LEUKEMIA & LYMPHOMA SOCIETY® is now

Blood Cancer United

The Bloodline with Blood Cancer United Podcast

A Podcast for Patients and Caregivers

Episode: 'Supporting the Supporter: Real Talk for Caregivers'

Description:

When cancer enters a family, it changes everything - routines, roles, and relationships.

In this episode, we talk with Lindsey and Thomas Kealey about what it means to navigate cancer together as a care partner and patient. From unexpected diagnoses to months spent living in a hospital room, Lindsey shares how she balanced caregiving, work, and self-care while learning to hold space for difficult emotions. Together, they offer practical tips for caregivers, like creating healing spaces, communicating with care teams, and finding small moments of gratitude amid uncertainty. This heartfelt conversation is a reminder that behind every patient is someone quietly carrying so much and they deserve to be seen too.

Transcript:

Elissa: Welcome to *The Bloodline with Blood Cancer United*. I'm Elissa. Thank you so much for joining us on this episode.

Today, we are speaking to Lindsey and Thomas Kealey, who will be sharing about life as a caregiver and leukemia patient. Thomas is a preoperative and post-anesthesia charge nurse and was diagnosed with multiple phenotype acute leukemia, or MPAL, in July of 2024. After a relapse later that year, his cancer transformed into central nervous system (CNS) leukemia. He completed his treatments in February of 2025 and is now in remission.

Lindsey is an instructor of Human Development and Family Services at Oregon State University and the author of *PAWsitive Choices Social and Emotional Learning.* Her experience teaching in elementary schools and higher education led her to create a curriculum that integrates neuroscience and problem-solving to foster children's resilience. Together, the husband-and-wife team host the *Brain It On!* podcast where Thomas shares about his leukemia experience, and Lindsey shares key learnings from her journey through her husband's cancer treatment to help others navigate adversity. Welcome, Lindsey and Thomas.

Lindsey Kealey: Great to be here.

Thomas Kealey: Yeah, thank you so much.

Elissa: So, our episode today is for all of our wonderful caregivers in honor of National Family Caregivers Month. But to give some context to your experience, let's start with Thomas and hear about your diagnosis of multiple phenotype acute leukemia, or MPAL. This is a pretty rare diagnosis. Thomas, could you please explain to our listeners what MPAL is and how you ended up being diagnosed with it?

Thomas: Yeah, of course. So, MPAL, like we said, is mixed phenotype acute leukemia, is both AML and ALL.

Elissa: Okay.

Thomas: It's like my body couldn't decide which one to do, so it did D, all the above.

Elissa: Yes. That's a good way to explain it.

Thomas: So, we had the acute myeloid leukemia and the acute lymphoblastic leukemia. And so, it's not a very straightforward treatment. In fact, only 2 to 5% of all acute leukemia cases are MPAL.

Elissa: Wow.

Thomas: Yes, so my diagnosis was MPAL T/myeloid and included the presence of high-risk genetic mutations within it, including GATA2 and FLT3. Basically, the mutations allowed each of those to progress and grow in my body.

Elissa: And how did you end up getting diagnosed? Did you have some signs and symptoms that brought you into the doctor?

Thomas: Yeah, so funny enough, it was really something that was akin to almost like a papercut on my finger.

Elissa: Oh!

Thomas: I had gotten a kind of dry papercut on the weekend, and by Wednesday, it was starting to look kind of worse. I put Neosporin® and a bandage on it and just assuming it would go away, but it started getting more purple and kind of concerning looking. So, I went to an urgent care, and they looked at it and said, "Oh, it's probably nothing, but if it's still there tomorrow or it's getting worse, go to the ER." And so, we went to the ER the next day, and they did an x-ray of my hand.

But then Lindsey mentioned that I'd been expressing recently that I was feeling more dizzy when I was standing up quickly. I just figured, it was a long winter. I didn't snowboard a whole lot, and I was out of shape. And so, I just kind of wrote it all off to that. But the docs went in and like, "Oh, okay, well, let's do a complete blood count then." We didn't expect anything to come of that.

And so, the ER was really busy that day, so our room was actually just a hallway. So, we're hanging out on the gurney in the hallway; and me and Linds like hanging out together. So, we were just having a good time laughing and joking about whatever,

and they came back and said, "Hey, are you taking any chemotherapy drugs?" And I said, "No, but my mom just got diagnosed with pancreatic cancer -"

Elissa: Okay.

Thomas: "-and we've been helping her with her housecleaning. And so, it's possible we might have been exposed to some drugs." And they're like, "No, it looks like you either have a blood cancer or mononucleosis." And they're like, "Okay, well, we're going to hook you up with Oncology tomorrow. So, here's a time for an appointment, and we're going to have you looked at."

And I guess, I sensed the urgency in their vernacular and what they were saying and how they were saying it, and I was like, "Oh, gosh. This must be pretty serious." And so, we went the next day, and I got a bone marrow biopsy right there, and no anesthesia or anything like that. They just went in there and pulled out some bone marrow and very shortly got the news that, "Yeah, it was cancerous" and everything and that within one week I was going to be starting treatment at OHSU (Oregon Health & Science University), which is in Portland, Oregon, three hours away from where we live. And so it all just really happened so fast.

