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00:02 Allison Yacht: Hello, and thank you for joining us for the More Than 4-Cast. I'm Allison Yacht. If this is your first time listening, we are here to share stories of pediatric cancer. I know when we were going through it I wanted to hear as many stories as possible. I hope hearing about Heather's experience today helps you to push forward. Today's guest is Heather, and she has four children from the ages of seven to ten months old. She is a busy stay at home mom who home-schools her kids. Her son Luke was diagnosed with Pre-B-ALL in June 2016 when he had just turned four. Prior to having kids, Heather earned her Master's in health administration and worked with parent and family-centered care in a large hospital system.

00:43 Heather: Hi Allison, I am wonderful. How are you?

00:45 AY: I'm very well. Thank you. Thanks for joining us on the More Than 4-Cast today.

00:50 Heather: Thank you for having me.

00:51 AY: Excellent. We are really happy to have you and to hear your story and all of that, so I'm just gonna get right into it. Could you tell us a little bit about your family and then tell us how you found out that your son has cancer.

01:04 Heather: Sure. I am married to my husband. We've been married for 11 years now, and we have four children. Our oldest is seven. And then we have a six-year-old, and a three-and-a-half-year-old, and a ten-month-old. We live in Denver, Colorado, and I'm a stay at home mom, and I homeschool the kids, and that takes up most of my day.

01:25 AY: You've got your hands full I bet.

01:26 Heather: My son Luke is my second child. He's my six years old, and he was diagnosed on June 27 of 2016 with precursor B acute lymphoblastic leukemia, which is ALL for short. We had gone on a family vacation the month before. So May of 2016, and when we came back, all the kids, the three that I had at the time, kinda came down with a virus at the same time. And his older brother and younger sister recovered normally, and he had this lingering cold or what I thought was a cold. We had actually been up in the part of the country near Old Lyme Connecticut. So my first thought was he either has a virus or he has Lyme disease. But he had never gotten bit by a tick. We had no... We never saw a tick, so I'm like that's probably wasn't it. So then I'm like, well, maybe it's just a virus, maybe it's just taking a while.

02:22 Heather: He got progressively sicker, and he was experiencing tiredness to the point where he would go to bed, put himself to bed before dinner, at around 4:30 PM, and sleep all through the night, completely sleeping through the night, would not wake up until the morning. He was having night sweats as he was sleeping. He was complaining of leg pain to the point where we couldn't even park in the grocery store and walk across the parking lot without him saying that he was in pain. But again, I chalked it up to growing pains or you know being tired because it's the summer,

we've been very active. We went to a splash park the weekend before he was diagnosed. So he was diagnosed on a Monday, we went to the splash pad around I think it was Friday or Saturday, and he just sat underneath the little awning with the picnic tables, he didn't wanna play, and I'm like, well, that's very strange, because he's a very gregarious, very outgoing, very playful child.

03:20 Heather: So on Sunday evening I told my husband, I said, "I think I need to bring him in." My husband is in the medical field and palpated his lymph nodes and said, "Yeah, these feel really swollen. Why don't you make an appointment Monday morning?" So I said, "Okay, I'll do that." So that evening I started to really feel like this is not just a virus, that something more is going on here. And I actually prayed about it, and I started to research some things and of course, cancer came up as Doctor Google is always willing to give us a diagnosis of cancer. And when I read the symptoms though, a lot of them rang true for what he was experiencing. And at that point, I was like, you know, I feel like this is something much more sinister than just a virus.

04:04 Heather: So we went to the doctor on Monday afternoon, and she immediately palpated his lymph nodes, she palpated his abdomen, and she said, "We need to take blood." So I said, "Okay." So she got the little machine, took some blood and came back and said, "I'm so sorry, something's wrong with our machine. This doesn't normally happen, but I need to redraw the blood." I said, "Okay." So they did another finger poke, redrew the blood, tested it again, and she came in, and she asked if I wouldn't mind if the children left the room, because I had all of the three kids with me. And so I said, "Sure." So a nurse came and took the other two children and she sat with... Actually, I think they even took Luke out of the room as well, and she sat with me by myself and told me, "Based on how his lymph nodes feel and his white blood cell count was so high, it didn't even register on our machine the first time around, I feel confident saying this is a diagnosis of leukemia." She was like, "Now, I can't be definitive, because they need to do a bone marrow aspirate to definitively say." But she's like, "I've seen enough in my practice to know this is leukemia."

