

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

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

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 second episode of this series, Nancy Cincotta, LCSW, MPhil, CPA will talk with parent caregiver, Maggie Tappana about the experience of caregiving for her young son, Benjamin, through the treatment stage of acute lymphoblastic leukemia (ALL).

Transcript:

Elissa: Welcome to the Bloodline with LLS. I'm Elissa from the Patient Education Team at The Leukemia & Lymphoma Society. Today's episode is part of a special series for parent-caregivers of 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 Maggie Tappana about caregiving during the treatment 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.

Maggie Tappana is the mother of Benjamin, a 7-year-old survivor of acute lymphoblastic leukemia, or ALL. Maggie is a former arts teacher who recently completed her Arts Integration Specialist certification and plans to return to teaching when the time is right for her family. She and her husband, Lance, had just moved from Idaho to New York, when Benjamin, who was 4 at the time, was diagnosed with ALL in February 2019. The family struggled with his very high-risk leukemia diagnosis and Benjamin was also diagnosed with PTSD, post-traumatic stress disorder, which caused outbursts of anger. With treatment for the PTSD, Benjamin has been able to successfully continue his leukemia treatment which is scheduled to end in June of 2022.

Welcome Nancy and Maggie!

Nancy Cincotta: Thank you.

Maggie Tappana: Thank you.

Elissa: So, Maggie, Benjamin had significant difficulty getting diagnosed with ALL. As his bone marrow was completely necrotic with few living cells. Finally, being diagnosed after the fourth bone marrow biopsy, he was put into a high-risk category. Would you tell us what that entailed and what the subsequent treatment was?

Maggie: Sure. So, they moved him to the very high-risk category due to this state of his bone marrow, and what that meant for treatment was that he had high-dose methotrexate in one, one of the phases which not all of the kids get. And then he had an extra course of delayed intensification. So the standard-risk and high-risk kids get

just one course of delayed intensification, and the very high-risk kids get delayed intensification too, which just amounts to more chemo essentially.

Nancy: And how was that experience for you, knowing that he was in a higher-risk category?

Maggie: It was terrifying. We felt a little bit better after induction and his MRD, the minimal residual disease, came back at zero. And most kids are placed in the very high-risk category for either a high white blood cell count at diagnosis or for minimum residual disease after induction. And his was zero. So that was really reassuring, both for us and for the team.

So, the decision to put him in the very high-risk category was out of an abundance of caution, and it was based on the fact that adults with a lot of bone marrow necrosis don't do well. Our research told us, and there's only one study that we could find, and it said that children don't respond that way. That core prognosis does not hold true for kids. However, his team felt that we still needed to go into the very high-risk category.

So, we did. As, as we proceeded and we could see things working, that was reassuring, and knock-on wood, he's continued to respond the way that they have wanted him to all the way through.

There are aspects of that additional chemo that really got to me, mentally and emotionally. I don't know if you've ever seen the high-dose methotrexate, but it's like a lime green color. And so, we would go into the hospital for these courses of the high-dose methotrexate and having such a strong visual of what was happening to him, he didn't know. But it really struck me, and I had a hard time with it. It was just such a - the color of it, you know-

Nancy: Right.

Maggie: -seeing it flowing into him, that was just really hard.

Nancy: So, it made it made it so very real; and it made the experience a very visual one for you. And you are a very visual person in general, right?

Maggie: Very visual, yes, yes.

Nancy: Would you let people know what you did as a career before entering into this cancer world?

Maggie: Sure, my background is theater. I have an MFA in theater performance. I spent several years in Los Angeles doing the actor thing. Throughout that entire time, and previous actually, I've always had a special interest in educational theater. And so, after Benjamin was born, I really transitioned more towards education. I earned my K-8 teaching credential; and I took a teaching position, and since then have really tried to focus on art integration, incorporating the arts into education. It's on pause right now, but that's really where my heart lies.