Elissa: Yeah.

Thomas: Within a day and a half our life plans just totally changed. And it was like, all right, pack your bags, we're going to Portland. And we'll figure out housing, and OHSU was great about helping us figure out logistics of everything. They went above and beyond getting us housing and making sure we were brought in the loop with all the decisions they made and everything. They were amazing.

Elissa: That's wonderful. You know, major cancer centers, I think they often realize that patients don't always live very close. And so, it's good that you had some

resources available to you; and they were able to hel. And then also when you mentioned that you didn't have anesthesia with your biopsy, I'm sure all of the blood cancer patients listening that have had a biopsy in their hip are just cringing right now-

Thomas: Yeah.

Elissa: -because we all know how awful that is. And so, Lindsey, what was your reaction to Thomas's leukemia diagnosis? That must have just been a shock.

Lindsey: It really was. It was just such a whirlwind of emotions, and I think disbelief at first. We were going into the Bend Cancer Center very routinely for his mother, taking her to her appointments for her pancreatic cancer. And so, at the ER when they said, "We're not exactly sure what it is, but we're going to have you see an oncologist tomorrow," I paused and I said, "Is there availability in the schedule?" Because I was used to calling and making appointments for his mom, Julie, and they'd be booked out a week or two in advance. So, when they said, "No, tomorrow morning we'll have you come in," I knew this sounds serious. This is an emergency, so it was something where I just wasn't expecting it; and I was really focused on his mother's care, and that was kind of the world that we were in. So, to think that Thomas would also be a patient, that was something that took a while to get used to and certainly a surprise.

But for me, I feel so blessed because Thomas is an amazing husband and person, and he handled the diagnosis with such grace that it really created space for me to process my feelings. And he was so supportive of me, so I feel very fortunate that he was someone who could help me stay grounded throughout the diagnosis and immediate transition to treatment phase.

Elissa: That's great. So, let's talk about treatment. What treatments did you get for the MPAL?

Thomas: Yeah, for the MPAL, my treatments began with an inpatient pediatric ALL regimen, actually-

Elissa: Oh!

Thomas: -of induction chemotherapy. And so, I was inpatient for five weeks initially, and that was including getting intrathecal chemotherapy which is injections of the chemotherapy into my spine, in my cerebral spinal fluid because that's a sanctuary site where leukemia likes to hide and hang out.

And so, it took five weeks doing that, and after a short break, I received a consolidation round called FLAG-IDA; and shortly after that I achieved remission.

Elissa: Wonderful.

Thomas: And so included with that five weeks inpatient, I was getting total body irradiation at the same time.

Elissa: Okay.

Thomas: It was a type of radiation that hits the whole body to destroy cancer cells and prepare for the new stem cells, really just trying to wipe out everything before putting in the new immune system.

And then I had the allogeneic stem cell transplant on October 23, 2024, and it was from an unrelated donor, actually. They tested my brother, but he wasn't a match. And so, I joked with him that he was adopted.

Elissa: That seems to be a common theme on this podcast.

Thomas: Yeah. And so, it was amazing. It was a German donor, 21-year-old gal. That's all I know about her. We've named her Olga, just so it's easy to talk about when we talk about her immune system and how well it's doing.

But we were pretty in awe at the whole process of how worldwide this whole process was of screening people in different countries on different continents, and it being transported within a certain amount of time. And so, I was really and still am very, very grateful for that gal.

So that was my initial stay at the hospital and my initial remission.

Elissa: Okay. But then you ended up relapsing and then found out that it had transformed into central nervous system leukemia?

Thomas: Yeah, so it was on Christmas Day actually that we got the test results; and I'd already gone to bed and poor Lindsey got on MyChart® and checked just the test results just out of routine and got the message that, "Oh, yeah, he has a relapse in his cerebral spinal fluid." And so, the rest of my bone marrow's okay, but about 11 to 18% of my cerebrospinal fluid was AML, actually, which is really rare.

Elissa: Okay.

Thomas: And so poor Linds was up all night, just trying to wrestle with that. And I don't think she got much sleep; and I got up the next morning and could sense that she wasn't feeling her best. And so, after I inquired a bit, she shared with me what she was shown; and so, we both kind of had to grapple with that. And we talked with our oncologist, I think, that day immediately about what the new plan was, what the new treatment was going to be. And so, they figured it out pretty fast and said, "All right, we're going to have you do concentrated radiation of your spine and your skull. Right off the bat they had a treatment ready; and we jumped right into it.

And since then, I have gotten more biopsies and checks within my CNS; and there's no cancer. So, I am in remission again-

Elissa: Wonderful, yea.

Thomas: -which is fantastic, yeah.

Elissa: That is wonderful news. Now Lindsey, that must have just been heartbreaking to see that information on MyChart.

