

I have parts from everybody

Candice Coghlan: [00:00:00] Welcome to Living Transplant. The podcast that takes you behind the scenes of the transplant program at Toronto General Hospital and brings you open and honest conversations about the transplant experience. My name is Candice and I'm the Education and Outreach Coordinator for the Center for Living Organ Donation.

I'm also a kidney transplant recipient. This is where I developed my passion to support others in their journey to navigate the world of transplant. Full disclosure, I'm not a physician and I'm not here to give you medical advice. Think of me, your guide through the world of transplant, to educate, inspire, peak your curiosity and fuel your passion.

Living Transplant will show you the world of transplant you've seen before.

Welcome back to the Living Transplant Podcast. Today, I am joined by a remarkable person, Sara [00:01:00] Murray. We will be discussing Sara's journey living with cystic fibrosis, her multiple transplants and her family life. Later, we will be joined by Dr. Cecilia Chaparro our Respiriologist and Medical Director for the Lung Transplant Program at UHN.

Thank you for co-hosting this episode with me, Sara.

Sara Murray: Yeah, you're welcome.

Candice Coghlan: So I'm wondering if you can bring me back and tell me a little bit about your childhood and when you were diagnosed with cystic fibrosis.

Sara Murray: Sure. I was actually diagnosed at three months old.

Candice Coghlan: Wow.

Sara Murray: And it was, through my parents' persistence, I was youngest of five children. So when I wasn't gaining weight and I was screaming all the time, they knew, "Okay, this is not a normal baby thing." So they kept showing up at the doctor.

It's why I do this now, but, it just kept going back and going back and [00:02:00] saying, "No, this is there's something wrong." And one doctor actually told my mom that I was just a spoil of brat and that was my problem.

Candice Coghlan: Oh, no.

Sara Murray: You know, not even at three months old, I learned how to be a brat. So she got a referral to Sick Kids Hospital and within not even 48 hours of being there, they had diagnosed me with cystic fibrosis.

So then I began like they switched me over to a predigested formula. And as soon as they did that, like I took off, I was gaining weight and I was happy. And I, my mom said I never cried again, because I think prior to that, I'd been in so much pain because I couldn't digest my food, that was gone, so I was like, "Oh, this is perfect."

Candice Coghlan: Right.

Sara Murray: This is a good life. And then my parents raised me, like my siblings, you know? I got in trouble. I had chores, I had responsibility. Like I got no special treatment. I did have to, well when I was a little bit older, but learned to take pills and take pills with my meals, but they just [00:03:00] would put them on the table beside my food. And it was on the discussion or a fight. It was just an expectation that that was part of the dinner routine, you take these pills, you eat your food. And same with school. I went to school as normal. It was a little bit different. I think back then it wasn't the same as now with the excessive germ fears we have, right? And I had a great group of friends, a lot, some of 'em I'm still friends with today.

Candice Coghlan: Oh.

Sara Murray: And I was treated like everybody anywhere I went. Now I didn't look sick and then I had the inhalation max and physiotherapy I had to do. But that again, I had to do in the morning, no matter what, but in the evening I could come home from school, do it right, then have the evening free. Or I could go out with friends, eat dinner, and then do it. Like my parents let me have some flexibility with that, I always felt normal.

Candice Coghlan: That's good.

Sara Murray: You know, there was just a ease about the way everything was handled.

Candice Coghlan: So it was almost like you didn't know any different than, what your routine was, that you were able to participate [00:04:00] in everything else that any other kid was.

Sara Murray: Yeah, exactly. And then, like my older siblings would help me with whatever when I was younger. I couldn't do some of my physiotherapy, myself and my parents were out, they would help. It was just part of being in the family, right? It was just what we did.

Candice Coghlan: Mm-hmm. You all helped each other in whatever things were needed.

Sara Murray: Yep.

Candice Coghlan: Wow. And so throughout your childhood, were there any times that you had issues that landed you in the hospital or were you pretty healthy with being able to be on that routine?

Sara Murray: I was quite healthy, really. I didn't have a lot of lung stuff going on. And even my digestive issues were managed easily with enzyme pills. Some people get bowel blockages and this and that. I didn't have any of that.

But what happened when I was about, I guess it was started when I was nine and I got a really, really bad flu, it lasted for a while.

And then I didn't eat, you know, like when you have really bad flu, you don't eat. But with CF, you maintaining good weight is [00:05:00] important because struggling to breathe and whatever burns, more calories. So you have to have that consistent amount of food going in.

Candice Coghlan: Okay.

Sara Murray: So I started to lose crazy weight during this time. And then I got stuck in this weird spiral of, I just had no appetite left. I didn't want to eat. And I lost and I lost and I lost, and my lungs got worse because I was so underweight. And I was in and outta the hospital at that point. And they eventually put in like a G tube into my stomach. So that would feed me a high calorie liquid. I don't know what you would call it, smelled clean, but I didn't taste it. And that would go all night while I slept. And that had like crazy high calories. And I know in the first month after getting it, I had put on well, over 10 pounds, right? So it made a huge difference and I never had it removed, like even when I got to weight

Candice Coghlan: Okay.

Sara Murray: I chose that. I wanted to keep it. It was like my safety net, my backup [00:06:00] kind of thing. And I had that from, I guess when it was put in, I was about 10 and it stayed until a year after I had my lungs.

Candice Coghlan: Okay. Wow. And so how did that affect you as a kid? Like, were you still able to play sports?

Sara Murray: I didn't play sports.

Candice Coghlan: Okay.

Sara Murray: I, I'm not sportsy.

Candice Coghlan: Okay.

Sara Murray: But it didn't like initially when they put it in, it was a long tube. So you wrapped it in a circle and taped it down to your skin. And then as you got into your early teens, then it's awkward because you're in a bathing suit and there's something there.

Candice Coghlan: Right.

Sara Murray: So that at times was weird. And then they came out with a button version.

Candice Coghlan: Okay.

Sara Murray: Was actually just came up past the skin and it had like a little flap that would open and close to access it. It was almost, almost invisible.

Candice Coghlan: Yeah.

Sara Murray: Compared to this giant long tube that you had taped your stomach. So that was [00:07:00] better, you know, and then I would buy bathing suits that maybe had a ruffle or like something across that way. So it just blended it in better. So it wasn't so bad and compared to the old one.

Candice Coghlan: Yeah, I remember at one point when I was on dialysis, I was switching over to peritoneal dialysis. And so I had my peritoneal dialysis tube in my abdomen, and then I had my hemo tube in my chest.

Sara Murray: Oh.

Candice Coghlan: And I was dating my, my now husband, but at the time, you know, I was 24 and we'd only been dating a year before I'd been diagnosed. And so it was this strange place to live in where, you know, you're in your twenties, you're in your head you're like, "This is where I probably will look my best and I'm supposed to feel my best. And yet I have these tubes hanging off of my body." So, you know, as much as I could, I would make jokes about being bionic or, you know, you know, just to lighten [00:08:00] the mood.

But did you were you dating, you know, before you had your lung transplant, when you had those tubes, like, how did that affect.

Sara Murray: I dated on and off.

Candice Coghlan: Yeah.

Sara Murray: You know, a couple years here, there, whatever, like typical teen dating stuff. Most people, like, I just found it's easier to be transparent, right?

Candice Coghlan: For sure.

Sara Murray: I would say, this is my situation. You can't handle it. You don't like it. Whatever. Right.

Candice Coghlan: Off you go.

Sara Murray: Especially in teen years, it's not like I had an expectation. I was going to marry any of these people.

Candice Coghlan: Right.

Sara Murray: So I'm like, whatever, this is what it is. This is my life. I have to do these treatments. I have to take these pills. I have a tube in my body. It's not going anywhere anytime soon.

Candice Coghlan: Yeah.

Sara Murray: You know, and it's surprising, like maybe just people I met along the way, whatever everyone was for the most part was really okay. But I think cuz I was okay with it and I mean, I did all the care for myself. I didn't need somebody stepping in and, [00:09:00] and maintaining my tube or, you know, getting my meds. Like it was all me. So I think that that possibly is part of it, right? Like I imagine had I met someone and been like, "You have to do this, and this, and this, and this for me," they may have been like, "Whoa."

Candice Coghlan: Right.

Sara Murray: Forget it.

Candice Coghlan: And how early did that happen, where you were in, you know, total control of caring for yourself and your meds?

Sara Murray: Fairly young. Yeah. Oh geez. It's hard to remember for sure. But I know when you do the percussion physio, there was a machine you used for it. And part of what you have to do is on your back, you lay on an incline board.

Candice Coghlan: Okay.

Sara Murray: And the percussion would happen on your back. And, but this machine, it was fairly heavy. So I used to have like a family member would do this for me cuz you know, and I, I thought it through and thought it through and figured it a way I could hold my arms on the board that I could do my own back.

Candice Coghlan: Wow.

Sara Murray: So, and I was [00:10:00] probably 13, 14 when I started that. So I literally didn't need anybody. Which is, you know, like I'm hugely independent person. And I don't like relying on people. So when I figured that out, I'm like, oh, you know, I can go anywhere and do anything cuz I can just do it me. Right? Like just doesn't have to be that second person involved.

