

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

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

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 first 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 diagnosis 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 diagnosis 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: We'll start with Dave. You had started noticing signs and symptoms several weeks prior to Andy's AML diagnosis. Could you tell us about those?

Dave: Well, he was graduating from the sixth grade, moving up to the seventh grade, and he got sick. I thought it was nerves for that particular day. But he was throwing up in the bathroom. So, I had to get him out of there, and he was able to finish, but then it went away. His fever went away. Everything went away.

It happened in June, and then several months passed, and he had put a weight vest on because sometimes I run with a weight vest. And since then, his back was hurting. So, I'm trying to figure out, okay, what's going on because I started finding ice packs all over his bed. Every single day I started seeing him getting more pale. I was just kind of concerned at what's going on.

But Andy being Andy, he was always a happy-go-lucky kid. He's constantly laughing, playing jokes, so I thought it was another one of his jokes, to be honest with you. Until I came from work, and then his mother had made him his favorite meal, which is a chicken cutlet, and I found out he was sleeping. I just assumed, okay, well maybe he stayed up late, he went to school, he's taking a nap. But no, this was outright sleeping. That's when I knew something was seriously wrong with him.

And he was looking very pale. Very, very pale. He didn't want to eat anything. The fevers were coming in and going away, coming on, going away. We didn't know what to do until one day he basically just said, "Hey, dad, take me to the hospital. I've got a stomach ache," and that's how it began.

Nancy: When he said that, did you have any idea that it might be something like leukemia; or was that like the furthest thing from your mind?

Dave: That was the furthest thing from my mind. I honestly thought, he hasn't gone to the bathroom, so I just assumed he was constipated. Cancer wasn't even in the book. It wasn't even thought of. It never happened to any of the kids.

Nancy: It's also not in the book for not just any parent but even pediatricians because once it happens to you, it doesn't feel like it's so rare. But it is so rare that there are so many other things in the differential when people begin thinking about like what could be going on. So, it makes sense that all the things that you were thinking were really like normal responses to things that he might be experiencing at that time.

Dave: That's exactly right. I mean he didn't have a fever the day that I brought him in. He just complained of a stomachache. They did an x-ray and a blood culture, and that's when the doctor came back and said, "I ordered you an ambulance. You're being transferred to Manhattan. It appears as though he's got anemia." And I'm thinking to myself, everything's going fast now. I'm like this is something that he could actually fix here. Why are we going to another borough for this? So, it caught me off guard.

We have one car. I had to go back to the house, pick up my wife, pick up my son in kindergarten, and then I allowed my eldest son to take him to the hospital.

Nancy: So, your eldest son went in the ambulance to the hospital.

Dave: That's correct.

Nancy: And you got your wife. How was that, telling your wife that there was something going on with your son that he had to be taken in an ambulance to the hospital?

Dave: Again, we didn't know what was going on. I mean in her mind, it didn't even dawn on her. She was just as surprised as I was because now, we're trying to figure out what's going on. She's like, "Well what did he tell you?" "The doctor said he had anemia." And she goes, "But why would he send us some place-?" And I said, "I don't know what's going on."

Nancy: Right. And do you remember that car ride at all? Like the two of you?

Dave: No.

Nancy: Yeah, because you had said you didn't even remember how you got from the hospital in Brooklyn to the hospital in Manhattan, right?

Dave: I know it was a flash. I don't even know if I took a tunnel. I don't remember anything.

Nancy: So, when you got to the hospital in Manhattan, what do you remember? That, you were in the Emergency Room again?

Dave: No, we were actually in his room.

Nancy: Okay, so you went, he got admitted directly?

Dave: Right to his room. Yeah, it seems like everything was already taken care of. And they put him right in his room, and we went to his room and he's laying in his bed; and they put an IV. I remember that. And then I remember the doctors coming in, whisking us away from the room and into a conference area.

