

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

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

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 fourth 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 survivorship 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 post-treatment survivorship stage of young adult cancer. Sage Bolte is the Chief Philanthropy Officer and President of the Nova 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: So, Sage, what is survivorship? Some people consider themselves survivors after diagnosis. Some people consider themselves survivors after they are in remission. What is your definition of survivorship, and what are the connotations behind the term survivor?

Sage: It's such a loaded question. I think the term survivor is actually really triggering for many people. And so, they don't use the term. But for those who do, for us in the field of oncology, I come from the perspective that the moment you make a decision to do something, and that decision to do something does not have to mean treatment. Right, it means you're making a choice to be empowered on what you're going to do; and sometimes that person makes a choice to enter into palliative care or hospice care, and I think that choice is part of surviving. Right, you are taking something that was thrown at you and you are making a choice in the midst of that. And that's really when I think about survivorship, what that is.

Unfortunately, it often gets lumped with this idea that somebody's cancer free; and I don't think somebody needs to be a survivor to be cancer free. In fact, I think people can thrive even in their cancer diagnosis. And so oftentimes that word gets very limiting and small, so I like to expand it a little bit more on that.

And again, the opportunity that people have to define how they feel comfortable. There are some people again who just don't feel comfortable with the word they think of, that they're a survivor because something bad was done to them and they got through it. And in some I've heard in group, like I wasn't raped. I didn't survive this horrible thing. And other people say, "Absolutely. This was thrown at me. I grabbed it by the horns, and I kicked its ass; and I'm a survivor, right?" I think there's just, everybody has a different response or reaction.

So as family caregivers, as social workers or therapists in this field, being sensitive and creating more curiosity and dialogue about what does that word mean to you or what word motivates or inspires you is a much more meaningful conversation than assuming that somebody wants to be even connected to the word survivor.

And Lisa, I'm wondering, you know, as a parent, as a caregiver, survivorship is one; and there's survivorship as a caregiver, which has a whole different set of connotations. And then this word caregiver, so I'm wondering if you could speak to actually both of them.

Lisa: Yeah, I appreciate the opportunity.

In terms of survivorship, it's funny, I just had a conversation with my son because he's been struggling with, he was a patient. Now he's technically not really a cancer patient. He's called a survivor, or he's called in remission or he's whatever, but he's really struggling with what that is.

And I told him, I said, "Dude, I've got to tell you, I actually kind of thought you'd go a little bit crazy. I thought you kind of whore around a little bit. Not that I'm pushing

you to whore around. I'm like not getting you to swipe left, swipe right. Yeah, that's not my business. But I'm just saying-

Sage: Go live a little.

Lisa: -"I kind of thought you'd like live a little." And I think what he told me was that after his first remission, the very first one after his first CAR T, when he had about six months, that's exactly what he did. And he just went out and, oh, so many stories that I probably should never tell on; but I'll let him tell them. They're too funny.

But, yeah, so he did kind of do that. And he has built in the belief that that kind of contributed to his relapse. Might have, might not. I don't know.

When I see him step into survivorship, what I believe I will see is a young man who embraces what's happened as something that happened and not be living in its shadow and will really be making whatever those choices are that he feels are best for him and enjoying it. And I think I'll see him having more fun and just smiling more and being happier if that makes sense.

Sage: It does. And I'm going to ask you about caregiver in a moment. I just wanted to comment on something that piqued my interest.

So, I'm wondering, you know, as the identity. So, I've listened to Will before like being a cancer patient. I'm actually really careful about not calling somebody a cancer patient but saying you're a person who has cancer because I feel like even the word patient, the word survivor, it's so loaded with stuff, whether it's paternalism or like us/them. But I'm wondering even if those words get you stuck or get him stuck in a space.

Lisa: Oh, I'm sure that they do. And in our conversation, I'm like I just want you to be Will. Just like be Will again, and I think that's what he's struggling to do is find out who is Will now? And that makes a lot of sense.

Sage: It does. And for you, the word caregiver - also another loaded word. Mother is one word. Caregiver is another word. Tell me a little bit about what that means for you?

Lisa: I don't know if I ever really saw myself as a caregiver. I don't know, I'm his mother. He's in this particular circumstance and needs my help, and so I'm the one there to provide that.

And then as time evolved, I think I sort of adopted the label, if that makes sense, because everyone told me I was the caregiver. Like, "Oh, you're the caregiver." I'm like, "Oh, okay."

