

Melissa Sidhu - - 2021-01-23, 21.59

Brittany: [00:00:00] [00:00:00] Welcome to Living Transplant.

[00:00:03] **Courtney:** [00:00:03] The podcast that takes you behind the scenes of the transplant program at Toronto General Hospital,

[00:00:08] **Brittany:** [00:00:08] and brings you open and honest conversations about the transplant experience.

[00:00:12] **Courtney:** [00:00:12] My name is Courtney and I'm the communication specialist for the Centre for Living Organ Donation.

[00:00:17] **Brittany:** [00:00:17] And my name is Brittany. I'm a bedside nurse in the Ajmera Transplant Centre.

[00:00:21] **Courtney:** [00:00:21] Full disclosure: we are not physicians.

[00:00:24] **Brittany:** [00:00:24] No. And we are not here to give you medical advice.

[00:00:27] **Courtney:** [00:00:27] Think of us like your guides through the world of transplant, as we know it,

[00:00:30] **Brittany:** [00:00:30] Whether transplant is your past present or future your passion or your curiosity,

[00:00:35] **Courtney:** [00:00:35] Living Transplant will show you the world of transplant like you've never seen it before.

[00:00:40] **Brittany:** [00:00:40] So our interview today is with a member of the ethics board. At women's college, her name is Melissa to do, and she donated a piece of her liver over to her brother who had Bellaret a Trechia when he was little, when he was born and ended up requiring a liver transplant.

[00:00:59] **Courtney:** [00:00:59] So we have, a [00:01:00] couple corrections in this episode. Melissa makes reference to a Gary Cooper, who donated his liver. It's not Gary could wear it. John Cooper. So that, that article that she mentioned from the star is in the show notes. And then also,, in the episode, when I am talking about the circle of excellence program, I say they, and what I mean by they is the Canadian system. You have transplantation. So CST, is who I'm talking about and that, a link to that program and CSTs website will be in the show

[00:01:30] notes as well

[00:01:31] **Brit:** [00:01:31] This story is all about her experience. With transplant over 10 years ago. So lots of things have changed in the last 10 years of right. TGH. =And, we hope you enjoy this show. I don't want to give away too much, but, have a listen, let us know what you think. Rate, review, subscribe on Apple podcasts and enjoy

[00:01:55]

[00:01:55] So [00:02:00] welcome back to Toronto General, Melissa.

[00:02:02] **Melissa:** [00:02:02] Thank you Courtney. Nice to see you .

[00:02:04] **Courtney:** [00:02:04] Britt, I think I was telling you that we met on Instagram, through the Centre's Instagram, which was kind of neat. I've actually met a few people that way now. So shout out to our Instagram followers, if you ever want to send me a message.

[00:02:15] **Brittany:** [00:02:15] Maybe you'll be next on the show.

[00:02:17] **Courtney:** [00:02:17] Yeah, you never know. So, Melissa, what drew you to ethics?

[00:02:22] **Melissa:** [00:02:22] Well, an opportunity presented itself to me back at the end of 2008, actually I was working in the pharmaceutical industry for a clinical research organization. So we were running a clinical trials on behalf of pharmaceutical sponsors. So a friend of mine transitioned to academic research. And he was working in research quality auditing and clinical monitoring. And he said, there's actually a position open at the UHN research ethics board, why don't you apply?

[00:02:52] And I thought, you know, this is, this could be an opportunity, a great opportunity to work on the other side of you know, the [00:03:00] academic side, as opposed to the industry side. And I have to say working at UHN was quite the experience. I, I was able to bring my clinical trials, like experience and sort of sit and watch the UHN oncology board or the multidisciplinary boards and see how they actually review all the protocols, the research protocols that they receive and the difficult decisions they have to make.

[00:03:24] The thing is it's interesting, once, you know, you look at these research publications and you think, wow, what an amazing scientist to come up with this research protocol and, and run this amazing study and have these, you know, groundbreaking, impactful findings, but no one ever looks at the, the actual publication and thinks, wow, that must have been difficult for the research ethics board to review and approve. Because for instance, here at UHN, you have like these procedures that are developed here, you've got, you know, surgical techniques. You have the organ donor program. I actually worked with people during the paired exchange. Research application. [00:04:00] So I was, I wasn't part of that directly, but my close coworker was part of the review and approval process for that.

[00:04:06] So it's quite amazing. If I think if anyone ever has a chance to volunteer on a research ethics board, you should strongly think about it because research ethics boards have to be comprised of scientific members, legal members who are specialized in health, law, and privacy. So community members as well, someone who's actually not affiliated with the institution and someone who has no research ethics background, someone who can look at the consent forms and actually understanding like, if there's actual, like the lay terms being understandable.

[00:04:36] And also we also need, you know, people with various backgrounds, so statisticians as well. And also not. So it's not just like scientists, but you've got like a good mixture of experienced in order to make those decisions. And there is voting involved, you

have to meet quorum requirements. So as long as you meet the requirements, research can be reviewed and approved.

[00:04:59] **Courtney:** [00:04:59] Wow, [00:05:00] cool. That's intricate. Detailed.

[00:05:03] **Melissa:** [00:05:03] It is. I highly recommend it. It's it's -

[00:05:05] **Brittany:** [00:05:05] Nurses too?

[00:05:06] **Melissa:** [00:05:06] Nurses, too. Pharmacists. Yeah, exactly. We call it good nerdy fun. And it is, you could sit there and listen to some of these investigators, present their research and you just the questions and the, the exchange and, and, you know, people become really passionate about, you know, certain things like once I was in a meeting and we had a naturopath and she, she made this one statement.

[00:05:27] We need to be careful because this is a new research technique. And a lot of people, like a lot of lay people may think, "Oh, if it's new, it's gotta be better." But new means it's like, it's not proven yet. Research is a theory yet to be proven. Right. So you can't just like, people always think, "Oh, old technique might not be right," but no, no, no, no. Like the new technique still needs to be further studied. Right? So that's the thing you have to, like language really matters. And you need to make sure that studies are not, you're not using coercive language or, you know, you're not overselling the benefits of being in research. [00:06:00] You've got to just kind of, it's always the balance of clinical equipoise that we're always after.