Candice Coghlan: And so I don't have knowledge about cystic fibrosis, so that machine that you were doing, what was the purpose of that?

Sara Murray: So it was called a precursor, and it's like a modified jigsaw.

Candice Coghlan: Oh, okay.

Sara Murray: But where the blade would be was a cup kind of like a rubber suction cup looking thing that was covered in a leather piece and it would hit the chest, and that while you're on the board with your head facing down, and it would loosen mucus in the lungs.

Candice Coghlan: Okay.

Sara Murray: So, because in CF lungs, the mucus is very sticky and thick.

Candice Coghlan: Okay.

Sara Murray: The [00:11:00] idea of, I, I don't believe they do so anymore, but it would loosen the mucus. So then you'd be able to cough it out, whatever was there.

Candice Coghlan: Okay.

Sara Murray: That had come loose, could move. So it wouldn't settle and stick so much in there.

Candice Coghlan: And how often would you have to do that?

Sara Murray: Twice a day.

Candice Coghlan: Twice a day.

Sara Murray: Right before my transplant, when my lungs were bad, I would do it three or four times a day.

Candice Coghlan: And did that give like a little bit of relief afterwards?

Sara Murray: Yeah.

Candice Coghlan: Like you would feel better?

Sara Murray: It did. It just felt like, I don't know. I think again, that comes down to me being controlling and trying to cause I knew, "Okay, I'm losing control of this situation at this point. So if I do more treatments or I do whatever, then I can kinda reel this in."

Candice Coghlan: Mm-hmm and I, I hear that from a lot of people who are living with chronic disease. We lose so much control over certain things that the things that we can control.

Sara Murray: Yeah.

Candice Coghlan: We grab onto, right?

Sara Murray: Yep.

Candice Coghlan: It's that comfort that, "Okay. I can control this." Like for me, [00:12:00] my meds are something that I can control. I take them at the exact same time, four times a day. That's my little bit of control in my world that, if I get sicker, if something happens, I can at least say to myself, "I did everything in my power to make sure that I was as healthy as possible, right?"

Sara Murray: Exactly. So then it doesn't come back on you, right? It's like, I didn't screw it up.

Candice Coghlan: Right? Yeah, it's, it's almost like a, our small level of comfort that we're doing everything we can. Yeah.

So you're doing this treatment two times a day, and then as you get older, you're doing it more and more. So once you got to that point where things were getting more difficult to breathe, when was that discussion that a transplant, maybe something that you'll need?

Sara Murray: Well, weirdly enough, when you, maybe it's just me, but because your lung function just slowly goes away, it's not like you feel it.

Candice Coghlan: [00:13:00] Okay.

Sara Murray: You don't just wake up one morning going, "Oh my God, I can't breathe."

You kind of learn to live in that situation. Right? So as much as I knew, like I'd go up the stairs and I'd have to sit at the top stair and rest for a few minutes, that's just what I did. So I never myself thought, "Oh no, I'm in bad shape."

I had this maybe, I don't know, denial or what you would call it. That I would always be okay.

So it's actually Dr. Tellis at St. Michael's Hospital, who in an appointment said, "Okay, your lung function's 23%."

Candice Coghlan: Oh.

Sara Murray: And at which I, I mean, I knew what it was but she's like, "You know, at this point, once we hit 20%, you have less than two years to live. So I want you to go be assessed for lung transplant. Well, you're strong enough to do this stuff and whatnot."

And I'm like, "Okay, whatever." Right? Because again, even at that point, I'm not buying into this, this is gonna kill me [00:14:00] thing. And maybe it's just like something in my head trying to balance me or whatever. I don't know, that I'm not gonna accept that, this is it at 26, I get to two more years. No.

So cuz I really like her. I'm like, "Okay, I'll go do this fine. Sure. Whatever you say."

So I did all the testing was in the summer and I dunno, I was, perhaps end of July, beginning of August. Anyway. So it's like a week kind of you're down there for a week.

We stayed at a hotel and they test everything, right? Like your heart, your kidneys, your liver, they look at everything and anything to find out that, everything will work. And so I did all those tests and I ended up being able to squeeze everything in and getting to leave on the fourth day instead of the fifth.

I don't know if cuz when I get run down, I'd pick things up easier. So after that week, then I was sick. I caught something like I, I had a long infection. So I got set up [00:15:00] to do home IV cuz that's what I did. I didn't go in cuz I was there every few weeks. So I would do a lot of it at home. So I went and got a pick line put in and went home to do two weeks of IV antibiotics.

It was labor day long weekend and it was the Saturday and I was supposed to come off of everything at the beginning of the week and I started running a fever.

Oh.

And this isn't right. I shouldn't get a fever now. Like the infection should be gone. What is happening?

Right.

The VON nurse had come in and she checked and it wasn't crazy high or anything. And she's like, "okay, it was a long weekend."

Of course on top of everything. Right?

Candice Coghlan: Right.

Sara Murray: Okay. Well, let's see what we could do. And so then on a Sunday it was worse. And then the Monday, I was like horribly sick.

I had oxygen in my house to use if I got on my treadmill. [00:16:00] So my dad dragged that upstairs just to put me on constant oxygen, cuz like my fingertips were blue. My lips had gone blue. I felt like death. Like it was awful how sick I was.

Candice Coghlan: That's so scary.

Sara Murray: We called the hospital and we could only get some respirologist on call who really had nothing to do with CF and said, "Oh, well bring her down tomorrow when her clinic's open."

So how the heck I made it from the Monday to the Tuesday morning. I can't tell you. I was so, so sick through the night.

And then my parents drove me and got to St Mike's and they admitted me. On the spot and they actually put me on a mask that was like shooting oxygen at me too, because I like the little prong thing wasn't enough. And they put me in a bed and they told me you can't get out of bed.

Like heart rate's crazy. You don't have enough oxygen.

Candice Coghlan: Oh.

Sara Murray: I remember cuz they put me on a bipap machine it's called it's like a cpap idea, but [00:17:00] I was kind of getting like crazy and it is because the carbon dioxide level was building in me. Cuz I wasn't breathing right I wasn't expelling that. So they hooked me up to this thing and it would like push the oxygen in and pull it out to get rid of the carbon dioxide.

I remember my brother coming in and visiting me and he's asked me questions and I'd start to answer and I couldn't remember what he'd asked me. Like, it was really weird.

During all this time, I got the call from Toronto General saying you were approved to be on the list for your lungs. Okay. But at this point I don't care because I'm messed up in my head. I'm thinking, "Okay, I have to figure out how I'm gonna get better."

Great. I'm on the list, but I gotta get better from this one.

Candice Coghlan: This is my priority here.

Sara Murray: And so then doctor came over from Toronto General to St. Mike's and I signed the paperwork there and I actually had to do a will and power of attorney. [00:18:00]

Candice Coghlan: Oh my goodness. This is age 26.

Sara Murray: Yep.

Candice Coghlan: Oh my goodness.

Sara Murray: A lawyer came in and I had to sign all that. But again, I'm not taking this in because I'm messed up kind of, and all my priority is, is getting through this infection.

Candice Coghlan: Right.

Sara Murray: Like, I don't care about the rest of it.

Candice Coghlan: Right.

Sara Murray: That's like in the future, I'm in this moment. And then, so that was all happening. So there's labor day long weekend, all in that first week. And then, I kept like slowly getting better. And my sister had come down to see me and give my parents a break. And it was on the Saturday and she'd come down and we hung out and we went for a walk.

I had a wheelchair at the time, so I pushed a wheelchair, like two city blocks.

Candice Coghlan: Oh.

Sara Murray: We got in the wheelchair and she had brought me back. And that was like the furthest I had gone since I'd gone in the hospital, which seems like [00:19:00] nothing, right? But at the time, like this is huge, cuz I wasn't even able to go like anywhere initially.

Candice Coghlan: Right.

Sara Murray: And she had said, when you got back in the room, she's like, "When do you think you'll get your call?" and then I'm like, "Oh, well probably in February," cuz my best friend was getting married in February. And I used to be in her wedding. I'm like watch be right around her wedding so I won't be able to go or something.

And she left about eight o'clock that night. And then it was about quarter to five Sunday morning that they woke me up.

And that they had the lungs.

Candice Coghlan: Oh.

Sara Murray: Days. I waited days. People wait years, but I didn't know I was so sick. They put me to number one on the list. When I went in, I knew nothing of any of that. I call my family, you know, like middle of the night, "Wake up. Guess what guys?"

And I was moved over to Toronto General by paramedics and [00:20:00] it was crazy. They test you, they x-ray, you, they do blood work, all this stuff because they have to see like your fit for this surgery.

Candice Coghlan: And what are you thinking through all of this?

Sara Murray: I was scared to wake up from the surgery, the amount of pain I would be in.

Candice Coghlan: Right.

Sara Murray: I focus on weird things, right? In my head. I knew I wouldn't die. The surgery wasn't gonna kill me. But I knew when I woke up, it was guaranteed, it was gonna not hurt.

Candice Coghlan: Right. Right.

Sara Murray: How much pain is this gonna be? This is gonna be not fun. So my parents had gotten there first and then my sister got there. A friend drove her down. My nephew was a year and a half, so my brother-in-law stayed home with him. And then my brother came and then you've hurried, you've done all this stuff. And then you just wait.