Lindsey: It really was. I've talked to several providers, and they've said, "They really wish there was a feature where they could just not have results published, so it's not at 10 PM on Christmas that you're seeing these results happen." I had gone on the MyChart app to see what time our appointment was the next day, just to make sure we were up in time for it, and the results were right there.

So, it was a decision I made to not tell Thomas. I knew that the next day would be a day of appointments and strategizing, so I wanted him to get some good sleep. So, I think it's so important as a caregiver to have a tribe of people who you can call at 10:30 on Christmas or 11 PM who are there for you; and they just kind of know they're on standby when they're in a hard season. So, I went through the list. A lot of people had their phones on silent. Understandably, I'm glad. But there was a good friend of mine whom I could call and process with. But it was something that we weren't expecting. You know, 60ish days post-transplant is really soon to have a relapse, so it was an unexpected unfolding of his treatment. And it was something that we just took it as the next step. You know, just do the next right thing is one of our mantras; and Thomas is such a wonderful reminder of that to me. Like, "Okay, we're just going to do the next right thing; and that means we're going to be across the street at our outpatient appointment at 1 PM, and we're just taking it one step at a time," which I

think is so crucial when you get really shocking news. So, you just take it one day at a time, and sometimes one hour at a time, honestly.

Elissa: Yeah,now were you treated at OHSU for that as well or were you able to get local treatment?

Thomas: It was at OHSU, as well.

Elissa: Okay.

Thomas: And so, we were staying at the Ronald McDonald House® there called the Rood Family Pavilion. We were given an extended amount of time to stay there and deal with the relapse, which was great. They were wonderful with us.

Elissa: That's good. Now, before the relapse, had you had a chance to be able to go back home yet or had you been staying at OHSU that whole time in between your stem cell transplant, because you weren't quite at the 100 days yet?

Thomas: Right. Yeah, no, I hadn't reached that 100-day mark, so I was still staying at the Rood Family Pavilion across the street. And on Christmas, that's when we got the news and just stayed in that same room for the next 100 days, I think. We were there for a total of like 160, 170 days. But no, I didn't get to go home between that. Just one thing into the next.

Elissa: Yeah, that's so hard, just being about three hours away from home. So, you ended up moving to Portland. That's quite a long time that you had to stay over there. Lindsey, how did that work for you, with him being treated so far away? Were you living there the whole time? What was happening with your job and finances because he wasn't able to work during this time, correct?

Lindsey: Correct. It happened so quickly, as Thomas mentioned. He had the bone marrow biopsy, and next week, you need to be at OHSU in Portland. So, luckily, they were able to switch some of my classes to virtual. I teach at Oregon State University, Cascades Campus (Bend, Oregon). At the very beginning, I wasn't able to teach that summer term. Later on, they switched me to virtual.

I also do podcast consulting, and so I did have some clients who stuck with me, and I actually did it from the hospital room. And sometimes, his little IV pole would beep or there would be a provider walk behind me and I'd have to pause. So, I had to have some flexibility there with my work. Certainly, had to make it a lot less.

And in terms of the living situation, we weren't able to access the outpatient housing, the Ronald McDonald House until after transplant. And so, for that first part of treatment, I stayed with Thomas in his hospital room. I moved in, and they have a little bench bed that's not quite a full bed. It's very small and not great lumbar support.

Elissa: Did not look particularly comfortable.

Lindsey: Nope, not very comfy. But I was very blessed; I could stay there with him. So, I lived in the hospital. I think, we counted it out based on all the stays, over 80 days in the hospital. So, learned how to get that hospital living in. I have some tips for that. And also, I think just finding balance, finding a way to thrive, and knowing that it is possible to live in a hospital. And if you do certain things, it can certainly make it a lot easier.

Elissa: And how did that work as far as Thomas not being able to work?

Lindsey: Yeah, that was definitely a challenge, and he was able to go on paid family medical leave for a little bit. Then that came to a point where that was no longer an option once you exceed a certain amount of time. And so, then you look at, long-term

medical disability, which is something that is amazing. His employment offers that, so there were certainly different resources that we had to research and utilize, which takes up a lot of headspace, I'd say. And I highly recommend that caregivers and patients reach out to the social worker at the hospitals because they can help you navigate that whole system. They can tell you who to call and what processes to go through.

I am a binder person, so I just got a different binder for each category. I love stationery, so it was an excuse to go get new tabs and highlighters.

Elissa: There you go.

Lindsey: I think organization is such a huge part of being a caregiver and utilizing supports like a social worker can make a big difference.

Elissa: So, what was life like as a caregiver for you? Did life as you knew it kind of seem to just change as soon as Thomas was diagnosed?

Lindsey: It really did. My focus prior to Thomas' diagnosis, I was in that realm helping take care of his mother who, as we mentioned, has pancreatic cancer. So, I had a little bit of experience with that in supporting her. Prior to that, I worked as a kindergarten teacher, so I loved working with little kids. And then at the university, I teach people how to become educators and focus on child development. So, my background really was with helping people support children and their development so that they could thrive.

