

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'Cancer & Caregiving: Navigating My Child's Cancer - Survivorship'

Description:

Join us for our special series where we focus on parent caregivers of children 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 a child's cancer journey – diagnosis, treatment, post-treatment survivorship, and the child going back to school.

In the fourth episode of this series, Nancy Cincotta, LCSW, MPhil, CPA will talk with parent caregiver, Dave Garcia about the experience of caregiving for his young son, Andy, through the post-treatment stage of acute myeloid leukemia (AML).

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 children 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 pediatric cancer journey – diagnosis, treatment, post-treatment survivorship and schooling during cancer. At LLS, we recognize the unique challenges that come with caregiving of a child 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 Nancy Cincotta and Dave Garcia about caregiving during the post-treatment survivorship stage of pediatric cancer.

Nancy Cincotta is a Psychosocial Consultant in New York, New Jersey and Maine. She has extensive expertise working with children with life-threatening illnesses and their families.

Nancy has worked with Camp Sunshine, a retreat for families of children with life-threatening illnesses in Maine and is on the social work faculty at Columbia University, the Zelda Foster Studies Program at NYU, and Smith College. She is widely published in this area, has presented extensively on a national and international level, and has received numerous national achievement awards.

Dave Garcia is the father of Andy, a 14-year-old survivor of acute myeloid leukemia, or AML. Dave is currently a Corrections Officer in New York City and his wife, Lydia, works for the NYPD as a dispatcher. They have 5 children and had recently moved back to New York when their son, Andy, who had just turned 12, was diagnosed with AML in October 2019. He and his wife worked together to stay with Andy in the hospital, while juggling parenting duties for their other 2 minor children. Andy was eventually put into remission and is now back at home and is a happy, healthy teenager.

Welcome Nancy and Dave!

Nancy Cincotta: Thank you.

Dave Garcia: Thank you.

Elissa: So question to Nancy. What is survivorship? Some parents would consider their children survivors after diagnosis. Some would consider their children survivors after they're in a remission. How would you define survivorship?

Nancy: It's a great question because I think it really is different for different people; and some of it matters how you think as a parent and how you think as a child, right? Like it's interesting, you'll hear the phrase, cancer mom; and then sometimes you'll even hear cancer dad. But you will not hear the phrase cancer kid, right? And if you

think about it, you think about kids being, I think, more survivors from when they start this journey and as they move forward.

And kids will see this time of having had cancer in their lives very differently, depending on who they are, what the experience was like, the age they were when they were diagnosed, and the things that they remember. I don't think there's a one definition that fits everybody. But I do think that there is something about having been on the cancer journey that makes you connected to these other people who've been in that same club that you've been in. It's almost like you guys have a secret because you know that world, and you understand, I think, things about life that I think maybe not everybody else understands.

Dave, when did you start seeing your son as a cancer survivor?

Dave: I guess it was our last chemo session. It was also during COVID, which he got. And it was kind of weird because I tried to shelter him into not getting COVID. And we went to the hospital and all of a sudden, he was diagnosed with COVID. So, we had to come back for two weeks. Two weeks later we went back for his last session. He still had COVID according to what their note said.

But he was able to do it. He took his last chemo as a champ. It's almost as if nothing was really phasing him. His hair was already starting to grow back, so I just felt like it was over. He wasn't getting the pain. He would sleep at night. He wasn't using ice packs anymore. But then I found myself being a little more vigilant with him.

Nancy: So as his symptoms got better during his treatment, it felt to you like that was already a sign of survivor hood or of things getting better or moving forward?

Dave: Yes, because I would ask him, "Hey, Andy, how are you feeling? Hey, Andy, how's it going?" I would always look into his, where his Broviac was. I made myself more vigilant. It's hard to describe. It's like you know it's over. You can feel it. You can sense it. At least you can think it, and I want it to stay there.

Nancy: How long did it take him to start feeling better?

Dave: After round three you could see he received color back, he didn't have any hair. But he got color back. He was more himself. He wanted to wrestle with me, even if he has his IV on. He would play jokes with me. Stuff like that, we would have a pillow fight in his room.

Nancy: Right, so has he regained his strength and has he started feeling more like himself and acting like himself?

Dave: Oh, yeah.

