THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

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

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 third 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 moving home 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 moving home 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: Sage, often young adults find that they need support from their family after diagnosis. In the case when they are not married or have a significant other, parents usually become primary caregivers. This can mean that the young adult moves home for treatment after they have lived independently. Can you speak to the challenges this presents to the patient but also to the parent caregiver?

Sage: Yeah, it is a challenge for both parties. And I think specifically for our young adults, they have just launched, and it depends on where they are because an 18-year-old versus a 30-year-old is a very different experience. So, I don't want to minimize that somebody at 30 moving home is the same as somebody 18 and moving home. But again, unique challenges of they've launched. They're moving into their life. They are building greater autonomy, greater independence. They're with their peers more. We just think about the developmental phases of young adulthood. They're identifying, who they might want to have as a partner? They're thinking about potentially having children. They are in charge of their schedule, and they don't have to report back every day to their parents, and they don't really have to report back to anyone.

And certainly, this pulls the rug out from under them in so many ways because it also often leads to greater isolation of their peers because their peers' lives keep going; but I think specifically as we look at moving home and survivorship, that continues to be a challenge for so many young adults of the disconnect of my life stopped for one year, two years, three years and everybody else's kept going. And I had to grieve that.

And I think for the parents, it's not that different either. They've also oftentimes built some more autonomy and not had to think about their child 24 hours a day; and they've built some life and routine and sometimes that's going back to work. Sometimes that's backing down work. Sometimes that's traveling more.

And having a child move back home can create all kinds of dynamics; and I always joke, especially in the young adult group, like I still at 43 will go home and I find myself regressing back to my teen years. And I think it's common as we go back home that there is a tendency for us as young adult children to regress. And so, it's also hard for parents because parents can easily regress back to parenting in a way that sometimes can be really supportive and sometimes be less supportive of the young adult still having their autonomy.

And one of those greatest challenges I hear a lot from our young adults is when the parent is still hovering and they don't feel like they have any control over some of the decisions made, whether it's treatment, whether it's just even sitting with the doctor by themselves without a parent in the room; and yet the parent wants to be present because they've been caring for them. So those are some of the challenges we hear often. And as Lisa had said in the episode prior, when you're forced into making decisions again for your child after you've been making fewer and fewer for them and allowing them to do that, that certainly can shift back to a very different parenting mode than had been begun to be established.

So, Lisa, I'm going to turn this question over to you on when we think back, we had ended kind of on so he's through his stem cell transplant at this point, right, and then moves back home. Or is he home and then goes back for a stem cell transplant?

Lisa: We had been out there for quite some time prior to the stem cell transplant; and the stem cell transplant was really we'd finally gotten into remission over the Christmas time. And they said, "All right, we're going to do it now." And so, we did the pre-protocols and went right into transplant.

Sage: Okay, and so he comes home; and you're having to adapt and adjust your home life. You were talking about your girls noticing how much more you were doing for him and trying to educate them on what he physically can't do versus what he mentally can do, right, how did that feel? It wasn't just you that was affected, especially because you had more people living in the house. How did you all navigate that, both Will and you as a parent and the siblings?

Lisa: Will really isolated himself a lot. We came home during the pandemic this summer, part of the pandemic for COVID-19. He didn't have much of an immune system yet; and so very germophobic as he should be.

And so, I think the girls felt a huge responsibility to not bring illness into the house; and that was stressful for them. And then they also, I think, felt slighted about my time away because I spent more of two years away in Baltimore than in Indiana with my family, just completely committed to caring for him. And then I was still working my job for my organization as well, just doing it remotely.

And that was a big strain on them because then they were picking up a lot of slack. So, there was definitely some stress in that, me and Will reentering the home.

We had to work it out with conversation and walking the dog and reestablishing roles and kind of who fits in where, much like somebody coming back from the military. It's the closest I could probably compare it to.

Sage: I agree. Again, I think that's when we were talking earlier about, it's not just the young adult that often has some PTSD-like symptoms. Right, that's not necessarily how post-traumatic stress, although some do.

