THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

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

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 third 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 schooling 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 schooling 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: Nancy, children of schooling age often have significant disruptions to their education after a cancer diagnosis, whether it means that they have to miss school completely, start homeschooling, or go part time. Can you speak to the challenges this presents to the child, but also to the parent caregiver?

Nancy: There's so many things to say about school and the challenges that are posed, and I think I'd like to frame this for everybody to think about. Like, at times when you have felt your sickest in life, right, you think that sometimes our expectation is that kids can go through this entire rigorous chemotherapy process and then can just be doing academic work the way they were doing before. And I think that that's kind of an interesting way to think about like even where some of the challenges start for children because any child diagnosed with leukemia and any other form of cancer and going through treatment is not necessarily going to feel their best. Yet we're going to have some expectation that they will be able to learn at the same level that they were able to learn before.

So just as we think about that, I think that the stops and starts are complicated for children. I think the age a child is, is really significant to what some of their educational experience is. And for some kids, it's the gaps in social interactions that provide as much of a complication as some of the educational features. And then that doesn't even take into account what some of the medical issues and cognitive issues may be for kids based on certain chemotherapies and different things that they were facing related to their illness.

So, it is not just one thing that impacts education for children with cancer. It really is a process of several different things kind of happening at the same time. So, I think that there are unique challenges that children with cancer face, and I think that they need different kinds of help, depending on their situation and their circumstance.

Maggie, I would like to hear your thought on that too.

Maggie: Sure. I mean, the points that you have just made, I have seen reflected in Benjamin's experience. Particularly the social aspect of it. That's been such a gaping hole in his life. We're in our third year of isolation now, so for the past 2-1/2 years. And he's a social, social kid. So, it really is something that has impacted him.

We're really lucky that he has managed to keep up academically in terms of, he has the skills and knowledge that he should have as a kid completing the end of first grade. He has managed to remarkably, online build those skills, and I'm so grateful for that.

Nancy: It's an interesting point when you make it that this is his third year of being in isolation, and you think about the magnitude of that for a child of his age. You want to remind everybody how old he is.

Maggie: He is 7 now. He was 4-1/2 at diagnosis.

Nancy: So, he had everything that happens within a cancer diagnosis and also a world filled with COVID so that he has had to really deal with both things as he goes on his educational journey.

What was he doing from a school point of view when he started treatment?

Maggie: He was in preschool, and he had been in preschool for a year and a half. But we had just moved from Idaho to New York prior to diagnosis, so he had been at this new preschool for a couple of months.

I suspect that he had been sick for a good portion of that. He never adjusted well to this new preschool. He didn't want to go. He didn't connect. He wasn't strongly connected to the teachers or the other students which was a complete opposite of how he had functioned in preschool in Idaho where he was, incredibly connected to the teacher and the other students. He still speaks to a couple of those kids. They have Zoom playdates still to this day, the kids from Idaho.

And I can remember dropping him off at the new preschool here in New York, and just he had this complete look of defeat on his face because he had not managed to talk me into taking him home with me. And I think it's because he didn't feel good.

Nancy: Yeah, I think in the course of kids' diagnosis, we always hear stories like when looking back, there's always the thought that maybe this was happening then or maybe this was going on. And yet the rarity of childhood cancer diagnoses are such that they really wouldn't be what people would think about at certain stages and in certain responses to things.

But as you were talking, you made me realize the uniqueness of his situation, right, that he was doing Zoom visits with friends from where he used to live.

Maggie: Yes.

Nancy: And schools he used to go to. And then he came to this new place, and then he was diagnosed and then there was a pandemic; and so, then there's Zoom things. So, for him, in his world, it's almost like one continuous experience of alternate education. And so, it's interesting to think about both what he's adapted to and what he's learned and what he's coped with and then what some of the challenges he will face when he enters into that environment again.

Maggie: Yes. I mean when you say it like that and lay out all of those things that happened one right after another, I'm just blown away by his resilience because I think if you met him and talked to him, you wouldn't really necessarily know that he had been through all of those things.

Nancy: Yeah, so that's actually like a great testimony to kids' resilience and strength and ability to negotiate in all of these systems. And in some ways, when adults are diagnosed with leukemia or other types of illnesses, their adaptation may be even harder; and their resilience may be less great. So even though he's faced so many different challenges, it sounds like he has continued to learn and to learn different techniques in coping, and to be moving forward, which is very exciting.

Maggie: Yes, yeah. The next step hopefully being that he can return to school and to some semblance of normalcy.

Nancy: Now as an educator yourself, can you identify what you think have been like the hardest school challenges or potentially what the hardest school challenges are going to be for him based on his experience?