[00:06:05] **Brittany:** [00:06:05] So Melissa, what is your connection to transplant?

[00:06:08] **Melissa:** [00:06:08] Well, my connection to transplant happened while I was working here, at the UHN and research ethics board. My brother, my younger brother Donald he was born with biliary atresia. And so when he was very young, he was, I think about three or four months old, he needed to have what's called the Kasai Procedure done where you sort of fashion a temporary - because he was born with a bile duct - so you'd fashion, a temporary sort of bile duct out of the baby's intestines. So it was a procedure developed by medical surgical doctor Morio Kasai in Japan and basically, my brother ended up being the recipient of this procedure in Miami, in 1976. That surgeon who performed the procedure, literally that was his first time ever performing it. I would imagine he probably might've learned the technique at a conference [00:07:00] that he attended recently. And they presented it to my parents that like, literally this is our only option.

[00:07:06] Like I, unless you want to fly your son to Japan and have the procedure done there where it's, you know, been done many times, that's the other option. So they did the procedure and it was literally one of those, this something like, you know, it's like it, I think it would have cost them back then, like 30, \$40,000, which in the seventies you know, it was like really, really a substantial amount of money, Right. So, so I think there was like a telethon, one of those, you know, raise money to save Donald like those things. And then of course my mom and her relatives all did, I was going to say the old school, like, you need to call in and like, like actually like give your credit card Yeah.

[00:07:53] And so that was, you know, that carried him through until his early thirties, when he started to experience [00:08:00] liver failure. And his bilirubin was up and his jaundice started again, like as something that you'd see when he was much younger. So I wasn't aware actually of the UHN living donor program. And I worked literally across the street at the Toronto Hydro building for the ethics board. But my brother was under the care of Dr. Leslie Lily and he, he still is today actually. And he actually said to me once, "did you actually know there's a living donor program at Toronto General Hospital?" and I said, "no, I had no idea. And I work here." There's so many programs, like I had no idea.

[00:08:31] **Courtney:** [00:08:31] That is the funny thing about UHN is it's so big. I feel like sometimes you're just reading the news and it'll be like amazing discovery of whatever, whatever at UHN. And you're like, Oh, what?

[00:08:42] **Brittany:** [00:08:42] Yeah. I just did something recently in the news. And I was like, yeah, yeah,

[00:08:46] **Melissa:** [00:08:46] yeah. It just so happened. It was so timely because like literally days later I opened, I still get the Toronto star delivered at home and there was a living liver donor story. I think his name was Mr. Gary Cooper.

[00:08:58] If you could find them on the Toronto star [00:09:00] website and his story was. Unbelievable. His daughter experienced liver failure. And then I think she was on the transplant list and he didn't match. But then she somehow ended up making some great recovery and she survived. And he was so moved by the whole fact that she survived, that he signed up to be an anonymous donor and he ended up being a match for someone and he donated. His account of the experience is amazing. So if you ever get a chance to find them on Toronto Star, I'm pretty sure his name is Gary Cooper. Okay, cool.

[00:09:32] **Courtney:** [00:09:32] We'll put that in the show notes. Hopefully we can find it for sure. For sure. Yeah. That's awesome. So the Kasai procedure carried your brother all the way through to his thirties, and he lived just like a normal life up until then?

[00:09:43] **Melissa:** [00:09:43] He was, I'd say it like - he has a twin, a twin brother that's three minutes older. And he pretty much lived, for the most part of normal life, except he would easily get like colds or flus or sometimes his platelet count will be low. He's definitely the [00:10:00] brother, of the two twins, the one that would get sick more often, but otherwise he didn't really need any, you know, any medication or anything or you know, he never had to take much time off school. It's just, he was more prone to getting sick. I would say.

[00:10:12] **Courtney:** [00:10:12] That's incredible. That's wild.

[00:10:16] **Brittany:** [00:10:16] So was the twin of Donald, your other brother? Was he ever tested for any type of liver disease or anatomical liver issues?

[00:10:26] **Melissa:** [00:10:26] No. Perfectly healthy. And it's interesting because I think my mother actually was born with a twin and she passed away at age three months. So I suspect that she may have had some, maybe she also had biliary atresia. I'm not sure. I mean, this

was like the 1940s. Right. So yeah, so maybe there's a genetic component to it in our family that I'm not sure about. So yeah, the, the twins definitely do run in our family. There's literally five sets of twins for three generations.

[00:10:53] Okay. Wow. It doesn't skip a generation in our family. So, so it's interesting, the funny thing [00:11:00] is, is at UHN, once I submitted my application and I wrote that, you know, the recipient, my brother actually has an identical twin. They actually screened my brother as well, of course. But at the time he was in the restaurant field and he was like, sort of engaging in the typical chef diet.

[00:11:19] **Courtney:** [00:11:19] Yeah. So were you the second person to apply then?

[00:11:23] **Melissa:** [00:11:23] I started first. And then once they realize, Oh, he has a twin, you know, it might be better.

[00:11:28] He might be, my brother might be better off with a twin donating. And then my brother, unfortunately, didn't pass because of his liver enzymes being a bit elevated, then they put me back on the front burner. Right, right. Which I think, honestly, looking back, I think was it just worked out perfectly because I don't, I don't think mentally and psychologically, I don't know if my brother, I think he was a bit too overwhelmed with the risks and me, being in research and working here at UHN and being a research geek, I was like, sign me up. This is so cool. Right. Whereas my other brother was like, there's no [00:12:00] way I would ever like, he was like, aren't you afraid?

[00:12:02] So, so no, I think, I think it just worked out well in the end, but that I ended up being the match and everything fortunately worked out very well with the surgery because I don't know. I think my brother was a bit more afraid than he led on.

[00:12:15] **Courtney:** [00:12:15] Right, right. Which makes perfect sense. It is major surgery. Was this your first major surgery?