But both parties often do because of what you've watched and when your other part of your family hadn't walked with you in it in the same way that you had walked with him in it, how did you begin to reestablish some normalcy, connectedness, and, you know reestablish that family unit when there has been a unique experience that you and Will had isolated from the family? And they were having experiences without you as well.

Lisa: That's a great question. I think this is going to sound crazy, but this is where the pandemic actually forced the interaction, if that makes sense.

Sage: You were on lockdown together.

Lisa: Yeah, exactly. So, we were stuck at home together anyway, and it forced us to do things like puzzles together and play games together. And it forced dinner at home together, right? We weren't just doing our own thing, and clearly, we weren't joining in with a lot of friends and that kind of thing.

But the other thing we did for the other kids was, we allowed them to establish a pod of people that were allowed to come into the house; and we had gotten permission from the oncologist and everything. But they were just a small pod. So, my youngest daughter's two best friends were allowed to come and go because they had been coming and going previously. And my daughter Caroline has a really close friend here, and that person was allowed to come and go. And so, reestablishing a couple of those little pod connections was huge for them, to help them not feel like everything was about the family, because that was part of it too.

The other thing was having individual discussions with each of them. So, I remember in particular going on a walk with my daughter Isabelle, who's now 15, and I asked her. I said, "How do you feel about Will being home and me being home and just Will's entire sickness journey?" And she said, "I'm not as afraid of him dying now as I was when I saw him in the hospital the very first time he was diagnosed." Because at that time he was bedridden and incapable of any selfcare. And she said, "That really scared me," and sometimes I still think back about that. And so we had the opportunity to talk about that for quite a long time. And, but she let me know that she was good and that's kind of when she said, "You know, mom, you're doing too much for Will," and all the things.

One of the other things we did, and every one of your listeners is going to think we're completely insane. We got a puppy.

Sage: Oh, no, lots of people did that. That's like the COVID puppy. Everybody got a COVID puppy.

Lisa: Will was just always on the couch, or always just laying around. And so not that he didn't deserve to be tired, but we're like we have to do something to get him off the couch. And so, we're like, "Well, we're going to work every day and having to do this stuff. Let's get a puppy, and he'll be forced to let it out."

He was so pissed when we did that. He's like, "I'm not the one," and he absolutely adores that dog. They spent all their time together. They hung out together all the time. So I don't know that I'd recommend that for other people, but it worked for our family.

Sage: Right. There can be passive ways to get people motivated-

Lisa: Yup.

Sage: -and maybe some more aggressive ways to get people motivated.

Lisa: Yeah. So, I'm a little diabolical, I'm not going to lie.

Sage: It sounds like it worked, so that's good.

Lisa: It did work, thank goodness.

Sage: Yep.

Lisa: Yep.

Sage: And I'm wondering when we were talking a little bit earlier about just the stress that was added to the family in bringing him home. And I hear from some families, like treatment's one kind of stress. But bringing a child home and doing the healing process is a whole other level of stress.

Lisa: Yes.

Sage: And was that true for you and tell me how?

Lisa: It was really stressful, actually, bringing him home because he was so hypervigilant about all the things and was so anxious that that was like constantly the theme of the house felt tense and anxious, and it was hard to break that. And the girls, especially my daughter Caroline, who is his sister and also was his donor, the other dynamic during that time that we were managing was she felt unseen as someone who had also been through this trauma with him. She had served as a caregiver, and he tells a story in one of his TED talks about how, quote "his sister wiped his ass" because there was no one there to do it. So, his sister had to step up, right. So that's the joke between the two of them.

But Caroline had some very specific memories, and as a person who's totally needle phobic, for her to be the stem cell donor and sit for four hours in a chair while they harvest her stem cells and stuff; for her was an absolutely terrible experience. And she felt completely unseen.

So, one of the things that we did was, I just mentioned it to Will; and I said I think Caroline needs recognition or affirmation from you that you see the gift the way we see the gift, which is this amazing blessing. And he wrote her the most beautiful letter and gave it to her, and she framed it and hung it on her wall.

