

Living Transplant S1 E2 – Colleen Shelton

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[00:00:02] **Brittany:** [00:00:02] 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.

[00:00:23] **Brittany:** [00:00:23] No. And we are not here to give you medical advice.

[00:00:26] **Courtney:** [00:00:26] 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.

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[00:00:40] **Brittany:** [00:00:41] So I love Colleen. I really enjoyed this interview. Before this I had never really met her. When we met in preparation for this, I was just like, "oh boy," she really sucks you in. She's so engaging and honest, I could talk to this woman for hours. Honestly, everyone says that.

[00:00:58] **Courtney:** [00:00:58] I mean, for sure I can [00:01:00] see that she's been at Toronto General for over 25 years. She's a Nurse Manager and in this interview we talked to her about a patient's first transplant workup call. So the first time you get called in for a transplant and everything that entails.

[00:01:13] **Brittany:** [00:01:13] And I think this interview will be really helpful for people who are recently listed and anxiously awaiting the phone call that says, "hey, we think we may have an organ that might work for you."

[00:01:23] **Courtney:** [00:01:23] Is that how they say it?

[00:01:24] **Brittany:** [00:01:24] Exactly like that.

[00:01:25] **Courtney:** [00:01:25] She also talks about what it's like having conversations with families whose loved ones are dying and it's time to make the decision about organ donation.

[00:01:33] **Brittany:** [00:01:33] Yeah. It gets really emotional, but we really need to start bringing tissues because yeah. Shed a couple tears a little bit. All right...before we give too much away, but this interview here's Coleen.

[00:01:45]

[00:01:45] Colleen, thank you for coming today.

[00:01:52] **Colleen:** [00:01:52] Thank you. Thank you. I'm really excited to be here.

[00:01:54] **Brittany:** [00:01:54] How did you get involved in transplant?

[00:01:56] **Colleen:** [00:01:56] I used to work in critical care and at the time I belonged to [00:02:00] a critical care association, a colleague I had, used to work in transplant and knew that a new position had opened up and recommended that I actually apply for the clinical nurse specialist position, which I did. And I've been here ever since.

[00:02:11] **Brittany:** [00:02:11] Do you enjoy it?

[00:02:12] **Colleen:** [00:02:12] I do. I really do. I like the, certainly the people, the patients, the challenges and the innovation that comes with a really leading edge program.

[00:02:22] **Brittany:** [00:02:22] And so you've worked for Toronto General for how long?

[00:02:26] **Colleen:** [00:02:26] 25 years.

[00:02:27] **Brittany:** [00:02:27] Why did you stay in transplant?

[00:02:29] **Colleen:** [00:02:29] I've stayed in transplant because I think part of it is being addicted to the chaos transplant is a very unpredictable service. It requires high energy and spontaneity, thinking on your feet, some really agile, critical thinking and the program because of where it sits in the acuity of healthcare. And because it's one of the few programs that deals with this very specific patient population. It's constantly innovating, so it does [00:03:00] not stay stagnant. There's always something going on, and there's a lot of opportunity to stretch yourself clinically, to learn more about your practice and to develop a lot of other professional skills, whether it's in leadership or teaching. And I'm not sure that those opportunities are always prevalent in other clinical arenas.

[00:03:17] **Brittany:** [00:03:17] What does the transplant process look like from your perspective?

[00:03:22] **Colleen:** [00:03:22] So typically somebody who's developed an illness, some sort of organ failure and they're being seen by their family physician or community health care provider who then likely refers them to a specialist within whatever organ group. So

whether it's hepatology, respirology, nephrology, and then they'll be assessed by that community person who does as much as they can with their care, and at some point determines that there's no more that we can offer in the community. The only option is to basically replace that organ, and that's a transplant. So they would be referred to our teams. The referral comes in. The various organ groups have different assessment teams that will receive the [00:04:00] referral process, the patient through an assessment determine their suitability for transplant for that particular organ. See if they're surgically suitable, if there's really nothing else that can be done for them, and if the patient agrees that they're interested in transplant and they recognize that this is their only option for either an increased quality of life and or quantity of life. Then we would list them for transplant they would wait on the list for a varying period of time. some organs wait a little shorter, some people wait a little shorter time, and then the patient would be called in for transplant.

[00:04:36] A donor would be found somewhere in the province or maybe in another province. The referral to our program for that would come through Trillium Gift of Life Network [TGLN], which is the organ donation agency for Ontario. We would vet the offer, determine is the donor suitable to donate organs? And we would look at that organ and based on the allocation system that [00:05:00] TGLN has, it would advise us who is the first patient in Ontario suitable for that organ, and it might be an organ that comes to our program or one of the other five transplant programs in the province. And from there, if it's the organ comes to us and we see that it's patient X, , my team, the MOTC team, multiorgan transplant coordinators, we call in the patient, advise them that the team believes that we may have an organ for transplant. We do a quick phone screening with them, bring them into hospital. The nurses and the whole team on transplant kind of swarms the patient and gets them ready as soon as possible. Sometimes we have a few hours, sometimes not so much time, so we're going to admit the patient. Chest X-ray, ECG, blood work. Kind of do a good once-over on them and prep them for surgery ASAP and wait until our retrieval team goes, retrieves the organs from the donor, brings them back here to Toronto General. We set [00:06:00] up the OR and the patient goes down for surgery and the surgery can take varying lengths of time, some times only, maybe two or three hours for some surgeries. 8, 10, 12, 16 hours depending on the complexity or if there's multiple organs involved. And then I think, you know the rest, of the patients an inpatient until they recover well enough, they can go into the community. and then there's a series of post-transplant appointments that they'll have with our ambulatory care coordinators and we will continue to monitor that patient pretty well from transplant to the end of later life. And we, in some cases, that's 10, 20 plus years that we help mind their health and that we're taking good care of the organ that we've been entrusted with by the donor family.