Maggie: I think one of the hardest things for him is going to be the fact that he didn't learn just classroom and school procedure. Like what does it mean to be at school with a group of kids that he's not the only child in the room. He has to wait his turn. He has to raise his hand when he wants to speak. There are certain routines that teachers instill in the day to get them and their students through the day in a hopefully, calm and organized and effective manner. And Benjamin has not learned any of those procedures that a child going into second grade would do now without a second thought. So, I see that being a challenge.

Nancy: So, he will need help learning those procedures or learning how to learn those procedures, right?

Maggie: Yes.

Nancy: So interesting to think about. And do you have any sense from the protocol he's on of any future issues he may face cognitively or-?

Maggie: Yes.

Nancy: Is that something you've-

Maggie: That's such a source of anxiety for us. We've read about all of the medications and what the potential side effects are. The biggest concern is the effects on things like his processing speed, his executive function essentially, his ability to like organize information, working memory, and so we see things in him; and we are not sure. Is this developmentally appropriate or are we seeing the effects of medication?

For example, right now I really am seeing some short-term memory issues with him, and there's so many things going on in our lives, isolation, the arrival of a new baby, and I don't know. Are we seeing effects of medication or are we just seeing developmentally appropriate issues and the effects of some other factors in our lives?

Of all of the things that we have dealt with, that is such a source of anxiety for myself and my husband; and there's a sense of almost mourning what Benjamin's life would have been like without this and coming to terms with how it will affect him in the future, how these medications will affect him in the future.

He's a very, very smart little boy. I see some of the students in his online class functioning at high levels; and I can't help think to myself that this is what Benjamin would have been like had he not faced all of these challenges over the last couple of years.

Nancy: You're describing a piece of this experience that I would describe as a type of ambiguous loss, right? Like you don't know what he would have been developing and thinking and doing, yet you perceive that it might have been different. And so, there's something that is hard to quantify and hard to deal with because it's so nebulous and also because the uncertainty is there for the future. Like there is what is today and there's what is the future?

Now, The Leukemia & Lymphoma Society has a really impressive set of documents that talk about some of the issues that kids will face and some tips and ideas and resources. So that would be good for you and for other parents facing similar situations.

The advantage you have is that you are already talking about some of the potential issues and you're aware of some of the issues. Many families don't think about having their children have neuropsychology testing done unless they've been like in the situation where they see that happening. I don't know if you've been through that process yet, but to actually do that so that you have a baseline of where he is.

And it sounds like he's a very smart and capable kid, and he will therefore then potentially compensate for many of the things that he may experience. And it would be helpful for you to know which of those things that you experience, or he experiences are things that are happening because maybe there are also ways in which there can be avenues of help that can be available to him early. But I do think that like when you're dealing with all of these other things, it is so hard to take that on as yet another mountain that you may have to climb. And I understand the feelings associated with that are very complicated because dealing with leukemia is a big deal. And then how the rest of your life and the rest of his life falls into play with that is also a big deal and I think a lot for parents to have to manage.

Maggie: Definitely. We did the neuropsychology evaluation at the very beginning. He's had a second one since then. That would be my recommendation as well to other parents is to have that done so you can identify the baseline and then if problems develop, you can put supports in place.

I will say it's startling to see the deficits on paper. His latest one came back with some clear processing issues. And it's not even something I would have predicted happening in the way that he functions in his daily life. So, to see it on paper was really startling, but now we know. And now as he begins school, we can take that information to the school or to the teacher and the psychologist and get a 504 written up and make sure that he has the support that he needs.

Nancy: Yeah, I think that as a parent, you do need to commend yourself for having done everything that you've done. And I think it's good advice to other families to do that so that they know what the baseline is. And I think that you may already be seeing him compensate for some of the things, because when you say it's startling to see it on paper, I think it really is. Whether it had been a result of chemotherapy or a result of the illness or life in general and what this past couple of years have been, I think it is important for parents to embrace that information.

One of the things that I think also really helps parents is to be in a situation or to be introduced to many leukemia survivors down the road who've actually experienced some of those issues but who have also learned to grow in different ways and to cope in different ways and to really adjust to some of the things that they have experienced.

So, I think that we can actually help connect you with people who are down the road in those kinds of situations. But I think you're at the beginning of understanding for him what may be things, and school is the thing that actually makes some of those issues come to light. Whether something is an issue or not, right.

Maggie: Right.

Nancy: Because you will see whether or not he can compensate and learn in different situations.

Maggie: Definitely. And that's been a lesson for me to not try to identify or create a problem before it actually arises, in wanting to support him as best as I can. And anticipating all of these things that he may or may not need, I have to remind myself, we don't need to do those things. We don't need to place those supports until he shows us that he actually needs them.