05:11 Heather: And his abdomen was so swollen, she said she could feel his pancreas, she could feel his spleen, and she was worried that we shouldn't even take our car to the emergency room. She wanted us to drive to the hospital immediately. Not even go home. Don't pass go, you know, do not collect two hundred dollars. Straight to the hospital. So she got on the phone with them, and she decided that we would be okay to drive ourselves, so it was an hour and a half trip, so I had called my husband. I had to tell him at work what was going on. He came, picked up the children, and Luke and I journeyed on our way to the hospital. In the ER, based on looking at his bloodwork on the slides, they were able to tell me leukemia, and we began a month-long in-patient hospital stay from that point on.

06:00 AY: Wow. Wow, how did that affect the rest of your family with you... I mean, obviously, with him being in the hospital, were you there all the time? Like how did that work?

06:11 Heather: I was there the whole time. So, that was a Monday, let's see... My husband... When we lived in Louisiana, because this all happened in Louisiana, we got diagnosed there, and now we live in Denver, and his work schedule was much different then.

06:28 AY: And what year was that?

06:29 Heather: This was 2016, so this was two years ago. And I don't remember what his work schedule was, but my first thought was, because he, of course, wanted to be there with us, and my first thought, because he was self-employed at the time, was, we need you to work because we need money. I don't know... At that point, I had never met anyone really close to me that had gone through a cancer diagnosis. I had never watched someone go through therapy for cancer. And I had no idea what the cost would be. There were so many questions swimming in my head, I didn't know what the outcome... I just knew nothing.

07:07 Heather: And so I said, "You need to work," I said, "You need to go to work so that we can afford..." Because in my mind, all I could think of was astronomical medical bills. That's all I could think of. So he actually went to work the next day. My parents came and took care of our other children, and I was with Luke. Luke got his surgery for his port the very next day, and they started treatment right away. He had his first lumbar puncture that day. That's when they did all of the genetic testing and all of those first tests that you do when your child gets a cancer diagnosis. So yeah, immediately, it was, "Is my son going to live?" That was my first thought, "Is he going to live? What does this mean for his life? How can we afford this? And what am I going to do with the other children?" They didn't tell me at first how long of a hospital stay we were in for. Of course, I don't know that they know right off the bat.

08:11 AY: Right.

08:11 Heather: And we didn't get that information till a little bit later. It all actually worked out very well though. We had a lot of help from my parents, my husband's mother, we had family friends. So, that part actually worked out really well. It would happen where, I would go home twice a week just to see the other children, shower, get new clothing, and then my husband would be with him on those two days. It was like a Sunday and then like a Thursday. So every Thursday, I would come home, sleep at home for a night, go back on Friday and do the same thing on Sunday. And that's how we spent that time.

08:45 AY: Wow, that must have been intense. So as I found out about cancer, every cancer has its own sort of cocktail and treatment of how it works. So I know a little bit about ALL, but tell us what his treatment, and if I'm correct, I think he's still going through treatment...

09:08 Heather: He is.

09:08 AY: Tell us what that looks like, the first year, the second year, and then for now.

09:14 Heather: Sure. So ALL, there's many types of childhood leukemia, and there's different sub-types within those types. So, ALL has two pre-curses. Precursor T as in Tom, Precursor B as in boy. And B is what my son Luke has. And depending on what sub-type you have and what type you have, treatment looks completely different. It also depends on how you present... So it's possible for you to have leukemia cells in your spinal fluid and in your brain. In boys, they can have them in their testicles. And my son didn't have any of that. If your child would present with those, then radiation comes into the mixture as well as the chemos and the bone marrow stuff. And those are

things they test for in the very beginning, and then they continually test for presence of those things throughout the entire course of treatment.