[00:06:44] **Courtney:** [00:06:44] So backing up to this phone call?

[00:06:47] **Colleen:** [00:06:47] Yes.

[00:06:47] **Courtney:** [00:06:47] The turnaround from the phone call to the surgery is very fast, like you said, sometimes.

[00:06:52] **Colleen:** [00:06:52] Sometimes what's challenging for all of us is we anticipate things to happen in a certain time period, but [00:07:00] we have no control over the donor

hospital or other influencing factors. For instance, if the donor comes from Thunder Bay or a further away centre, that necessitates a flight. I can't control the weather. So there might be weather interfering with our flight back, or if the donor develops, instability and the team needs time to stabilize them before they can go to the retrieval OR, that can interfere with it. Or sometimes another program is interested in a different organ and they may require additional testing that we didn't initially anticipate. , Or sometimes the family wants to be able to say goodbye and they may have a family member who's having trouble getting to the hospital quickly, and so we want to make accommodations so the family can have that moment with them.

[00:07:46] **Courtney:** [00:07:46] Right. Yeah. No, that makes perfect sense. From the recipient perspective though, do they have like a bag packed? Does it kind of similar to going into labour where they should just always be ready to go? If they're on the list?

[00:07:57] **Colleen:** [00:07:57] They really should be ready to go. So we tell all [00:08:00] our patients. From the time you're listed, the call to come in could come at any point in time for some organ recipients that wait may be a few weeks, some it could be a few months or longer. And it's dependent on a few things. One is we need to find a donor that's the right blood group and the right size for you as a recipient. And that can be the challenging part if you are sort of an average sized person in a blood group that is predominant within the population. You may not wait that long for an organ, but if you are somebody who's very big, very little , maybe the B blood group, you may wait a long time or longer for your organ while we find not only the right blood group, but the right size for you. And that can be really challenging because I can't put big lungs in a little person and I can't put a little liver in a big person. It won't be enough tissue mass to actually function properly. So there's a lot of variables the team looks at.

[00:08:57] **Brittany:** [00:08:57] Does it come to gender when it, [00:09:00] when you, well, like, yeah, cause the heart transplant, women's hearts are smaller than men's hearts, but a man can get a woman's heart transplant?

[00:09:09] **Colleen:** [00:09:09] Correct. And that's where the sizing is good. And we, we sometimes may look at, heights and weights of donors . And we do consider the organs will be slightly smaller, typically in a female versus a male, right? So it may mean if I have a female donor, I can pick a slightly smaller recipient on the other end. So we can look at a chest X Ray, see how big the heart is, or we can do an abdominal ultrasound to see how big the liver and kidneys are, so we can get a more accurate objective determination of the sizing versus just the complete body height, weight size.

[00:09:40] **Brittany:** [00:09:40] Okay. What if the patient's coming from another province? How does that work?

[00:09:45] **Colleen:** [00:09:45] The recipient?

[00:09:47] **Brittany:** [00:09:47] Yes.

[00:09:47] **Colleen:** [00:09:47] Yes. So we have agreements with a few of the provinces because some provinces don't have particular organ transplant programs. Like for instance,

Manitoba does not have, that's our liver program. The maritime [00:10:00] provinces don't have a lung transplant program. So what happens in those cases?

[00:10:04] Some of our patients have to relocate to Toronto in order to wait for their transplant. And that's really because of the difficulty sometimes transporting people and the interference with the timeline that that can create. But we have agreements with say Manitoba that are excellent, and Manitoba has an excellent system. LifeFlight. And LifeFlight has worked closely with their transplant program and ours. So if I have an organ, a liver, and it's being allocated to the next recipient who happens to be for Manitoba, it's great. I phone the recipient and then I call LifeFlight. I say, "hey, one of these patients that's on your list, I've called them in for transplant. How soon can you get them here?" And so I share with LifeFlight the patient's name, their Manitoba health card number, and the timing that I need for them to get to Toronto. And Lifelight will make arrangements to bring them and sometimes their support person or family member with them to Toronto and drop them off here for us.

[00:10:58] **Courtney:** [00:10:58] In a circumstance like [00:11:00] that, I know you said there are a bunch of different factors that determine how quickly someone's going to get that organ or go into surgery. How long can an organ survive outside the body?

[00:11:08] **Colleen:** [00:11:09] It's an interesting question cause it's variable. So for instance, there is a concept that we call the ischemic time and ischemic time is the time between when I clamp off the organ in the donor and when I unclamp the organ. Once it's been implanted into the recipient, and each organ has a slightly different timeframe that we sort of see as our maximum. So for instance, kidneys can bear an ischemic time, past 12 hours, maybe up to 20, 24 hours if we really push it, but only on a donor that's really good. And the circumstances for retrieval have been excellent. So in all organ groups, the shorter the timeframe from donor to recipient, the better. But there are some limits that we push. So for instance, for a liver we say typically we don't [00:12:00] want more than eight hours of ischemic time, but again, we'd have to appreciate that that is clamping off the organs and the retrieval team, that organ has to be packaged, brought to the hospital, brought to the OR, they have to take out the old liver implant, the new liver. And make all those anastomoses, all those connections between the vessels and then unclamp. So it's not just hospital to hospital. There is some surgical time that has to be appreciated in the process. So our teams work really hard at every level, making sure that we try and minimize that ischemic time as much as possible for the best patient outcome.