[00:12:20] **Melissa:** [00:12:20] First and only knock on wood. Yeah.

[00:12:24] **Courtney:** [00:12:24] okay,, so you started the assessment process. Did you tell any of your family, did you tell your brother or did you just kind of just go for it?

[00:12:31] **Melissa:** [00:12:31] I told no one. Literally, I'll never forget it. I was literally at my desk at Toronto Hydro, and, I was trying to get my, like my application in, because I knew the blood work had to start. And it was Friday at three o'clock and I had to ask my coworker, I needed him to be my witness. And the thing is, is we had worked together in pharma for so many years and. Now we both found ourselves on the other side, look with the consent form in front of us and we're analyzing the risks.

[00:12:55] And I believe in the consent form, it said, make no mistake, this surgery is [00:13:00] just as dangerous as triple bypass, which I thought was amazing in the consent form because it laid out all the risks. And then it, that was really good for someone who, if I was someone who was a lay person, I think that was a really good way to assess and present the risks.

[00:13:15] Right. Was I thought I wouldn't have thought of that. Right? And it's funny because when I looked at the risks, Dr. Levy, this, when I finally got to meet him my first assessment with him, it's interesting how people assess risk, right? It's subjective risk for everyone is different. I wasn't afraid of death, like I think I had a 0.3% chance of dying. I was actually afraid of the depression. Apparently some of the donor's experience depression, because you go from being like your average person, your average self. Then you're a hero. And then back to your average self, and that's, that's exactly what Dr. Levy explained to me. Because I asked him, how do, how, how would someone end up being like experiencing a bit of depression? And then he said, yeah, that's, that's actually what we found. And he said, you [00:14:00] don't seem like the type that's going to end up being depressed. He said, I'm sure things will be fine.

[00:14:05] But the death part, for whatever reason, I actually never believed that I had a chance of dying. Not once, not once. Did I ever think. This could be it for me. Like, I don't know why looking back that never was a reality to me, even though I probably should.

[00:14:18] **Brittany:** [00:14:18] Do you think that it was because you trusted the team?

[00:14:21] **Melissa:** [00:14:21] I think so. I think so because of the track record and I have to say that piece on Gary Cooper, his description of it and being part of the whole, process of the screening and then the surgical and then the follow-up afterwards is that it was such a well-designed procedure that there's almost zero room for error really. Right. Which of course, you know, you can't promise that for any procedure, any surgical procedure. Right. And it being one of the top five transplant programs in the world, that was, that was a big seller as well.

[00:14:55] exactly. Exactly.

[00:14:58]

[00:14:58] [00:15:00] **Courtney:** [00:15:03] How does that conversation go with your brother? When you tell him, Hey, I've been approved to be your donor.

[00:15:08] **Melissa:** [00:15:08] That was quite the conversation. My brother's a financial analyst and at first he said, you know, I really, I think he was overwhelmed. Cause we knew the call was coming. Whether it was a yes or no, that I'd be a match. But I think he really, truly didn't want me to, to actually go through with it. But I said to him, I understand that, but I need, I need you to understand, like, you're now at this critical point where what's your plan is your plan that tonight you're hoping that unfortunately someone will get into a motorcycle accident and this guy is going to be, you know, a perfect match for you because what are the chances that that's going to happen tonight? Right. You need to understand, you're going to get to a point where it's literally a point of no return and you will rapidly decline. And then there was this long silence, and then he said, I am willing to accept your offer. Yeah. Like it was like some kind of like negotiation and there's money on the table.

[00:15:59] Yeah, [00:16:00] exactly. I'm willing to accept her off.

[00:16:05] Exactly.

[00:16:06] Exactly. Glad to know you accepted. So yeah, it was all sort of became very technical and formal out of nowhere, right? Yeah.

[00:16:14] **Courtney:** [00:16:14] And how did, how did the rest of your family take it?

[00:16:17] **Melissa:** [00:16:17] My mom at the time she was still nursing, practicing nursing, but being a medical surgical nurse for, I don't know, 40 years at the time by then-

[00:16:24] **Courtney:** [00:16:24] She knows too much.

[00:16:25] **Melissa:** [00:16:25] She knew too much. And that's exactly what Dr. Levy said. He said your mom knows too much. So that's when, and again, I'm not a parent I'm a dog owner, that's it. And so I couldn't imagine what it's like to have to of your kids out of your three kids going for surgery the same day. And I think for her, she just took it upon herself to just keep it all in. Instead of calling her friends and calling relatives and saying, Oh my goodness, I actually now need support. I'm the one who needs emotional support to get through this.

[00:16:51] I think she said she didn't really eat or sleep for like, I think three days before the surgery. And it's like, I had told her, I'm like, you need to get it together. You need to like [00:17:00] have friends that are going to be with you in the waiting room during that day during this, like when the procedure happens. So yeah, I think she was just a ball of nerves. Yeah.

[00:17:09] **Courtney:** [00:17:09] That's something we want to explore as well on the podcast of just like. Healthcare providers kind of in the position of caregiver, in the position of patient, it's so hard for people who are used to taking care of people to go back and be like, Hey, I need help actually, right now, this is my moment when I need support. Both my children are going into surgery. That must, that's be a hard thing to wrap your head around. Like, I don't know, Brett, you're a nurse. Are you, do you find it hard to ask for help when you need it?

[00:17:34] **Brittany:** [00:17:34] Yeah, but I haven't been in a position - knock on wood - where I've had to give that up. Do you know what I mean? But I always tell my patients and my patients, family members or their mothers, because we work with a lot of young donors or young recipients and I'm like, if I were a parent, I can understand your frustration. And like where you would need the support if I try and [00:18:00] empathize and lead with that. But I've never personally had to. Yeah, but I also, I'm trying to mentally prepare myself for that day when it does come, when I have to like give a loved one over to a different healthcare team that's not my own. So when I asked you like where, you know, why you were not worried about death, is it because you trusted the team cause you work with the team, right. Or you work in those walls. Right. Exactly. And I think I mentioned this in another episode, if I were to get a transplant, I would want it done here because I trust of course the team, but also at the same time, it's like, well, I don't know, like privacy and stuff, but I know this team, whereas if I go to any other hospital, no, it's not to like knock any other hospital of course, but I just don't know it,

[00:18:41] **Melissa:** [00:18:41] Absolutely.