10:08 Heather: So the first part of treatment is called front line, and that lasts anywhere from six to nine months depending on how your child handles it. Certain things will make it pause. Those things usually meaning low blood counts. Either their platelets are just too low to have treatment, or their white cells are too low to have treatment, or they are ill for some reason. Those things can put a pause in your treatment and can stretch it out.

10:34 Heather: After you finish front line, then you go into what they call maintenance. For boys, maintenance is about three years. For girls, it is at least six to eight months less time. And the reason why it's more time for boys is because they're trying to resolve any issues in the testicular region, because leukemia cells kind of like to set up shop in those regions in boys. So it really depends on what symptoms your child shows when they first got diagnosed, if it was in the spinal fluid, or in the brain, or the testicles. Some of it depends on the age of the child, too. And there's three categories when you get diagnosed. You can be very high risk, high risk, or they just call... I think regular, like normal risk. And those things too determine length of treatment and things. So there's a lot that goes into it.

11:38 Heather: We were lucky enough to get into a clinical trial. There are a lot of clinical trials going on with leukemia right now where they're testing the use of certain steroids in conjunction with chemotherapies and all sorts of things. So we actually got into a testing arm for one of these trials. And that can also dictate how long certain periods of your treatment will last.

12:00 Heather: So in the frontline treatment, you're getting lots of blood transfusions, platelet transfusions, you're getting chemo every day. You're getting chemo in the port, you're getting oral chemo, you're getting bone marrow biopsies, you're getting spinal taps, lumbar punctures, where they also put chemo in the spinal column to sort of kill anything that might be trying to live there. It's very intense. Sometimes you have to go into the clinic for chemo multiple times a week. There's overnight stays, it's very common. At one point, we were doing a six-week rotation of in-patient for one week, out of the hospital for one week, and we did that for six weeks during a certain part of it, because it changes every month or so. The treatment is different, and you get different chemos at different times, all these types of different things. You're on steroid pulses for some of it. And that's all very confusing, and it becomes sort of a blur. You have to kind of go back and look at your notes and remember what the chemo is for and what order they were in because it's just... You're kind of in maintenance mode at that point, you're in survival mode as a family. You're in survival mode as a caregiver. Your child is in survival mode. So it's just kind of going to the next thing and the next thing as quickly as you can to kind of get it over with, for lack of a better word.

13:27 Heather: Once you finish frontline, you're in maintenance, and maintenance is a much more smooth sailing time. Now we take oral chemo every day, and we also go into clinic once a month where he gets spinal taps, and then he gets steroid pulses, and he gets extra chemo in his port. So, provided there's no ER visits right now, we're only in clinic once a month, which is wonderful.

13:55 AY: Wow. Wow. That must be a big change, but that's...

13:57 Heather: It is.

13:58 AY: Still so much to manage. From my understanding, it's a lot of you giving him the medication.

14:04 Heather: It's a lot of us giving him the medication. It's funny because, so in the middle of treatment, in the middle of frontline, we moved from Louisiana to Denver. And our hospital in Louisiana, which was a wonderful hospital, they wanted to do a lot of the treatment in-house, in the clinic, so we would drive back and forth. In Denver at Children's here, they're much more comfortable letting the parent administer, anything they can do at home, they would like the parent to do it at home.

14:32 Heather: So there was one chemotherapy, I can't remember the name of it, but that he was used to getting in clinic in Louisiana, and we moved here. And then our oncology nurse, Virginia, told us, she said, "Okay, now you're gonna give this at home." And I'm like, "I am not qualified. [chuckle] I do not want to be in charge of giving this to him at home." And it consisted of, they had to put a little subcutaneous catheter in his arm, and it was delivered to my house, the chemo. It was like this huge setup, I had like hazmat material in the box, and it was in a syringe. You had to draw the chemo, it was in the syringe, and I had to put it through the little subcutaneous catheter in his arm, and that's how it was administered. And the first couple of times I did it, I was like, "I am not prepared." I'm like, "I am not qualified." And Virginia, she's like, "You can do this." She's like, "It's gonna be okay, you can do this," and it really was okay, but it was just... I'm like, "I am giving my child chemo," and I'm used to giving him chemo because he takes pills every day, but a pill is different than a syringe of liquid chemo. So, that was very...