[00:12:32] **Brittany:** [00:12:32] If it passes that, do you say no? Is there ever a time where it's like it's been, it's pushing the time and you go, okay, we can't -

[00:12:41] **Courtney:** [00:12:41] And how can you tell?

[00:12:43] **Colleen:** [00:12:43] Well, we time everything. Okay. Trillium accompanies our team to the donor site that that clamp time is marked down on the sheet and then that sheet comes with us into the OR and so we have a countdown. Everybody's got a count on calling on her head. So we say it was clamped at [00:13:00] 11 o'clock this morning. I've got til X time tonight to get it in. I can certainly say that we've had transplants before where

there's been a travel time issue or a weather delay, and that's impeded our ability to get the organ here within the tolerable ischemic time. We've had to say, no, but it's happened. Very, very few times. It's extremely rare.

[00:13:20] **Brittany:** [00:13:20] Who retrieves the organ?

[00:13:23] **Colleen:** [00:13:23] Our transplant surgical fellows.

[00:13:25] **Brittany:** [00:13:25] So if it was a liver, we have some of our liver team fellows, theym like, let's say it was in Ottawa, did they fly?

[00:13:31] **Colleen:** [00:13:31] So if the liver, if the donor's in Ottawa, it's the accepting program's responsibility in general to go and do the retrieval for their own program. So for instance, if the donor, like you said, would be an Ottawa, and we were offered the liver. And in Ontario, liver transplants are done by Toronto and London. So it could have gone to either one of those programs. So they would phone us, they would offer us the organ. If we accept, we then make arrangements with Trillium Gift of Life to fly our [00:14:00] surgical fellows. So we have fellows from around the world that come to all of our programs for training, and they're usually here for a year or two. And part of their responsibilities as surgical fellows is to go on donor retrievals.

[00:14:14] **Brittany:** [00:14:14] Wow.

[00:14:14] **Colleen:** [00:14:14] So they're on call to us 24/7 around the clock to be able to do that. And that's -

[00:14:19] **Brittany:** [00:14:19] I would love to do that.

[00:14:21] **Courtney:** [00:14:21] Would you?

[00:14:21] **Brittany:** [00:14:21] Yes.

[00:14:22] **Courtney:** [00:14:22] Really?

[00:14:23] **Brittany:** [00:14:23] Yeah.

[00:14:23] **Courtney:** [00:14:23] I don't know.

[00:14:23] **Colleen:** [00:14:23] We can, we can organize that. You have to be willing to be on call for like a week

[00:14:29] **Brittany:** [00:14:29] I would happily do it.

[00:14:31] **Colleen:** [00:14:31] Okay.

[00:14:31] **Brittany:** [00:14:31] I'm not even kidding I would - But what an experience, but I guess as a fellow. That's just something maybe they're not, that's not their, their drive. They - they- they want to be in OR doing the surgery as opposed to like going to go get the organ

[00:14:46] **Colleen:** [00:14:46] Remember the fellows are all in training. They're all learning the craft of transplant. Many of them will go on to be transplanters wherever they get a job.

Some may not necessarily, but you kind of have to know what the [00:15:00] donor organ looks like and what the donor particulars are to have a better appreciation of what you're going to deal with implanting in the recipients -

[00:15:08] **Brittany:** [00:15:08] For sure.

[00:15:08] **Colleen:** [00:15:08] And you also then have to be able to teach the other people who are going to be retrieving on your behalf, what your requirements are for how you want that organ to be retrieved. So do you want longer pieces of vessel? Do you want certain things done during the flush or I don't know, surgical stuff that the surgeons want. It's important that we're able to perform and give them an organ to their specifications as much as possible. Make sense?

[00:15:35] **Brittany:** [00:15:35] Yes.

[00:15:35] **Courtney:** [00:15:35] Question: what is the flush?

[00:15:37] **Colleen:** [00:15:37] What happens when we take an organ out of a donor is that we can't just let it sit there because there's blood in all the vessels and if we let the blood sit there, it will clot, the organs not usable for us. So all organs when they come out of a donor have to be cannulated or have a tube put in arteries and veins are the vessels so that we can flush it with a preservation solution. So we flush out the [00:16:00] blood, reduce the potential for clots, and we make sure that those vessels are open before they come to us or during that transportation time. And so they're in the better possible shape for the transplant surgery.

[00:16:12] **Courtney:** [00:16:12] Right. Thank you.

[00:16:13] **Brittany:** [00:16:13] Have you ever got to witness a transplant?

[00:16:15] **Colleen:** [00:16:15] I have - when I first came , the surgeons, the teams here were really accommodating when I first came as a clinical specialist years and years ago. And so I saw all of the organs except a heart transplant. So that was really interesting. And I know what we did back event is not what we necessarily do now. And certainly we've made advances with living donors with laparoscopic. Some of the procedures we use when we do implantation have changed a bit. So for instance, pancreas kidney, which we introduced in this program in 1995. The initial pancreas kidney patients, we would attach the pancreas to the bladder. And we no longer do that. So we [00:17:00] stopped doing that. After a couple of years, there was evidence that it was better to attach it into the bowel, like the regular pancreas would be okay. But at the time it was felt that attaching it to the bladder was the ideal. So we've changed that procedure. Over time. The lung transplant has changed over time. A number of surgical innovations have been introduced, so it's better, quicker sometimes to get the surgery done. The patient has an easier time recovering in some instances because we've changed our surgical procedures.