[00:18:42] **Brittany:** [00:18:42] I think it was weird to me.

[00:18:43] **Melissa:** [00:18:43] Right, right. And that's a good point that you make because I remember my brother um, just like two and a half months before the transplant, he woke up and he was feeding his dog and he started coughing up blood. He had to come in that day here at Toronto Gen, to the ER and because my mom was still a practicing nurse at the time. And [00:19:00] when the nurse came to draw blood for my brother, she couldn't watch, she pulled the curtain. Yeah. She couldn't watch someone drawing blood.

[00:19:06] And I think in that moment, if she could have, she would have done it herself.

[00:19:10] **Brittany:** [00:19:10] I even go - me as a patient when I go to certain places I'm like, like I once had to get blood work done, like, you know, normal. And I was. I have to bite my tongue because I'm like, let me do it. I'll just give me the needle. I'll do it myself. But it's cause it's hard to watch someone else do your work. Like you're like,

[00:19:29] **Melissa:** [00:19:29] Oh, absolutely.

[00:19:30] **Brittany:** [00:19:30] And then as a nurse, I see it. I hate when people are standing over me and hovering and being like you're doing a wrong or do it like this, so it's super annoying. But at the same time, I feel like I want to do that for someone else and be like, you're doing it wrong so I would just do the exact same thing, close the curtain and leave.

[00:19:47] **Melissa:** [00:19:47] My mom to work in nursing homes too. Right. So if there was a 95 year old with a vein that was difficult. They're like, all right, we're going to get it Dolores in here. We need to that's Brittany. He's the, so you're the goddess now, right? [00:20:00] That's what they used to call it. What was her name? The one nurse that was in transplant the time. Oh my gosh. They used to call her the goddess because she was so good. She's Jamaican. Oh my goodness. Natalie

[00:20:10] **Brittany:** [00:20:13] Oh, I love Natalie.

[00:20:16] the side hustle

[00:20:21] **Melissa:** [00:20:21] side hustle before it was assigned her full term. Like literally -

[00:20:24] Nat was good.

[00:20:26] They called her the goddess, whatever patient

[00:20:28] **Brittany:** [00:20:28] she is a goddess

[00:20:30] looking at her. You're like, she is. She is a goddess

[00:20:33]

[00:20:33] **Courtney:** [00:20:38] Okay. So for three days, Leading up to the surgery. Your mom is panicking. Not eating. What are you like three days leading up to the surgery? It's all becoming a reality.

[00:20:48] **Melissa:** [00:20:48] I was literally trying to figure out how I was going to tie up all my projects.

[00:20:53] Like I needed to like have them in good standing because I was going to be on leave for at least 11, 10 to 12 weeks. [00:21:00] So I knew that the thing is if I didn't finish some of my projects, then, unfortunately, it would be just reassign. My work will be reassigned to my other coworkers who were already overwhelmed. So basically it was a lot, I, I worked the whole weekend, the transplant was Monday morning. I had to be, I had to check in at 6:00 AM for surgery and I literally I finished my last project at 6:30 PM. Like the night before on, on the Sunday, I sent him my last, like, you know, documents to the chair of the board for review. I literally went to St. Mike's cathedral. I like lit a candle for my brother. And I said, some prayers went home. I started packing, I made my light meal, which was ramen noodle soup and perogies at the time. I don't know. And a side of edamame yeah, exactly. I don't know whatever it was. Easy to make. Cause you know, I have to get it done. And yeah, I just packed, like I was being deported like I'd had my hospital bag, whatever I could throw in there. And I think I, I probably

[00:21:56] **Brittany:** [00:21:56] A wad of cash.

[00:21:56] **Melissa:** [00:21:56] Exactly. Right, right. [00:22:00] Rosary. So then my mama knew I could pray. So it was like, it was like two in the morning. I think by the time I tried to settle into bed, I thought, well, what's the point? Right? Like I have to be there at 6:00 AM. And I think I woke up three hours later showered and. Got ready. I made sure I took a really good shower cause I knew what I was in for. And so my mom was literally trying to keep it together and I said, you know what, we're going to get an in cab. There's like a sheet of ice on our sidewalk.

[00:22:24] There's no way we're going to like drive to Toronto Gen and park. And it was just a cold day wintery day. And so she was like sitting there at the dining table trying to put on makeup. And I said to her, no, no, no, no, no, no. You have all day to do that. You put your face on when we get to Toronto General. I need to be there at six a.m.. I'm not going to be late because of your lipstick. Like it just like, but I think she was just, again, trying to maintain a sense of normalcy and like, right, . And I have to say, like, it was amazing how during the day apparently she was totally fine with my surgery.

[00:22:51] Everything went well. I had Dr. David Grant as my surgeon. And so I was lucky. .Cause of course. Well, so would you want, [00:23:00] and so he finished a bit early, but he's so used to this procedure. Right. And with my brother, obviously it took longer for him being the recipient. And my brother Don's his bowels had been a little bit affected by his liver, you know, being so diseased. And so atrophied that the procedure ended up taking at least an hour longer than it should've. And that later that day, when, you know, my friends and family were starting to check in on me when I was able to have visitors, my mom was like, it was like Christmas day. Once everything was fine, everyone was stable. She was a different person. And it was like, wow, finally, like she can actually be happy and excited again. And yeah, no that everything worked out because like you said, the nurses, they know too much.

[00:23:38] Right. They know all the things that could go wrong. Right. And at that point you literally don't have like any control anymore. It's like literally in the surgeon and God's hands. So that's it. Right? Yeah.

[00:23:49] **Courtney:** [00:23:49] So did you have any moments of being like, Oh man, this is really happening. I'm about to go on the table.