You're like, what's happening? They're like, oh, you're probably taking you for surgery around noon.

And then there's just this weird, really long wait. Silent wait. [00:21:00] And we chatted and whatever, cause I was in a room, like an actual patient room, and it was early in the morning. So they were coming in to see me like one at a time because there were still other people there.

It was in a step down unit, three other people. And and then they came in at like just after 11 and they're like, " Okay, we're going down." "You said at noon!"

Candice Coghlan: Right.

Sara Murray: What the heck? And so then I went downstairs and your family can only go so far and then the doors and you have to say goodbye. And I was okay. And then they put me in the hallway outside of the OR. There's not a soul to be seen. It's like you're in an abandoned part of the hospital. It was so weird, I guess, cuz it was like Sunday and whatever. Right? And I'm looking around and there's nobody and I'm outside the OR, and then I started to cry because it, now it's hitting me like, holy crap.

Candice Coghlan: It's real. It's real.

Sara Murray: I gotta go in there and this is what's happening [00:22:00] to me. And I remember somebody came out and they're like, "Don't cry. Why are you crying?" I'm like, "I think I'm scared."

Candice Coghlan: Yeah. It's all hitting you, right?

Sara Murray: Yeah.

" Well, aren't you happy?"

I'm like, "Well, I'm happy, but at the same time, this is like daunting task ahead of me here." and then they wheel me in, they strap you down on the bed and they're all like running lines and things into me. And then they have to put the line into your jugular. But I'm like, "Please don't do that while I'm awake."

Candice Coghlan: Right.

Sara Murray: "Put me under."

"Oh, you wanna be under?"

I'm like, "Yes, I don't wanna that." I'm overwhelmed because you're all doing stuff to me anyway. I don't think I can handle my neck.

Candice Coghlan: Right. There's enough happening.

Sara Murray: Yeah.

Candice Coghlan: Yeah.

Sara Murray: They're like, "Okay." And then they put me out and then my surgery was 10 hours.

Candice Coghlan: Oh my goodness.

Sara Murray: When they got in my lungs were so bad, they were like mush. The doctor said he doesn't even know how the hell I was alive, because like, it was literally like, they were just mush in his hands. So they had to put me on the heart lung machine.

Candice Coghlan: Okay.

Sara Murray: During the surgery, so [00:23:00] that extended the period of time. I mean, my, my family's upstairs waiting, but nobody.

Candice Coghlan: Was telling them.

Sara Murray: Nobody's there to come update them or whatever. And they're like looking at the time going, "What the heck?"

Candice Coghlan: What's going on?

Sara Murray: You know, this has taken a long time. Eventually they found somebody who looked into it for them and said, "No, she's still in surgery." and then the doctor came in 10 hours later and said, "I'd done well." And they were like, probably the best pairs he's ever seen.

Candice Coghlan: Oh.

Sara Murray: And then I was put in the ICU and they all got to come see me. Apparently I waved at them, but I don't remember.

Candice Coghlan: Oh.

Sara Murray: Yeah. And then they came back the next day.

Candice Coghlan: It's wild to think everything that happens between when we're put out for surgery.

Sara Murray: Yes.

Candice Coghlan: And then when we wake up these amazing people who are using their hands to bring us back to life.[00:24:00] And so you wake up in recovery, most of us don't remember a thing at all that first day. When do you come back to Sara and, and know what's happened?

Sara Murray: My first memory was the next day, and they let my whole family come in again. And I remember seeing them, they kept calling me. Right. Sara, Sara, the nurse. And I'm like thinking, "Oh my God, woman,"

Candice Coghlan: "Let me sleep."

Sara Murray: "I'm out. Leave me alone. And I finally opened my eyes. And I saw everywhere. Like I could see everyone. And so I looked at each person, I remember they're standing like around to my bed and I can't talk because they got the tube down my throat or whatever, and I kind of smile and then I think I was out again. But I do remember them being there.

And then it was, oh gosh, I lost time in the ICU it's weird and then I kept [00:25:00] insisting, like later I came to, no one was there and I kept insisting, they pulled this stupid tube outta my throat cuz it felt awful and I couldn't talk. Right?

Candice Coghlan: Right.

Sara Murray: And they're giving me a piece of paper and pen so I could write down what I wanted and I was so weak. Like I couldn't even write really. I'm struggling to write things and kept pointing, so I wrote on the paper, 'out'.

Candice Coghlan: Out. Oh.

Sara Murray: Cause I hadn't been using it and they're like, "oh we gotta wait." I hadn't used it since I came for the surgery. So they did end up pulling it later that day. And then I became more and more aware fairly quickly. I mean, I was out of bed a couple days, like walking on the spot beside my bed. I bounced back fast, but I'm super stubborn so that's part of the rain.

Candice Coghlan: Yeah. Could you, could you feel a difference, like once you were aware of what was going on, you felt it immediately?

Sara Murray: Yeah. Cuz I could breathe. For me, by the time I got to around transplant, breathing was like, that's kind of your breath, right?

And then suddenly [00:26:00] I'm just naturally on my own, my body was using my full lung and taking like real breaths again. And like that's weird.

Candice Coghlan: And so you noticed that that difference, like for somebody like me, that's just something that happens. I don't even think about breathing, but for you, was that such a conscious thing before the lung transplant that you had to think about breathing?

Sara Murray: I don't think I'd thought about breathing. So if I laughed, I would start coughing and coughing and coughing. Right? So you learn to kind of not laugh, or just be like ha right, because you knew if you really got laughing that you would cough to the point you wanted to throw up. Right?

So things like this. So I was aware of, or if like I went up the stairs, I'd be like, you know, like you could feel these things. Right? But I don't know if I thought about my breathing, but you would notice when it was really hard or if you went outside in the cold, I had to have a scarf on my face or I'd cough. So as soon as I have this, and then I notice I could, well, a [00:27:00] little hurt to, to laugh because of my incision and stitches, but, you know, I could laugh, I could do things.

And when the first time they said to me, "Okay, get dressed, you're leaving and going out to dinner." and I went outside and it was kind of cold and I stepped outside. And then my immediate reaction is like, "I'm going to have coughing fits and I don't have a scarf." And I started walking towards a restaurant and I was walking a good speed. I wasn't coughing. I wasn't short of breath. And I'm like, "What? What's happening right now?" So you start noticing as you go along that it's easy to breathe. It's easy to do things. I don't cough.

Knock on wood. Haven't had any lung infections or any issues in which I cough. I have no sputum or flem, whatever they wanna call it anymore, like haven't in almost 19 years.

Candice Coghlan: Completely different life. So you've almost lived now close to the same amount of time with your new lungs than with your old?

Sara Murray: [00:28:00] Yeah.

Candice Coghlan: Is this lung transplant a cure for your CF or are you still part of the cystic fibrosis community?

Sara Murray: It is not a cure. It fixes the lung issues in the sense of you don't have CF. So once you have the transplant, you no longer have cystic fibrosis in your lungs. Okay. The why of it? I don't know.

And it doesn't like come back to your lungs.

Candice Coghlan: Okay.

Sara Murray: For whatever reason. But the rest of me still has CF.

Candice Coghlan: Okay.

Sara Murray: So it still affects your pancreas. Hence, so I have to take enzymes to eat, cuz I, I don't make enzymes when I eat, I have nothing to break down food and digest it and do what's supposed to do. You have enzymes in your body, so you eat and they automatically work. And I don't have them like nothing. I'm diabetic. The prednisone from the transplant didn't help that, but I already had issues with it. Cuz my pancreas doesn't work. My body doesn't make the insulin right, or at all, although CF diabetes is different than regular type one or type two, [00:29:00] like every once in a while, my body will make insulin. So I don't have a day where I have more lows. I'm like what? The, so it's strange.

So it affects that and it can affect your bowels and luckily you knock on wood. I don't have that issue. It can affect, like a lot of people with CF suffer from infertility. Just basically anywhere in your body that you have mucus. Most people's is watery, with people with CF it's thick and sticky.

So anywhere that would come into play is affected through CF.

Candice Coghlan: Okay.

Sara Murray: So you have to still see the CF clinic and be followed by them for those aspects. My lungs no longer have CF, but then, you're trading it for different problems. It's not like, I have new lungs I'm fine forever. You have side effects in whatever that come with the medications for, as you know, with transplant.

Candice Coghlan: So, you have your new lungs [00:30:00] and you've got these new experiences ahead of you. And so six years later, you become a mom.

Sara Murray: Yep.

Candice Coghlan: can you tell us a little bit about that experience?

Sara Murray: Yeah. I actually met my husband maybe eight months or so after I had my lung transplant.

Candice Coghlan: Wow.

Sara Murray: So he never knew the CF life of it per se. And we got married and then we wanted to have a kid. I went to Mount Sinai, the high risk pregnancy clinics and whatnot, and it kind of came down to, because of the medications I take and think everything like I'm complicated. Right. So I could have had a baby. I could have carried a baby. Probably would've been born premature, but they, they told me, they could guarantee by the time the pregnancy was done, I would be on dialysis.

Candice Coghlan: Wow.

Sara Murray: So I'm like, "Well, I don't wanna do this to be sick. Right?" Like, how's that fair to a child that I have it, and then I'm sick. And I can't give a hundred percent. Right? I wanna give a [00:31:00] hundred percent to my kid.