They put me at the head of the table, while they sat around me, and started asking me questions about if it happened in my family, if any of my family had ever had cancer. And I said no. But once they started mentioning cancer, that's when everything just went sideways for me. I just started thinking what are we talking about? I'm not sure where this is going. And then when they finally explained AML, I just broke down. I broke down. And I know parents have to be strong, but I wasn't. I wasn't. I admit it.

Nancy: Well, parents have to be real, right? Like you were in the moment. Somebody said, "Your son was going to be dealing with a diagnosis of leukemia." It had to feel like your world was falling apart in that moment.

Dave: It did. I mean me and Andy, the way him and I are so close, because there was one point in my life where I was unemployed. I was caught in the recession, and I was out of work for a while. So, Andy was a baby, so I became Mr. Mom, taking care of him, hanging out with him morning, noon, and night.

And then once I got a job as a corrections officer, he would stay up for me. I'll get home by 11:15; first face I see is Andy, just staying up for me. Wanting to watch TV and hang out with me for a little bit so we can go to bed together.

Nancy: How did it make you feel? Like in those first couple of months, do you remember what the feeling was like for you?

Dave: So, I had to go to work, work my eight hours, and then go straight to the hospital. And so, I started living at the hospital, staying with Andy, making sure he ate, making sure he had everything he needed, washed his clothes. He had to change his clothes several times, because of the medicines that they were giving him. So lucky for me, the hospital had a washer and dryer for the patients, for the kids who had leukemia.

Nancy: That's something you never really think about, right, that a hospital unit might have a washer and dryer so that you could do that.

Dave: It was amazing.

So, what happened was my wife stayed with him the first three days. I had to leave that night because I had to go to work the next day. And his words, I never forget because I have a little notebook that I carry, that I started putting every day what I was feeling and what he was feeling. Even when I took a post sitting with the inmates, I would sit there. They didn't know anything, of course, but I would sit there and write on my little pad what I was going through.

And I never forget the words he said to me. He goes, "Dad, don't worry about me. I'm okay. Just have a good day at work and just come home safe."

Nancy: So, he was taking care of you as much as you were taking care of him?

Dave: Right.

Nancy: Remind everybody how old he was at the time.

Dave: He was 12 when he was diagnosed. He just turned 12 October 16. We received the diagnosis on October 25. His favorite holiday is Halloween, and leukemia

is orange. And so, it happened on that whole thing. I knew nothing about leukemia. I knew nothing, absolutely nothing.

And they asked me not to Google it. The doctor said, "Don't Google it because, you know, they come out with different things"; and I Googled it because what it was. I started learning a lot about it from what I was taught at the hospital and from what I read. And I knew when they did the spinal tap thing, I thought it was something that they had to do, but I never knew that it was to really find out whether or not it's reaching his brain. So that's what concerned me because when I found that out, I was like, "Oh, no. If it's there, it's worse. What do I do? What do we do? But thank God it wasn't.

Nancy: Yeah, it's so complicated at the beginning because you learn so much so fast, and you kind of hold onto those pieces of information; and sometimes it makes sense and sometimes it doesn't. And it's almost like you're, suddenly you're following a roadmap, kind of in a village that you've never been in before, right, and everything is-

Dave: Absolutely.

Nancy: -somewhat foreign and then you have to understand what does the spinal tap mean, what's the difference with an aspirate, what's the medication going to do? And you're suddenly in a position where you have to be an expert and even make some decisions about something that you didn't previously know. So, I think it's a really hard thing as an adult to have to deal with it.

Were you and your wife similar in how you coped at the diagnosis?

Dave: No.

Nancy: Or similar kinds of learners?

Dave: No.

Nancy: So, tell us about that a little bit.

Dave: My wife was more along the lines of she didn't want him to see us suffer. So, she wouldn't cry in front of him. She wouldn't show him any kind of, like we're scared too. And I tried to do that, but it was a little more difficult for me because he was, I mean we have boys. I have four boys. One that I raised, three that are mine, and one girl.