A lot of people I would consult with, even teachers, would help students who were experiencing a variety of adverse childhood experiences or trauma. And so, in my research and in my experience in helping people who experience trauma, and especially kids, I was able to apply that in the medical arena because when you go

through, I think, cancer treatment and multiple family members with cancer, there's certainly a level of, trauma that can happen. The emotional side of things, seeing Thomas in so much physical discomfort is another layer, I believe, of that trauma or that difficulty in this season. So, I had to learn how to reapply the strategies that I was teaching other people in the context of medical adversity because a lot of those strategies for building resilience, taking care of your brain, cultivating healthy relationships, all of those apply in the medical setting. So, I had to reapply that learning and figure out how could I thrive in this season of my life.

Elissa: Okay, so you were able to utilize some strategies that you had already been cultivating through your work?

Lindsey: Yes.

Elissa: Incorporate them into your caregiving?

Lindsey: Yes. In fact, Thomas and I had a podcast called, the *PAWsitive Choices* podcast years prior to his transplant and diagnosis. And so, we already had the podcasting equipment, so it was neat. We got to a point after his induction chemo and consolidation chemo when he was in for his transplant. We thought, okay, let us start a new podcast. Thomas came up with the name, *Brain It On!* And, ironically, he came up with the name *Brain It On!* before the cancer relapsed around his brain. So, a little foreshadowing there, but-

Elissa: Oh, wow!

Lindsey: Now we look back and we can laugh about it at this point, but basically, we chose the name *Brain It On!* because we wanted to help others and also ourselves with how do you love and care for your brain and your psychology when you go through

something that's difficult and challenging like this? So, we reapplied those strategies for self-compassion, gratitude, mental resilience just in this new context.

Elissa: That's great. Now, you mentioned a little bit of the emotions that come along with being a caregiver and the trauma that it brings. What was the emotional impact for you?

Lindsey: Yes, great question. I would say one of the hardest things for me is to watch Thomas experience physical discomfort; and in our podcast, we talk about the power of your words. There's psychoneuroimmunology, which is basically the study that talks about the way you think about things and speak about them affects your psychology which affects your immune system. And so, it's so important your mindset and the words that you speak.

And so even as I just described that, truly Thomas was in pain. We learned how to shift their vernacular of saying he was experiencing discomfort, because your brain hears the word comfort, and it's like okay, I can relax. But if your brain keeps hearing you say the word pain, it can put you in a flight or fight state.

But in terms of the challenging thing for me was watching Thomas experiencing that severe discomfort. And so, something that I had to learn how to do was to hold space for my feelings, like, "Wow, this is causing distress in me to see Thomas connected to a pain control pump," and just really holding space for that. I think that's something I encourage people who listen to our podcast to do is to allow yourself to feel those feelings.

Some people have advised, just push it down or don't think about it. Stay positive. And I think positivity is so important, but I heard it once before in the *Happiness Lab*, if you think about your feelings as a beach ball, so let's call this anger or fear or sadness. If you try to push that fear or sadness down under the water like a beach ball under the

water, it takes a lot of energy to keep it down. And eventually, all that energy you're exerting, you're going to slip and it's going to come shooting right back up.

So, I think the idea is hold space for what you're feeling. "Wow, I'm feeling really upset or scared right now." Hold that, be okay with that, and then shift and say, "And what can I do next to help myself? What can I do to help Thomas?" And I learned over multiple months that sometimes taking care of yourself means to go on a walk. It's to be there. I love you, Thomas. I'm here with you, and I'm noticing these feelings are really strong, and I need to go for a walk. I need to go to the gym or call my mom. She had a lot of phone calls from me when we were in the hospital.

Elissa: I'm sure.

Lindsey: And so, it's just this balance. I think the sooner that you can feel comfortable with your emotions, holding space for them and also finding ways to shift to adaptive coping strategies, the better you'll start to feel and the more resilience you'll start to build.

Elissa: Yeah. Self-care is just so important for caregivers and that was really good advice for patients, as well, to feel whatever you're going to feel. That was what my therapist told me after I had started therapy after cancer treatment. And she said, "You know, you're just going to have to feel what you're going to feel. Those feelings will come in, and you cannot push them aside because that's why you're here talking to me now because you pushed all of them aside." But it was so good that I had to actually finally sit with my feelings and sit with the trauma that had come with cancer treatment; and so it's really good advice for both patients and caregivers that it is good to just feel whatever you're going to feel.

Lindsey: Definitely, and I love what you mentioned about getting therapy. That's something that Thomas and I did and continue to do, having a therapist on Zoom®, or

whatever platform if you're not allowed to be in-person, can be so healthy and helpful. And I think the sooner that folks are able to do that, the better. I wish that we had started that from the beginning in the hospital. Later on, we started that, but I think it's really helpful to have that space where you can take the emotions out, examine them, and come up with some good strategies.

Elissa: Yeah, definitely. So, Thomas, let's go back to you. Now, you finished treatment and you were able to ring the bell just this past February, so we're not that far out. We're just a few months, at the time of the recording of this podcast. So, how has life been since treatment for you? Have you been able to get back to work yet?