And so we're like, it doesn't feel like the right option. Right? Like it's just not fair. So then we started looking at adoption and private adoption. Well, I'm not a good candidate because they will look at my medical history and say, Hm. You know, despite we had a house, we had, okay. Income. Like we could, we had a cottage, we had like lots of supportive family. We, you know, I have this heavy medical thing in there. So it's through private adoption, which on its own takes a long time for people to do.

Candice Coghlan: It does.

Sara Murray: I'm not someone, people are gonna easily choose.

Candice Coghlan: Okay.

Sara Murray: So that's kind of a door closed. We could have put our names in and waited 30 years. There's no guarantee on it.

Candice Coghlan: Yeah.

Sara Murray: And then we knew some people who adopted through Children's Aid and we started looking into that.

And I'm like, "I don't know, because I have health stuff. I have to be on top of me. Can I take on a [00:32:00] child that was given a really bad start in life? So I don't think I can step into that role.

Candice Coghlan: It's a hard thing to think about. You already have so many health issues that you have to care for. And then thinking about, could I care for a child who also has health issues? If then, I have flare ups or if I have things that go wrong, do I have the capacity to do that? That's a hard question to ask.

Sara Murray: Yeah. And at the end of the day, it truly came down to, I probably will only have one child. I, I can't, I can't make the situation, the worst case scenario right off the get go. When the baby's born and there's something there, then it's there. Like my parents didn't plan on having a child with cystic fibrosis. If that lands in my lap, it's because it's meant to be, but I can't set out into a situation I already know will have a lot of work behind it.

Candice Coghlan: Right.

Sara Murray: So we [00:33:00] decided this was not the method to go per se. Well, during all this time, my sister came along and said, "Just let me be your surrogate." And I'm like "No."

Candice Coghlan: Wow.

Sara Murray: I can't do that to you. She had my nephews and they didn't want any more children. And she's like, "I get pregnant easy."

Like with both boys, she got pregnant right out of the gate. She has like five hour labors. She's made to have babies.

Candice Coghlan: Made to have children.

Sara Murray: I, I said no. And she kept coming back to me and saying, "Let me do this for you."

And I kept saying, "No, I can't."

And then finally, when things were so crazy and I said, "Okay, well we need rules."

Candice Coghlan: Rules. Okay.

Sara Murray: Because I can't just have it. Open ended, like, so we agreed. There'd only be three tries and et cetera. We set our boundaries because it has to be [00:34:00] comfortable for everybody.

Candice Coghlan: For sure.

Sara Murray: So then, we went and saw surrogacy clinic thingy and, and I dunno, did the first attempt. And then we were at the cottage and, I dunno why. And she was like, "I'm gonna have a glass of wine." I'm like, "No, you can't."

Candice Coghlan: Right.

Sara Murray: "I'm gonna have a glass of wine."

And I'm like, "No, you're pregnant. I can feel it. It worked you're pregnant."

I wouldn't let her have a glass of wine.

Candice Coghlan: Amazing.

Sara Murray: And she's like, "Oh my God."

I'm like, "No, trust me. It worked. I know it like a hundred percent in my heart."

And then sure enough, it had worked the first try.

Candice Coghlan: Wow. The first try.

Sara Murray: Yeah. Just like that. And then my daughter was born and the same thing, like a five hour labor, boom.

Candice Coghlan: Oh.

Sara Murray: Then I had a daughter.

Candice Coghlan: Incredible. An incredible relationship you must have with your sister and is your daughter like very close to your sister as [00:35:00] well?

Sara Murray: Well, yes and no, like their aunt and niece, right? That's what they are. My daughter I've always told her from the beginning that auntie grew her and, and had her and stuff. Cuz I couldn't.

Candice Coghlan: Yeah.

Sara Murray: You know, when she was real little, like I just simple terms like "Mommy's tummy was broken." Now she's 13.

We have, she knows bigger talks, but it's always been open. Like this is, this is how it happened. Kind of thing.

Candice Coghlan: Amazing. And so have you also been open with your journey with cystic fibrosis? Does she know a lot about that?

Sara Murray: Yep. She knows everything. We've never kept anything from her. She knows that I had CF, she knows about the lungs. She knows that I'm diabetic. It's all open. Right. She needs to know it's only right .

Candice Coghlan: Wow. And so you, you have this beautiful daughter and your lungs are working well. And then at what point did you start to notice that you either weren't feeling [00:36:00] well or was it a clinic visit?

Sara Murray: It was about eight years post when they said, "Okay, your kidney function is getting lower," and you know, eat this drink, lots of water, kind of thing. And then it just kept slowly going down and then eventually, you know, drops enough that they're like, " You need kidney transplant."

I'm going "Great." Yeah.

Candice Coghlan: What was that like?

Sara Murray: I have parts from everybody. Well it felt stressful. The thought of waiting for deceased donor kidney is 10 years or whatever. Whatever it is at the moment, I'm not certain. And it's just one more thing, right? I feel like I jump these hurdles and then I'm like, "Okay, I'm in a good place. And then, oh, here we go again. Thanks."

So it felt overwhelming and then I didn't wanna have to do dialysis. And it ended up my sister, same sister who carried my daughter said, Let me [00:37:00] give you a kidney."

We're back to this thing again. Anyway, she's the same blood type, da, da, da. We start proceeding with this and I have antibodies against her. So if I got her kidney, I would reject it, which I thought was kinda funny. All those times we fought as a kid. these antibodies.

Candice Coghlan: It came through.

Sara Murray: So then they suggested the pair exchange program. We opted to do that route.

Candice Coghlan: And so for someone who doesn't know what the paired exchange program is, what goes on with that?

Sara Murray: They throw us into like a pool of people who have agreed to be in. So I have somebody willing to donate who's not a match to me. And Joe has someone willing to donate. Who's not a matched to him. So they gather all the people. And a couple times a year, they sit down and, and crossmatch everybody and try to complete like, imagine like a circle.

A goes to B and B goes to C and C goes to, and [00:38:00] so everybody gets a new kidney, but they're not from their own person. There's somebody in this circle who does it. And it's, it is really kind of cool and is really super coordinated and I had a large circle. It was like seven or eight people.

Candice Coghlan: Wow.

Sara Murray: Are pairs in like the circle and we were matched originally. And then they called and said, "The match fell apart." Oh, this is partway in because it, someone ended up developing antibodies against who had they paired them to. So that felt like super disappointing.

Candice Coghlan: For sure.

Sara Murray: And then I right on the cusp of having to be on dialysis. So had I been able to get that kidney, I wouldn't had dialysis because the surgery would've been really soon.

Candice Coghlan: Right.

Now that's not an option and they are only matching couple times a year. It's months away before they're gonna do this again.

Right.

Sara Murray: What do you do? So I opted to go ahead with peritoneal dialysis [00:39:00] and start it. They did call and say, "We can cancel your appointment and you can wait." And I'm like, "Nope, cuz I don't know when this is gonna work out. And I don't wanna feel like horrid before."

Candice Coghlan: Right. You wanna be healthy before your transplant. As healthy as possible, right?

Sara Murray: Exactly. So they put in the catheter and then for the dialysis and then you have to wait that little bit before you can start it.

So it was the December that they started. I actually started on the peritoneal dialysis and it does make huge difference. Right?

Candice Coghlan: It does.

Sara Murray: I felt way better. I was carrying so much excessive fluid. It took away like 10 pounds of weight off of me just from the fluid. And I was less tired and whatnot. And then in the February they did the next match and they matched and it worked. And then the surgeries were in April.

Candice Coghlan: Wow. So you did dialysis from December to April?

Sara Murray: Right. I did the last dialysis the night before my surgery.

Candice Coghlan: Wow.

Sara Murray: And then they said, "If the kidney turned pink and starts making urine right away, we pull the catheter and if it doesn't, then [00:40:00] we leave it for a while," which I'm sure you heard the same.

The kidney started working right away. So I came out and they pulled the catheter already. And

that was that.

Candice Coghlan: And so this is your, now your second transplant. Were you thinking similar things or did you kind of feel a little bit more comfortable in that you'd done this before?

Sara Murray: I had comfort with medication aspects. Comfort with the hospital, because I've now been here for so many years.

Right.

All of that was there. It was weird, cuz I didn't really know a lot about renal. My whole life had been lung.

Candice Coghlan: Right.

Sara Murray: I found the pain was really different because it's your abdomen now versus like your chest area.

Candice Coghlan: Yeah.

Sara Murray: It almost hurt a bit more in recovery than, like lungs is a harder recovery, but the abdomen hurts longer just because of where it is. Right. You

set it on these muscles in your stomach and you use your core for everything. Right? So there was pain longer. I thought at the time I am too old for this stuff I have to.[00:41:00]

Candice Coghlan: And so again, when you woke up this, now second transplant that you've had without a peritoneal dialysis tube, that must have felt fantastic seeing that bag hanging from your bed with pee in it.

Sara Murray: I was free.

Candice Coghlan: You were free. Yeah. And once again, there's this feeling of freedom and you know, you're gonna get your life back again.

Sara Murray: Yep.

Candice Coghlan: And so your kidney worked and you woke up feeling, other than the pain, did you feel different when you woke up?