And all of them are different. But I wanted to make sure that with Andy it was different with him because he was my little buddy. He would go to the store, and everything I wanted to do, it was with Andy. Andy, "I'll go." "Or we'll do this." You know, and it was always with Andy. So, she didn't want him to see her suffer, but the minute she got on the phone and spoke to family members, that's when she broke down.

Nancy: Was she okay at seeing you be emotional?

Dave: No because she was getting emotional. She'll see me, and then she would get emotional. She would totally break down.

Nancy: It's interesting when people are coping differently and have to coexist during that time, somehow being respectful about what the other person wants but also sometimes you can say I don't want to be emotional; but you can't not be emotional.

Dave: Right.

Nancy: Like you kind of have to be-

Dave: That's exactly right.

Nancy: -who you are in that situation.

Dave: Right.

Nancy: So it's hard.

Dave: At the time I was blessed because I had just graduated the academy to become a corrections officer in New York City. So being that I was a corrections officer prior, I met a lot of people. The first thing they did was give me my FMLA paperwork. And of course, a lot of captains were like, "Well they're not going to approve it. It'll take two months." But I met a lot of people during that time that I was in the academy. They approved it in two days.

Nancy: That's great.

Dave: So, I was able to use it with my son. And although I was grateful for that; and a lot of officers had a lot of respect for me because they were like, "I don't know how you're doing it. I don't know how you're living at the hospital, and then you come here to work." I was taking a shower at the hospital. I would get dressed in my uniform, come in, but I was learning so much; and I was learning so much from Andy.

After he had the spinal tap is when the pain in his back was settled in. And as a father, with all the kids, whenever they're sick, you know, we run and go get the medicine at night. If it was something that we didn't have, I would go. I don't care what time it was. Find the 24-hour drug store and get ibuprofen or Tylenol, whatever we needed. But when I saw him suffer and get up with the pain that he had, there was nothing I could do.

And that's what I think got me the most.

Nancy: Do you think that was the hardest part, his physical experience, out of the whole thing?

Dave: I couldn't do anything.

Nancy: Yeah.

Dave: And he would stand next to the bed, moving his legs, and he's like, "It hurts so bad." And I don't know what to do. I'd try to rub his back; he tells me, "No, don't

touch it." He sat on the couch. He would get up from the couch. He would go back into the standing, marching position. He's everywhere.

Nancy: And as a parent, you really want to be able to ease your child's suffering. Right, you really want to be able to help them, whether it's because they fell down and hurt their knee or they're in this situation with leukemia. You're still the same person wanting to be able to take care of it, to make it better, right? Like you are the person-

Dave: Right.

Nancy: -who ran to get things and did things and here you are in a situation where you don't necessarily have control in that way. You're reliant on the physicians and the medical team to really make him better.

Dave: Right. There's nothing I could really do. The only thing I could do was like look at the doctors and say, "Okay, what are we going to do? We have to do something. I don't want to see my son like this." And then the chemo started, of course, and it was making him really tired. It was taking a slight toll on him. At first it wasn't as bad, once his body started settling in with that-

Nancy: He was hospitalized a long time, right, with his chemo?

Dave: Yes, yes.

Nancy: On several different occasions. You have any idea how many days in total you were in the hospital?

Dave: I counted them. I actually counted all of them, all the days that we were there. So basically, the first round, we went in October 25. We were able to get out just before Thanksgiving. So, it was like maybe 30 days, 31 days on the first one.

And I was blessed because we were able to get out just in time for these holidays. He didn't spend it at the hospital during this holiday. So, his second round, we took him back immediately after Thanksgiving, like the next day or something like that, and then

he was able to come home just before Christmas. And then from Christmas, that was the longest. We didn't get out till like end of February probably. So, we were there for the longest-

Nancy: Yes, the beginning days with AML is a really long time in the hospital, right? So, you go from being home, wondering what's wrong with your child to this long stretch. Like it was great that you were able to get out for the holiday times.

Dave: Absolutely.