[00:17:31] **Brittany:** [00:17:31] Do you know if the patient's coming back into the hospital? Is there a way that you know that they had that old surgery? You know what I mean?

[00:17:39] **Colleen:** [00:17:39] You know what ...I don't know that we do. And that's actually really fascinating because a few years ago, when I was managing the floor, so this had been at least seven or eight years ago. I remember one of the nurses coming to me and saying that, you know, this patient didn't receive proper education. They don't understand about the transplant that they got. And my patient keeps saying that his [00:18:00] pancreas is attached to his bladder. And I tell him, no, no, no, it's not attached to your bladder. And he keeps insisting that it is. And I looked at her and said "when did he get his transplant?" She said "oh long time ago." I said, "when?" And I think it was 1996. I said, "yeah, that's how we did it back then." Right. So I only knew because I've been here a long time. Right. But we don't have a way of doing that. And there's probably surgical notes, so the surgeons can certainly tell if they ever have to go back in and see that there'd be the operative notes that they could reference. But I think for the nursing team, that's not always front and center to how we are given information to help us care for the patients better, and sometimes it's only details that really wouldn't matter too much, but it's clinically interesting and something to appreciate and how you're caring for your patient.

[00:18:44] **Courtney:** [00:18:44] How much do recipients and their families get to find out about their donor and where the organ is coming from?

[00:18:50] **Colleen:** [00:18:50] So my team never discloses any donor information to patients and families, recipients, and families. So we're prevented from sharing any details because we're trying to protect [00:19:00] the donor's privacy as well as the recipient's privacy. So when I call a patient in, I simply let them know that I have a donor, I have an organ for them. Patients sometimes do ask. They ask, well, "how old is it? Where are they coming from?" And we just simply say, "I'm so sorry. I'm not at Liberty to disclose that information due to patient privacy." And it's a hard, it's a hard, I mean, I, if it was me, I would want to know. I would, I would want to know clinically some of the information. So somehow I am comforted that it's a good organ. But really, I mean, the people here know better than anybody. They're not going to where they're always striving for the best performing, best functioning organ. So that's never a concern, but it kind of also want to know are they a good person? What were their families in life that, so you want to know about them because it's going to be part of you, but we really can't disclose. That doesn't mean that people don't find out. It just means I can't be a part of sharing that information.

[00:19:58] **Courtney:** [00:19:58] Right.

[00:19:59] **Colleen:** [00:19:59] So. [00:20:00] People have lots of ways they can go about it. It's just that for me as a healthcare provider, I can't disclose that. And we live by that very strictly. I never actually know the surname. I don't know much more details than height, weight, and their clinical information. And that's kind of it. And so that helps us keep in check the amount of information that's available about that donor. And none of that is documented ever in the recipient charts. So that's never available either.

[00:20:27] **Courtney:** [00:20:27] What about, I'm not sure if this applies to your position, but what about the reverse? How much does the donor family find out about where their loved one's organ is going to?

[00:20:36] **Colleen:** [00:20:36] That's a different situation because we do want to encourage a donation and part of encouraging donations so more people can benefit from transplantations and making sure that donor families have a positive story to share about organ donation. So we know from a marketing at least, this is the quotes from a few years ago, that if you have a good experience with a product or service, you will tell four people. [00:21:00] If you have a bad experience with a product or service, you will tell 14 people. And that was in the days before social media. Now you could have an audience of hundreds, so we do want our donor families to have a positive experience. For many of them this can be the meaningful end to a very tragic situation. And so we always focus on, you know, sometimes very tragic passings or deaths of donors. Maybe this can bring meaning for the family and something positive that they can hang on to. So we do have a way of communication between donors and recipient, donor families and recipients. And what happens is we encourage all our recipients to write a thank you letter to their donor family, and it's written anonymously. It's vetted by the coordinators here so that there's no identifying information about the recipient. It gets sent to Trillium Gift of Life, they have the donor information, and then that is again vetted and passed on to the donor family. The donor family in turn can write letters back to the recipient through [00:22:00] TGLN, same thing, anonymous, vetted, to make sure there's no identifying information. And that's extremely comforting to the donor family to know that what they did was a good thing and it was a positive thing, which can be two very different ideas.

[00:22:15] **Courtney:** [00:22:15] Have you ever had to have the conversation with someone's family about organ donation?