And that was really super meaningful, and I think some of those relationships started healing in those ways because I think she felt like, "Wait a minute, I was part of this team too, not just toward your healing, but also had to make this additional sacrifice and also walked with you during this time when you couldn't feed yourself and do all these things. And so those relationships were tense when he came home.

The other thing was he was struggling to navigate between patient and just a well person; and he has struggled to cross over that bridge-

Sage: Sure

Lisa: -and just be this person, right? And I know that he'll say things like, "I don't just want to be defined as a leukemia patient." And I said, "I get it. I don't want to be defined as just a mother. And that there's nothing wrong with just a mother, right? It's that we're just, when we put that in our own minds and we play that loop.

Those are the things that have been really hard to navigate; and, and watching your kids, you can't fix that for them. That's their solo journey, and you can support them in it; but as a parent and as the siblings too, it's hard watching them navigate that. But I would say by the time we got to Christmas, I felt like those relationships were solid and healed and the laughter was back and the teasing was back and the lack of paranoia about all the things was back. So, I felt that's about the time frame that it took anyway.

Sage: Yeah, yeah, so that would have been about a year post?

Lisa: Yeah, a year post-transplant. We got home July 1 of 2020, because we were there for approximately six months.

Sage: Yeah. The year mark. So, it's interesting as you look at what it looks like in this healing trajectory for individuals and families and oftentimes, we say during treatment, no matter how long that is, it is a pull up your bootstraps, stay focused on the angle, and get there. Then you hit the end goal, and there's this expectation like, the clouds are going to open and there's angels crying with you and celebrating, and everything is all good. And yet that's really when the shit hits the fan. When people actually wake up and go, "What the hell just happened?"

Lisa: Yes.

Sage: And the emotional healing is just beginning. Right? There's, the physical healing is a whole other ball of wax.

Lisa: Right.

Sage: But the emotional healing for both the young adult and the family is that it takes a good year for that healing to come to that, the end mark where you go, "Oh, ahh." There's that lightness again in my chest. There's the laugh I haven't heard in quite a while. There's that impulsive behavior that used to be there that's back, right? Was that your experience?

Lisa: That has really been our experience. So when we hit Will's one-year mark, we had a birthday party and brought in all of our framily. And even, say it was as COVID safe as we could make it. But we did that with our friends; and we invited some of his friends who had been consistent supporters throughout that and literally had him blow out the one-year birthday cake candle and the whole thing.

And then we showed a video of his homecoming to the whole group that our friend Eric, who's a photographer, had taken the day that we finally got to come home for what should be for good post-transplant. And that was pretty extraordinary to be able to show that to everybody because none of us had seen it, so that was pretty special.

Sage: Wow.

Lisa: I think that for myself as the caregiver, I would say I'm still in a stage of healing a little bit. The exhaustion that I felt when I finally got home and slept in my own bed and knew that I was likely going to be home for a while, the lack of productivity at work for a period of time, just like feeling like I couldn't make one more decision or take care of one more person or one more thing. The exhaustion and caregiver fatigue was so intense that I remember telling my husband, "I just, I can't take care of any of you. I can't even take care of myself. I need to go on a vacation by myself or-"

Sage: I need like three months by myself, yeah.

Lisa: Yes. And I mean in silence.

Sage: Yes, on a Caribbean Island with no one bothering me.

Lisa: Yeah, I'm pretty sure if a monastery would have taken me during COVID, I might have gone because I just was really, I was spent. And this last fall was a real rough go.

Sage: So, I'm really glad you said that because I am confident there are people on here that feel that way and don't know what to do about it and haven't been able to articulate it. And, in some ways, I find, especially parents, to have such a judgment of themselves. Like I should be able to manage this. I should be able to rally. I should, right, should, should, should. They “should” all over themselves around what they should be doing.

