

# Season 4 Episode 2: I Got My Voice Back

**Candice Coghlan:** [00:00:00] Living Transplant is a podcast that takes you behind the scenes of the transplant program at Toronto General Hospital, with the goal to educate, inspire, and fuel your passion about transplant. I'm your host, Candice Coghlan. In this episode, I'm joined by Ivica. An opera singer who loves baking, teaching others, and above all else, his family.

Ivica discusses his journey with kidney failure and how his brother stepped forward to be his donor, giving him back the strength to sing beautifully. Later we're joined by Margot Mitchell, a retired social worker who worked over 20 years at UHN. She speaks of the importance of good mental health and how we can all move through grief to gratitude.

Enjoy. Thanks Welcome back to the Living Transplant Podcast. Today, I am very excited to have a guest joining me, Ivica, who's going to talk to us today about his journey with living donation and his kidney [00:01:00] transplantation, as well as his amazing journey as an opera singer. So welcome. Thank you so much for joining me today.

**Ivica Balaban:** Thank you for having me. My name is Ivica. I'm a kidney transplant recipient. 32 going on 33 and still trying to be an opera singer despite some setbacks. Singing opera is kind of all consuming sometimes just because there's so many things to do with it. It's not just singing, you gotta act, you gotta movement, languages, all this stuff.

I like languages, but then that also relates back to singing. I love television, sitcoms. I mean, life's already dreary enough, so when people are like, watch a horror film, I'm like, not happening. Right! I'll watch any comedy you could throw at me, but anything else, I'll watch every Hallmark movie. I think I've watched everything with my mom.

Right. I unabashedly love those. Cause I think it's just the whole, you know, what's happening. Our lives as transplants, recipients is you never know what's going to happen. Right. You kind of have an idea, but it's just like, whereas those ones they're formulaic, you know, what's going to happen. No matter how bad the dialogue is or the chemistry, you're just like, [00:02:00] okay, I know it kind of still have an ending.

And so it's kind of nice. It's like a, a refuel. Yes. I used to be a rugby and football player. So that, that, that was part of me, you know, being, I'm a bigger guy. So that's, I always enjoyed that. Uh, I'd say the NFL is a guilty pleasure because I know how, how bad, I know, normally people wouldn't say that, but for me it is, it's because of what football meant to me.

So, but I still enjoy watching it. I've taken up baking. When I was a little kid, I wanted to be a pastry chef. I enjoy baking. Especially when, with, with, you know, all the dietary restrictions we have, or at least when we're on dialysis now, that, that was a big thing. Um, I lost a hundred pounds when I was on dialysis.

So that was another thing. I mean, a lot of it was water, obviously, but some of it wasn't right. And so now, now I'm finding it, it's a little different because when you're on dialysis and you want to eat low carb, it's pretty easy because you can just eat all the protein you want because they're like load up on protein.

It's fine. And now it's the exact opposite. And I was [00:03:00] just like, well, so I'm, I'm struggling with that a bit, but you know, working

**Candice Coghlan:** on it. So can you bring us back to before the kidney transplant, when you were touring and singing, and when you started to notice that things were a little bit different with your health and what that was like?

**Ivica Balaban:** I guess I'll go back to 2017. I was still quite healthy and I was in Germany doing a summer program. And so I used to be a baritone and then they're like, you're actually a tenor, so you should retrain. And I was like, okay, which is hard enough already. But I was like, okay, I'll do it. And I retrained and then it was, it took me a while, but I think at the beginning I was.

2019. So January 2019, everything's kind of started to work and I was feeling great. And like, my voice was like, ready. Um, and I was 29 at the time. So I'm just on the cusp of, of aging out, but I'm also right. I'm ready for everything. I went for an audition. I was like, I sang that. Okay. But not as well as I used to.

And I'm like, [00:04:00] that's fine. And then I think by June. I'd gone for a coach because that's really the only extreme kind of physical exertion. I would have had to really show if I was really getting tired or not. Okay. Otherwise, like there was no measure. Whereas my voice, you have to be at kind of top health to be able to do what I was doing.

And in June I went for a coaching and I was singing the same arias and I was just, I kept getting tired. And I was like. Maybe I over sang, maybe I didn't warm up enough, right? I mean, at the same time, I'm also gaining weight and I was quite depressed. So gaining weight was no, I was always, I've always been big, right?