Sage: Yeah, that's what I am, sure. I'll get a T-shirt, so everybody knows.

Lisa: No, my T-shirt says, "Ringmaster of the Shit Show."

Sage: I love it. I want that shirt. That's kind of caregiver as well. Yeah.

Lisa: Yeah, so, but yeah, I think I kind of adopted it. I do understand that caregivers and caregiver fatigue and stuff, it's like a real thing. And so, I don't really shy away from the label of that. But I have had trouble extricating myself from the label in terms of, so what is my role now?

I mean I know I'm a wife and a mother and a daughter and a sibling to my brother and, a friend and all those things. But the caregiver label has been a little muddier for me because, yeah, I'm a caregiver of all of those people to just in -

Sage: In different ways.

Lisa: Or equally, yeah, emotionally intense ways but not maybe as physically and emotionally intense with so much at stake if that makes sense.

Sage: Sure, absolutely, absolutely.

Before Will was diagnosed, he wanted to be a YouTube star and was huge in social media, right? He already had this established presence. And I know because you knew he was committed to that, you also captured much of his story.

And one of the things that's interesting I think with the young adult generation is not only do they share everything, and there are very few boundaries within the sharing of social media, but social media is out there; and it's forever out there. And I've actually had conversations with some of my young adult survivors to remind them that if you don't want this to be part of your story, don't put it out on social media because it will forever be there. You can't take it back once it's out there, right?

It doesn't have to be your defining story. It's not who you are. It's a part of your story, but make sure you're controlling that narrative because social media can control the media for you if you aren't careful, right? And I know he has felt very comfortable in sharing many details and now has the podcast that he talks a lot about illness and other people's struggles through illness.

As a mom and as a caregiver, are you as open about your experience? Do you feel as comfortable as him sharing your experience as publicly as he has?

Lisa: No. I'm perfectly comfortable in like this kind of a format and having conversation and knowing the audience is going to hear it and that type of thing doesn't bother me one bit. But you know, the joke in my house growing up from my father was, "Honey, you can never run for political office because your past could not withstand the scrutiny."

So with that, I'm grateful that social media was not alive and well. Anyway, in our family, we have a no Facebook rule. You can take as many pictures as you want, but the minute that anything shows up on social media, you're immediately out of the frame. We're very grateful for that rule.

So, I have not always understood, but I definitely honor his desire to do that; and I don't have any trouble answering questions or having him include me in those things. He always asks me ahead of time, "Is it okay, mom?" And are you willing and that kind of a thing. So, I don't have any problem with that, but I don't really see that as a path for myself.

Sage: And that's okay, right? We can have our own separate paths. And his journey, I think he feels called to share now at this point because I've heard him say how he wants to help other people, which is super commendable. Right, it's not just about being a famous YouTuber. It's also about sharing in really meaningful ways and helping people.

And in a lot of ways, social media can be friendly in the healing in that it allows them again to share in both retelling their story which can, in and of itself, be healing. It can also be retraumatizing, but it can be rehealing. And then the sharing of stories with others who have shared similar experiences can be such also a real healing experience which I think is where a lot of these young adult survivors find themselves, right, connecting in a social media way.

And young adult caregivers might connect in other ways, maybe a phone support group or connecting online and just doing more one-one-one supports.

Did you find, whether it was a caregiver support group or another couple moms, I know you talked about making sure that you connected with other parents on the unit. But did you find like a posse that you went through this with at all?

Lisa: I never did find sort of my people in terms of young adults, who also had ALL, their caregivers that were parents. What I did find was a cohort of people. One had osteosarcoma. One had Ewing sarcoma, and the friendships that have come from that are lifelong; and some of those young people have survived and some of them haven't. And it's been really instructional to me for how to move through this process gracefully, no matter what the outcome, and not being so invested in the outcome that

you don't enjoy right now, and so those relationships are really treasured. Those were forged in blood for sure. Do you know?

Sage: For sure, oh absolutely for sure. Just like a war buddy, right? When you experience something traumatic and that doesn't mean that can't lead to post-traumatic growth. Right, but when you experience something traumatic like this, you grow together. You bond in a way that nobody else can ever understand unless they've walked in your shoes. And I think that speaks to an important point is it's not always possible to find somebody who has your child's exact diagnosis or an exact genetic makeup. But you can find parents who are walking in similar paths as you; and it doesn't matter about the diagnosis because the shared experience is so similar. The feelings are so similar, so I think to that point, Lisa, it's really important to remind parents that it's not just, leukemia, right? You can connect with someone who has a child of osteosarcoma and make a deep meaningful connection in the parenting together.