Sara Murray: No, not really. Not like with the lung. I was still, which is like probably weird for some people cuz some people don't realize when you go on to dialysis, some people stop going pee. That never happened. I always still was going to the bathroom up until my surgery, but I wasn't that far into dialysis yet. So there was nothing different in that way. Other than in the initial, a few days where you're [00:42:00] stuck on a, in bed with the catheter to go to the bathroom. Which was awful. I hated that feeling.

As soon as I was cold and I can get up and go to the bathroom and do my thing, it was just back to normal life, but I wasn't tired and cold and that sort of stuff. But I was prior, so that was improvement.

Candice Coghlan: Right. And so, did, were there any major differences between your experience with the lung transplant and with the kidney transplant?

Sara Murray: Well, the surgeries itself of course, is very different. The recovery lung was probably a bit longer of recovery, cuz it's such a bigger incision.

Candice Coghlan: Right.

Sara Murray: And so many more hours in surgery and whatever and but nothing like crazy. It's still major surgery either way. It's still, you gotta come back. I found I did every single thing the doctors told me.

Get up out of bed, walk. I did it, [00:43:00] even though I'm like, "Oh, I wanna curl up in a ball and cry right now." It really hurts. I'm very pro get active move, do what they're saying. Don't go against the advice. So, you know, I'm able to push through and do that.

Candice Coghlan: So your recovery was probably faster because you were trying to do all of these things. Get up and walk around.

Sara Murray: Yeah. And I'm not pro pain meds.

Candice Coghlan: Okay.

Sara Murray: I don't really take them and I believe them that would allow me to know, "Okay, I've done enough," because the pain was at such a level that I knew to back talk.

Candice Coghlan: So after your kidney transplant, how did your relationship change with your sister or maybe it, it didn't at all with her being part of that paired exchange program.

Sara Murray: We were our whole lives. Like we've been close. Like almost a five year age difference between us, but we were just close, right?

Like, by the time she'd be like my mom. Right. She's so much older. She'd try [00:44:00] to get in trouble and stuff. I don't think it changes, it. There's a weird sense of guilt you have from putting someone through that, there's a weirdness that comes with the idea, you can never repay this.

Candice Coghlan: Right.

Sara Murray: No matter what you do, you can't say thank you enough and you can't like even adapt, right?

It's not like, she's like, "Hey, you owe me."

Candice Coghlan: Right, right.

Sara Murray: But you still feel like, "wow, crap. I put you here a lot." And not only for that, I'm now in the situation where she carried a baby for nine months, for me had to give birth to the baby. And then she gives me a kidney and has a, you know, a big recovery from that cuz it's not a small surgery for her, either on that end. So there's definitely guilt at times and nothing put on me, it's just internally that I can't ever do anything for you that way. Right? You know, when my daughter's born, I bought her a diamond necklace.

When, you know, I, when she was pregnant, I made [00:45:00] sure to take care of my nephews and do anything I could, help her that way. But it's like, it's still, it doesn't seem even . Right.

Candice Coghlan: Right, right.

Sara Murray: I can't give her an organ back to go, "Okay. You gave me your kidney. I'll give you part of my liver." It doesn't work that way. I'm not in the position to do that. Nor does she need a liver. It's just, it's strange. But she's there for me. I'm there for her. She's my sister. It's not an everyday discussion. I don't think about it every time I see her, like, "Oh no. She did this for me. What should I be doing right now?" It's not like that. But occasionally if I think about it or talk about it, then I'm like, "Man, she's like a better person than most," because a lot of people wouldn't do all she's done.

Candice Coghlan: Absolutely.

For myself, I feel the same way, in a different way. You know, it was my mom who was the donor for me. She donated her kidneys. So, trying to think about ways that you can [00:46:00] show gratitude to them and how to express our gratitude.

Like you said, we, can't not, not that my mom needs one either. She doesn't need a liver, but you know, I I'm with you. I couldn't do that even if she needed one. So you know, I guess for me, it's just making sure that I take really, really good care of the kidney that she gave me. And that I, I live my life in a way that I think she would be proud of and that, you know, she would be happy that she was able to do that for me so that I could go on to do the things that I'm I'm doing. And I, I feel like that is a little bit of helping me with, with the guilt that I have as well of knowing that I put her through that situation is trying my best to live a way that I think she would be happy that she gave that kidney to me.

Sara Murray: [00:47:00] Right.

Candice Coghlan: So I'm wondering thinking about that, do you have any advice for people who might be Hesitant to accept a kidney or a liver from a living donor because of those reasons that, they may think, "do I deserve this?" "Do I wanna put my family member at risk?" All of these things that come into our heads when we're thinking about saying yes, and I think I'm like, you, you say no enough times that, you get you get torn down by the person.

They're like, "it doesn't matter if you say no, I'm, I'm doing this either way. I'm gonna be your donor." and that was my mom. "I'm gonna be your donor, whether you say it or not, this is happening." And so I was very grateful and, and lucky that she was my donor and it worked out the way that it has. But do you have any advice for people who are thinking that, you know, having that difficulty?

Sara Murray: I would just do it unless you have some like weird, bad [00:48:00] situation with this person then maybe no, but simply because the odds of getting one another way aren't as good. Deceased donor list is so, so long. If you get a kidney from deceased, the success rates aren't as good as if it's a living donor and, and this is your life you're playing with at this point. And if the other person's healthy and strong and have gone through everything and really can say, I still want to then do it.

Like the feelings I have aren't so consuming that I hate myself or my life. And I'm like, why did I do this?

Candice Coghlan: Right.

Sara Murray: You feel bad that the other person suffers, right? I'm used to having, this sounds weird, but I'm used to suffering, like I'm used to basic, I'm used to having bad medical things done to me and I can cope. Right?

Candice Coghlan: Right.

Sara Murray: I felt bad that she had to suffer when she's never like, really other than had her boys. Being in hospital or had anything happen. Beyond that aspect, if the person's [00:49:00] fully in and understands all these things, then I would say, yes, I wouldn't undo what I've done. I wouldn't mm-hmm go back in time and not have taken it. You just have to understand that you'll have funny feelings about it at times, which is okay.

Candice Coghlan: Yeah, absolutely. So I'm wondering, you know, another piece of advice. Do you have any advice for people who are, and this may be

completely different pieces of advice, people who are living with CF and how to, how to manage that, or people who are living with, end stage kidney disease? How did you get through this with such a positive attitude, it seems?

Sara Murray: With CF and it wasn't pushed when I was a kid, but. Exercise, exercise, exercise. Work, those lungs. Do what you can with the situation you have. But I think it's very important. I believe it's now more of a, a thing within the CF community, but when I was a kid, you know, it was like, "Oh, don't do that because of your lungs."

Candice Coghlan: Right. [00:50:00]

Sara Murray: And prior to my lung transplant, I joined the gym and I really work out hard. Right. I think that's why I had such a fast bounce back from it. But I think it's very important to be exercising, taking your medications, don't skip your enzymes or this or that, because it's embarrassing. Follow what they tell you. They know what they're talking about. They know what they're doing.

And then with kidney, it's different with kidney in that, you get started limiting foods and you have to drink water up into a certain point. And then you shouldn't drink wa like that's, it's just such a different thing.

With kidney, I would just say, as they tell you to like, go off certain foods, or you only drink two litres a day, or this or that, like again, you just have to follow what the doctors say. You don't know, better seeking out weird and wonderful ways to try and cure something isn't always the best choice.

A lot of people do that. But I think in any situation you have doctors, you have specialists, they [00:51:00] know what they're doing and if for some reason you don't feel safe or comfortable, then you find a different doctor that you do feel safe and comfortable with. But at the end of the day, I believe that they have your best interest at heart.

Candice Coghlan: That's good advice.

Sarah, I can't thank you enough for sharing your journey with us today and letting us be part of that ride. Even after the fact years later, after all of this has gone on you have been incredibly brave in, in sharing some of the most difficult things that you've been through and, and were so grateful.

I know that the listeners today are definitely going to be having some tears. But also you really inspire me and a lot of those people listening today. So thank

you so much for being here with me today. Now I would love to ask you to introduce our expert today. [00:52:00] Dr. Chaparro, as you have a relationship with her as well.

Sara Murray: Dr. Cecilia Chaparro is the Associate Professor of Medicine, University of Toronto Interim Medical Director, Toronto Lung Transplant Program, Fellowship Program Director Respiriology University of Toronto and Staff respirologist at The Ajmera transplant Center and Cystic Fibrosis Program, St. Michael's hospital. She's a first respirologist to hold a joint appointment in this St. Michael's hospital, Cystic Fibrosis Clinic and Toronto General's Lung Transplant Program.

And I met Dr. Chaparro years and years ago. Now at St. Mike's while I was cystic fibrosis patient. And it was in a similar timeframe that I was going over to Toronto General had my transplant that you were kind of starting to do both, I believe, because I know when I went over to Toronto General, you were there at points. So, [00:53:00] that was kind of nice to have a face I knew. You're going to this huge hospital with all these people to know that there's like a connection within the, the program, right. Was a comforting feeling. So welcome Dr. Chaparro.

Dr. Cecilia Chaparro: Thank you very much, Sara and thank you Candice for the invitation and having you with you today.