So it was nothing new. And I was just like, well, this is part for the course. Right. And, and so I didn't really think of it all that much. I mean, I'd seen some swelling and I was like, well, I'm, I'm, for anybody who's interested, like I'm Eastern European and eastern people, Eastern European people, it's, it's not salt with their food.

It's food with their salt. Right? . So I wasn't like overly surprised, right. I was like, oh, okay. Eat less [00:05:00] salt, you'll be fine. Right? . And the swelling would kind of go down and I was like, okay, that's probably what it is. And then I guess in October I had an audition with the, I hope I said that right, Montreal Opera.

And I remember going in and I sang my first aria. And I crushed it. Like, it's the best I'd ever sung in my entire life. Wow. I was like, and then they asked for a second one and I, my, my body basically just gave out. Oh. I was just like, I tried to sing and I tried, I made it through, but it was just like, I could see the looks on their faces.

Right. Cause I saw the looks on, normally audition panels are very stoic and unemotional. Right. Right. And the first hour, they're like, yeah, holy crap. And then the second hour, they're like, wait, something's not right here. I'm like, sure you got, you got through one hour, but you didn't get through the second one.

And then, uh, just before that audition, so the auditions at the COC on front street for anyone in Toronto. Um, and then I was walking from union station to the, to the audition space, which is about a half [00:06:00] hour walk. And I never get nervous before auditions. I get a little, a little anxious cause I want to sing, but I'm never, I'm usually relaxed.

I know I'm prepared and stuff like that. And this is, I, from walking from union to there, I found every single place that I could have thrown up and like hidden it. Cause I was. So nauseous. So like, I thought I was, and I'm like, I'm wearing a suit and I'm like, Oh my God. I'm like, what, like what's going on?

And like, I found every flower pot, every garbage can. I was just like freaking out. And then I got there and I kind of calmed down and it was okay. But then

the same thing, like, on the way back, when I took the train back home, I was just like, oh man, there's no bathroom here. Like, what am I going to do?

Right. Right. And I didn't think, I was like, maybe it was just all the stress from the audition. Like, I didn't really think of it all that much. And then I, then I got sick. So I go to my doctor and she measures my blood pressure and the machine she has measures it six times. And she's like, the average blood pressure was, I think, 230 over 140.

Oh my goodness. And she was like, you have to go straight to the [00:07:00] hospital. Oh my goodness. Right? And even when I got to the hospital, they measured it like four more times before they did anything. And then they're like, okay, we're going to do your blood work. Right. And they're like, okay, yeah, your creatinine is 500.

And I'm like, I don't know what that means, right? And they're like, you know, I'm like, what's it supposed to be? They're like, 100. Oh, okay. That's probably not good. So they're like, you have very high blood pressure and your kidney's not working. We don't know which one it is, right? Kind of chicken and egg.

We're going to figure out which one's affecting which. So they admit me and then I have a biopsy and they're like, yeah, your, your kidney's fried. Like you have stage five, you need a transplant. And so I was very fortunate. I mean, I cried, like they told me and then like the nurse is like, are you okay? I'm like, yeah, I cried for half an hour.

I'm like, we just got to move on, right? There's nothing we can

**Candice Coghlan:** really do. Yeah. That's the wild thing, right? That often when I talk to people about their journey and people will ask them, like, how did you get through everything? And there's no other choice, right? Yeah. It's just, what's next? [00:08:00] What are we going to do next?

Right? Like we have to. Keep going forward because we don't want to stay where we are, but it's, it's an, a different situation. Like you said, you're surrounded by people who are triple your age and you are in this new weird world of this brand new diagnosis with no information and you're just thrown

**Ivica Balaban:** into it.

Yeah, I, I remember, I think the next day my doctor came in, I was sitting on the bed and I was like, my only question was like, how much of this was because of

how big I am, like how heavy I am. He's like, none of them. He's like, if that was the case, like everybody would have it. Right. It's not just you. What he told me was, he's like, all you really can control is your weight.

Like, right. So that's all you have to focus on. If you can lose weight, like that's, you can get the transplant. Just everything's better. Right. And so that's all I really could focus on. And so they told me I had IgA nephropathy. So it's basically where the, the white blood cell floods the kidney and then it kind of damages the nephron.

