THE BLOODLINE WITH LLS
A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'Cancer & Caregiving: Navigating My Young Adult's Cancer - Treatment'

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 this second episode of the 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 treatment 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 treatment 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, as mentioned in our introduction, we met William as he was featured in a prior podcast; and he explained his initial treatment and then subsequent treatments after relapse, which were extensive. How, as a parent and caregiver did you feel after his treatment began?

Lisa: Well initially, Elissa, I just felt completely unprepared in that we had a ten-hour drive to wrap our heads around it; and then he was so gravely ill when we arrived at the hospital that, as horrible as it sounds, in the back of my mind was, is this the right thing to do? I mean we had already said, "Yes, let's move forward." However, our family kind of has a quality of life over quantity of life philosophy; and I was literally bumping up against sort of that set of beliefs that I held really firmly. And I didn't feel confident in the decisions I was making at that time, and so that was really disconcerting; and I'm someone who makes big decisions a lot in terms of my personal and corporate life. And so it just kind of shifted the foundation under me quite a bit; and that was really disconcerting.

And this might be upsetting to some people; but I was actually more prepared for him to die than for him to live when I really absorbed what was ahead of us. And so his survival has really been a shock to me as a parent, but his initial treatment, I just really felt unprepared as to how to make good decisions, because he was incapable of making decisions – completely delirious, totally out of his head hallucinating, and so we really had to move quickly.

The other thing at that beginning stage is I also realized how as a parent of a young adult, how unprepared I had been legally to take care of my son. When my kids went to college, I didn't even think about getting a Power of Attorney or a Power of Health or those kind of things. And what I've learned from that emergency was that we had to act quickly to get those in place while he was still capable of signing them and was still considered sound mind, so to speak. That was very difficult, and, luckily, we had some attorney friends of our really rally and get that taken care of for us. But that too was like, "Oh, my gosh." It struck me while we were standing in the emergency room. He's an adult. He had just turned 21. We didn't have any authority over him beyond 18. So that piece was really big for us too.

Sage: Yeah, wow, I think Lisa, you pointed out a couple things that a lot of parents are thrown into in this in just identifying that the legal piece was one area that suddenly you were blindsided by, but also this reality of am I making the right choice for my child? Am I going to do what is right for him, not just now, but ten years from now? And especially given kind of your philosophy of life, that must have been challenging.

I'm wondering, who did you call upon or how did you gather information to then come to a place where you felt at least strong enough in the "Yes, we're moving forward," that you were able to do that?

Lisa: We, very early on, sat with the care team. I think Will said in his podcast that we actually beat him to the hospital where he's ultimately going to be treated.

Sage: That's right.

Lisa: The gift in that was that we actually got to meet with the treating physician prior to Will's arrival; and we were able to let him know what we knew as a family, which was quality over quantity was our highest priority, and that if he could not have quality, we did not want to proceed and put him through extended suffering. And I felt really heard in that moment, while we advocated for that.

The other thing is, he was very realistic with us, and we told him, "Don't paint a picture of hope for us. Paint the picture that's real." And he laid out, "This is going to be really hard, and the chances of survival are slim based on where he is right at this moment. But it's not without possibility, and here's what I'm proposing we do. What do you guys think?" And then we got to have a really good discussion about that.

So, I think we went in with a strong relationship then with that care team, and they included us. Every time the doctors rounded, they included us as a family unit and were able to say, "Here's the next plan. Here's why we're doing this. What are your questions? What don't you understand?" And really kind of moved us through the process too. We leaned on them to give us extra education, not the book that you get at every single cancer center that you go to; but I'm a little bit of a science nerd, so I wanted to understand why my son's cancer was so different from other leukemias. And I literally got a genetics lesson on my son's specific cancer, white-boarded out that I could take pictures of and then sit with later and really like think about.

So, we leaned on the care team heavily. I will tell you that I didn't personally lean on family and friends, other than for emotional support. I have a tendency to go into, they call it business mode, right? I'll fall apart later, but I don't have time for that right now.

Sage: Yup.

Lisa: So that was kind of my mode.

Sage: Yeah, I hear that a lot, the pull up your bootstraps and get focused on what you've got to do; and you'll have time to process later. That right now-

Lisa: Right.

Sage: -we need to make these decisions.

Lisa: Yeah.