[00:22:21] **Colleen:** [00:22:21] So when I worked in ICU, Wellesley had a neuroscience program and the neuro programs in the city. So there's one in Mississauga, the Western, Sunnybrook, Saint Mike's, and there used to be Wellesley. And the neuro programs would often get head traumas, strokes, aneurysm, those kinds of things, which can be a good portion of our donors that we, that we get. So because I was at that center and we had neuroscience we did have a number of, of organ donors as our patients. And so in ICU you take care of them. And back then the care providers at the bedside and critical care were the ones that had the [00:23:00] conversation with the families. So I had participated in a number of them as the nurse caring for the potential donor and had that conversation with the physician. When I came here as the clinical nurse specialist, I did training so that I could approach families here on site. And so the program sent me to a one week long training session and then we learned how to have the conversations sensitively, in a meaningful way that's very respectful for everybody involved and what actually helps donation move forward. Things like, we know that if the care providers are the ones that ask the family, there can be mixed messaging because the family wants to be assured that as a care provider, you're doing all you can to save them. And it's hard sometimes for them to hear that you're changing your path and now talking about donation. And so you don't want to confuse the issue or potentially have them think that you haven't done absolutely everything you can. [00:24:00] So the ideal now is that the care provider team talks to the family and says, "I'm so sorry. This is what's happened with your loved one to this time. And at this time there's no more we can do. , but at this time we have a Trillium Gift of Life come and talk to families like yours." And then what's supposed to happen is somebody from

TGLN will come, somebody who's been trained and they will have that separate conversation with the family and acknowledge what they're going through, what the donor story has been, and what we can do to determine whether the person was interested in organ donation because sometimes people have registered. So if somebody had registered to be an organ donor we would ask the family if we know that, how can we help them honor their loved one's best wishes if there is no indication that the person wanted to be a donor, how do we talk the family through what that decision might look like for them? And it can be tricky because sometimes you [00:25:00] have. People who don't understand the process very well may have some -

[00:25:05] **Brittany:** [00:25:05] Language barriers,

[00:25:06] **Colleen:** [00:25:06] Languages or beliefs and a couple of need more clarification or are uncomfortable, at least on first blush. And so it's a, it's a long process. And then the TGLN staff are great because they then work alongside the donor team to make sure that everything's being done to maintain the donor, to optimize functioning. But then also is there a support the family until the retrieval occurs.

[00:25:28] **Brittany:** [00:25:28] Does anyone get defensive? I mean in your experience, has anyone ever been defensive?

[00:25:34] **Colleen:** [00:25:34] Yes. Sometimes. I think years ago I approached a family when I was part of this program about organ donation, it was a large family and everybody wanted to be involved in the conversations and most of them were pro donation. And then there was somebody that the family. We're sort of an extended family member who really felt that this was not what should be done at this point with [00:26:00] their, with their loved one and had very strong opinions about not going forward. And so we had a bit of time and they had certain objections from religious grounds. We explained, through some information, pamphlets that we had that actually the religious leaders in their particular denomination supported organ donation. So we help clarify and educate them a bit and gave them some time to talk amongst themselves. And within, I think it was the next afternoon, the family had come together and they were all able to support going forward with donation.

[00:26:32] **Brittany:** [00:26:32] Okay

[00:26:33] **Colleen:** [00:26:33] So sometimes it's just patience, trying to get them some time because they're grieving, they're in shock. There's so many things going on. It's just not a yes, no answer. Sometime on the other hand, I'm always, remarkably impressed by families who at this horrible time in their lives, can think of somebody else, right? Because if your loved one dies unexpectedly, [00:27:00] it's gotta be so hard in that moment, even though you might want to help somebody else. But in that horrible moment when you're grieving and sad and in shock, um, to be able to focus on that as as a, what's going to help drive you forward through that situation.

[00:27:22] **Brittany:** [00:27:22] Yeah.

[00:27:22] **Courtney:** [00:27:22] Yeah. It's such an interesting juxtaposition of stories, right? They're just at complete odds and then they're so connected forever. But it's such a weird

transition to have someone who's, a family that's so sad and grieving and then have their organ go to someone that, you know, they've been sad while taking care of their loved one who is so sick, and then they get better. Like it's such a weird.... it is weird connection.

[00:27:47] **Colleen:** [00:27:47] And I think our patients feel it too, because I think , our patients, you know, it's, it's , I can tell you one of the most rewarding moments in my career with transplant here is the moments when I get to phone patients and say, "I'm calling from the transplant [00:28:00] program. We think we might have an organ for you." And people are elated. You can tell when they're excited and they've been waiting and they're so hopeful and they're, they're just so happy that their moment has come. And that's just so comforting. It's just makes it all worthwhile. Everything in that moment is encapsulated in that joy. And then many times our patients, you know, sometime after transplant are also reminded that they've only been able to have a transplant because somebody died,

[00:28:27] **Brittany:** [00:28:27] Right.

[00:28:27] **Colleen:** [00:28:27] And so there's this tragedy on the other end of their joy, and that can be really challenging. And a lot of them have difficulty writing the thank you letter to their donor family cause they're like, how do I say thank you that this horrible thing happened to you and your family? And we tell them often it's not about necessarily thanking them for that, it's about saying, this is who I am and I'm going to take good care of this organ. And that's all people really want to know. They want to know that somebody cares and somebody is going to be [00:29:00] responsible and honor that gift.

[00:29:01] **Courtney:** [00:29:01] We keep meaning we need to bring tissues, man. I keep forgetting to bring tissues and this happens.

[00:29:07] **Colleen:** [00:29:07] I'm, I'm, I just have flashes of specific people in specific situations, and it's just this torrent of emotion. Yeah. And it's hard and it's hard when people are, you know, happy and sad and, and, and we're that in between where that seesaw in between.