What [00:09:00] happened was both my brothers were like, yeah, no problem. We're gonna, we're gonna do it. And I was, I was like, okay, great. And the, the renal coordinator gave all the forms that both my brothers needed to my mom. She's like, here. They need to fill this out. They got to do these tests. That's it. Right.

And so they, and I was very lucky. I was just like, you know, obviously you're feeling like crap because they're lowering my blood pressure and trying not to faint, all this stuff. And you're trying to process all this news. But at the same time, I'm like, well, this is really cool. Like I wasn't as afraid as maybe I'd been an only child or my brothers weren't maybe healthy enough or unwilling to donate as part of me kind of feels almost undeserving.

Like I was on dialysis, right. But you're kind of like, you know, people who are there for like, We're desperately need one. And I was just like, I was in the, as soon as I found out I had two, right. It was just like,

**Candice Coghlan:** Holy cow. Yeah. I feel you with that one. I, my mom was my donor. And similarly, while I was the crash start in hospital and they were telling me [00:10:00] about dialysis, she was asking them, how do I get started to know if I can donate a kidney to get her off dialysis?

So I was on dialysis 15 months and. For me, it felt like a lifetime because dialysis is terrible and I would never wish that on anyone, but in the big scheme of things, like 15 months is so fast. Like you said, there's some people wait seven, eight years to get a kidney. And I had tons of people who were.

Willing to step up and I, I agree with you. I sometimes there's that like strange feeling of, of guilt that you got one so fast. Yeah, totally. But I mean, trying to turn that into gratitude and we're lucky that we have such amazing families that we have those people in our lives to, to do that for us. Yeah.

**Ivica Balaban:** It was, cause I remember my doctor said, he's like, you're seven to 10 years. Oh. Like you're going to wait. I mean, I had to [00:11:00] start dialysis, right. And I was on for 23 months, just under two years. And, uh, yeah, it was like, it was crazy because it was just, you don't realize how sick you are. Right. But at the same time, I think as I was on dialysis, the, not that the guilt went away, but the gratitude certainly increased because I started with three times a week for four hours.

And then after a year, they increased me to four times a week. And so I was already like, well. That's not a good sign, right? I mean, I was using, I had the central catheter and so the clearance isn't as high. I mean, for anybody who hasn't been on dialysis, you have speeds that you can pump at and I had to pump at 400.

So the top speed you could for four hours, like, and then I was okay. I could get an okay clearance. And then I would, I'd be fine. I know a clearance on the catheter isn't as good as Paris and official or graft. Right. So maybe things would have been okay. I had a gun that had been the case, but did

**Candice Coghlan:** they decide to stick with the.[00:12:00]

Catheter because you had a donor being worked up. Yeah. So

**Ivica Balaban:** I got sick October of 2019, and then my workup was supposed to start March, April of 2020, and then the world shut down. So I did a lot of my tests. All that stuff was done, but like meeting with the team, doing any tests that at UHN and stuff like that, like they couldn't.

And so that shut down for, cause they said the fastest I could have had it done is what was a year. If everything works out, you could do it in a year. So first everything shuts down, then it's, since transplant, living donor transplants are considered elective surgery, so they're, they're stopped as well, and so it's just kind of the start, stop, start, stop, so first they have to get mine, and then my brother's stuff, and he's busy, and so it's just, well, it worked out, obviously, um, yeah, so my brother got approved, he's, he's in perfect health, they made his ego, his head swell even more, like all the tests he had to do, he's like, they told me, because they told him, He was like, once [00:13:00] a kidney that's left grows to normal size, I could donate again by based on my GFR.

And I was like, all right, stop like rubbing it in. Right. So that's amazing. Yeah. So he, but he's, I mean, It was never really an issue. So that's fantastic.

**Candice Coghlan:** So you got a good one. You got a really

**Ivica Balaban:** good one. Yeah. Yeah. His, his, it works. I mean, I'm still, the one thing they told me, it was like, cause I'm a lot larger than my brother, even with the weight loss and so like, Hey, your Kraton is always going to be kind of higher, right?