15:44 AY: Scary.

15:45 Heather: That was something that when we had, that was... Luckily, he doesn't have to do that anymore, and it didn't happen that often. It was like two little week-long sets of it, but... And they do give you a calendar, which is nice. And I know not every hospital does this, but I feel like they should almost be required to because it's so much to keep up with. There's so many dosages, there's so many things. And we do get a calendar that tells us what to give him on what day, which is very, very helpful, 'cause I know some parents have to make one on their own, which can be really hard.

16:16 AY: Right. Yes, that's what I have seen. So, oh, the thought of having to make that [chuckle] must be very hard.

16:23 Heather: Again, yeah, I was like, "I don't wanna be responsible [chuckle] for this. It's so much, because of the dosage." It's so... You can't miss a dose. You can't... It's so precise, it's so precise. And I was so nervous about that, but like anything, the more you do it, the more you get comfortable with it. And now it's very... It's kind of like we give him vitamins. We give him his chemo at night, and that's it. It's very cut and dry and simple now.

16:55 AY: Right. For sure. It's a hard thing to have to get used to, but it's probably better...

17:00 Heather: It's a very hard thing. It took me a lot of... Emotionally, it was very difficult, because as a mother, you wanna protect your child from all possible instances of harm, and it's hard to reconcile giving them chemo, which you know is a poison, and you know that it has some debilitating side effects with it. But you also know that if you don't, it's gonna be even worse. So it's very hard as a mother to wrap yourself around that and to get comfortable with that. And still, sometimes to this day, it still kind of gets to me, and I have to sort of refrain my perspective because it's difficult.

17:41 AY: That's so true. And I'm guessing that you've had a similar experience, where I remember they're putting all of this equipment on to give her chemo. [chuckle] And I'm thinking, "If you guys need to be so protected from this, with face masks and all this stuff, how can... "

17:58 Heather: The first time he ever got chemo in his port, I remember, because I had never seen anyone... I didn't even know what chemo was. I knew the word obviously, but I had never seen anyone get chemo. I had never been close to anyone who had chemo, so I didn't know if it was a pill. I didn't know anything. Literally nothing. So I remember the first time they hooked it up to his port, and I was like... And then they turned on the little pump, and I was like waiting for something to happen. I didn't know if I thought something was gonna explode. I was just like so nervous. And then when it was over in 20 minutes or however long the infusion took, I was like, "Okay, now what happens?" And the nurse was like, "Well, that's it. It's in his body." I'm like, "Okay." I expected it to be this very... I don't know what I thought, but I was very nervous about it, and...

18:48 AY: Very...

18:48 Heather: Very... I didn't know what to expect. But yes, when I actually got pregnant when he was just finishing frontline treatment, so I got pregnant in January of 2017, and he had still had a little bit left to go of his frontline, and they were very, very cautious with me, in terms of handling, not only the chemo, of course, but then also any time he soiled the bed after any sort of hospital stays or chemos. I had to be very careful how I cleaned it up, how I changed any diapers he might have, how I cleaned up any vomit of his. I had to be very careful, because I was pregnant. Now that I'm not pregnant, I honestly don't wear the chemo gloves when I give him his oral pills anymore. I know I'm probably technically supposed to, but I really don't. We just wash our hands really good after. Because it's so normal to us now, it's... Yeah, I don't. I should probably take more precautions than I do, but I just honestly don't.

19:55 AY: That makes perfect sense, absolutely. How is he doing now? I know he's got some time left, but as far as treatment goes, how is he...