[00:23:56] **Brittany:** [00:23:56] When you're going into the doors? Like the

[00:24:01] [00:24:00] **Melissa:** [00:24:01] I, I really wish that that was filmed because I wish I could watch that because it was one of the best moments of my life, because I was literally laying in the surgical check-in Bay. And they were introducing me to my transplant team. There was a resident who came in to say, okay, you're here today. You're having left liver donor surgery done, and I'm going to mark you now for surgery. So they follow

[00:24:26] **Courtney:** [00:24:26] Wasn't your mom trying to get you to take a prayer book.

[00:24:28] **Melissa:** [00:24:28] So she was right beside me, literally. I mean, she literally had, she's like, here's the rosary. And then I had my nurse, she was taking my vitals and everything and making sure that everything was fine. And then my mom was like, and then the nurse said, she's like, I'm Catholic too. I get it. Like, just don't worry. Right? Like, cause I'm like, I'm sorry. I actually have to get through these beads. Right. I know this is, I know you've got a job to do, but

[00:24:50]

[00:24:50] And then, you know, they introduced Dr. Grant to me and then it was great, but I couldn't see. Cause there was a curtain pulled and then they said, Oh, here comes your anesthesiologist. And. [00:25:00] All of a sudden you've rounded the corner and my mom's still, she's still like a bag of nerves. Right. And so he rounded the corner and he said, let's do this. Oh my goodness. He's a research ethics board member. Yeah. So I first, yeah, I should have been happy. Right. But I'm thinking. What is he going to see? And I have to face him again in a meeting and I have to work with them. Right. I think my mom caught wind of my reaction and realized I knew him and she burst out laughing. It was exactly the moment of comedic relief we needed or she needed it.

[00:25:35] But then that's when the panic set in for me, like I was. I was loving everything. I'm like, this is so cool. I've never been in surgery. This is neat. This is exciting. And then that's when I thought, Oh no, I know him,

[00:25:49] but that was literally - I think I took it as a sign. I'm like, this would be a sign from God. Like you are not going to die. And like, if God has a sense of humor, I felt him laughing in that moment. Like, you know, like [00:26:00] literally my mom and the nurse both started laughing cause they saw my - I couldn't imagine what my reaction was in the moment. And he's just like, are you ready? Let's do this. And I'm like, I think my mom was happy too, because at least she realized that someone in there in the OR, my mum obviously couldn't be there.

[00:26:16] **Brittany:** [00:26:16] Right.

[00:26:17] **Melissa:** [00:26:17] Someone actually would be like, you know, on my side and, would have like a personal interest. Right. And so then he, he was fiddling with stuff behind me and he said, so he started asking me questions like, You know, what did you do before you came to UHN? What did, where did you work? How did you get into ethics? And then after the third question I was out, so it was good. He did like, he literally pulled a fast one on me and it was perfect.

[00:26:39] Right. And I have to say, yeah, it did, it was like someone was looking out for me that day because when I woke up in recovery, I remember going through the screening process. And they said, even though everything looks good on all the scans and you look like a perfect match, there's a 3% chance that you won't be a match.

[00:26:58] And if we open you up [00:27:00] and we see that that's unfortunately in that 3% chance, we literally close you up and that's it. And you, you, you can't be a donor. So I thought, Oh my gosh, I, when I woke up, I think I must have been delusional because I could hear someone who sounded exactly like my brother beside me, like, like fumbling and trying to like get out of his bed. And then I, then I started panicking and I think it's just your subconscious takes over. And it's like, Oh my God, I wasn't a match. And it was this overwhelming sense of defeat. Like I can't - as if like some huge wave crashed over me and that was it like we were done. Right. And it's like, I don't know how to say it without sounding so dramatic, but then all of a sudden I started calling up my brother's name and then my anesthesiologist doctor came over. And he said, no, Melissa he's not here. Your brother's in surgery. Like he's not here. You're here in recovery. He's in surgery. And let me tell you, I needed him in that moment to just reassure me that that is actually what's happening because I guess I was just, I don't know if it was [00:28:00] delusional or if I was just like, I had gone into surgery with that subconsciously as a worry that was in my mind. I don't know, but I've, cause I've never experienced anything like that in my life. And that was incredibly reassuring. And he said you did really well. The surgery went really well. I, I have to say, to have someone there to reassure me that I actually knew to say, everything's fine. You know what? Your brother's in surgery. Don't worry. That was like everything. I can't even like, I can't speak to that enough, that like that, yeah, that moment was like, Oh my gosh, the reassurance was amazing. He was there. It really did work out.

[00:28:35] **Courtney:** [00:28:35] I mean, earlier you spoke about being terrified about, the depression as opposed to the death. But I actually think the idea of waking up post-surgery and realizing nothing happened and that you actually weren't a viable donor, that's really scary to me and like heartbreaking. It must be devastating - and with liver too, like it's so like urgent and like, you really do need to get it done as quickly as possible. And like I can't even imagine what that [00:29:00] feeling is like, and, you experienced just a sliver of that, it must have been horrible.

[00:29:03] **Melissa:** [00:29:03] It was because it was like, I'm like, why am I hearing his voice? And it's like, and I don't know if it was another patient that was struggling or maybe it was literally something I had imagined in my mind. But, but no, having the reassurance that no, no, everything's fine. Everything worked out. Yeah. Yeah.

[00:29:18] **Courtney:** [00:29:18] What was it like the first time you saw Donald after surgery?

[00:29:21] **Melissa:** [00:29:21] I have to say I'll never forget it because he, I believe was in the ICU almost 48 hours post-surgery so I didn't get to see him. Of course. And then once he was able to have a visit, the way he described it was waking up, like seeing his new room where he was, and like, knowing that he survived the surgery, I think he was overwhelmed. And he said to his nurse, like, Can you believe, like, can you believe it? Like I've survived and like, can you believe my, my sister donated, can you believe my sister did this? And the nurse was like, Oh my gosh, I'm so overwhelmed. She's like, stop. You're going to make me cry. She said, that's it. We're going to get your sister in here or we're going to get you to your sister. And she [00:30:00] figured out a way she like wheeled him into my room, actually. Yeah. That's why that picture that you have is, yeah.