Nancy: So, as you talk about a chemotherapy that has a very visual component to it, I think about its connection to your professional life and your life in general. But I also think as we heard you say in that first couple of minutes, you sound so sophisticated in your medical knowledge that I think people would jump to think that your background was in medicine, as opposed to that you are a parent who has become an expert in this issue and these things related to your child so like very quickly when you had to deal with treatment decisions.

Maggie: Yes, absolutely. I mean, there's the blessing and curse of Google, and it became my best or worst friend, and I just tried to absorb what I could.

And there's so many things about all of the information, all of the factors, all of the science that I understand now that I did not understand at the beginning. And things that should have had a greater impact on me in the beginning that I only later have come to understand. Like, for example, the minimal residual disease factor and how they look at that at day 28.

I can remember our nurse practitioner coming to us and sharing that news with us. And she had such joy on her face, you know, because it was negative. And I was just like, "Oh, okay. That's great. I understand that that's great." I only understand now just how great it is that we achieved that at the end of induction.

Nancy: Well, it's so interesting because usually people talk about like the things they don't understand at the beginning and the medical things that they don't understand. And I think it's interesting that you're talking about also there's like a good thing that you didn't really understand that you only understand more now.

And if you think about life, right, and you think about when you have to sign that informed consent after somebody gives you this diagnosis you never imagined your child would ever have, it's like you're signing something that you're informed about, but you don't really completely understand. So, I think it is interesting to think about that gap in knowledge, but then you're thrown into it.

Maggie: Yeah, and in the beginning, and even now, it's 100% trust in the team, in the doctors. I'm going to sign this because I trust this paper says what it needs to say in order for my child to be taken care of and that you are asking me to sign it because you have the knowledge that I don't have that is going to lead us on this path.

Nancy: Yeah, so there really is a trust in the medical team that you're working with and a transfer of your hopes and dreams for your child to that team that's in front of you.

Maggie: Oh, that's an incredible way of saying it. Yes, definitely.

Nancy: I also think you had some real complications at the beginning that caused your child to have to go through a lot of different procedures and things and had some issues, right, that he had to face, behaviorally because of those things you think?

Maggie: Yes, yes. I knew, of course, that treatment was going to be hard, obviously. I did not anticipate the behavioral aspects of it, the mental-emotional impact.

So he was, it took two weeks for them to diagnose him because of the necrotic bone marrow. In that period of time, he had daily blood draws and multiple IV placements; and he developed PTSD because of that experience – very centered around needles. And, of course, needles are a huge part of it; and, and the access process with the needle going into the port placed in the chest and then out again is, especially in frontline, practically a daily experience.

And he got to the point where he could not handle it. He had to be held down by multiple people. He, would scream, and he would say very, very hateful things. And, you know, these things are coming out of the mouth of a five-year old.

And really the tipping point was when we had to transition to the Erwinia (Erwinia L-asparaginase) after he had developed an allergic reaction to the PEG. And the Erwinia is typically given by injection. For every, one dose of PEG that he would have received, there are six injections of Erwinia.

So, we went through the first course of Erwinia, the injection, and it just sent him over the edge. At one point, I remember him saying to me, because he would sort of target somebody in each of the accesses or the injections that he would focus his anger at; and this particular time it was me. And he said, "If I have to hurt, you do too." And so, he was just, you know, taking swings and-

Our team had never tried the Erwinia by IV, but they decided to do it with him because it was just such trauma to do the injections. So, for every course of Erwinia, they actually took him inpatient. We went inpatient for ten days, and he did the whole course by IV. And the decision to put him on Zoloft saved us all mentally and emotionally.

Nancy: People think about you have a child with leukemia and they think about some of the decisions you have to make and some of the issues that they face, but I don't think that people understand the intricacy of some of the things that you-

Maggie: Right.