Sage: And it sounds like you not only had an immediate sense of confidence in the team; but there was established trust which always makes a difference. And I also know that he started chemo and it wasn't working.

Lisa: Right.

Sage: So when Will became aware and when you became aware that that first round or second round was not doing what they'd hoped, how did you feel about that? And then how did you make the decision to keep going with your ultimate goal of we want to make sure that, you know, he has quality of life?

Lisa: Again, we had that same kind of conversation about, all right, tell us what we're actually facing; what's the best outcome; what's the worst outcome? If it's the worst outcome, what are we really looking at; and how does this change the trajectory of his life? Will he have time to accomplish some of these things that he dreams of accomplishing or those kinds of things?

And really spent our time learning about how his illness works. And so, we had to look at Will a little bit. Here's Will the person, but his disease was just this thing that was happening to him. And so, we had to separate that out and say, "Okay, we're having to figure out the tips and tricks that work with this particular disease that happens to be in my son, right?"

And the team was just really good about, "These are our options. This is why we think we should go this direction. But this is your other choice. We could do another round of this. However, we think that this will be the outcome." And so, they would give us these choices, and I think they were treating me like a toddler, which was fine. They were giving the mom a couple choices, so, I got to pick.

Sage: Well, and lucky for you, your pick worked.

Lisa: Yeah.

Sage: And I know initially the chemo wasn't working; and then he did reach remission for a period of time. And what as a parent for you, as you look on your son, and he's been beat up by treatment, and remission happens. What was that like for you?

Lisa: That first remission, I remember not trusting it. I remember feeling like we'd come far, yes definitely, and I could see the benefits. But I just had this gut thing that was like, "We're not done with this yet."

Sage: You had the Momma Bear instinct, as we call it.

Lisa: I did. And I knew it, and I remember telling my husband, "I think this is great. I think we need to celebrate this milestone with family and let everyone rally around, and let's celebrate success. But I have this feeling we're going to be back doing this again, and it won't be that long." And he was like, "Well, let's just enjoy right now." And so, we did.

Sage: Yup. I think that it's really important perspective, even when you have the Momma Bear instinct of this may be short-lived. Even in the short-lived there is still celebration. And those memories that you build in that period of time are really important. Was there anything that you all did as a family to kind of commemorate that first remission?

Lisa: We did. We live in Indiana, and the rest of our family is all in Nebraska. We picked everybody up and went to Nebraska, and we had a huge party at my former husband's and his wife's house and like all the grandparents came, extended family came, and friends. Just lots of people showed up. And then at our home in Indiana, we had hosted another party and just commemorating that as well. We call them our framily, our friends that are now family.

Sage: Sure.

Lisa: And they all came over and just, like, "Wow. Can you believe we made it through this so far?" kind of a party. I really think that was important. The other thing that we did is we purposely didn't spend a great deal of time talking about remission. Does that make sense?

Sage: Totally.

Lisa: We're just like let's just ride this wave of remission. So you go do you. Let's plan on, getting things back on track and see what happens. I think that freed Will up if we weren't carrying worry and transmitting that to him. I think that freed him up to be able to just be a kid again.

Sage: I bet a lot of parents struggle with that because there is that inner worry of any parent. Right, even when we send them off to college for the first time. What's going to happen?

And when you watch someone medically get so, so sick and then literally come back to life and know that this may not be over; but wanting to protect his own youth. Right? Letting him live it while you still being aware of, he's got to go live, and we've got to be in the *and*.

Lisa: Yeah.

Sage: Which I mean the I'm here *and* I can anticipate that we might be back in treatment again soon. But I can be here.

Lisa: Right, yeah, very much so.

Sage: It sounds like you already knew that relapse was a possibility.

Lisa: Yes.

Sage: So, when he relapsed, talk to me a little bit about how the family moved forward with that.

Lisa: When he initially relapsed, it was after almost six months. And then we did a second round of the CAR T-cell therapy over the summer and spent a month at the hospital, and then went back, he was in what they've told me was a deep remission. And I remember talking privately with his oncologist; and I said, "Tell me what you mean by a deep remission."

He said, "Well, it means that, yes, technically he's MRD-negative, so there's no minimal residual disease. However, his genetic marker showed this, this, and this." And I'm like, "Okay, that means that potentiality, right, is still in there brewing. And so, I said, "Okay, that's good to know. Thank you. I'll be watching for signs."