Nancy: Stuff like, you knew things were going in a positive direction.

Dave: Yeah, once he got his appetite back too because, out of all of the kids, he's a little heavier. So, once he started going into the kitchen and making like a midnight meal, I'm like, "What's happening here?" He would make himself a pizza with extra cheese. And I'm thinking what? I guess he's back to normal. For him it's a normal thing. Even though we tell him not too, right, he does it anyway, so. At that point I didn't care. I wanted to make sure he was all right.

Nancy: How did it feel when he stopped treatment? How long ago did he stop treatment?

Dave: He stopped treatment May of last year.

Nancy: So, when he stopped getting chemotherapy, do you remember how that felt?

Dave: Yes. I thought it was great. All he wanted to do was get the Broviac out because he didn't care about the treatment portion of it at this point. He just wanted the Broviac off of his chest already. He said, "We're done. I feel better. I just want this out. When is the appointment?"

And that's how I knew things were getting much better for him because he wanted to get back to normal. He wanted to go back to school. But being that COVID was what it was, he couldn't do that. So he was, he was homeschooled at the time. But he was like back to normal.

Nancy: What about for your wife? When he came off treatment, what was that like for her?

Dave: She wanted to just hang out with him more. She wanted to make him everything special that he wanted, his favorite foods. "Oh, I want my chicken cutlet." "You've got the chicken. What do you want tomorrow?" You know, like make up his own menu. Didn't matter what we wanted. Everything was about Andy at this point.

What also helped me is I had a coworker who was a corrections officer in Pennsylvania. He gave me a call, and for us, it's a brotherhood. And he gave me a call, and I never knew his daughter had cancer. So, he knew what I was going through because there was one point in what I was going through that my son's godfather called me up and kind of a made a comment that kind of threw things off. And this is what I learned.

You get family members, and you also have friends who don't understand what you're going through; but yet they try to give you an advice that is not good advice to give. So, I kind of blew up, and I let him know. I said, "You have two healthy kids. I have one who's really sick. I'm not sure if you're there to give me this kind of advice."

At that point, I had the other friend call me because he found out about it, and then he proceeded to tell me about his daughter who's gone through all kinds of chemo. And he says, "Dave, you're going to find people who think they mean well, but they don't. They think they're telling you the right things, but they're not. You know, don't do this, do this, do it this way, do it this way.

And meanwhile your mind as a cancer parent is going everywhere. You're not going off the right exit. You're going through the wrong exit. You're trying to get to the right exit in order for you to make it towards the end of that road. But he was able to speak to me in a way as another parent, a cancer parent, and that made me feel at ease and made me feel comfortable.

Nancy: Dave, you raise a really good point; and I've heard many parents talk about this, that you enter into this cancer experience, and you expect that certain people are going to be there for you and they're going to be there to help you, and they're going to understand, and they're going to be with you on this journey. And then you learn that all the people you think are going to be there, well some of them maybe really can't be there, either because it's too hard for them or they don't understand, or they have too many opinions about what you should be doing. And then there are other people who you don't expect who kind of come to the plate and it's almost like they rise up, and they are able to help you in a way that you would never have imagined. And then there's these other people you meet who are going through the same experience, who also connect to you.

So, it's a very interesting situation about what happens with families and friends. I don't think that people think about it as much, and I think it's a really, really good point for you to have come in with because your whole social life and support system changes. Some of it gets stronger, some of it gets weaker, some goes away, and some emerges. So, it's helpful for people to know that other people go through that experience.

Dave: Yeah, it's when you know who your true allies are. You get to see for yourself who claims that they're going to be there and then when something like this happens, it's like they're not.

Nancy: Yeah, it's an interesting part of survivorship, right, because it's almost like through the process of chemotherapy, you have also gone through a process of

evaluating your relationships so that when you come out the other side, there's so many things that are different; and they're a little bit invisible to people who haven't gone through the experience. But for anyone who's gone through, they will chime in and say, "Yes, the people I was connected to changed. Some things got stronger, and they will be part of our life and those people forever. And then other things really just kind of fade away."

Dave: Yeah, and that's exactly what happened to me. So once things started settling in for Andy, I kind of closed that chapter of my life. I closed that chapter of the book. There was no reason for me to reopen that book and try to, "Hey, let's talk." No, I'm good. I'm good with that.