Nancy: But it is really like a long haul in the hospital. What do you think really helped you cope in those early days?

Dave: The doctors and the nurses at Hassenfeld Hospital and also Friends of Karen, the social workers. They took a certain burden away from me that I didn't have to really worry about too many things. He had a, I forgot what they're called.

Nancy: Child Life Specialist?

Dave: Child Life Specialist, exactly. And this young lady was just a total blast with him; and he got to befriend her. But this one particular nurse, she was actually, his old project. And we used to try to get her all the time; but they switched nurses from time to time. And of course, his doctors were great. Absolutely great with him. They were great with all the patients because they treated them, of course, the diagnosis is different. But they treated them like they cared.

Nancy: And I'm sure they did care.

Was there any time in that beginning intense period where you were in the hospital where you had any fun with Andy? Was there anything that was fun?

Dave: Well Halloween was great. The only downer is that he broke down. He couldn't get his Halloween costume because that's his favorite holiday, and we had just got into the hospital. But what they did was they were able to do a trick or treating on

the wing. So, I have these bathrobes. One's Batman; one's Superman. So, they were able to give us some masks, and he was able to do a trick or treating thing, just going around seeing the other kids. I got to meet a lot of parents. I got to see what they were going through.

Nancy: So, there were some avenues for support for you which is-

Dave: Very much.

Nancy: Great to hear. If you were thinking about other mothers and fathers who are at the beginning of their journey with a cancer diagnosis for their child, what advice would you give them?

Dave: Just be patient. I mean, one of the main things is you have to let the doctors do their thing. Because some were impatient. I saw a young lady leave with her child. She just felt like her daughter wasn't getting the proper attention, and she walked out. I did speak to her; and I said, "Listen, you have to give it a chance. You have to give your child a fighting chance. You can't just take her anywhere. You want to be able to be patient and let the doctors figure this thing out."

Because with the cancer, what I learned is like it's kind of a hit and miss. The first couple of times. It's like, "Okay, I'm going to give them this chemotherapy with this medicine," and if it doesn't work, then, of course, they've got to work on the next phase, trying to figure out what works to see his counts or her counts be as normal as possible.

So that's what they've got to do. They have to learn to be patient and try and be involved. Of course, you have to be involved.

Nancy: Be patient. Be involved. And what gave you hope at the beginning?

Dave: The fact that he had a doctor who made it a point. He had several doctors, but they were all on the same page. The nighttime doctor with the daytime doctor,

one was the head and then the other ones were the tenacles; but they all worked in tandem. They worked as a team. And they allowed me to be involved in the meetings. That was the key. prior to them coming around, they'd say, "Hey, Dave, we're coming around." "Okay, great." And I'm in the room. I'd walk out of the room, we start talking.

Nancy: I had one concluding thought for the moment. So, my question is what did you learn about yourself during that time when he was being diagnosed and then during treatment that you will kind of carry with you for the rest of your life?

Dave: It has to do with all of the children that were there. I mean I love kids in general, and I'm a very giving person. Even when I don't have, I believe that there is another side to everyone. I just want everybody to get better. Like when this cancer thing happened to my son, I know what it is. I know what it's like. I did speak to some parents who were just going through things. Some of them got to tell me that it's a diagnosis that they really can't do much with. And of course, I helped them out there. I was able to, to pray. I told them to be patient. Let the doctors do their thing. It'll be figured out. Everything will be figured out.

But what I learned that I carry was, I just want to be around the kids. I want to be around, meet them, support them, help them out.

Nancy: Well so, we want to thank you, Dave, for inviting us into your house to talk at this time about what the experience was like for you when your son was diagnosed.

Dave: Thank you.

Nancy: And I think for all mothers and fathers, caregivers everywhere, we're very appreciative of your efforts, and you went through a difficult experience, and you did it. So we applaud you and we thank you-

Dave: Thank you.



Nancy: -for your involvement today. Thank you.

Dave: Thank you so much. Thank you for inviting me.

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