20:05 Heather: He is doing great. So when he first finished frontline, they kind of go through this phase where they're coming off this incredibly difficult regiment of intense, intense chemo drugs and going down to a much more step-downed regiment, and because of that, normally their counts all completely tank, and they end up in the hospital for one reason or another. And that happened to us on a couple of occasions. Now he is much more stable. His ANC's have been wonderful, all of his counts. He hasn't had a blood transfusion or any sort of transfusion in well over a year. So he's

doing really well. We still have to be careful of course around cold and flu season and anyone with any active infections, I keep him away. But he has not been neutropenic in months and months and months. His activity level is wonderful. He is sleeping well, he is eating well. He has gained all the weight back that he lost.

21:02 Heather: He's doing really well to the point where most people don't know that he is a cancer patient, they're usually shocked when I tell them. His hair has grown back. Yeah, most people don't know that that's what he is going through unless I tell them.

21:18 AY: Right. And that's so hard, because it's do you tell them, do you not tell them. It's like I imagine...

21:24 Heather: It is hard. And it was kind of humorous, because at some point in the past six months, his hair for some reason fell out again. And the only reason they can give me is because he had the flu in January, and they say sometimes when a child has an illness like that with the chemo, maybe like six weeks later, you'll notice the hair falls out again, because of the stress on the body, and it just goes. So his hair fell out again. And in our family, whenever his hair falls out, all of our hair falls out. So we all shave our heads, and it was funny because at church, people that didn't know that we were sick, and all of a sudden they see us come in one Sunday, and the whole family, minus or three-year-old little girl 'cause she doesn't shave her, but the rest of us do have a shaved head. And we were getting a lot of stares, a lot of, "Are you okay? Is he okay?"

22:16 Heather: And that's when I had to tell people, "He's fine, it's just his hair fell out because he's in treatment and..." So that kind of was our tell, it kind of gave it away for us. Not that we tried to hide it, but we definitely don't try to make it everyone else's business unless we have to.

22:34 AY: Sure, sure. And how do your other kids deal with everything that's going on?

22:41 Heather: His older brother Arvin is 17 months older than him, so they're very close. Initially, when he first got diagnosed, we had a wonderful child life specialist who helped us have the words to explain to Arvin what was happening. And Arvin being, he's very scientific, and we had already kind of studied a little bit about the body and blood and how it works in school. And he took to it right away, in terms of understanding the intellectual part of it. He has trouble with jealousy. Luke does get some special attention that Arvin, I think, wishes he would get. But he does enjoy the perks, though, of Luke's diagnosis. We went on our Make-A-Wish trip, Arvin got to come. Luke got a Kindle when he was diagnosed through the hospital program and Arvin gets to enjoy that. Arvin likes to come to the hospital with us, because they have a sibling playroom, and Arvin likes to go there and play while we are in the clinic.

23:44 Heather: So, I don't know, emotionally, that he is very effected, because Luke is doing so well. Now, there are times when Luke does get sick, especially in the winter, normally we'll end up in the ER at least once or twice for flu or various colds and things. And then you can see the worry kind of creeps into his face. But as long as his brother's doing okay, he's doing okay. His younger sister, Evangelin is two-and-a-half years younger. So Luke is six, and Evangelin's three-and-a-half. I don't know that she really has any kind of concept as to what is happening. She can say the word

chemo, and she knows the word leukemia, and she knows that we go to the hospital, but I don't know that she really can connect any dots as to what that means.

24:35 AY: Right, right. Which is probably a blessing.

[laughter]

24:39 Heather: Right. I often think, when they get older, what they're gonna look back on this time as, because Luke had just turned four when he got diagnosed. I mean, we were still in the same month as his birthday and I don't know how much he will remember when he's 20. I really don't know.

24:57 AY: I remember the doctor, my daughter was almost five, she was a couple of weeks away from five, and I remember the doctor saying, "This is a good age, because she won't remember it." And I remember just thinking to myself, "How is she not gonna remember this? Of course she's gonna remember this." And she does remember some of it, but I'm so surprised and happy that she doesn't remember a lot of it. [chuckle] Unfortunately, that's for the parents to do. [chuckle] So we carry that around with us. But I do think it's a blessing in a way that they don't remember a lot of it.