Nancy: Do you think as a family now, as you approach the world, right, like you had to deal with COVID, you've had all these other things. Do you think that you are stronger as a family going through things together now?

Dave: Yes. We definitely are. We definitely are because I had my two eldest children, and they were living in Florida; and they couldn't come up here to see him at all. And that was devastating for them. I mean they would call me up constantly crying. "How's he doing? What's going on?" And then finally I started taking pictures. I started taking pictures of him when he was going through that suffering point. He's hugging his mom. I just took pictures. Here's a shot. Here's another shot. And then I was noticing Andy's artwork at the hospital and stuff like that. So, I would keep everything. Everything I kept like a pack rat, and I tried to keep as much as possible.

But I saw other families going through worse, so I used to say to myself, "Well, you know, I'm going through something; but the person in the next room appears as though it's a little harder for them and so on and so forth. So, I was okay with that. I settled in, settled in as a parent.

Nancy: And do you think it's the same for your wife? How do you feel like your wife has come through the experience?

Dave: She definitely has been. I think she came through it very good because knowing that I was there for Andy, that she's not handling things on her own, she had the other kids to take care of, so even though she knows I could go either way, take care of the other kids and leave her with Andy, or vice versa, she felt more comfortable with me being in the hospital, knowing that I'm a lot more vocal than she is. So, if something's going on, I'm going to kind of grab the bull by the horns and let them know.

Nancy: So, you guys shared your strengths through this process, right? You did kind of a divide and conquer method?

Dave: Absolutely.

Nancy: Yeah.

Dave: Yeah, thank goodness for Facetime, you know.

Nancy: Yeah.

Dave: So, exactly.

Nancy: Yeah, it's really hard to imagine what people did before you could have Facetime or you could text or you could, right? It's a different experience.

Dave: Absolutely, absolutely. It's just a phone in the room. And the times, I'm going to just imagine, you have a phone in the room; and when he or she is going through that stage where it's hurting, and he or she is crying, you can't pick up that phone and let them hear that or let whoever's calling hear that. So, you want to just let it keep on ringing until the dust settles.

Nancy: And what about Andy? How do you see him as a cancer survivor? Like do you think of him as a kid who has gone through all of this or do you think about him differently than that. What's your feeling now?

Dave: Andy is a champ. Recently when he was doing the classes, his science teacher sent us a letter praising us and praising him because he got involved. They were doing a project, I guess about blood, and Andy knew so much about it. So, when he got involved in this particular project, I guess his science teacher was in awe as to how much he knew because he is a cancer survivor. So, Andy's okay with it. It doesn't appear as though it bothers Andy, and if it did, he would let me know.

But going through what he went through, he feels, all right, I went through it. You know, whatever I could do to help. So, when the Friends of Karen reaches out to us and say, "Hey, can I use Andy's image," Andy automatically, "Yes, of course." "Hey Dave, can Andy participate?" "Yes, of course." Andy just wants to,

Nancy: To help.

Dave: -be involved. Yeah. You know, if he can help another child, he'll do it in a minute.

Nancy: Do you or your wife worry?

Dave: That he'll get it again?

Nancy: Um-hmm. Yeah.

Dave: Yes, yes. I'm a jokester, so I joked around with Andy. And I still say it to this day. I said, "Andy, when you leave the home, because I know you're going to want to leave the home eventually one day." You know, go to college, go someplace, "The radius of where we live at and where you were going was a lot bigger prior to getting cancer. Now your radius is small. It's more like 2-mile marker. You could only live 2 miles from the house because at least I know I could get there a lot quicker." He laughs at that. He's like, "No, I'm moving to Canada." And I say, "Well I think that's funny because what's going to happen is you're going to go to the ATM machine. The first thing you're going to do is see my face." "Hey, son, you okay? You need anything?" You know so we joke around about that a lot.

He's happy. He's got a great head on his shoulders. He wants to do things. Not exactly sure what.

Nancy: Yeah, that's all right.

Dave: He wants to do things.

Nancy: And do you feel like as a parent you are protective of him, you're overprotective? What do you think?

Dave: I think I've gotten overprotective lately, and he's trying to shake me off. Once he hit 13, he feels that the affection should stop. I can't hug him anymore. He's growing up now. His voice is changing. He's reached teenager status, so he just assumes that. But I'm still like that.