[00:29:21] **Brittany:** [00:29:21] I've worked in transplant for the past four, four and a half years. I've never had the opportunity to see, both sides of the coin. Right. And it sounds like your, your position. Or I should say the multiorgan transplant coordinating program gives that opportunity to see both sides of the coin in terms of that. That it's a very tragic time in one person's life, but it's also very rewarding. It might sound a little cheesy, but it is really the gift of life. But like truly. It's, it's really amazing. It's really amazing [00:30:00] and some, and you don't, we don't really get to recognize, I don't really get the opportunity to recognize that off as often as -

[00:30:06] **Colleen:** [00:30:06] And I think that's one of the things we'd actually like to bring to our team. So our team's new, like we've only been, yeah, as a team together for seven years, just recognizing that we needed some team of nursing professionals to bridge that coordination of events between the donor offer and the transplant surgery cause there's so much going on and it's a, it's, it is chaos in, in the best of times.

[00:30:32] **Brittany:** [00:30:32] There was one question I wanted to ask about the retrieval. Yes. You were saying that they, they don't really get much information about the donor -

[00:30:41] **Colleen:** [00:30:41] The recipient's don't, yes.

[00:30:42] **Brittany:** [00:30:42] Yeah, the recipients don't get too much information about the donor, but when it comes to a high risk donor, do they get that information?

[00:30:51] **Colleen:** [00:30:51] So there are two categories of donor that allow us to [00:31:00] disclose some information to the recipient. So one is the exceptional distribution category and what happens is there is sort of a standard person that doesn't have too many questions in their medical history or too many risk factors. And then there are people who may have some social situations or some previous very specific serological like hepatitis or something in their background that does pose a risk to the recipient. Right. In those circumstances, we approach the recipient and say, it's the, , either the staff physician or the fellow approaches the patient and advises them that the donor falls into this exceptional distribution category and lets them know what their risk is. Generally, it's very low. Like one in 3000 or 300,000 whatever the, the issue is, and that we have gone to all the lengths that we can to mitigate any of those risks and that we're confident that we can go ahead and either deal with any consequences [00:32:00] or we don't believe there will be one for that recipient donor pair. At that point, the recipient has the choice to say, "I'm okay to proceed. I trust the team has done their due diligence and we can go forward." Or if the recipient is not comfortable, they can decline the transplant at that point. So that would be for all organ groups.

[00:32:19] **Brittany:** [00:32:19] So what if they have allergies?

[00:32:20] **Colleen:** [00:32:20] So allergies are really important for us to know about the donor. Because there is research that has shown that in some cases and for anaphylactic allergies have been passed onto the recipient. So if you have a donor that might have an anaphylactic allergy to peanuts, we caution the recipient that there may be a transmission of allergy. We don't know how strong that reaction may be, and it may not be forever. It may only be for a certain time period post-transplant. So we would caution all our recipients, if there was an anaphylactic allergy in the donor, that this was something that they had to be aware of and we would recommend further testing with an allergist post-transplant.

[00:33:00] [00:32:59] **Brittany:** [00:32:59] Okay.

[00:33:00] **Colleen:** [00:33:00] Okay. So the allergies are important, but it's really only the life threatening and anaphylactic ones that have been shown to be a potential risk for the recipient, and it's not absolute, it just can happen to very few people, but we want to be on guard and make sure our patients are protected.

[00:33:15] **Brittany:** [00:33:15] Right.

[00:33:15] **Courtney:** [00:33:15] Absolutely.

[00:33:17] if you're on the list for a transplant, when you get the call, does that mean you are guaranteed to get an organ?

[00:33:29] **Colleen:** [00:33:29] It means that at the time we believe that we have an organ that is the right blood type and the right size for you and at that moment, everything is showing us that this is going to go forward. So every time we call, we believe it's going to be an organ for transplant. Having said that, probably 35% or so of our transplants do not go through because sometimes all the testing can look wonderful and we're so optimistic that this is going to go forward, [00:34:00] but until the retrieval team actually goes in there and actually sees the organ, we can't guarantee, and of course, we can't do that before we, we call the patient, right? So sometimes we've had circumstances, the retrieval team goes in, we expect everything's going to be fantastic. They take it out, and maybe the blood vessels aren't going to be great enough for reattaching. Maybe there's a hard spot that needs pathology and there's something that we believe might be a risk going forward, so we won't use that organ. Maybe there is an infectious process that wasn't appreciated beforehand. There's a number of things, and even at the time I call all the bloodwork can look great, and then because the donors are aren't super stable, you know, neurologically there's things going on that may compromise some of the function that donor can deteriorate from the time call to the time we retrieve. And so we don't know how quickly that may happen or if it's going to impede our ability to actually retrieve and transplant post until we get to that moment.

[00:34:58] **Courtney:** [00:34:58] Right. And what does that [00:35:00] conversation look like when you have to tell someone that this organ isn't going to work?

[00:35:03] **Colleen:** [00:35:03] All patients receive information about this is a possibility and some organs can experience cancellations more than others because the organs are particularly delicate.

[00:35:14] **Courtney:** [00:35:14] So which ones would those be?

[00:35:16] **Colleen:** [00:35:16] Sometimes we find, for instance, like the, the lungs may see more cancellations than the others, and that's again because of the delicate nature of the patient getting adequate oxygenation and the lungs functioning well at this moment. The chest X-ray can look great. Their oxygenation, their ABGs arterial blood gasses can look great. And then in those hours between that phone call and that surgery, deterioration can happen, or an infectious process is identified. Or, there could be something else wrong with one of the other organs that we then say, "whoa, not going ahead with that." Cause we were worried that that could actually have an impact on lung function. Maybe not today, but maybe in five years. So if I find cancer elsewhere in the body, I can't, [00:36:00] I can't take the risk that any of those cells might be then transplanted into the recipient so that we'll just stop it right there.