[00:30:05] **Courtney:** [00:30:05] We'll share that picture in the show notes.

[00:30:07] **Melissa:** [00:30:07] She was amazing. She was amazing. She was sweet. She was really sweet. She was Greek. I don't know why I remember her being Greek and yeah, she was just really sweet. And she just said, no, no, no, no, don't worry what a story. She's like, we've got to make sure you guys see each other. And it just so happened in my room like that day. And the sun was shining through the room. It was just one of those moments that you're like, it all worked out somehow. And it was - yeah, it was a great picture. He, my brother hates that photo because he still had the oxygen and he still looks - I love that photo because, I think it was a great photo.

[00:30:35] **Brittany:** [00:30:35] Authentic.

[00:30:35] **Melissa:** [00:30:35] Authentic. Right!

[00:30:36] **Brittany:** [00:30:36] So did your brother have any complications post-surgery?

[00:30:40] **Melissa:** [00:30:40] No, none like literally they said like the transplant team, they said your brother did so well with the liver that he got that he is being discharged a week early. I know his numbers came down like his, like bilirubin, like it's insane. It's like, it's like, it was like a dead cell phone. And then you put in this new battery [00:31:00] and like, there you go. Right. Yeah, exactly. So, yeah, it was like Christmas day when they discharged him. Like, cause it was literally a week after the surgery, when it should have been. Two weeks. Right?

[00:31:07] So, but then I had complications. So I had to stay another week instead of being discharged after one week. And it's interesting because my mom didn't - because my brother had already gone home and he was wondering and asking, why are you still in the hospital? Shouldn't you have gone home by now?

[00:31:22] And I kind of wanted to be, you know, tale tell the white lives. Oh, you know, just they're keeping me more for observation another day or two. And then my mom, of course didn't want to lie. And she's like, and then the nurses in the room, like we asked them, what should we do? And I said, mom, You know, I didn't come this far for my brother to be at home recovering and then like be worrying. He needs to focus on his recovery. Like he and

his wife need to like focus on his recovery and nothing else don't be stressed out about me. And so the nurses, it was a bit of a dilemma for them. I remember there's one younger nurse calling in another senior nursing. What do we do? Like, how do you handle this moment? This is like, you know, do we call my brother and tell [00:32:00] him, yeah, no, Melissa is probably going to be here maybe up to another week and my mom just refuses to lie. And so, yeah, eventually we had to say, yeah, I'll be there for at least another three days. My white blood cell count was elevated, but I had no fever. So they had to go in and they had to do the ultrasound guided needle and have a bag to drain - there was some fluid in the, in the space where the liver had been vacated from like the empty space and they tested it for any infection. There was no infection, so it was bizarre, kind of stumped the team. But I made a recovery and then I was discharged the week later. So it was fine.

[00:32:35] **Courtney:** [00:32:35] So you worked at UHN at the time that you donated, but did you get paid leave to donate?

[00:32:40] Cause I know you donated like a while ago, like almost 10 years ago, right? So like, living donation is still fairly new. I think a lot of places consider it still. I guess UHN included at the time an elective surgery because you're not the one who's sick, so, and it's more, I think that just like the framework doesn't really like exist to understand these things. [00:33:00] So, yeah. How did that, how did that kind of work out? Like cause obviously you need, at least I forgot how much time, six weeks to recover, something like that?

[00:33:07] **Brittany:** [00:33:07] You said 10 to 12.

[00:33:08] **Melissa:** [00:33:08] They told me like to plan for 10 to 12 weeks, 10 to 12.

[00:33:12] **Courtney:** [00:33:12] That's a lot of time off work. You'd have to be in a very specific financial situation to be okay with that. What was that, what was that like for you? And what was it like knowing that you were doing something for your brother that was lifesaving, but that you wouldn't get paid time off to do it?

[00:33:27] **Melissa:** [00:33:27] Excellent question. It was interesting because here I was working at UHN and this procedure's developed here, right?

[00:33:34] According to the HR guidebook for coverage, I wouldn't qualify cause I wasn't sick. It was my brother that was sick. I was healthy. Right. So I didn't qualify really. I didn't meet the, like the terms for short term leave for sick leave. So I had to discuss with my director, if there was a way, like, would I have to take unpaid leave?

[00:33:53] Luckily was able to help with HR and HR was able to cover me. They made an exception. It's interesting [00:34:00] because you know, research staff are not unionized. So I, you know, this was something that I guess it's not something that normally HR policies would account for, especially back then, right.

[00:34:10] Someone wanting to be a donor, mind you, if I was pregnant and going on maternity leave, I would have coverage. Right. So yeah, I think, yeah. That's what some of my coworkers were really surprised at that, the ethics where they, they said, well, it's kind of

interesting because you know, you've helped us cover so many mat leaves, but yet you can't take like 12 weeks off.

[00:34:28] **Brittany:** [00:34:28] It is, it is very backwards. And I actually never thought of that until about an hour ago when you mentioned it, I was like, oh, yeah.

[00:34:36] **Courtney:** [00:34:36] It's very strange.

[00:34:37] **Brittany:** [00:34:37] Unfortunately.

[00:34:38] **Courtney:** [00:34:38] Yeah. Today. I mean, this won't obviously be accurate when, when we release this episode, but it is, you know, November, 2020, today they are or launching the Circle of Excellence, which is something the Centre for Living Organ Donation is helping to support. And the Circle of Excellence recognizes employers whose employees choose to become living donors and it provides them pay time off. And basically all the [00:35:00] supports that they need to eliminate the barrier of

[00:35:04] **Brittany:** [00:35:04] donating

[00:35:04] **Courtney:** [00:35:04] yeah. Donate - the financial kind of barrier that that is to donating. So that's something that, hopefully we can get a lot of employers to do, because when you think about it, like no matter how large your company is, the chances, well in such a large company or any company, the chances of someone then being a living donor in that company, you might not even ever have to follow through on it, but you could just have that set up in place and then you get recognized for it. So the benefit to the, to the organizations is huge. And then, you know, when the time does come, the benefit to the people is literally lifesaving.