So, this time if he goes to college and calls me and says, "Mom, I've got night sweats" or "Mom, my hands hurt," I'll be like, "Okay, get to the doctor immediately for bloodwork."

So when it happened like that second time, he had already moved into college. And we got the results. I waited till his physician talked to him, and then he called me, I had already been called. And he's like, "Well, mom." And I said, "Yup. What do you want to do?" And he goes, "I think I'd really like to come home and just leave school and then go back to Baltimore and start this treatment that they're wanting to do." I think at the time it was either blinatumomab or inotuzumab, I can't even remember which one, but one of those drugs.

And I said, "Okay, well then that's what we're doing." And so he and I left and my husband and one of our best friends picked up all of his stuff at school and loaded it in the truck and took it home. And that was it. It happened literally within 48 hours we returned, and he was back in the clinic. So it was very quick.

We wanted him to have as much power over his treatment and how he was receiving it and where he was receiving it as possible with support from us in whatever way he felt he needed it. Mostly as a young adult, what he needed, once he was capable of making decisions for himself, was for us to say, "I think you made a really good decision." He just needed confirmation.

Sage: Just validating.

Lisa: Yeah, it was validating. He knew what was going on by then, he would always be like, "Well what do you think, mom?" And I'd say, "Well, I think you made a really good decision," and just leave it at that, you know, because he needed some power over it.

Sage: Yeah, I think, it's interesting, Lisa, having worked with many, many young adult parents over the years, I will say you are unique in a really amazing way, in the way that you not just trusted your child but empowered him to also take ownership, as he could when he was able, take ownership of some of those health choices as well and supporting him in that.

I find sometimes parents, and it's not a bad thing, but sometimes parents step in and want to dictate and become, the dictator of care; and you need to go to sleep, and you need to eat, and are you doing this, and are you taking your vitamins, and are you, right? They become almost like the drill sergeant in the child's life which, which obviously leads to greater distress; and it leads to conflict, and it leads to lying off and on sometimes, right?

Lisa: Yeah, right.

Sage: "Did you drink last night?" "No, I did not." Right, of course you did. Yeah, you're 21, of course you did.

And so I'm guessing that's been a parenting philosophy of yours for a while. And can you talk about how you get there, especially when you have a child who's sick? Again, I know you made some decisions early on for him to get him in a place where he could start making decisions but tell me a little bit about that.

Lisa: So early on, I would say that I fell more into the not super dictating, but definitely much more controlling. I'm a natural decision-maker. I am a control freak. My husband will tell you that I am a control freak.

Sage: I can relate, sister. I can relate.

Lisa: I like things my way. I admit it. We used to say it to the kids. Adult decisions have adult consequences. I'm not going to rescue you from your adult consequence.

So that's always been part of it, and then trying to empower them to make decisions for themselves, that are good for themselves, I think, was always part of it.

But I will say early on what happened is Will was so sick that I did have to remind him because he literally mentally would not remember whether he ate or took a pill or whatever. So that did happen early on.

But then what I noticed; I'm sure other parents have probably noticed this too. What I started to notice was he became so dependent on me that it was almost anxiety provoking for him if I wasn't there. And I remember my husband and I went for a walk one time when I was taking a break from caregiving; and I told him, "I am very worried about this dynamic that's being created." I'm like Will is just literally depending on me for everything. I'm like, "I've got to start cutting ties, and he's going to be pissed." And Mike goes, "Well, you know, the only one that has to endure that 'pissosity' is you." And I said, "Yes, you're right."

At that time, we were staying at the Ulman House in Baltimore where young adult cancer patients can stay free, which is fantastic.

Sage: Yes, shoutout to the Ulman Foundation. I love them.

Lisa: The Ulman Foundation's fantastic. I had a conversation with him. I said, "Hey, I'm really, I'm starting to feel like you might be coming more dependent on me for your care than you are willing to really, maybe you don't even see it. Maybe it's just been a habit because we've been together so much. I said, "I'm going to start having you handle all your own medications. I'm not going to keep track of your refills. I'm not going to keep track of your pills, that kind of stuff." And so he went and bought himself a big pill box, and once a week, Sunday nights, he would load the pill box for the rest of the week. And then he started talking to his practitioners about, hey, I'm going to need, such and such pretty soon; and he really took that.