Thomas: No, not yet. Speaking with my oncologist, she estimates that it'll probably be about February before I can go back as far as like my blood counts go and my immune system in the state it's in.

Coming back was a lot different than I anticipated it to be. I pictured in my mind, "Oh, I'll go back home, and I'll be able to see everyone I love and socialize. But to come back and learn that, oh, shoot, I barely have any neutrophils, and I still need to isolate. It's been probably the hardest part of the entire ordeal is just dealing with isolation and not being able to do normal things like go to a store or go to a restaurant or go to my friend's house or go to my family reunion. And so, things are very, very slowly starting to get back to normal.

I can now hang out with people outside with masks on, so-

Elissa: Good. That's a good start.

Thomas: Yeah, better than nothing for sure, yeah. I'll take it. But as far as going back to work is concerned, they said it's about a year from when they did the secondary treatments.

Elissa: Okay.

Thomas: And so that's going to be, yeah, February. And I was hoping initially that it would be like October, but it got pushed out a bit because of that CNS relapse.

Elissa: Yeah.

Lindsey: We've been able to spend some really precious time with his mom since returning from Portland.

Thomas: Yeah.

Lindsey: And she's still doing amazing. Her spirit, her attitude is so strong and positive. She did just go on hospice, and so the level of treatment, the focus has shifted to more of a palliative and comfort care. And being in Bend has allowed us to spend more time with her, which has been really beautiful.

Thomas is still navigating graft-versus-host disease (GVHD). He has the chronic version, and so that's another part of our life is taking care of that and treating that. So, life looks different than what we expected; and we're still finding beauty and connection with his mom and different ways to have that vitality.

And one of the ways that we really do that is continuing on with our podcast because it does give that space for us to reflect on where we're at in our journey. If we're both feeling like, man, we're having a hard time this week, we pull out the textbooks and the research and we say, "How can we help ourselves? What can we do to stay more positive or to help our brains, have more vitality?" And then it's really an act of self-care for us to do this podcast, and it's great when people learn from it. That's our goal, and also, it's really helpful and therapeutic for us.

Elissa: Yeah, that's great. And I've notice certainly from patients coming on our podcast and sharing that they find it very cathartic to share their story and just talk about it. And not everybody feels like that, which is totally fine. But I would think that, yeah, continuing to share and to help people would just feel so good and kind of help you heal along the way.

Lindsey: Definitely. I think you turn your pain into purpose.

Elissa: Yeah.

Lindsey: That's something that can be really beautiful when you think if I'm going through this hard season, there's something that Thomas says. You came up with a great saying.

Thomas: If I'm going to go through this, I want to grow through this.

Elissa: I like it. That is great.

Lindsey: How can we grow? Post-traumatic stress. There's also post-traumatic growth. So, that's one of the beautiful things is how can I grow? And I think there's also this deep appreciation for life. Sunsets are sweeter, drinking-your-coffee moments with loved ones become so much more precious and important than they were prior to diagnosis and prior to cancer I would say.

Elissa: Yeah. It seems to be easier to just slow down and recognize all the things around you and appreciate the things around you that maybe you just didn't notice before.

Thomas: Um hmm, definitely.

Lindsey: Totally.

Elissa: So, let's talk a little bit more about the podcast. So, you shared why you guys started it and what you talk about. So, what are each of your roles on the podcast? What are each of you trying to get across to your audience?

Thomas: Yes, so being the cohost as my role, and my purpose being to provide an honest look into the reality of living with cancer and giving hope to others that are on a similar journey. On my side of things, I explore the patient's perspective, focusing on fostering brain health, building resilience, and finding moments of gratitude, even in the face of adversity. And also having an RN background and just incorporating kind of the medical side of it that I'm privy to and able to share that maybe caregivers and other patients might not be aware of.

Elissa: Yeah. Lindsey, what about you?

Lindsey: Yes, so I think that there's so much power when you listen to a story, when you hear from people who are going through what you're experiencing. And that's what I love about your podcast. We love listening to it, especially since different episodes have different perspective, whether it's a medical provider or patient or caregiver. So, I think there's so much value when you're able to share your story and when people can connect with that and when it resonates with them.

So, one of the things that I provide as the other cohost to our show is just talking about what it's like to be the person who is a care partner. I really like the word. I think care partner is important.

Elissa: Yes, I hear that a lot.

Lindsey: Caregiver is certainly what's the normal usage in our vernacular. And care partner is just another way of wording it where you think how can I partner with the person I'm loving and taking care of, and how can we support each other? So, you

know, Thomas and I are both working on his health; and also, he's helping me in focusing on my health. He's a partner for me.

And so, the other night I was editing some of our podcast episodes, and he came in and brought dinner that he had just cooked. And he's taking care of certain chores. At first after transplant, as a patient, you can't clean or really do anything that involves dishes that are dirty or laundry or trash.

Elissa: Yes, yes.