Candice Coghlan: Thank you.

Sara Murray: Dr. Chaparro, what inspired you to go into line and work with cystic fibrosis patients?

Dr. Cecilia Chaparro: I never saw CF a patient before I came to Toronto. I was born in Colombia, South America. And at that time, the possibility to diagnose patients with cystic fibrosis was really low. So I actually did never saw one patient with that.

When I came here, I, I met a few patients that were post transplant already with CF and they inspired me because first of all I knew before and after transplant, they were dealing with issues [00:54:00] that not any of the non CF patients would live with, but despite that, and despite some struggles, they wanted to really go on with their lives.

And, and that is something really, really to admire. So, so I, I started having an inclination towards the CF patients and, and everyone knows I am really

advocating always for the CF patients and the capacity to see them like going through a life that they are having ahead of them. To me again, it's inspiring and that's where probably move me, move me to go to CF.

Candice Coghlan: Incredible. And so thinking about your line of work with, with CF patients from a medical perspective, what are some of those challenges that those CF patients face?

Dr. Cecilia Chaparro: Yeah, I'm, I'm sure Sara already mentioned to you, but both before and after transplant, cystic fibrosis is not as the other lung diseases where you have only lung disease. [00:55:00] Right?

As a CF patient, we are facing a, a person who has multisystem disease. So the cystic fibrosis abnormality occurs in every organ that has mucosa. So that means many organs in, in the body. So it starts maybe with the sinuses, goes into the trachea, the lungs, but also the gastrointestinal system, the reproductive system, the urinary tract.

So all those organs will have abnormalities that will remain after the lung transplant. So we transplant the lungs, but we don't transplant the rest. So the body will continue having cystic fibrosis and our patients will continue dedicating time, post transplant to treat those diseases and complications.

Before transplant, of course, the main organ that gets damaged in more than 95% of our CF patients are the lung. So that's why they come to a lung transplant. And the main organ, the lungs that require plenty of [00:56:00] work. So our, our CF patients will dedicate long hours every day to chest physiotherapy in order to clean the lungs from those mucus so I know they can dedicate one hour two hours as the disease progresses, this production of mucus increases. And I'm talking about not at two table spoons or so we are talking about cups of the sputum that they have to manage and really treat. They need to use the inhale antibiotic treatments and parents or husbands or any family members will help them with the chest physiotherapy. Keep active to try to also get the exercise as a part of maybe that component that will help also move discretions because they produce every day there in, in a good amount. So that will take you any, any time meeting. I, I would just say two hours to four hours. It depends on how many treatments you do. But I said, this progresses that time is more and more.

You also have [00:57:00] pancreatic insufficiency. So the amount of calories that a CF patient would need to have is maybe in some occasions, double than what we normally will eat. So part of their job which is interesting because they

find this is not a pleasure. It gets up to a point where they don't enjoy food, as many of us would do, because they just feel forced to eat all the time. And of course, along with that, plenty of pancreatic enzymes. So I am telling you, they could have in a table more than a hundred tablets to eat a day to be able to also deal with the pancreatic insufficiency.

They could have gastroenteric reflux. They are taking anti acids to deal with that. Another problem that they could have is called the distal intestinal obstruction syndrome so that means the bowels are very slow. So there is difficulty really having normal daily bowel movements. So you need to take extra medications to deal with that. Some of our CF patients will have kidney stone, et cetera. [00:58:00]

So those are the things that are necessarily completely different from any other patient that requires only lung transplant. So that's why it's different post transplant. We may impact some of those preexisting conditions. And especially, I would probably mention that the gastro esophageal problems. We may sometimes make them worse post transplant because of the medication that we use.

So again the nice thing post transplant is they don't have to deal with all these care that they have to do for the lungs and they can breathe. They are not on oxygen, et cetera, but, but they still have CF. And there are some conditions that we need to be more on top of taking care of that. And surveillance is screenings to make sure that we are not missing anything. So they are not the patients that we followed per life, post transplant, as we do with other diseases because our CF patients will continue going to the CF clinic, so they are in a [00:59:00] limbo because they are not completely CF. They are not completely transplant. They are in the middle. But what we are trying to really work on is to maintain good communication between the two teams so that they are always even though they are here, they have care in one side and the other.

Sara Murray: And what kind of appointments and medical care can someone expect if they're living with CF?

Dr. Cecilia Chaparro: Well, I guess again, by seeing our CF patients before transplant, they have very, I would say rigid schedule. If they are even stable, they will have to come to our clinic every three months, at least. And in between if they have any extra symptoms or so that we can really review them because always they will have treatments. And I'm talking about not only since they are adults, I'm talking about since they are born, right.

The parents are taught to do, treatments from the beginning, they could grow different bacterias, different fungus. So they will have to be on [01:00:00] treatments. In many cases, they will have to come into the hospital, receive treatments for a long period of time. So again, that could start early in their infancy. And then if the disease progresses, it will be more often admissions to the hospital are, are quite common.

We do plenty of tests to, again, evaluate how their other systems are, nutrition evaluation, rehab evaluation. So plenty of follow up. So they are not a person that we treat and they disappear and they don't have routine follow up. So there are plenty of follow ups.

Post transplant again I would look into two areas, the transplant and the CF. So with the transplant, especially the first six months, I would say we see them very often. We need to make sure that we are not running into complications with the lungs, but we emphasize, that after that we need to go back to our CF teams so that they can follow the routine follow ups with their other systems, gastrointestinal urinary tract, gynecology, et cetera, [01:01:00] so that , the other systems are taken care of, and we don't miss anything.

From the transplant point of view after two years. And if everything is going well, then we see them yearly. But of course, in between, if we feel that there is a problem with the lungs, we will take care of that. We don't have CF care directly here at the Ajmera Transplant Centre so that's why we rely a lot in our CF colleagues at St. Michael's hospital or the Sick Kids where we also have the expertise, especially from GI to help us with our patients. So again, plenty of, of follow ups anyway even if, if they are doing very well from the lung transplant point of view.

Sara Murray: It's been a few years since I've really been in the CF world.

A lot of my stuff is transplant related. Now I do go once a year, back to St. Mike's for check up with my CF situation, but, what innovations or changes have happened in the past, like 20 years since I've been [01:02:00] a transplant patient?

Dr. Cecilia Chaparro: For both the pre-transplant and post-transplant, I can tell you what we have seen in the CF world. I am very happy to see changes that I never thought I would see. And that is the existence of medications that actually act directly on the abnormality of the cystic fibrosis. So that means the CFTR abnormality that the mucosa has in the patient that has cystic fibrosis. So there are medications that today actually are fixing that.

And we see the patients having various low progression of the disease. So it's been an experience, not only here, but around the world, where even patients who were already listed for transplant, they are taking off the list or they are, they are postponing transplant. We don't know if maybe at some point they don't even need a transplant.

We, we don't know, this is just really relatively new. But it's amazing to see that happening in my lifetime because I [01:03:00] never thought I would see that. So we are quite happy with that because there are less and less patients in the CF lists for transplant. So again, we don't know where are we going from here? So hopefully this is a permanent change and we would see long function improving.

So when the patients come to us, it is because there are not medications that are for their specific mutations. They are still on end stage lung disease. But we will really hope that even those patients will have at some point, the capacity to have any specific medications for them and then we'll see what happens.

In the CF world regarding transplant, I think that there are plenty of changes. I have to tell you when I came here 20 something years ago, we were transplanting CF patients that were like really not having many other issues.

First of all, I have to tell you that the CF patients didn't want the physicians and surgeons didn't want to transplant CF patients. So the transplant, it started here being successful in [01:04:00] 1983 and four years went by before we considered a CF patient. And it was not only here but around the world. And what the reasons were one that they, they were very afraid of these patients that normally will have infections in the lungs all the time. So they were afraid that those patients being exposed to immunosuppression, the risk of infection and deteriorating and failing post transplant was really high.

The second issue was that the nutrition was poor because of the pancreatic insufficiency. So they thought these patients are not really going to do very well.

And the third concern was they were afraid that even the new lungs will have the recurrence of the cystic fibrosis, which was not possible. And it's not possible because it's, this is a genetic abnormality, but those were the concerns. And that's why people didn't want to transplant CF.

When the first transplants were done for CF, everyone really saw how incredible their lives were and [01:05:00] despite all these things they were

doing extremely well. And again, we see still our, our CF patients going for many years, doing extremely well, having the capacity to enjoyed a full life as Sara, best example is, and she had that full life with even kids and so that, it's amazing. So that's what probably changed completely, the view of everyone again, not only here, but around the world. So, so that's what I can tell you.

So going back to your specific question about what changes we have seen post transplant CF. So in the past, I remember when we were discussing CF patients and we would say, "Oh, this patient has some liver disease, so we cannot transplant them."

And most of the patients will have CF and liver abnormalities again, because of CF. And so over time we realized we shouldn't relegate these patients for transplant. So we changed that.

Then we would have patients that have had previous [01:06:00] pleurodesis. So that means that because of the infections they CF patients will have pneumothorax. So that means that at some point the lungs will collapse. The air will go there and then will require this medication to try to expand and stick the pleura to the chest cavity. And that was considered a contraindication to transplant our patients because they will have more complications during the operation that was removed also, so even if the patients come to us after pleurodesis, we transplant them.