Nancy: -have to deal with. And you think about like when he was kind of acting out and saying, "If I have to be in pain, you have to be in pain," well that's like a symbol of his love and connection and trust in you; but it doesn't feel that way when it's happening. And then I think that the thoughts that you have to put your child on a medication to be able to tolerate this when they're already giving them so many other medications is a hard decision to make. And, yet it becomes a decision that saves the circumstance.

Maggie: 100%.

Nancy: Yeah. So, you had to go through a lot. How long is his treatment and how long has he been on treatment now?

Maggie: So, we just hit the one-year countdown to the end. It's in total, 3-1/2 years for boys. I know that's changing a little bit now, but Benjamin's team has made the decision to keep the third year in his protocol. So, 3-1/2 years total, and we have 1 year left.

Nancy: And is the treatment now a little bit easier?

Maggie: It is. We are in what they call maintenance, and so it consists of daily medication at home – an oral chemo, and then he continues to take the Zoloft. And then actually we had our clinic day today. Once a month we go to clinic for another type of chemo, and then every 12 weeks we go to the hospital for intrathecal chemo. So that's the cycle, and then it starts over again.

Nancy: Is it hard to imagine that you're in this routine and you're doing it?

Maggie: I was just thinking about it when I was laying out the supplies for clinic last night and how normal it is and how from the outside if somebody saw a parent laying out all of this medical equipment or saw our meds set up at the end of our kitchen

counter where it always stays, all laid out and ready for each day's doses, how overwhelming that would seem. And I remember being overwhelmed by it at the beginning, but it's very normal now.

Nancy: Do you have any sense of how long it took from overwhelming to normal? All right, like when did that transition happen?

Maggie: I would say that happened after the Zoloft took effect, and Benjamin began to be able to cope better. So that would be, I don't know, maybe eight or nine months into treatment.

Nancy: So, it's really interesting to think about like psychotropic medications that help you, not because you're taking it, but because you're experiencing life with somebody else taking it and doing better.

Maggie: Yes, yes.

Nancy: Right? It's just so interesting to think about that process. What do you think helped you cope the most as you transitioned from like that induction phase to the maintenance phase?

Maggie: Well, number one, just seeing him functioning better. At the height of his mental/emotional dysfunction, he was truly flipping into a fight or flight mode every time he was triggered by a needle or by something unfamiliar, whatever it was. We had spent so much time trying to teach him these tools to cope with these situations. And because he was in fight or flight mode, he could not access those tools. But he began to be able to access them, and that was a turning point.

The other thing for me that really helped, and this speaks back to my identity as an artist, is I started painting. I had never painted before, and a friend of mine had gifted me watercolor kits just after Benjamin was diagnosed. And they were so perfect for the situation because they were a creative outlet for me, but they were tutorial, so I didn't have to do any thinking. I just could follow the tutorial and paint.

I'm part of the Momcology Support Group on Facebook; and one of the moms there started an art therapy group, and I joined that. And from that developed like a cancer mom character that I would paint. And I painted myself and Benjamin according to these different prompts. And so that is what has allowed me to process everything from diagnosis to that point. And as I continue to proceed forward, it's art that's getting me through.

Nancy: That's great.

Maggie: And I encourage him as well because I'm hopeful that it can play the same role for him.

Nancy: And what about for your husband?

Maggie: I feel like my husband is very similar to the way that I've heard other people describe their husbands in that he just soldiers on. He doesn't like to talk about it. He doesn't see the point in talking about it. From his perspective, it doesn't do any good to talk about it. You just need to do what needs to be done.

And that's what he does. He does what needs to be done. He works. He's providing the financial support, the insurance. I worry that because he doesn't talk about it that it might rear its head at some point. But he's a very steady, solid person; and maybe it will and maybe it won't.

Nancy: It's so interesting to just think about how people cope with the same treatment, in the same treatment situation differently. And I think that in some ways we always think it would be good if people coped in similar ways and dealt with things and talked about things. However, it seems to me that sometimes what happens is that it's actually the different ways of coping that enable people to kind of find their own way in this journey. And it may change. You know, it may change when treatment is over.