[00:35:36] **Melissa:** [00:35:36] Right. So, and to add to that, I didn't realize that until my brother told me when we were going through the screening process that Dr. Lily told him, like, you know, your sister she's a match. And if she donates to you, she's actually saving two lives because the person who gets the deceased liver would have been on the list yeah, would have gone to him. Right. Yeah, exactly. So you're saving money. If I get paid time, leave to do this, I never would've thought [00:36:00] of it back then. Then you're saving money for the healthcare system. Someone's occupying a bed. Like people need to understand that it does translate into healthcare dollars.

[00:36:08] **Brittany:** [00:36:08] Like yeah, totally.

[00:36:09] **Courtney:** [00:36:09] Like one of the things I feel like people don't really think about universal health care aside from the fact that, you know, we have free healthcare, but like,, when you really think about things, little things like this that we can do to save the system money, it benefits everyone. Yeah. And that's the same, especially with kidney and dialysis, you know, so.

[00:36:26] **Melissa:** [00:36:26] Right. Yeah.

[00:36:27] **Courtney:** [00:36:27] It saves lives, right. It saves money and lives.

[00:36:29] **Melissa:** [00:36:29] Exactly. Yeah.

[00:36:30] **Brittany:** [00:36:30] So you definitely have, have to be in a position to be able to donate financially. You have to have benefits for some of the drugs that you have to be on post, which I don't assume they're cheap. Like mm, well,

[00:36:43] For the recipients, definitely not. But if they were a donor, and you like, I mean, you're not on like a crazy amount of drugs, Tinzaparin,

[00:36:53] **Melissa:** [00:36:53] Tinzaparin, it was just the Tinzaparin and like, I had to get Tylenol threes. Right?

[00:36:58] **Brittany:** [00:36:58] Exactly. It's pain meds and blood [00:37:00] thinners, but at the same time for, for somebody that may not have the resources to pay for that, what do they do, right.

[00:37:07] **Courtney:** [00:37:07] Yeah, exactly.

[00:37:08] **Melissa:** [00:37:08] No, absolutely. And actually that's a really good point because my sister-in-law said you're not going to pay for Tinzaparin, I'll pay for it because I didn't like, I wasn't covered for it because I normally wouldn't need it. I don't, I don't, I don't have an existing health condition that will require, Tinzaparin It was only like, I don't know, two, \$300, but she said, no, it's the principal, you're not going to pay out of pocket.

[00:37:28] **Brittany:** [00:37:28] Exactly.

[00:37:31] **Melissa:** [00:37:31] These are the things you don't think about, right? The principal. Yeah, absolutely. Yeah.

[00:37:35] **Courtney:** [00:37:35] And that's, that's one of the things the Centre is, you know, really working on is increasing access to living donation. Because there's so many factors you don't really think about that, just because you could donate anatomically, can you take time off work for the assessment appointments? Can, do you have a car? Is it easy for you to get to Toronto General? All this stuff.

[00:37:55] **Melissa:** [00:37:55] All these things that I never thought of. Like, I was so fortunate that I worked across the [00:38:00] street. I literally had just had to on my lunch break on my like coffee breaks. Right.

[00:38:03] **Brittany:** [00:38:03] That's crazy.

[00:38:04] **Melissa:** [00:38:04] People don't realize. Right. But you know, hopefully with STEM cells. No, I don't know.

[00:38:10] **Courtney:** [00:38:10] We'll see what the future is. It could be, I think there's someone in Kitchener who's like looking into 3D printed kidneys. So like, who knows, we could just have that and there, or we could eliminate the need for transplants at all or like, there would be no need for human organs.

[00:38:26] So who, who knows what the future has in store? Actually one of our founders, I interviewed her for her and her husband who donated his kidney to her through paired exchange. And I did ask her a question of like, are you scared of, you know, potentially needing another kidney?

[00:38:39] And her answer was like, no, like I'm in Toronto. I can go to Toronto General and like, who knows what they'll have come up with in the time that I need another kidney. Isn't that a great answer? She's wonderful. How's your brother doing now?

[00:38:53] **Melissa:** [00:38:53] Thank you for asking. He's great. I have to say he's really lucky. He's really lucky. Knock on wood. He didn't really have any, [00:39:00] he hasn't had any major rejection episodes. But otherwise, you know, he's, he was able to return to normal life. He went to back to work in July. So that would have been about four months. Post transplant.

[00:39:10] **Brittany:** [00:39:10] Thank you, Dr. Lilly. Thank you, Dr. Lilly. "I determine when he goes back to work, not you." Dr. Lily is a power house. That is exactly how he operates.

[00:39:29] **Melissa:** [00:39:29] But it's interesting, when I went back to work, I couldn't work on Dr. Lily's projects because conflict of interest, right? Yeah, Dr. Lily, Dr. Levy, anybody like I couldn't work on any, anybody who was in my circle of care or who was in my brother's circle of care, I couldn't work on their projects. It's interesting though, right? Yeah. Yeah. I said to my brother, I said, I hope you realize how fortunate you are to have been in his care since 2003. Wow. Yeah. All right. I, yeah. I don't know how my brother would have managed without him. Yeah. Yeah. [00:40:00]

[00:40:00] **Brittany:** [00:40:00] What's something you want everyone to know about living organ donation.

[00:40:05] **Melissa:** [00:40:05] Excellent question. I would love for everyone to know that it is, you know, it's not frightening. It's, it's not scary. It's you know, if you sign your donor card, you can save up to eight lives, right? I mean, now we're in this pandemic, you know, every day is a gift for all of us.

[00:40:25] You just don't know what each day will bring, but for living. Donor surgery. I'd have to say here at Toronto gen, because the program is so well established and they've. They've worked every detail out, like everything from the psychological aspects, the diet the time when you have to take off work, the recovery aspects, everything, the team that you have.