[00:36:06] **Brittany:** [00:36:06] When I have a patient that comes in for a workup that it's usually like their, their wife or their husband or their family member is looking at me and they say, "so does this mean that the transplants actually happening? Is it for sure?" And "I always tell them, the transplant is not confirmed until it is in your body."

[00:36:29] **Colleen:** [00:36:29] And, and that's exactly the answer because up until the moment before. Anything can happen. Any new piece of information could surface that then changes our decision making. So I think you're exactly right when you're talking to your family members. I think what we need to assure them, I was at this time, our team is confident that this is going ahead, but that could change and we're trying our best to get you in organ, but there's things we have no control over.

[00:36:58] **Brittany:** [00:36:58] Yeah. And honestly I [00:37:00] feel for them like I really do cause they're so anxious when they come in as they, as I would be. And I, and it's such a weird, I would imagine it's such a weird feeling to feel like you're excited, but you're also worried cause you're, is this happening? Like should I even be excited because I'm not sure if it's going to happen.

[00:37:22] **Colleen:** [00:37:22] You don't want to be disappointed,

[00:37:23] **Brittany:** [00:37:23] Right? Like, I'm like, but I always try and tell them , "I just want to set the expectation, but it's not confirmed until the organ is in your body."

[00:37:32] **Colleen:** [00:37:32] And the advantages, I mean, it's gotta be a really challenging situation for patients, especially if they've had far to travel or they have a lot of arrangements to make for when they come cause not everybody lives right near the hospital, they can live two, four, six hours away and have to make their way here, and especially in winter, all those kinds of things, but we believe in every circumstance that we call them in that we're going ahead and like I said, we have no control over some things and we're trying to make the best decision possible. And it [00:38:00] really comes down to from whatever happens up until that point of transplant, do we believe this is still a great functioning organ for this individual? And all the circumstances are right for this to happen and expect a good patient outcome.

[00:38:12] **Brittany:** [00:38:12] So tell me the difference between deceased donor.

[00:38:16] **Colleen:** [00:38:16] Well, there's different kinds of donors. So there's first of all, living donors and deceased donors. So living donors would be, right now we have the ability to offer living donation for patients needing a liver transplant or a kidney transplant where you have a friend or family member, or in some cases, that anonymous person will step forward to offer, an organ or part of an organ in the case of liver so that somebody else can have a chance at life and for a living donation, it's great because the donor is there. We can ask them all their health questions. We can coordinate that day where we do the donation and the transplant surgery and. It is a fantastic opportunity for people to get their transplant sooner [00:39:00] from a donor that we vet as healthy and suitable for that individual. So they're living donations. Excellent for patients who need a liver or kidney transplant.

[00:39:11] For deceased donors, there's two general categories. One is NDD or neurological determination of death, and that would be, we used to call that a brain dead donor, and that's somebody who is going to be in the ICU. They've had some sort of neurological event, typically an aneurysm or maybe a head injury or an anoxic events, so where they're not getting enough oxygen to their brain where their brain is no longer functioning. So they no

longer have reflexes. They're unable to breathe on their own, so the ventilator would need to breathe for them in the ICU, and there is no chance that this person is going to recover. There is absolutely no chance, and for all intents and purposes, they are dead, but their heart, because of the way - the [00:40:00] heart's pathophysiology - is the heart just keeps beating and the only reason they haven't passed is because we're breathing for them and providing oxygen and keeping IV fluids and medications in them. There is no hope of recovery for that individual. So a brain dead donor or an NDD donor is one of the categories of deceased donation. In those cases, when we accept the organ, we go and retrieve . It happens generally at the time we, we hope or planned for, and then the organs come back and we go right away to the OR for transplant.

[00:40:33] The second category of deceased donors is DCD or donation after cardiac death, and those would be individuals who are likely in the ICU. They may have had a protracted illness that's going on for an extended period of time. There likely is no real hope of recovery for them. And the family at that time generally wants to consider ending their [00:41:00] suffering in the ICU. And in general, we sort of historically asked, you know, say that we're withdrawing care right, or we're discontinuing life support, that kind of thing. So that would be the time you would turn off the ventilator and discontinue some of the medications that may be maintaining their blood pressure or heart rate or whatever it is. And so in those cases where the family is going to look at withdrawing care anyway, we go to them and offer them the opportunity to consider organ donation after that event. So what happens in that instance is that the family's approach, they consent to donation at the time we're going to withdraw care. The family is typically there, so the patient would be extubated. We would discontinue the ventilator in any of the medications that they would be on, and we would wait for the donor to pass on their own. And if they pass within generally two hours, there's probably still enough circulation going on that we would have the opportunity [00:42:00] then to consider transplantation for lungs or kidney, the donor would have to pass a little quicker for us to then to consider liver or pancreas transplantation afterwards. So there is these two categories of organ donor. DCD was only introduced several years ago as an option that extended our donor pool a bit and also gave families the opportunity again to have some sort of meaningful outcome for their loved one passing, a tragedy like they're experiencing in that moment.

[00:42:34] **Brittany:** [00:42:34] What if the recipient doesn't answer the phone?

[00:42:38] **Colleen:** [00:42:38] Oh my. I mean, I can certainly appreciate, you know, we, we tell recipients that their call can come anytime day or night. The reality of our business is most of the calls to be coming in for transplant happen on the weekend or at night, like evening, nights is generally we call people in. [00:43:00] I'm not sure why that is, but it just seems to be the timing of how things work out. Sometimes it's in the day, but most times it tends to be evenings and nights and weekends, mostly evenings, I think is probably fair. And so what happens is our process is that I have one hour to get ahold of you as a recipient.