Lindsey: He dusts. Right, he got to a point where he could start to do that. So, I think there's so much beauty when you find a partnership where you're supporting one another and you're cultivating that, I guess, helpful and reciprocity in your relationship. So that's kind of my goal is to talk about how do you come alongside someone who's going through cancer or adversity? How does that impact you as the care partner? And then how do you find adaptive ways to cope with that stress?

Elissa: Yeah, it seems like your podcast is definitely helpful and provides strategies, but also that connection. And, you know, feeling like I'm empathizing and I'm connecting with what you're saying because it seems like close enough to what I've been through myself that it can really kind of help both patients and caregivers navigate cancer and navigate their loved one with cancer and all that comes with it.

Lindsey: Definitely.

In terms of other things that we aspire to do with our podcast, we also are creating more video content so we can talk about things that we've learned from other nurses and doctors and even the social media manager from OHSU. So, we want to get different perspectives other than our own. So, it's been really neat to start to do other interviews.

We started our podcast in the hospital during his bone marrow transplant, so we asked his doctor and the nurses if we could do this. And it was amazing. They gave us permission, and so they even made a little sign for us whenever we were recording in between chemotherapy or radiation. They put a sign on the door saying, "Podcast recording in session." And it was just so neat that they were supportive in that way.

There's these little periodic beeping that happens because there's the IV pole. I think we named him Ivan or something. We personified him. But I think another thing that we aim to do is to help folks who are going through living in the hospital like we talked about before. We have a hospital hack series. How do you turn your hospital room into a healing space? So, we got fake plants from Target; and the first nurse that came in said, "You can't have plants in here." So that just shows you how realistic they looked. We assured them these are not real. But, having some throw pillows, having a nice little blanket. We have motivational posters that we put up on the walls.

Elissa: Okay.

Lindsey: Pictures of family. We even got little lamps that we brought in. So, there were so many doctors and nurses who'd walk in and say, "Whoa, where am I? This doesn't feel like a hospital room. I feel like I'm in someone's apartment." And there's so much research behind creating a healing space, a comforting space. Even if they're not real plants, they still have a similar psychological benefit to you.

So, we like to give tips for people. If you are going to be in a hospital for multiple months, turn it into a space that's healing and that brings you comfort. We also have tips for communicating with your doctors or nurses. One of our biggest things you can do – it's kind of a silly one – but we had a big bowl; and we put candy in it. And we had that by our hospital room door so whenever a doctor or nurse would come in, we'd say,

"Please help yourself to some candy." And we had the good stuff. We had like Snickers®-

Elissa: Nice.

Lindsey: -and Reese's Pieces® and all of those. And it was something that was a small gesture, and people really seemed to appreciate it. We even decorated for the holidays. So, for Christmas and Halloween, we had lights and trees and pumpkins. So, that was really fun, and we did the different seasonal chocolates for the Reese's. Right, Thomas? There was like the tree, the pumpkin, the bat – so it was kind of controversial in a way. Which one's the best out of the different seasons?

But it was really neat to find a way to give back and to cultivate relationships with the people taking care of you.

Elissa: Yeah, absolutely. And then outside of, making that feel like more of a home, the hospital room, Lindsey, how was life like for so long just living at the hospital as the spouse as the caretaker. Did you leave much? Did you eat there at the hospital? How did that all work?

Lindsey: Great question. So, I did eat at the hospital. One of our tips is to buy your own seasoning or Chick-Fil-A® sauce.

Elissa: Yes.

Thomas: Bring all your sauces.

Elissa: That's good.

Lindsey: Bring all the sauces because the food sometimes needs a little something to make it taste a little better. So, if you have a variety of sauces. We had barbeque sauce. All different kinds of-

Thomas: Siracha, yeah, all of it.

Lindsey: We'd keep it in the refrigerator on the bone marrow transplant floor. They'd bring it to us. Oh, there's the sauce people. We've got to go bring them their little sauce bucket, which was kind of funny. But having different ways to shake it up with the foods, something that if I could go back and tell myself a year ago would be living at the hospital was certainly what was financially feasible for us as well as something that I felt like I stayed connected. I provided that emotional support for him.

But if I could go back, I would certainly go to a hotel once a week maybe. I would have gone home maybe a few times in between. I had to do that a couple times when I got sick, but I think for caregivers who are attempting to live in hospitals over a long period of time, taking more breaks.

Elissa: Yeah.

Lindsey: Going to stay with a friend. Maybe going home and making sure you have the people in your life who you can pass the baton to. It was beautiful; we got to do that with his mom. I got really sick after he was discharged from the hospital, so his mom came up from Bend; and she lived with Thomas at the Ronald McDonald House, I think in total for a couple of months. So, having another care partner with you, who can, be with Thomas while I went to the store to go grocery shopping and have that support is huge.

So, I would say find ways to prioritize sleep. I would sleep in his room at first, I did that a lot. And then when they would draw labs at midnight, a lot of those sounds would wake me up. So, OHSU had a family sleep room. So, I would encourage folks to see are there any sleeping rooms in your hospital if you have to be there? Can you utilize that certain nights of the week? And then getting little memory foam mattress toppers,

both for his bed and then for my little bench bed. I was able to get one. Customized to the bench, so it gave it, some good support.