And then as he became more physically able to move around and that kind of thing, then I said, "You know, I think it would be a good idea if you started doing your own laundry." And so literally it started with just little tasks like that.

Sage: Sure.

Lisa: And then just slowly, instead of me making his smoothie for him, "Hey, all the ingredients are in the freezer. You can go ahead and whip that up for yourself. I'll be happy to do the dishes later." You know what I mean, that kind of a thing.

Sage: Yup, yup.

Lisa: And then just over time he just became more and more independent. But it had to be purposeful because that dynamic got a little weird.

Sage: Yeah, I think the intentionality of that, again initially, they are fully dependent, right?

Lisa: Right.

Sage: They're so sick and they need that, especially with all the medication they're on and the clarity of thought is not there. But as they begin to lift, there is their own distrust of themselves, right? They've already had this experience of feeling like, and actually I heard Will say this, that my body betrayed me, right? And so, is my brain going to? Am I going to think wrong? Am I going to make the wrong decision? There is a period of time where a lot of young adults just start questioning everything. Can I make a good decision? Will I make a right decision? Will I hurt myself? If I do this, will; and it's easier to let somebody else do it than to take it on, especially when they're feeling insecure. But I like that slow and intentional step by step, not kind of throw him out into the water and saying, "Swim," but really just one step at a time that I think parents or any caregiver could really learn from.

Lisa: Yeah, and my daughters, I have a 27-year-old daughter. She's the oldest. She's Will's biological full sister, and then my daughter Isabelle, who's 15; they both recognized that I was doing a lot for Will when we first came home from the hospital. And I had to have a conversation with them about what his physical limits were because he had to learn how to walk again. He had to learn how to feed himself again. He had a lot of problems.

And so, I had to explain to them that I did see it, because they were like, "Mom, you're doing everything for him" and blah, blah, blah, blah, blah, you know? I'm like, "I know. You're right. You're right."

Sage: Yup. We're going to get more into details on when he moved back home, but before we do, one of the things we hear from caregivers a lot is it’s not just my child who had cancer. And not that the parents or the caregivers have it, but that this is oftentimes a family illness. And you're going through this treatment, this diagnosis right alongside of him. And in some ways, you're holding onto more than he is because he doesn't remember.

Lisa: Right.

Sage: And I know you gave him the gift of recording a lot of this so he could have it at another time, but how as a caregiver going through treatment, talk a little bit about what you did to stay course, to kind of take care of yourself? I know that you're a doer and you get things done, so that wasn't a question. But you were going through this treatment too. How did you manage that?

Lisa: I walked about a million laps inside of Johns Hopkins Hospital, first and foremost. I really did. One of the gentlemen who works for me has been a therapist for over 40 years; and I remember when Will was initially diagnosed and he was so gravely ill, and it was really touch and go. I remember calling him. It was the only time that I really just like lost my stuff.

And I sobbed on the phone, and I said, "Tell me I can bury my son if I have to." And he just told me, "You can do anything you have to do, and it will be the right thing." And I was like, "All right, I can do this. I have to do this, whatever that looks like." First of all, just kind of one day at a time, you don't have to be the expert. It's okay to ask for help and really leaning into that was helpful to me.

And I'm not going to act like I didn't lose my stuff, because after Will finally had his bone marrow transplant and we got home this last summer, I will tell you it was Christmas before I started to feel like myself again. It was a good six months. I was a wreck.

Sage: Yeah, and I think that's really important; and I'd love to talk more about that as we look about when he moves home because I do think the post-traumatic stress that families experience is just as significant as the post-traumatic stress that survivors experience.

And again, sometimes when they're in treatment, the families are experiencing it more because, thank God for drugs that make them kind of out of it while they're going through some of the most hellacious treatment ever. Right, but those watching, those sitting at bedside, those holding hands, those wiping sweat, right? You're left with memories that you can't fog away.

Lisa: Right.

Sage: So, I think that, that day to day is really important.

Lisa: And it's super hard, Sage. My parents lived abroad and they said, "Unless you're with someone else who's lived abroad in a foreign country, they don't get it." And so, you have to find other parents who've been through it to even sort of capture someone who understands what it feels like to have the good feelings and the ugly feelings through that whole process. And that was helpful to me to just really communicate with the other families, whether they were babies or young adults as well.

Sage: Really important point. Thanks so much, Lisa, for your time.

Lisa: Yeah, thank you, Sage. I enjoyed it.

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