[00:43:19] **Brittany:** [00:43:19] Okay.

[00:43:20] **Colleen:** [00:43:20] And when I call you, you have up to two hours in general to get to the hospital for people who live beyond the GTA. For us, we have to, we make special

arrangements for people that have to travel a little further and we try and make sure we call them early in the process and that the timing is going to work out for the travel that they have to incur to get here. So when I call you, generally people have one, two, three, four, sometimes more contact numbers, phone number, a cell phone, their husband's cell phone, their daughter, their son, their aunt, their grandma. They have a whole range of people that they may give us the phone calls. So myself as the coordinator, I would start calling you now. I would run through [00:44:00] all your phone numbers continuously for an hour. So I might call you four or five, six times at your number in an hour, but I've also called all your other contacts. But generally I'll call the first time, I'll leave my name and I will say, "I'm from the transplant program. I need to speak to you urgently. This is my phone number. Call me immediately." And I'll give it the time and date that I've called, and then I'll run through all the other contacts. I might take care of a few other details with cases and then get back. I'll call you all again. I may not leave voicemails every time because we tend to then fill up people's voicemails. But we will still keep trying to call. If I don't hear from you or I don't make contact with you in an hour, I have to move on to the next recipient. Donors can't always wait at the donor hospital, they are not gonna remain stable forever. So their stability is a little in limbo. So we need to have this happening as soon as we can.

[00:44:55] And if I don't hear from you in an hour, I need to move on to the next [00:45:00] recipient. And so I've had circumstances where I call a recipient and then the hour is up. And then I go on to the next person and then I've had the first person call me back saying, "oh, I just picked up your message." If I have not yet called the next individual or made contact with them, there may be an opportunity to still take that first person. But if I've already made contact with patient B and have them coming in, then that first patient a has lost the opportunity for that particular transplant. We just do not have the ability to wait, and so it's really important people answer their cell phones, keep their cell phones on, don't turn the silent mode on when they go to sleep. Keep your phone by your bed with the ringer turned up because we have had people call the next day and say, "oh, I just picked up your phone call. Can I still come?" "Uh, that was 11 hours ago. What happened?" "Oh, I left my phone in my jacket. Well, don't do that."

[00:45:57] **Brittany:** [00:45:57] Yeah. So is that an ongoing issue or -

[00:45:59] **Colleen:** [00:45:59] - [00:46:00] it is, it doesn't happen all the time, not all the time. But there are occasions, and I think when it's most difficult for us is when we have a donor that's of a, say a really big or really small size, a hard to place size. Right? And so that may be your one opportunity. And if you don't come maybe the organ doesn't stay with our program, maybe it actually goes to a different program. So our entire program loses that opportunity. Somebody else in Ontario will get a transplant, so it's all good. It's just, you know, we all feel a little disappointed when we can't reach the person, and make that happen for that particular individual at that time. So that's unfortunate. But I think when people do finally call us, it's our opportunity to remind them. If I'm calling you, you're getting to a place on the list where you're going to start getting more offers. You need to be available and people need to be mindful of things like you know, keeping it by their bed, keeping it where they can hear the phone. Remembering too that sometimes the phone number that may come up on their cell phone doesn't say Toronto General Hospital. It

[00:47:00] says private number or unknown number because the hospital has so many hunt lines and so many extensions and main lines, there's no way for it to show up as Toronto general or at least not that I'm aware of. So people need to know if it's an unknown number, you got to pick it up anyway, cause it might be me.

[00:47:15] **Brittany:** [00:47:15] So do people, do they say, "no, I'm not going to take this one. I have plans or -"

[00:47:24] **Colleen:** [00:47:24] So when I call somebody in for transplant, our expectation is if I call you, it's because you're on the list and you're suitable to come in for transplant. There are occasions where people, okay, have circumstances where this is going to not be a great day for them. So for instance, I remember years ago calling a woman, it was her daughter's wedding day and, uh, like, what do you do? So we just, we just talked about timing quickly and I said when is the ceremony, like can you miss the reception? Like [00:48:00] this is it. And in the end it actually worked out in her favor cause there was a delay with the donor. So she was able to stay for like the first dance or the speeches or whatever, and then ran to hospital and her beautiful little dress.

[00:48:11] So that was really cute.

[00:48:13] **Courtney:** [00:48:13] Thank you so much for joining us today.

[00:48:14] **Colleen:** [00:48:14] Thank you for inviting me. I think this is a really exciting project. I hope it reaches a lot of people and congratulations to you both and congratulations on the work that you've put into it. I completely admire what you're trying to do here and the dedication you're bringing to it.

[00:48:26] **Brittany:** [00:48:26] Thank you.

[00:48:27]

[00:48:27] **Courtney:** [00:48:27] Thanks. Thanks for listening to this episode of living transplant. If you have questions or suggestions for future episodes, email us at livingorgandonation@uhn.ca.

[00:48:39] **Britt:** [00:48:39] Don't forget to subscribe, rate, and review living transplant on iTunes, Spotify, or wherever you listen to podcasts.

[00:48:46] **Courtney:** [00:48:46] And follow us @GiveLifeUHN on Facebook, Twitter, and Instagram.

[00:48:50] **Brit:** [00:48:50] See you next time!

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