25:28 Heather: Absolutely.

25:29 AY: Oh, good. And before we move on to tips and tricks, 'cause I bet you have a lot, [chuckle] anything else you wanna add about your story or anything else that's going on that might help?

25:40 Heather: There's one thing, it reminds me, when I was talking about the child life specialist, there is a wonderful little movie called Paul and the Dragon, it's on vimeo, it's on YouTube, and it's a little animated movie, but there's no words in it, it's just music and action. And it was created by a dad whose child had cancer, and Luke used that through his child life specialist when he first got diagnosed as a way to process, because it's done in such a way where Paul gets cancer, and he fights the dragon, the dragon is the cancer, and the little chemo medicines are involved, and it really is the most precious way for children to sort of take what they can from the movie to sort of understand and kinda leave the rest, so you don't have to worry about overwhelming them with too much information.

26:31 AY: I love it.

26:31 Heather: And that's kinda how we introduced his diagnosis to him and to this day, he asks to watch it sometimes because it's humorous and lighthearted, and it's called Paul and the Dragon and I recommend that.

26:43 AY: I love it. I'm gonna put a link to that where we post the podcasts, so other people can see it. Thank you, I think I have heard of that, but I'm not sure to be honest so I'll...

[overlapping conversation]

26:53 Heather: Yeah. It was truly precious and gave us ways to talk about it. And even though there's no words in the movie, it gave us ways and avenues, and it opened windows for us to talk about it with him that I don't think I would've thought of without the movie.

27:09 AY: That's awesome. It's such a wonderful community, and that's what we're trying to do with our podcast is sort of help other people get through this, and there are so many parents and other people doing things to help the families that are going through it now, and that always just makes me so... It gives me the chills, so.

27:27 Heather: Yeah.

27:27 AY: That's awesome. Okay, so tell us about some tips and tricks, either your stays in the hospital, we heard a little bit how you got to go home a couple of times, but tell us stuff that you packed in your bag or something you intentionally left out of your bag, and stuff like that.

27:42 Heather: Tips and tricks. Okay, for the parent, always bring an extra pillow, at least one extra pillow. There is no guarantee that you'll get a pillow when you're in the hospital.

27:56 AY: That's true.

27:56 Heather: So you bring a pillow always. Bring for the children, bring more clothes than you think you'll need, in case they get sick, in case they have night sweats, for any number of reasons, bring more clothes than you think you need. For eating too, I found, I did gain quite a bit of weight when he was first diagnosed, from a mixture of terrible hospital food and stress eating. And if you are faced with a long hospital stay, try as hard as you can to pack healthy things or have people bring you healthy things, or if you're blessed to be in a hospital that has a good cafeteria, make healthy choices, because it's so hard to take care of yourself when your child is diagnosed with cancer, and I think most, if not all parents, completely abandon self-care for a little while because they're in survival mode.

28:52 Heather: And later on, when you're more stable, you have to sort of build that back into your daily routine in your habits of taking care of yourself. But it does do so much good for your own frame of mind, for your own physical health, and from that well you can sort of give that to your child, because you have more energy, and you have more stamina, and you're in a good place of mind. So, as hard as it is to take care of yourself, my probably the biggest tip would be you need to try to take care of yourself and make it a priority as much as possible.

29:25 AY: I totally...

29:26 Heather: Because it is so hard.

29:26 AY: I would second that. It is so hard, but it's so important. Absolutely.

29:33 Heather: For the food, and I know every child's diagnosis brings different things, but I know

chemotherapy usually makes kids nauseous or changes their taste buds, it actually physically changes their taste buds so things taste different to them.

29:46 AY: Right.

29:47 Heather: And to not stress out about the food and the diet, especially in those first few months, kind of if they're eating, even if it's not the healthiest thing in the world, even if it's something that you might have cringed to see them before, if they're eating...

30:03 AY: Absolutely.

30:04 Heather: You have to kinda let it go, and you can worry about building those healthy habits back up when they're a little bit further along in treatment.

30:13 AY: That's right. What were some foods that Luke had a problem with?