Elissa: Oh, yeah.

Lindsey: So, finding ways to make it work.

One of the things I would add as well, as a care partner, a lot of times people say, "Make sure you're taking care of yourself, Lindsey. Make sure you're practicing self-care and get pedicures and facials and make sure you're taking care of yourself." I think that's important, and sometimes as someone who's a caregiver, a care partner, it can feel like one more thing.

Elissa: Yeah.

Lindsey: Or I could feel a little bit of guilt. Like, "Oh, I'm not prioritizing my self-care. It feels like one way that maybe I'm dropping a ball." But if you shift and you say, "I'm going to focus on being self-compassionate versus self-care," it's very similar. But sometimes self-compassion is more about acknowledging, "I'm going to do the best I can today." And sometimes self-care would be taking a shower. Like that's going to be my big self-care is just washing my hair today.

So, finding little ways to be compassionate with yourself when you aren't doing the things that maybe in an ideal situation you would. So, just having so much compassion. Treat yourself like you would treat your best friend, right? So, would you tell your best friend, "I can't believe that you dropped the ball and didn't send this email off to insurance" or "I can't believe you haven't practiced self-care in three weeks." Right? You would probably, as a good friend, you would step back and say, "Wow. You are going through so much right now. How can I help you?" Right, you're carrying a lot when you take some of that burden off of you, so I think that's

something that Thomas says too is practicing self-care. Treat yourself like you would treat your best friend and really change up that internal dialogue so that you're being more compassionate.

Elissa: Yeah. And that's why we love to do things that are focused on caregivers, as well, because that's a whole different ballpark, right, than being the patient and going through the treatment. I think caregivers often feel like they have to be there at every moment. They have to be providing all the emotional support and just be there, be on all the time and be okay. It's hard; and I think patients recognize that it's hard. We see that in our loved ones.

And what I appreciated when I was in the hospital was my parents would come during the week, and they lived three hours away. So, they would come during the week; and then they'd go home for the weekend. They'd go and get their emotional support, and then they'd come back. They were always staying with family when they came back, but they would come back, be refreshed, and be ready to go, and have that emotional support for me again.

But I appreciated it. I could see it that they would come back refreshed because they were going to get their emotional support. They were breaking away from the hospital for a while and it matters to even break away for a little bit.

I loved that you talked about walks and there's great places at OHSU. There's a wonderful terrace. You can go out there, have a coffee, go eat some snacks or food, and just break away from all of it for just a little bit.

Lindsey: Yes, that's so important. Target® was one of my favorite places. This was a wonderful place to go.

Elissa: Wander mindlessly.

Lindsey: Yep, smell the candles. Very good form of self-care.

Elissa: Yes, yes, whatever you need to do.

So, you've gone over quite a bit of helpful strategies for caregivers. Anything else that you would like to share that could help caregivers navigate a cancer diagnosis of a loved one?

Lindsey: I think as we mentioned before, plugging into the help with the social workers, making sure that they're able to support you with your resources or the resources that they have. And something I would encourage the caregivers who are listening to this show, is to really recognize that vulnerability is a strength and not a weakness.

Elissa: Yes.

Lindsey: There was a medical provider who told me once, she said, "Lindsey, you need to be strong for Thomas." I had some tears in my eyes. We had just been told by the ER doctor, "You need to be NPO. You can't eat or drink anything because you might be having brain surgery this afternoon." They had found an aneurysm. And so, I was crying a little bit because I thought here we are. He came in and now we might be having brain surgery. So, I was emotional, and a provider, well-intentioned, told me you need to be strong.

And so, for people who are feeling like they need to be strong, and if they equate strength with not feeling feelings and appearing to be one way but then sad on the inside, I would encourage them to reconsider what vulnerability is and the work of Brené Brown is so incredible. She talks about how vulnerability is showing up and being seen. And sometimes the most vulnerable thing that you can do is to cry or say, "Wow, this is really hard for me" because when I have cried in front of Thomas or when I have shown some emotion, Thomas has shared with me how helpful that was for him to see

my vulnerability. It gave him space to say, "I'm also sad about this. I am struggling with this as well emotionally." So, I think, understand that your vulnerability can be your strength. Let yourself feel those feelings, and crying is actually really good for your brain. Your brain gets all kinds of feel-good chemicals. When you do cry, it's very adaptive. So just, show up, , be seen and really find the strength in your feelings.

Elissa: Yeah, and I think Thomas and probably other patients listening could agree that we can tell also when we're with our caregivers if something's wrong and they're not showing that they're feeling like they have to be strong. But then you kind of see it's just a kind of sadness behind their eyes or their smile doesn't quite reach their eyes, right? And you just see it, and it's hard if they don't want to share what they're going through. And or that they're not getting their emotional support anywhere or not taking care of themselves or not breaking away at all. I feel like we can tell as the patients. And even if they don't say it, I feel like if you know your partner, if you know your caregiver well, then you can tell when something's just not right.