I have been doing this for about 40 years, and I have seen people change over time in how they cope with things. Some people talk about this whole situation while it's going on. Some people talk about it after it's all done. You know, kind of in a different stage. But I do think it imposes a challenge on relationships because it's hard to have people cope with things differently and maybe even need different things during the course of a child's illness, right?

Maggie: Absolutely, yes, yes.

Nancy: So, it is nice. It is a wonderful opportunity at times to bring mothers together and fathers together so that they each have the opportunity to kind of express themselves; and we're hoping there will be also some interest at the end of these recordings that there'll be an opportunity for people to come together and talk online. So, we're hoping we do attract some dads and some moms, and we will see how that goes.

For you, when you look at like this past couple of years of your life, what do you think that the hardest part of the treatment process was for you?

Maggie: It was the mental/emotional challenges that he faced, and I felt a real sense of failure that I couldn't help him through that. That it took a medication to get him through that. With my background in education and 15 years of working with children under my belt, and some of them in some pretty intense settings. I had been a recreation counselor and behavioral counselor with severely emotionally disturbed kids in residential treatment; and that's the population that showed the same kinds of challenges that Benjamin was showing. And I couldn't figure out how to help him tackle what he was facing. I tried to give him all the tools that I had been taught and that I had used with other kids. And this was my child, and nothing worked. And it took medication.

It's just looking back on it that I realize, I was part of what was happening to him. I was part of the trauma, and I was experiencing my own trauma. And it's no wonder that I couldn't get him through it.

Nancy: Yes. And as a parent, you are so responsible for his physical and his mental health, and you have so much that feeling that you should be able to be the person who makes him better and who takes care of him that it really does pose kind of an interesting challenge for all of us who are parents who when we have to face those kinds of situations in our own families. So again, it sounds like you have also worked to find pretty amazing solutions that have worked for him.

So you have reframed the concept of problematic behavior and responses to something that seems much more functional. And I think the introduction of art now is also, like it's a way that you are coping and a way that he is coping; and it's kind of impressive to hear those things working in your life. And I think that it will be good for other parents to hear that you can be in this very difficult place, and that it can turn around to be a better place. Right, that it doesn't mean when you hit a difficult time in treatment that you're always going to be in that place, that there is hope for movement to the next place.

Maggie: It was so hard to see that when we were in the thick of it. But it is 150% better now. We went through the access process today. He had clinic today, and his nurse practitioner had not seen him through the access process in a long time. And she sat in on it today, and he's like a different child. That was her reaction. She just couldn't believe how well he was doing.

Nancy: Yeah, that is pretty remarkable to think about; and for you who have a child who's this age, right, it's also interesting to think about what developmentally happens to him over the course of these 3-1/2 years of treatment, right? He really develops into the individual that he is becoming. And so, you are also in a place whereas your

child ages, the story changes. Right, and that's another, I think, very interesting part of this.

Do you have any advice that you would give to other parents who are dealing with kids that are having trouble with treatment?

Maggie: Yes. Seek out help. Ask the team about therapy. Benjamin works with a psychologist at clinic doing play therapy; and that has been really effective for him. And then there's a psychiatrist who oversees the medication management.

I also would say, and I wouldn't have said this prior to our experience, I would say don't be afraid of the medications that are targeted for the mental/emotional challenges because, at least for us, I can't speak for everybody, but for us, and he's on a very low dose, it got him to a point where he could use the tools that we were trying to give him to make his way through all of these challenges. And he couldn't have done it without it, and it was really a turning point for all of us once he could use those tools.

Nancy: Maggie, that is great advice. I just want to say we all really, really appreciate your sharing this part of your story with us; and what a pleasure to hear what you have to say. So, thank you from everybody at The Leukemia & Lymphoma Society.

Maggie: Absolutely. Absolutely, thank you.

Elissa: Hello and thank you for listening to the 2nd episode of Cancer & Caregiving: Navigating my Child's Cancer.