We really have seen many of our patients going through a lung transplant, then a kidney transplant, then a liver transplant. So even we have had patients that we have done at the same time, three transplants. We were the first in the world with lung liver and pancreas. So that means even patients who have other organ's disease, we don't want to reject them. We want to really take them. So innovations that really have gone by.

In the past, we didn't transplant the cystic fibrosis patients from ventilation. So that [01:07:00] means that if the disease progress, they will go into a ventilator, this machine that will keep you breathing for some time.

Well we also have plenty of experiences, not only here, but around the world. Well, those patients were transplanted and they will do very well. So we accepted patients to transplant from ventilation. And then now we have something even higher than ventilation than is the ECMO. So the extracorporeal machine where people will be ventilated or even have perfusion. So that means blood going through that machine, where we will increase the oxygen into their bodies while we have the chance that maybe we'll get a donor in between to be

able to transplant them. So again, plenty of innovations that have benefit not only non CF patients, but CF patients also. So I think that those innovations are great because we have been able to apply them to everyone.

In many occasions, our CF patients have the advantage of being young [01:08:00] and a young body, a young person definitely will tolerate better many things than another person, nothing against anyone is just nature.

Candice Coghlan: Right. Right. And so you brought up the lung, pancreas, liver transplant that happened. Is that very common for CF patients to need more than just the lung transplant?

Dr. Cecilia Chaparro: They have different organ diseases. It's not common to do at the same time, three or even two. But I would say that we have seen it occasionally, three organ transplants. It is more common to see just the lung going first, because again, the lung is the main organ that will damage first. But more so related to immunosuppression, we see the kidney, maybe being the second one being damaged because of the immunosuppression impact. And that we see, especially in people who have survived longer, the kidneys may suffer and then they will go for kidney [01:09:00] after a few years of their lung transplant. And a few of them will require liver. After a few years, we have seen also the other way around. So people who have gone through lung, then liver and then, kidney, but that also shows you that even with that, we have an option for them and they still are doing so well and strong enough to go through a different organ transplant so I would say that, that we see mainly, mainly on cystic fibrosis patients, this you don't see on other non CF patients.

Sara Murray: I've read that 18% of lung transplants performed at Toronto General have been for patients with CF. Do most CF patients need a lung transplant at some point in their lives?

Dr. Cecilia Chaparro: First transplant, I would say, not necessarily. Again, CF, it really depends, many factors, one is the genetic, mutations that you have. Second, could be also about the diagnosis, if it was done early, or maybe late when the disease was advanced or progression of the disease, [01:10:00] that it depends in many occasions on treatment or identification of bacteria, et cetera, that could cause farther damage in the lung. So it is variable, but, not that everyone will require a lung transplant. There are some people who are born with the CF and, and then they many years go by, they have not even diagnosed. There are some mutations that could be worse than other ones, but not every CF patient will require transplant anyway.

Post transplant. There are risks to fail with the transplant and that in most occasions is due to chronic rejection. That again, could happen also to non CF. But going back to our CF patients that are young and, and of course, again, full of life ahead of them, many could required are re transplant.

So if we assess them and we find them, an acceptable candidate, again, we could re transplant them and truly they highest number of re transplant are also then in CF, that's [01:11:00] life .

Candice Coghlan: Wow.

Sara Murray: Go in so young.

Dr. Cecilia Chaparro: Absolutely.

Sara Murray: About one third of all transplants that Toronto General are due to the innovative Toronto ex vivo lung perfusion system. Can you explain what the EVLP is?

Dr. Cecilia Chaparro: In simple words for people to understand the Ex Vivo, lung perfusion machine is a machine that was invented here by Dr. Marcelo Cypel and Dr. Shaf Keshavjee and what it does is to allow the lungs to be connected to that machine that will function as the, maybe the heart and the body that is external so that the lungs are kept alive, but not only to be kept alive, but also if, for example, they have infection, we can treat them. So we apply antibiotics to the lungs or do other treatments and inflammatory treatments or so to get those lungs to a level that are transplantable in a good condition.

So in other words in the [01:12:00] past we rejected lungs that were not considered good enough to be transplantable, but then we bring them to these labs where we use the people lung perfusion machine and then treat them and hope that they will improve and then we can transplant them.

So that's what happens. So in general, a few hours and lungs that in the past, we will just discard, then we can make them work. So as you said, there is a good presentation that comes from that machine. So that means we are recovering lungs that in the past we will just discard and be able to transplant people who are waiting the list.

It's an amazing thing that has happened with the lungs and I know and you may know that it's now expanding to other organs also to do similar things. So, so

that for us has been incredible because it's been really a way to expand the pool of donors in order to be able to, to increase the number of transplant.

Candice Coghlan: And so there, would there be [01:13:00] any major differences between let's say, a set of lungs that are, are from a deceased donor or a set of lungs that have gone through that process?

Dr. Cecilia Chaparro: Yeah. Most of them will come from deceased donors anyway. It's just that we, we take them and then we'll come through to the machine.

There are studies where we have compared the outcome of those lungs coming from the Ex Vivo lung perfusion and just regular lungs, not going through Ex Vivo lung perfusion, and the outcome is been is actually the same.

Candice Coghlan: Wow.

Dr. Cecilia Chaparro: So it's great to be able to demonstrate that those organs are as good as lungs that don't require to go to its Ex Vivo lung perfusion so that means that the amount of lungs that we recover are as good as any other organs that don't require that. So we are happy to see that.

Candice Coghlan: That's remarkable. It makes the pool so much bigger, which in turn, would make the wait list, I'm guessing would make the wait list for lungs shorter because you would have more [01:14:00] available to transplant. That's incredible.

Sara Murray: Since the past two years have been COVID, COVID, COVID can you tell us how COVID has impacted your work in the transplant program?

Dr. Cecilia Chaparro: One is of course the impact on the transplant per se. We have been trying to avoid that, I guess, during the first months of the COVID and of course not vaccines et cetera.

We didn't have impact because many donors, maybe were non-existent. Unfortunately have to say that many donors could come from accidents that were not happening because people were not outside.

Second, percentage of patients that for donors that come from US and because of the incidence of COVID, we were not receiving those lungs. So definitely impacted in that respect. Impacted in the capacity for us to evaluate our patients and be able to see them in clinic, et cetera. So that really impacted that. And I

guess the other impact that maybe you are interested in, in listening is that [01:15:00] we also were seeing these patients with end stage lung disease as a result of COVID. And we needed to really think, is something that we will transplant? Is it something that we should do? How we would do it, et cetera?

So definitely the impact was in all those ways. And that's, maybe Sara knows everyone was hiding on our presence because they are immunosuppressed. They couldn't be able to do even the more routine test because everyone was afraid of going to any labs or anything and being exposed.

I think that the vaccines gave a little bit more of confidence, but as we know today is not a hundred percent. So I think that definitely, the transplant world was impacted in many, many ways.

Candice Coghlan: I know for myself, my husband was the one who, who suggested that we go into isolation before kind of the rest of the world had shut down. And I'll be honest. I was [01:16:00] annoyed with him because I said, "Oh, you're making a big deal about this. Sure, we'll go into isolation. I'll just see my family." And he said, "No, I'm talking full isolation. We need to be careful. We need to protect you and protect your kidney transplant and you're immuno suppressed. So we don't know what is gonna happen."

And so we had an argument over the weekend and I said, "You know what? Just to make him feel better. I'll do it for two weeks. I'll go into isolation for two weeks. Sure. I'll, I'll do that. And, you know, shortly after I think it was about a week and a half when the NBA decided to shut down and then kind of the rest of the world followed. And it was one of those, "I told you," so moments, but also, a very, "thank you for being so cautious with my health" as well to my husband. Right. So, you know, it was such a scary time for me as a transplant recipient, but for you, Sara, what was that like as a lung transplant recipient, that's a whole other layer on top of that as well.

Sara Murray: I'm on a [01:17:00] Facebook group with other lung transplant, Toronto General lung transplant recipients and we were all terrified.

Candice Coghlan: Yeah.

Sara Murray: We were terrified because you watch the news, like let's face it, it was a 24/7 thing in your face and you're watching the news and they're showing people on ventilators and dying and this was part of our reality. Okay. So we lost the ability to breathe. We had to go through kind of, sort of a similar idea, and thinking, "If we catch this, we won't live." There's no way with how we are,

being immune suppressed, being this and that, to be thrown a ventilator when we're done, there's no out for us if we catch it.

And that was, of course in the very beginning, when it just seemed like everyone was dying and nobody knew what the heck this was, what it was doing or why. Right. It felt terrifying. And across the community, people were [01:18:00] terrified, because it was so real. And the average Joe had some amount of fear and was hiding home.

Well, here as the most vulnerable in the community, going, "Oh, no, like I can't leave my house. I'm now prisoner in this house." My husband would gown up, mask up, put on gloves, the whole thing to get groceries we needed. They would come into a room in the garage where we would leave them for three days untouched. We would lysol while he would, I didn't do it. Lysol everything.

This is how it began because we were so afraid and luckily things have gotten better and they've figured out some stuff and whatnot, but yeah, it was awful.