[00:40:48] I had like going, even through the screening process, I had literally assessments with two internal medicine specialists, one of the CZ, the ologists two surgeons. I had, I. An RN transplant [00:41:00] coordinator. I had a social worker, like it was just such a robust team in my circle of care that I have to say that I, it's not frightening at all.

[00:41:08] And there's not one detail that like not one stone unturned, like it's literally, they've thought of everything from start to finish. And I think, I think absolutely I would highly recommend if anyone is ever in that position that I was in where. It's, you know, you

have you think about donating for a family member or a close friend, or, you know, I know someone who donated a kidney to like her son's classmate because she just thought, Oh my God, what if I'm a match?

[00:41:36] And she ended up being a match and it was worked out that she donated here trying Trojan and back to work and no time, like it was, people need to realize that it's not. It's not is it, yes, it is high risk, obviously it's a surgical procedure. But it's not something that you need to be so afraid of because you know, living like we're blessed that here in Toronto, we literally have these surgeries happening every day.

[00:41:59] Right. And [00:42:00] so, yeah, the team has just this amazing assembly of like the right healthcare professionals. And also it's just. I have to say, it's quite the experience. It's something that, you know, if you're if you have the health and you're able to donate and you can save a life. In my case, I was told that I was lucky enough to save not only my brother's life, but the next person on the transplant list, which was waiting, who was waiting for a deceased, a liver from a deceased donor.

[00:42:27] I think I would highly recommend, you know, Going forward and signing to be a living donor. And I think it was probably the most amazing experience of my life. Really. That's great. Credible.

[00:42:39] **Courtney:** [00:42:39] Yeah. Being healthy is such, it's such a privilege. If you can share it with someone else, like your friend who donated to her son's classmate, like, you know, putting yourself in that situation, it's like there, but for the grace of God go, I like it could be your kid just as easily.

[00:42:53] And like, if you have the. Do you have the health, the energy, the like kind of mindset to do it and [00:43:00] have really, it doesn't change your life then, then why

[00:43:02] **Melissa:** [00:43:02] wouldn't you definitely do? The response I have to say, it was interesting because the chair of the ethics board at the time she herself was an anesthesiologist.

[00:43:11] And she said, you know, I don't really believe in living organ donation because that's now two lives at risk. You have one person who was sick and now you're putting someone else. But she was the first, I'm not sure I'm telling you remember who visited me after, when I, after the procedure that day, because she happened to be here dropping off a patient because she was still practicing anesthesiologist and she checked in on me and she said, you know, I heard your brother did well as well.

[00:43:35] And you know, this is still amazing. Like, she's amazing that you did this. And I'll make sure to tell that everyone at work. Everything's fine. So yeah, even though for her, it was controversial. It's interesting how the ethics around organ donation, you know, it's, it's still quite a, a real dilemma for a lot of people.

[00:43:53] **Courtney:** [00:43:53] I watched it, Susan, Abby, give a presentation on like, you know, the psychology of living donors, but she starts the [00:44:00] presentation by saying,

The rule of medicine is, first do no harm. And she's like, well, we're going to do a little bit of heart.

[00:44:04] **Melissa:** [00:44:04] Exactly, exactly. You know? And someone had said to me during the screening process that a lot of women who come forward in the thirties at the time I was in my thirties, they're usually women who are childless and it's a way for them to sort of live on and someone else without having a child right.

[00:44:20] Of their own. So it's sort of like, it's interesting, the psychology behind it. They did some research on. The female donors. And a lot of them are women who are in their thirties who don't have a family of their own, like it's yeah. It's it's yeah.

[00:44:31] **Courtney:** [00:44:31] Having interviewed a lot of living donors, they are majority women and everything you just described really just based on my, just solely yeah.

[00:44:40] My own experience, right? Yes.

[00:44:43] **Brittany:** [00:44:43] Also important to note that signing your donor card is definitely important, but it's also, what's more important is informing your family members. And telling them that you absolutely, absolutely most definitely willing to donate your organs [00:45:00] because. It's up to them, it's up to them.

[00:45:01] They can override your

[00:45:02] **Melissa:** [00:45:02] decision and your decision. I actually only found that out after the surgery, I ended up working in critical care and trauma medicine. After I left the ethics board, I worked on organ donation project. And I didn't know that yeah, your family can override your

[00:45:18] **Brittany:** [00:45:18] mom or dad's says Nope, or spouse or your spouse or whoever that may be says, no, I don't want them to donate their organs, then that.

[00:45:26] Decision overrides what you

[00:45:27] **Courtney:** [00:45:27] decided for yourself. The moment that decision is so hard, if they haven't had that conversation with me, based on what I've heard, they have one, if one of your loved ones doesn't have the memory of you saying, this is what I want. Like, it probably won't happen.

[00:45:41] **Brittany:** [00:45:41] It's the one thing I remember that was the most important thing that came out of our transplant training was hearing that.

[00:45:48] And I remember going back home. That day and telling both my parents and was like, this is the most important thing you need to know is that I want to donate my organs. So. No matter what you [00:46:00] think. I think this, and this is what I want for myself. And they're like, okay, right.

[00:46:07] **Melissa:** [00:46:07] Yeah. Yeah. Well, this is a very enjoyable experience, ladies. I'm enjoying this.

[00:46:11] **Courtney:** [00:46:11] Yeah. Thank you so much for joining us and for sharing your story.

[00:46:14] **Melissa:** [00:46:14] My pleasure. Wonderful to meet you all and have this experience.

[00:46:16] And This is a great memory. Thank you. Lovely to meet you at all and just hearing your stories and their work. And yeah, this is amazing. Thanks for listening to this episode of Living Transplant. If you have questions or suggestions for future episodes, email us at livingorgandonation@uhn.ca

[00:46:37] **Brit:** [00:46:37] Don't forget to subscribe, rate, and review living transplant on iTunes, Spotify, or wherever you listen to podcasts

[00:46:43] **Courtney:** [00:46:43] and follow us @givelifeUHN on Facebook, Twitter, and Instagram.

[00:46:47] **Brit:** [00:46:47] See you next time.

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