Nancy: I 100% agree with what you just said; and then there's thinking about your child is still on treatment, still not in that place, right, where you're looking back at treatment and thinking, what has an impact and what doesn't have an impact because you're still in the middle of it.

Maggie: Right.

Nancy: So, I think that that's important to too.

I think there probably are a certain number of things that everybody can deal with at a given moment, and that even what you learn about your own learning is all affected by this bigger cancer process. So, I think that it's good advice to yourself, which is to think about what to be prepared for but to not create an issue until the issue emerges.

Maggie: Right.

Nancy: Right.

Maggie: I have to remind myself of that all the time. For the many different aspects of treatment that we're still in the middle of it, you know.

Nancy: Right.

Maggie: I can't expect us to be functioning beyond when we're still dealing with the trauma. We're still dealing with the medication, one day at a time.

Nancy: One day at a time. I think one day at a time is good advice. You think about kind of sibling issues and different family issues and different styles of coping. There's a lot of stuff going on all at once, and maybe partializing out the things that are happening and putting things in their particular boxes is good advice as people begin to think about the issues that their kids will face with school.

I think for some kids, there's also issues about anxiety about kind of reentry into the school process; and I don't know whether or not that will be something that he will face. But I think it's helpful for parents of kids of all different ages to think about how their child both may feel differently going back to school. So even if they're going back to a familiar environment, they may feel a little bit like a fish out of water, and that's true at all developmental stages.

Like I think of even like teenagers or kids who were about to be off at college and at certain ages where their peer group may be involved in activities and socializing in a world that they have been a little bit distant from and that different things may be important for a child who's just completed cancer treatment versus a child who's testing some of the waters of nearing adulthood. So, I think that at each stage of development and each stage of education there are different issues, both cognitive, developmental, and emotional that children face.

Maggie: Absolutely.

Nancy: Right, so I think-

Maggie: Absolutely.

Nancy: -it's a complex situation.

Maggie: We're in a really unique situation right now in that other kids have been isolated in the same way that he has. And so starting school in the fall, he won't be the only one that's been away for this period of time.

Nancy: Right. There may be really an advantage to that.

Maggie: Yeah, yeah.

Nancy: So, I know that the pandemic has been problematic in other ways, but I think you raise a good point, that he will be going back at a time that other people will be going back as well. And everybody will have to get used to starting again.

Maggie: Right.

Nancy: So, I think that might be a helpful-

Maggie: Silver lining.

Nancy: Yeah. So, are there any other questions or thoughts you want to share with people about your thoughts about school for kids with cancer?

Maggie: I guess I would encourage people to take advantage of the supports that are there. A couple of things that have made a big difference for us are that the district would provide a home teacher for Benjamin. You know, the doctors signed off on paperwork saying that he needed it. And so, once we were done with frontline and he hit maintenance and we were able to have him around somebody, the district provided a home teacher for that period of time. That was for the last couple of months of kindergarten.

Another resource for us that has made a difference, there's an organization called Hopecam. Do you guys know of Hopecam? And they provided a tablet to connect Benjamin to classmates. We didn't use it to its fullest potential because he was sort of between classmates. He had left his preschool group, and he hadn't really connected with the kindergarten group. But it's an incredible resource; and that connection to classmates, I think, as important as the academic aspect is, that social aspect is just as important. And so, facilitating that continued connection I think is really important and that there are resources for it.

Nancy: I thank you for that. And I will also agree that sometimes I think that in addition to the issues that a child faces, that parents may not want to address some of the potential academic issues. May be afraid to, may feel again a sense of loss or an inability to cope with yet another issue. So, I think that sometimes it becomes the professionals and other parents who become very helpful in helping parents deal with school issues. Leukemia is the big diagnosis, right, that people and support come to you for. But I think that additionally parents need support around some of the potential educational issues – whether they are about socialization or they are other deficits that have been created by virtue of the experience because it's almost as though it's a secondary issue. But even harder at times for people to face because both of the uncertainty and the fear of the sense of loss and the thought that there may be another issue that you have to deal with that will last longer than the treatment phase of leukemia treatment.

Maggie: Absolutely.

Nancy: We thank you, Maggie, for your honesty, your availability. I think this will be very helpful to other parents, and we're so excited that you're being willing to be here with us now; and we will see you as a resource and a connection in the future-

Maggie: Wonderful.

Nancy: -so thank you.

Maggie: Wonderful. Absolutely. I'm so glad that I could help.

Elissa: Hello and thank you for listening to the 3rd episode of Cancer & Caregiving: Navigating my Child’s Cancer.