Nancy: Yeah.

Dave: I could be the first one to wake up and the last to go to sleep, and I'll check in on them, make sure they're okay.

Nancy: Dave, you mentioned your other kids. And I wonder, we talk a lot about kind of what this experience is like for siblings. Do you feel like your other kids now, as they look back on this year, are doing okay? Did they have fears of their own? Are they survivors too?

Dave: Yeah, they are survivors. But as a family, we never sat down and spoke about it. Like we never had that powwow. Because of COVID, I haven't gone back down to Florida. My wife has, but she's never mentioned to me whether or not she had the powwow. You know, had a sit-down with them. But it's Brandon and Jasmine. It's his older sister and his older brother.

And what happens is, I know they went through a lot because, that was their baby brother. Andy's like the glue that keeps the book together. Brandon's a little more serious. Dave Jr.'s a little more serious. Nicholas is the baby. Jasmine is the only



princess we have, but she helped raise him also because he was always hanging out with her in the room. He would always bother her. So, when this experience happened, and it brought a lot of memories back. You know.

Nancy: How long has he been off treatment now?

Dave: A year and a month, going on two.

Nancy: Is it starting to feel like it's in the past?

Dave: Probably for him. But for me-

Nancy: Less so for you?

Dave: Yeah, it's always there. I worry about the other kids because it's never happened. When it happened to Andy, they sat me down and told me straight out it was a fluke.

We've never had this in our family. What happened in his particular case happens to 1 in a million.

Nancy: I think once you have, one of your kids have a diagnosis of something, it does leave you with that feeling that it could happen in your family because it did happen in your family. So I think you're not naïve to the fact that bad things can happen.

Dave: Right.

Nancy: But it's interesting. Some parents have described it that like when their child is on treatment, it's like there's a radio blaring. And then when your child comes off treatment, it's not that the radio turns off. It's still there, but it gets a little bit lower in the background.

Dave: Right.

Nancy: And then many years out, people talk about, there's still kind of like the hum of the radio. So it never completely goes away. Like it's never exactly like it was before the diagnosis, but it does change over time.

Dave: Absolutely. As days go, it gets better for me; but it's always in the back of my head that my son had this. And the tattoo that I created for him always keeps that in mind.

Nancy: Now I know we're not going to be able to see it on the podcast, but can I see the tattoo?

Dave: It's right there, that way.

Nancy: And you want to describe what it is?

Dave: But if you look at it- It's a leukemia ribbon, and in the ribbon, since leukemia's orange, it's mostly orange and black. And inside the ribbon I put a pumpkin, and of course-

Nancy: Because it was that time, yeah.

Dave: Yeah, and that's his favorite holiday. So, there's bats and the Halloween theme. And every time I look at it, I always say, "Hey, that's, my son.

Nancy: Five years from now when you're listening to this audiotape and then you're thinking, oh, I should have told other mothers and fathers and kids this one thing about the experience, what do you think that one thing that will be that will have stayed with you that you will think back on in the future?

Dave: I think the main thing is your faith. Wherever your faith lies, remember that there's an envelope on a desk; and it can only be pushed but so far, and that's your faith. He never gives you more than you can handle. But it's up to you to kind of figure it out.

So, when I knew for a fact that there is help, there is a way to kind of organize things. I knew for a fact he wasn't going to knock off the, the envelope from the table. I knew Andy was going to make it. It's his strength. What you can't do is ever give up. You can never give up. If you decide to lay there and just say, "I'm just going to," then that's when it happens.

Nancy: Right, so your advice to people, Dave, would be not to give up? To rely on your faith.

Dave: Right.

Nancy: To think about the team that you have to work with, and it sounds like moving forward is the theme in your family and your life. So, we are so appreciative of you sharing your wisdom with us, and we hope you'll come back and talk with us about other times. If you ever want to have that family meeting-

Dave: Yup.

Nancy: -please let us know. And we appreciate all that you've said here today.

Dave: No problem. Thank you so much. I appreciate it.

Nancy: Thank you.

Elissa: Hello and thank you for listening to the 4th episode of Cancer & Caregiving: Navigating my Child's Cancer.