30:16 Heather: Oh, he... Oh my goodness, his changed buds... His taste buds have changed so much, and he does do a steroid pulse once a week every month, and during that time he eats like, oh my goodness, I mean out of... When I say, "Eats us out of house and home," I'm not exaggerating. He will eat everything in the house. Salty things, crunchy things, sweet things. He really has a penchant for strong tasting things now. He likes sardines. He likes brussel sprouts.

[laughter]

30:45 Heather: He likes broccoli. He likes really stinky cheeses, anything that has a really strong flavor, he likes. He does not really like acidic things, and I think that has to do with the way his taste buds might have changed, maybe it gives them a metallic taste maybe.

31:03 AY: Right.

31:04 Heather: Yeah, and salty things, he always like salty things. I think anything with a really strong flavor he really tends to like, and I've heard that from a lot of cancer kiddos that they like those kinda strong flavors.

31:16 AY: Yes, I have not heard sardines.

[laughter]

31:18 Heather: Sardines. Yes. He went through a phase where for breakfast every morning eating sardines out of the can.

31:24 AY: Oh my gosh.

[laughter]

31:25 Heather: That was his breakfast. Mm-hmm.

31:28 AY: That must have been quite a sight to see.

31:29 Heather: It was quite a sight to see, and it was quite a smelly garbage can after he was done.

[laughter]

31:36 Heather: Yeah. He has a very different palate from most six-year-olds.

31:42 AY: That's funny. And any tips and tricks as far as your other kids? Keeping them...

31:53 Heather: One of our biggest tips, I think, is we talk about cancer. Cancer is not a dirty word in our house, and it's not a word that you have to go behind closed doors to talk about. We're very open with it, we talk about it, and it has bred a sort of familiarity among the children, I think, to where they're not afraid. And the same thing is true with hospitals. They have all been with me for ER visits with Luke, they've seen his port accessed, they've seen it all. And because of that, they're not afraid. They're not afraid to go to the hospital themselves, if they need to. They're not afraid of doctors and nurses.

32:27 Heather: And I think just carving out that one-on-one time too, because a lot of jealousy does creep in, because the wonderful thing about oncology in the children's world is that there is that special attention paid to the child, which is absolutely necessary. But in doing so, I think the older and the younger siblings can get sort of left out. So we've had to really carve out one-on-one time to spend with his older brother and younger sister to make sure that they know that, yes, Luke has cancer, that's something he's dealing with now, but you're still very much loved and valued, and his cancer doesn't make him any more special than you guys.

33:02 AY: Right. That's so hard because just the sibling relationship has lots of jealousy in it to begin with, and then...

33:10 Heather: It is.

33:11 AY: Adding this on top of it, it makes it very challenging.

33:14 Heather: It is. And lots of times when kids go into the hospital, they'll come back with little gifts that Child Life gives them or volunteers gives them, whether it's little stuffed animals, Legos, Playdough, whatever. And whenever those things come home, they're communal toys. Like Luke doesn't own just those toys, they're communal. The only couple of things that are his are a couple of stuffed animals that he got right when he first got diagnosed, they would give him stuffed animals for different certain tests that he had to undergo and those are sort of his, but everything else that he brings home is it's a communal toy, he doesn't get ownership of it that way. And we found that that kind of helps, so the other kids don't feel like he's building up like a toy arsenal and they're like not.

[chuckle]

34:01 Heather: Because it's been two years, so we have a lot of Playdough, and we have a lot of Legos.

[laughter]

34:07 Heather: We have a lot of things and markers and coloring books and things that he's come home with. Yeah.

34:15 AY: It's hard to find spots for all of that in your house.

34:18 Heather: It truly is, it truly is.

34:21 AY: Oh God. Okay. So then we talked just a little bit about silver linings, I can see some silver linings in there, but what would you consider silver linings? It's hard to talk about cancer and silver linings, because sometimes there aren't any, but hopefully there have been a few.

