit that he wasn't equipped to do that. And you know what, that's okay. You have to know what your limits are; and I don't hold any ill will against him for that.

**Sage:** I think families, you know, really honestly struggle with that; and some don't have a choice, right? Some have to figure out how to do it anyway. But some do, and then it's a matter of then what can you do? Right, and I think sometimes, especially in blended families, there is the I can't, but you can, but here's what I can do. Did you ever have a conversation about, okay, you can't be physically here, but what can you do to support us in this process? Was there ever a "what can you do" kind of conversation?

**Lisa:** There really wasn't a what can you do. He and I would have conversations where he would admit to me and just say I feel really helpless. He goes, "I appreciate everything that you're doing, and I'm embarrassed that I can't make that happen or help you in this other way." And he did tell me at one time. He's like, "I feel guilty

that I'm playing golf and getting to go live my life; and here you are, sitting in a hospital room and all that stuff."

We didn't really have the what can you do, but he and his wife did some cool things. Like one year for Christmas, we were in Baltimore for two Christmases in a row. And one year for Christmas his wife had notified their Christmas card list and had just had them all send Christmas cards to Will and gift cards for him to use.

**Sage:** Wow.

**Lisa:** And that was really helpful because it helped pay for the things that aren't covered like all the groceries and all the other things, living expense type things that we were having while we were down there. And that was really, really neat. I thought it was one of the coolest ideas ever. That was neat.

**Sage:** That is. That is. And I think that's, you know, when we're talking about coordinating care, whether it's within your family or not, that also is the emotional care, right? And so how do you coordinate, and I think gift cards is one great way. Handwritten letters from people who love them or support them. But when you also think about the coordination of care, one of the challenges is always if somebody hasn't been around, they have to get caught up. And sometimes even that catching up of he has to take this here, and he has to do this here, and make sure he gets here, that almost is more work than letting somebody come and step in and help. Did you struggle with that? How did you navigate that?

**Lisa:** Oh, 100%. And I know like after Will's stem cell transplant, I needed to come home to Indiana for a two-week period of time because we knew the pandemic was coming. We knew the states were going to be shutting down, and I was worried that I wouldn't be able to get back to help make some decisions and move us to a telehealth model and that kind of thing.

So, I came home for two weeks, and my former husband only lasted about a week. I mean the pandemic was driving that as well. So, I want to be clear about that. But he told me that it was stressful for him because he was worried about feeding Will the wrong thing or missing medications or that kind of thing. And you know what? At first, I was just mad at him. I was like, "You can't even suck it up for two weeks?" I'm like, "Dude, I've been doing this for months and months and months and months. How can you not just-" And then I got to thinking about how hard that would be if you're not the one in the know, and I kind of let that go. But at that time though, I was like, "You jerk." You know?

**Sage:** Right.

**Lisa:** How could you do this. It took me a minute to get over that. He never was uncommitted to the emotional support or kindness or those kinds of things.

**Sage:** Yeah.

**Lisa:** It was just a very difficult thing for him to be that close to the medical side.

**Sage:** Yeah. And again, I think when you've been immersed in it, so you learned the language, you know all the doctors' names. You know who to call when, you know what to be looking for. You know if his color goes gray, what that means. Right, you have been watching this; and I hear from a lot of parents that even if they trust their partner who's coming, or they trust the friend that's coming to give them a break, there's still a sense of anxiety, both for, can I actually pass this off to this person?

**Lisa:** Yup.

**Sage:** And then the person coming, can I actually do this? Because they don't have the same relationships, and so I can imagine that was something that you had to tread water very carefully and figure out together. And it's tough for a lot of families.

And honestly, part of the reasons why a lot of families just choose one person to be the point and they, unfortunately, don't get a break because of that. But I do think there are some ways that families can use, whether that's spreadsheets or online tools or some of the resources that are out there to keep people more in the know of the day to day so that if they have to step in, they can. Is there anything that you look back on and you think, all right, if I had to do this again, here's what I might do to keep people in the know so if I had to step out, somebody could step in pretty easy?

**Lisa:** Yeah, I think I would have kept more detailed notes if that makes sense because I'm a thinker personality. And I keep everything here, and then I expect you to know what is been in here for like ten years. And then you're just supposed to automatically- And there's no floppy disc or a thumb drive for me to hand over to you for that. So, boy, floppy disc, that dates me huh? That's funny. Anyway, so I did recognize that.

The other thing that I wished that I would have done better is my former husband's wife set up one of the caregiver pages on one of those websites. I can't even remember which one it is.

**Sage:** CaringBridge or Lotsa Helping Hands.

**Lisa:** CaringBridge. Yeah, CaringBridge. And I wish I would have designated someone that I could have just done a data dump to that they could have filled it out because for me, honestly, it felt like one more thing. Like after a long day of caregiving to have to write out all the things from that day, I just wanted to vomit. So, I didn't do it. I wasn't being rebellious. I just was too emotionally exhausted to like do that data dump. But if I had chosen one of my close friends and said, "Could you just do this for me? If I just like data dump for you, could you do that?" I would have done that.

On the flip side for families, one thing that was really cool, mealtrain.com, is a great website; and our friends here in Indiana did that for our family and just would talk with

my husband and say, "How can we help? What if we bring meals on just Monday, Wednesday, Friday or something like that?" And it didn't have to be anything fancy. That was amazing.

**Sage:** That's fantastic, and I think the resources that families can use, both in coordinating meals for the family that's at home as well as things like gift cards and others that can help offset some of the expenses while they're there. But also, to your point, often when I'm working with families, I say, "Who's going to be your quarterback because it shouldn't be any of you?"

Right, and to the point of I wish I had somebody I could have called to dump on, and they would have been the one sharing the information, I think that's a really important thing for people to keep in mind because when you are that data source, it's emotionally exhausting. It's physically exhausting, and it's one more thing. And so, if you have somebody that you trust that you can call and give some high-level details to that they then can take and share and/or again share the meal train or share what the needs are, or share updates from doctors, or share updates from what you need from gift cards or what you're struggling with or what you specifically, Lisa, need. Right, it eases the burden off you of having to take care of one more thing.

And family and friends are so eager to help, and there's so little they can do. Right, I mean they can't save him and they can't save you. But they can come and wash your laundry, they can give you meals, they can send gift cards, they can send notes of encouragement and gifts, they can pray, they can meditate. Like there's a lot of things they can do. And if we don't, as parents, as caregivers, give them permission to be part of our team in meaningful ways, they again feel really helpless. And then they'll do things like bring you spaghetti six days in a row which gets really old. So, if you give them some direction, it can be really helpful.

**Lisa:** Yes, yeah, yeah.



**Sage:** Well, thank you again so much for sharing your journey on the diagnosis and your shared insights as a mom.

**Lisa:** Yeah, thanks, Sage. I appreciate it.

**Elissa:** Hello and thank you for listening to the 1st episode of Cancer & Caregiving: Navigating my Young Adult's Cancer.