And there's no recognition of the war you just went through and literally being the battle buddy, right, where you're carrying your child through this war zone. Not just him but all the shrapnel and everything else that's hit you. And you get to the end, and you haven't treated a single wound yet. Right, his have been, being treated. His were being dressed and freshly changed, and yours are like a year old and oozing and pussing and need that real tender loving care that when families don't understand it, they feel kind of cheated of your presence. Right, cheated of them primary because they're not available.

So, the fact that you could even communicate that and that your family could hear it is great. What would you recommend to other parents or caregivers who need to have a conversation like that around- I know I have them in here, but I need time. How **would you recommend having that conversation?**

Lisa: I think you have to, if you have a spouse or significant other, have the conversation first with them and, and let them know I'm going to say a whole bunch of really ugly stuff; and you're not going to like any of it. And it's how I feel right now, but it's not necessarily how I feel about you or about always. And it's things like, I mean maybe it's TMI, but like I didn't want to have sex because that just was too much work.

Sage: Sure.

Lisa: I didn't want to be intimate at all. Like please don't hug me because I can't take it.

Sage: Right, right, nope. I totally get it, yeah.

Lisa: You know, I'm like, yeah, touching hurts. Like stop.

Sage: Right, everything hurts right now. Thinking hurts.

Lisa: Yeah, and so I had to like have that conversation with him and say, I know you were there for me like on the phone and you've always been supportive and you were willing to do all the things and that you took care of the finances at home and you took care of the kids and you took care of the dogs, and you made sure the plants stayed watered. I mean, I had to really recognize his contribution first.

Sage: Yeah.

Lisa: And by recognizing his contribution, he was able to recognize, first of all, all the things that I normally do while I'm there. And so, he was able to affirm. He's like, "You know, until you were gone, I didn't realize everything that you actually do, so thank you for that." So that one piece helped me feel, okay, he saw me, first of all, which was important to me because words of affirmation, that's my number one love language.

Sage: Love language.

Lisa: That and gifts. Bring me the gifts. I love presents. But then when I told him, I was like I just, I feel like I don't have anything left. Like I'm completely emotionally bankrupt. And I said it doesn't mean I don't love you guys. It doesn't mean that I don't want to be the best mom, wife, daughter, all the things. But I said I can't.

And the other person I had to have that conversation with was my mother because my parents live far away. My dad has Alzheimer's, so as all this is going on, my dad is rapidly declining. And I know this, but it's almost like I can't help her. Do you know what I'm saying? Like I couldn't bring that full circle for her. But I remember how understanding she was. She's like, "Honey, it's okay. You do that, I'll do this, and eventually the two of us will be back together and we'll work it out." But she's like, "Don't even think about it." So that was really helpful too.

And then, of course, the kids after that, having the conversation with them that sometimes I might need to checkout. And so, I wore my headphones more while I was working around the house, and I would just say, "Okay, I'm out of touch for a bit. Just let me do my thing." That kind of thing. And it was very helpful to me to just have them understand that.

Sage: Yeah, so important. It's so important to prioritize your own selfcare too and do that in a way that's intentional and let go of any judgment of being selfish. You've kind of earned it.

But I also think, one of the other things I heard from you was the choice of who you also let in and your framily. And not everybody has that team or that group to rally; and some people have some really toxic people around them that expect more and expect more. And so, I think the other thing for listeners who may have what I call toxic people, and you'll know it's a toxic person when you go around them and you leave more drained than when you got there.

Lisa: Right.

Sage: And I think even that assessment of what can I put in my bucket when I am already literally depleted, and the sponge is dry? I don't have to put that person in my bucket. I can choose to put my headphones on or choose to go for a walk or choose to retreat for a while or choose to connect to other parents who get it. And the intentionality of filling that bucket as a caregiver is so critical.

And we learn some of that as being a parent, but it's very different than when you're caring for a sick child or a healing child. So, I think that's a really important thing for our listeners to be reminded of. So, thank you and thank you again for your time and your story and your willingness to be so open. I know again people are just really going to value hearing from you, so thank you.

Lisa: Yes, thank you Sage. I appreciate it.

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