34:37 Heather: There have been, and we are extremely blessed that Luke is doing well, and I know that that is not the case for a lot of parents. Cancer is funny, because sometimes if the child is doing well, you can kind of forget that cancer is something you're dealing with until they get a virus that puts them in the ER or until counts come back that aren't favorable. And then it kind of all comes to like, "Oh, yeah, we're dealing with cancer still."

35:01 Heather: And I think that that is really hard to have to live in those two kind of worlds, where on the one hand everything is, on a great day, everything feels normal, everything's fine, but then it's very easy for you to get brought back to the fact that we still live in the cancer world very much, and we're gonna be here for quite a bit longer. I think across our whole family though, it's given us a very good sense of perspective as to what is important. We've been able to let go of a lot of stuff that we considered important in the past, material things mostly, and just kind of cling to each other.

35:37 Heather: I think our family is very close now. It's opened up doors to our faith, but not only for us, but for other people too. So that's been a wonderful blessing to see that. Yeah, as a mom, I would say, that just the change in perspective. I don't worry about just things that I consider superficial anymore. And I look back at the things I used to worry about, and how much of it was just really superficial. Like it's really not important. I don't really worry so much about other people and what they think anymore.

36:14 Heather: So, our perspective has really changed for the better. I think it's made us tougher. It's made us appreciate good moments more and really work on the gratitude, 'cause sometimes it gets really hard, really, really hard. And sometimes all you really have to cling to is those things that you can look around and you have to look for gratitude. You really have to put effort into it and look for things to be thankful for.

36:38 Heather: But when you sort of develop that practice, I think it can really help you with

perspective. And I think that's ultimately what it's all about, is perspective. A lot of people, when they first find out he's diagnosed, they're very sorrowful and they're like, "Oh, I'm so sorry." And I'm like, "Thank you, but it's okay. I feel blessed to be receiving the treatment that he is. I feel blessed to be at this hospital. I feel blessed to be in the country that we're in, receiving the treatment that he is." It could be a whole lot worse in a lot of different ways.

37:09 AY: Right. That's exactly it. Oh, thank you. Heather, thank you. Is there anything that you'd like to add otherwise?

37:20 Heather: No, just if you're newly diagnosed, it is hard and that's okay, and to let it be hard if it has to be sometimes. Just kind of live in whatever moment and whatever truth you are currently in. If it's hard, don't be afraid to reach out to others and let it be hard for a little while. You don't have to pretend like it's great and wonderful when it's not, because it will be hard sometimes. But on the other hand, there will be times when it's a lot better and you'll actually be kind of amazed, especially if you're newly diagnosed. I remember I was amazed thinking of what the pediatric cancer world looked like. I expected it to be very sad and very somber, but it was the complete opposite.

38:01 Heather: It is full of hope, it's full of light, it's full of wonderful people who want to help you, resources that are there for you. So it's not this terrible place like you might be envisioning it in your mind. There really is a lot of light here, and a lot of humor, and a lot of beautiful things as well.

38:21 AY: That is such a great way to end our interview. Thank you so much for sharing your experience. I'm so grateful to be able to listen to it and to share it with other people who are either going through it newly now, or have been through it, or are just interested in the topic. So I so thank you for sharing your story.

38:44 Heather: You're welcome. I'm so glad I could possibly help someone.

38:49 AY: Wow, that was a great conversation. It's so interesting to me how many of our stories have similar threads running through it. Every person and every family has their own very personal experience, but there are some themes that carry over from family-to-family, including how siblings deal with this experience. And now I have to do a quick commercial for BraveHoods, the organization that sponsors this podcast.

39:10 AY: Did you know that we've donated almost 4,000 BraveHoods to kids all over the country? We get our shirts out in several different ways. First, we send packages to hospitals with pre-packed boxes of BraveHoods and ask Child Life to distribute them. Also we deliver to camps and non-profits, like the Ronald McDonald house. We also send directly to families. So, please drop by our website and fill out a form if you are the parent of a kiddo with cancer. Thank you so much for listening. We have our next interview lined up, so stay tuned for more stories of pediatric cancer and The More Than 4-Cast. Thanks so much.

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