Lisa: Yeah, and it's been unique with the young adults. And what I found is there were tons of groups online for children, like young children.

Sage: Pediatric.

Lisa: Pediatric, the typical pediatric. But for those of us that were in the peds unit but young adults, that was a little bit more challenging. And some of the things that our kids wanted to talk about. I mean I remember Will had questions about sex. He had questions about drinking alcohol, and he had questions about, you know, what's this going to mean for me? And an 8-year-old isn't ready to probably ask those questions yet, right? Those aren't on their mind. They want to know how soon can I play soccer? That just wasn't his concern at that time.

Sage: Yep, yep, and I think the resources out there to help navigate young adults, obviously, have increased. But certainly, we have some work to do around making sure that whomever that caregiver is, whether it's a partner or a sibling. I've known



many young adults whose siblings are the ones that come and move in and take care of them.

And I think each of those have uniquenesses to them; but all of them are bonded again by the journey that we need to do better at providing more support and resources to those caring for these young adults because it is such a different experience. And specifically, around like is dating, okay? Is sex, okay? Can I travel? Is it safe for me to go to Mexico? What is and isn't safe? What do I tell my friends? How do I talk to them? When I go on a date, do I disclose that I've had cancer? Is that like the first thing I say? The questions they have are just so different than a 9-year-old who wants to know if Santa's still coming to the hospital.

Lisa: Yeah, exactly. And you know, some of the things that have been odd to navigate, like as all of us as parents have gone home with our 20-somethings is just this, even the idea of like finishing college and is that the best path for me? And how to navigate those conversations so that it would be easy for me to say, "Well, of course, you've got to get your education; and you've got to, you know, this, that, and the other." But the truth is he has to live the life that he dreams for himself, whether it's long or short.

So, me getting out of the way of that and understanding that was hugely important, and it was conversations with my two closest parent friends that really helped me get past seeing it a certain way. Like that had to be so important. He's choosing that on his own, but we didn't put that pressure on him to do that.

Sage: Yeah, that's so important.

And I'm going to ask you a question that we really haven't talked about ahead of time, but it just came to mind because I think with your willingness, this actually could be really helpful. So, you had mentioned when you got home that like being touched or sex or any of that was like, "Ugh, too overwhelming. I just can't take one more thing that feels like it's something that takes work." And actually, a lot of couples really,

really struggle with reclaiming intimacy; and let's forget sex, right? Let's just talk about intimacy, like reconnecting in a more intimate way, finding their sync again, right, communicating and about things other than kid and cancer. Taking time out to go on a date or just spend time alone without having to think about the kid or kids now in the house.

How have you and your partner intentionally set forward, and we've got to find time to reconnect and given space for that?

Lisa: Yeah, we had a conversation pretty early on. I just had to like let out like the stuff, right? So, I just had to explain to him that I wasn't rejecting him, that I just didn't have capacity, and I had to explain to him that that was two different things.

That it wasn't about attraction. It wasn't about desire. It was about just literally not having any capacity left for that kind of giving. And he was really awesome and did the sexiest thing any man can do and started doing more housework which was like-

Sage: Oh, acts of service.

Lisa: Best thing ever. Yep. He understood that there was like just no more drips of water in the bucket, and so he was going to have to take on a little bit extra for a period of time in order for me to just quietly recharge my batteries. And we did some things together. We also did some things with friends because that actually paved the way, just the silly banter and just with our core group and you still couldn't go anywhere; but, you know, getting takeout and sitting-

Sage: Right, makes you laugh.

Lisa: Yeah, and just laughing and being silly. And he just gave me the space but without allowing our sex life to languish too, right? Okay, he still would walk up behind me while I was cooking and rub my back or give me a kiss on the cheek and just say something nice. He was just very intentional about making sure that I knew he was still interested without making me feel attacked or groped or-

Sage: Put in a corner, right?

Lisa: Right.

Sage: It's so important and I think again that the earlier that couples can communicate where they're at and that oftentimes they haven't had to communicate about that for a long time. There hasn't needed to be the conversation because they've just been together; and it just happens and they have the routine, right?