Thomas: Yeah, definitely. And like Lindsey mentions, yeah, when those feelings are kind of stuffed like a beach ball, we can kind of tell that tension is there. And so, it takes a lot for both patient and caregiver to reach a place to feel like they can be vulnerable and through that find, a good, safe place to process and heal. But I certainly understand and emphasize with caregivers not wanting to put more on the patients than is already there. We as the patients, I'm sure, already feel a certain amount of – I wouldn't say guilt necessarily – but just we own it that we know that we're all going through all this stuff, and my caregiver is going above and beyond because they love me and to be able to support that and see that I feel like can give a lot of courage to both the caregiver and the patient. But, Linds and I, we've almost been married nine years, and like we said, we both have our own therapists for just about as long. Just learning to communicate.

Elissa: Yeah.

Thomas: I think emotional intelligence is something that has been such a huge cornerstone of our system of being able to heal and walk through things together and know when to call it and be like, "I need respite. You know, I need a break." And being able to notice it in each other as well, even if they can't see it in themselves. So, I feel like, again, this is just a plug for therapy.

It's easier than ever now with like things like BetterHelp® online and everything like that since COVID. And it's so, so worth it to be able to learn to have the language to put to the feelings that you're going through to share with your spouse or caregiver or whoever is taking care of you.

Lindsey: One of the things that we learned in therapy, speaking of therapy, is when you're helping someone, when you're being a sounding board, or you're sharing your feelings, maybe your loved one, the patient is sharing their feelings with you about how things are hard, something that Thomas and I do is we'll say, "Do you want me to be a problem-solver with you or do you just want to feel felt?" Because there's certain times when Thomas just wants to share how hard it is for him that he can't go to the family barbeque. But if I'm in problem-solving mode and I say, "Well you can't go to the barbeque because your transplant doctor said your neutrophils are at 300. So, once they're at 600, maybe we could do Zoom." And if Thomas is able to say, "You know what, I appreciate your perspective, but I just want to feel felt right now." Then I can pause and say, "Okay, Thomas this is so hard. I get it. We're in a really hard season right now." And sometimes that's all he needs to hear, and other times it is him saying, "You know, I would really love your perspective right now. This is hard for me, but I want someone's outside opinion on this."

So, I think if you're able to have that open dialogue and ask your partner or your patient/care partner, what have you, just say, "What do you need right now? How can I best support you?" And you see where's your partner's capacity at, right? So, if they're having a really hard time, that might not be the time for you as the care partner to be sharing your big feelings and all of these hard things. You're kind of gauging each other's emotional capacity and then finding a helpful time to be vulnerable, to share when people are in a good headspace for that. I think that's an important caveat.

Elissa: Yes, definitely. And so, speaking of advice for caregivers, our final question today for each of you, on our patient podcast home page, we have a quote that says, "After diagnosis comes hope." What would you say to all the caregivers listening today to give them hope after a loved one is diagnosed with cancer?

Lindsey: I would say the hope comes in knowing that you have strength. You have inner strength. You have the ability to grow, to have post-traumatic growth through this challenging experience. If you're able to recognize that there is going to be really hard seasons and yet there are people who can come alongside you and that you'll be able to look back at these really hard times and see the ways that there was beauty, that you were able to find strength, and that you'll see life very differently.

In the moment, it can feel very hard and disorienting; and yet if you're able to know that this will become a part of your life that helps you view everything differently, you will develop such a joy and appreciation for things that ultimately this diagnosis, this difficulty can be a gift, even when it doesn't feel like it. I would say that could be the hope. You'll have a different view of life.

Thomas: That's a good answer.

I'd let them know that you're so not alone in this fight. I know we all have different family backgrounds, different friend backgrounds, social backgrounds. But even just your care team at the hospital, they're with you and for you; and I think recognizing all the resources you have at your fingertips, including LLS. There's so many organizations, depending on your disease and your process, but there are so many more resources out there right now than there have ever been. And, yeah, you're not alone.

And please use every resource you possibly can at your disposal, and don't be afraid to look into it because it's certainly a strength to so many people that have gone before and that are going alongside. There are support groups and all sorts of things out there like that that can be a strength to you.

Elissa: Yeah, that is great advice; and we will definitely have some resources for caregivers in the show notes . We have a caregiver page that has so many different resources, peer-to-peer support. We also have a caregiver workbook that caregivers can get sent to them. There's so many things.

And so, thank you both so much for coming on here. I've been listening to your podcast, and it's been a lot of fun to listen to; and we appreciate you sharing all these wonderful tips, Lindsey, for caregivers and, Thomas, sharing your story of all that you have been through. And I'm hoping it continues to get better. And so again, thank you both so very much for being here with us today.

Lindsey: Thank you so much.

Thomas: Yeah, our pleasure. Thank you.

Elissa: And thank you to everyone listening today. *The Bloodline with Blood Cancer United* is one part of our mission to improve the quality of lives of patients and their families.

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