Candice Coghlan: Wow. And so for you, Dr. Chaparro, I'm wondering if someone had COVID and they got it and they got to the point where they did need a lung transplant, what would be the requirements that you would see somebody who had [01:19:00] COVID that would then need a transplant and were those happening and were they successful? Was that something that was going on during COVID, or now I guess as well?

Dr. Cecilia Chaparro: Yeah. I think that again, everything was so new and then we start seeing these patients that definitely as any other disease will have end stage lung disease. So that means the lungs were practically destroyed and they were in ventilator and many of them were young people. And then you start wondering how we could consider these people, a transplant candidate. So, so yes I think that transplants were then initially outside in Europe.

Of course we have a team that is amazing and they want to continue innovation. And then the question was about, okay we have certain young people, we need to really consider this. So we all got as a group and Dr. Cypel and Dr. Keshavjee also have been working on, okay, "Which ones are the criteria to really be able to consider these patients?"

So, so maybe the main ones was to first make [01:20:00] sure that the lungs wouldn't have a capacity to recover, because also the recovery for these patients was very long. So they will be on ventilator for six weeks, eight weeks, et

cetera. Some of them will recover. So we needed to make sure that we wouldn't transplant a person who still had a capacity to recover.

So that was, of course important. Second, we needed to make sure that the other organs were not damaged. Of course, many of these patients, as you know, they would go into kidney failure, maybe liver failures. So, so we didn't want to consider person who was already on so many other organ dysfunction. So we wanted to make sure that the lung was the only organ failing. The other important point that has been part of our team is that we want to have the capacity to discuss with the person about transplant. So we wanted them to be somewhat away and participating of the conversation because transplant, you need to really understand, the good and the bad [01:21:00] things and it, it is always important to do that. So, so that was the other condition.

The other one is that again physical capacity it's important. Post transplant, one of the most important things is we want to see our patients moving as soon as possible because the lungs, again, depend really on movement et cetera. So, so we need to start that physio therapy as early as possible.

And we will just consider that mainly of course the other points are having a good support from your family, doing a complete assessment that is going to be really very complete and make sure that everything else is being taken care. Of course we are dealing with patients that we are just meeting from an ICU, the regular way is that our patients are referred from someone else and then we'll see them. And then we'll go through all this process. During that process, they will meet plenty of the members of the transplant program so that they are kind of progressively getting into find that moment where they need to be listed.

We were doing all these things [01:22:00] in the ICU and it was very, very difficult. And in many occasions we had a very limited time to do it. So definitely it's been done. We have done it here already. I guess, in outcomes, we still have to see where we go. These patients in many ways they are younger. So we hope that the capacity to recover has been faster because they were quite functional people. And then they are not the person who were dealing with a disease for years. It was kind of a relatively new thing and happening quickly. And maybe they have the capacity to recover. It's just that it will take a little bit of time.

So I think that we will see hopefully soon. Publications about, okay, what is the status of all these patients comparing with patients were not transplanted for COVID. As you know, COVID unfortunately affects many organs, even your mind. So there is no doubt that they will be probably some impact in many of

the other organs. But up to now, what we see is that, I mean, of course the [01:23:00] patients are happy because they were given the possibility of these and they are going back to their lives, et cetera, probably not perfect again, because COVID affects so many things but they are alive. We put them through this, not an easy thing. I think that over again, for over the next few months or so we will probably will be able to see more about the outcome of those patients, but we are happy with what we have seen so far.

Candice Coghlan: That's great.

Sara Murray: Have there ever been any living lung transplants and if so, how did that come together and work ?

Dr. Cecilia Chaparro: Yeah, that's a great question. And of course, yeah, that question comes because most of the other organs can really receive living related organ transplant. So these have been done as you know, the lungs are very, very vital organs in the body and you could survive with one lung only, but it's not easy to really go, through a complete pneumonectomy that means removing complete lung to give it to someone else. So what is being done is lower [01:24:00] transplant.

So the lungs are divided in different lobes so that means different parts. And then the idea is that maybe those lobes could be big enough to be able to function as the lung in a smaller person or a child. And that was how it was started. So the organ could be, for example, the way that this started was mom and dad will donate the lower part of the lung. So let's say mom will donate the lower part of their right lung. And then the dad will donate the left lower part. So that means those two lobes or pieces of the lung will become the lungs in a very small child also. So that is the way that's been done living related. Now, going through that requires plenty of work, completely different than what we are talking about our routine done transplant.

First of all, the teams to be completely different. From the team that [01:25:00] assess the patient and the team that assess the possible donors. You don't want to create any possibility of feeling push about proceeding for transplant. So you are completely assess apart.

The second thing is that plenty of tests needs to be done to prove that the person who is considering donation will have still a good lung function. So in other words, we need to prove that those lungs are big enough, so that even removing a piece, they still have long, good lung function. Okay. The lungs don't grow

and it, as it happens with the liver or so, so the long repeat, just expanding and working as the lung, which has worked very well.

The other thing is that, of course, post transplant, we, we will have not only one patient, but three patients.

Candice Coghlan: Right.

Dr. Cecilia Chaparro: Yeah. So complications can happen when you do that kind of operation for a donor, et cetera. But again, if it's mom, dad, very close family members, they are happy to do it and have a kid surviving with that.

So [01:26:00] it's been done. We are actually at the Toronto General Hospital, we are open for that. We haven't done one yet. We have gone through some assessments in, in some people for the possibility, but we have been able to get, a cadaveric donor on that. And then we have not gone that route. So far it's been done in Canada.

Yes. It's been done in Vancouver and it's been done in in Winnipeg. And I think Edmonton has done that also. Again, we are not talking about many, many because it really involves plenty of other things. So I think that in general, definitely is better to, to count with other type of donor, rather than going through a living related especially in lung. Lung really has more maybe possibilities of complications with that and involves plenty of ethics around et cetera. But we are open for that. And if we were to get to the moment that, that we are ready and, and we need to do it, we, we will probably be happy to do it.

Candice Coghlan: [01:27:00] That's fascinating.

Dr. Cecilia Chaparro: Yeah.

Candice Coghlan: I do have one more question for you and Sara, but before I ask that I was doing some research about some of your work and, and what you've done in the past and some of your incredible awards and one thing that kept coming up whenever I was reading about it were comments from patients who you have cared for over time, and there were so many comments that I just I doubt that many physicians actually get to hear them quite often. So I just wanted to share three of them that, that I had read. Just so that you can hear about what, what some of your patients have actually said on some of the forums that you may not have ever, ever been able to access. So, Sara, I'm wondering if you can read our first one.

Sara Murray: Dr. Chaparro is a beautiful person who took care of our son. As we journeyed through cystic fibrosis and the lung transplant. We'll [01:28:00] never forget the care we received.

Dr. Cecilia Chaparro: Oh my God.

Candice Coghlan: Here's another one. Dr. Chaparro is one of a kind. I'm so blessed that she is on my team before and after transplant. And then we wanted to leave you with one more. That is my favourite.

Sara Murray: Love, love, love Dr. Chaparro. She has been such an asset to those of us fighting this horrible disease. She's one of the most compassionate, caring women I have ever met.

Dr. Cecilia Chaparro: Oh my God. It almost made me cry. Well I have to say, I have learned so much from our patients, but again, our CF patients are, are just as special. I know what you go through and what you go through post transplant and also and I feel that I want to see everyone so successful with this and be able to live a completely full life.

So I, I enjoy that. I do it with my pleasure. I don't look for those comments, [01:29:00] but I, I'm happy to hear them, but again, I just tried to give the best that I can for each one of you. And, and that's what I would continue doing. I, I love this group of patients.

Candice Coghlan: Amazing. So before we sign off, I ask everyone this question before we end the podcast and I'll start with you, Dr. Chaparro If you were a tree, what kind of tree do you think you would be?

Dr. Cecilia Chaparro: I think that I love the trees that change color. I love all the maples. I love the Japanese maple tree that has all different colors, that one day is green, and one there is red, and one day is orange. For some reason it inspires me to really see changes and accept changes as they happen. And, I think that, that is the three that I would probably. Think I like the most.

Candice Coghlan: Beautiful. I love that. And yourself, Sara?

Sara Murray: I'm gonna go with a coconut palm tree.

Candice Coghlan: Nice.

Sara Murray: They're [01:30:00] in tropical hot environments, but they go through all sorts of crazy storms and they stay strong and standing. And I mean, they give you food too. So, you know, it's kind of fun. So I will pick that.

Candice Coghlan: I love it. I think both of your trees very much exemplify who you are. So, I love throwing that question on people cuz it kind of throws you off. You're not ready for it, right?

So thank you so much for being on the podcast today. Sara, for sharing your remarkable journey, everything that you've been through is such an incredibly positive attitude and for bringing us into your world, I'm very appreciative for everyone who's listening, who is gonna learn a lot from you.

And Dr. Chaparro, thank you for joining us and sharing your incredible passion for your work. We're so grateful to both of you for being here today.

Dr. Cecilia Chaparro: Thank you very much for inviting me.

Sara Murray: Thank you for having us.

Candice Coghlan: don't forget to subscribe to Living Transplant [01:31:00] Podcast, wherever you're accessing this today. Please share with your friends and if you have any ideas for future podcast episodes, you can reach out to us at livingorgandonation@uhn.ca.

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