Lisa: Yeah.

Sage: But when times like this happen and it kind of shakes you at your foundation, having those conversations about what does it look like for us now, and that doesn't mean it's going to look like this three months from now, but today, tomorrow, what is it going to look like and how do we stay connected without that added, this is more work for me than it is filling my bucket.

Lisa: Well, when I explained it to him, I said, "Hey, what it feels like right now is pressure. Like I feel pressured," and I said, "I know you're not trying to make me feel pressured."

Sage: Right, he just missed me and want to be with me.

Lisa: I know, you just want to reconnect, and I totally get that. And then just a warning to viewers. I wept like a baby the first time that we were finally intimate because it was just like this, "Ah," like okay. You know, we can do this.

Sage: And I can be here in my feelings.

Lisa: Yeah. It was quite the relief, just to be like, okay, marriage is okay. Will's okay. I felt like I was checking boxes, but it was such a relief to be like-

Sage: Sure.

Lisa: -okay, there's nothing wrong with me. I just needed to like regroup for a minute.

Sage: Yup, give space. I think even I've heard; you had referred to your former husband, saying he felt guilty at times. I think there's actually within couples even when a child is sick, there is some guilt about feeling pleasure or wanting pleasure or seeking pleasure, right?

And so, until there is a sense of like, the foundation now is solid. I have some room. I can sort of give in. I can lean in a little bit more. I can lean forward. I can give a little more so that I can feel, so that I don't feel bad about feeling. Also, I think it is really important for people to understand and that everybody goes at their pace. Some people, it's the thing that gets them through it. For others, it's the-

Lisa: Right.

Sage: This requires so much of me, I just need some space and time; and can you show me love in other ways for a little while?

Lisa: Right.

Sage: Really important.

And I know Will's hit the one-year post-transplant anniversary. Happy birthday, Will. And in the cancer world, we talk about scanxiety and living scan to scan in that kind of every three months. For many, it's every three months. And so, holding your breath like two weeks before that three months and then when you get a negative result. Do you as the caregiver hold any of either that scanxiety or the worry that Will may at times harbor?

Lisa: Oh, yeah, for sure. I think it's true probably with any caregiver, parent, brother, sister, whatever. As it's leading up to that, I know in our house, you can just kind of feel it gets heavier like the week before usually. And we do this thing at dinner called

high/low where you have to tell the best part of your day and the worst part of your day. And it's the bane of my 15-year old's existence, quite frankly, but that's why we do it, just to torture her.

But we do that and usually about a week out Will will say, "I'm starting to feel anxious about my scans" and then, I don't say it out loud, but my husband and I will sometimes pillow talk; and I'll say, "Yeah, I'm starting to have a little bit of, you know, getting in my feels about that stuff, yeah." Yeah, definitely.

Sage: Yeah. And is there any ritual that you've established to either manage that the day before or the day of or the day after while you're waiting? Anything you do to manage some of that space in the house or space inside yourself?

Lisa: Well, this time, for the next scan, we're actually going to take a little mini vacation for about four days to just take our minds off of it. Will's going to bring one of his friends. It'll be my husband and I and Will's friend.

But the normal in the house is just, honestly, we say it out loud, we recognize it, and then as everyone recognizes it, we're just like accept it and move forward. I don't know that there's anything special that we do. I wish we could like sage the house or something and it would go away.

Sage: Smudge it, I know.

Lisa: Oh, I'd be all for that.

Sage: Even if you just believe it's getting rid of the evil spirits-

Lisa: Exactly.

Sage: I mean you know-

Lisa: Exactly.



Sage: Emotionally cleansing.

Yeah, I think, everybody's going to find and as years go on, it shifts. I think people's anxiety shift to different kinds of anxieties. I've heard for a lot of people that if they escape for a little bit after the scan, they can actually go do something fun or meaningful that it does make that waiting period a lot more manageable and easier to manage.

Lisa: Yeah, I agree.

Sage: Yeah. Well, thank you again. As always, it's been a pleasure to be with you these four times and thank you for your willingness to share your own experience as a caregiver and be so open with us.

Lisa: Oh, absolutely. Thanks so much, Sage, for the opportunity. I really appreciated it.

Sage: Absolutely.

Elissa: Hello and thank you for listening to the fourth episode of cancer and caregiving, navigating my young adult's cancer.