It's never going to be quite the same. Um, cause they told me when I was in the hospital, when I, after the transplant, the doctor, one of the doctors was like, yeah, you need someone who was bigger than you to donate. And he's like, that's impossible, right? Because for someone to be that health, that big and healthy enough to actually be able to be allowed to donate, it was like, it's not going to happen unless Shaq said, you know, like somebody in the NBA or, or, you know, and I know if it

**Candice Coghlan:** likes, I was going to say, don't, you know, any NFL players

**Ivica Balaban:** or NBA players.

Can you help me out? Like I need, right. But unless someone like kidney, like the size of my head donated and [00:14:00] we're not going to, happen. So, but I mean, it was okay. I mean, they found a little bit of rejection and, uh, I think for anybody who is, this is good for, I guess, anybody who is a waiting transplant, or maybe just had it, I think the best advice I got with rejection, at least, was it's not if, but when, right?

It's not, it's, it's going to happen, but it's, it's just, can they catch it? Can they deal with it? So I had a little bit of rejection at the beginning. I mean, my, my Kratonin was stable. It just wasn't falling as fast as the doctors thought it would. And then they're like, we're just going to beat your, the doctor literally said, we're going to beat your immune system back at the submission.

So they gave me a huge dose of prednisone, you know, kind of tapered off and it worked. So

**Candice Coghlan:** I was like, okay. Prednisone is like our worst enemy and our best friend. I always say. Yeah.

**Ivica Balaban:** It's crazy because it does the job right but then at the beginning they gave me 80 milligrams of prednisone Wow So I was just like I remember I was watching the videos that they give you before discharge They give you four [00:15:00] videos and they're like I was like don't let anybody watch this when

they're on like a heightened dose of prednisone Don't let them don't tell them to watch it all four in a row cuz I was just like I like I was just like Cradling, but I was like freaking out.

Yeah Right. And I remember when I got home, I was like, I didn't want to touch my dog. I was so scared. I was like, man, I'm going to get something. Like I was like, my mom was like, you couldn't do anything. You were basically.

**Candice Coghlan:** And that's the thing, right? Like it not only impacts your body, your mind, but your mind is, is so altered because of that.

And like, oh, I joke about it now because I'm, I'm 13 years post transplant, but I remember like when I was on those higher doses of prednisone, I wouldn't sleep. Well, like I was up all the time. I remember one time I just couldn't sleep and I was up scrubbing my kitchen floor, like hands and knees scrubbing it.

Cause I was like, I can't do anything else. And it's been bothering me and I have all this [00:16:00] energy. Let's scrub the floor. Let's clean out the fridge. Like all of these crazy things that you're like, I could either do cartwheels or I could scrub the floor because you're shaking inside sometimes even. And it's like, how do I get

**Ivica Balaban:** this out of me?

Yeah. The one good positive from the super high dose was my singing was insane. Please

**Candice Coghlan:** enjoy Ivica's voice stretching five months post kidney transplant.

**Ivica Balaban:** The big thing with, with, with why I couldn't sing, it wasn't so much like a structural or issue or anything like that. It's all energy, right? So like I could be congested and I could be sick. Won't mess with my singing all that much. Um, but if you're tired, you got no shot. It's not, it's not so much like [00:17:00] pruning, like I can still sing jazz stuff and I could do easier things, but anything where I was singing operatically, where I actually, I was like, I was done, like the analogy I use is the fuel gauge was faster than the speedometer.

Right? Like as soon as I reach a certain point, it just, it just falls right. It just immediately, if I keep it under a certain level, I can keep going for a little while, but as soon as I try and do something. It's just, I'm done because like, I, when I



was on dialysis, you know, the kidney patient had the kidney walk and the second year I wanted to test myself, see how much, cause I wasn't sure, you know, who knows how long I'm going to have to wait, how, how good is my, what kind of condition is my body?

And so I was like, I'll try and do a half marathon. So I walked a half marathon with my friend. Wow. I didn't, I got to 19 kilometers and I was like, man, I can't do it anymore. He's like, don't worry. I'll kind of carry you. I'm like, you're not big enough to carry me. You're like, it's not gonna happen. Yeah.

Yeah. Yeah. And then, then like I took a break, got the 20 and a 20 to 21 was basically just, I was like, I don't even know what I was doing. I was like, I've [00:18:00] got to make it to Lake Ontario. That's where I was walking to. And I was like, so I was like, that I could do. But the thing about that was, is it's never really an intense, you're walking, but it's never anything too intense.

Whereas singing, which people would think isn't intense at all, but when you're trying to bust out high notes, your body's just like, yeah, no, it's not happening. So I remember the Predazon just gives you this. Like you said, like this huge amount of energy and you're just like superpower wired. And I was saying, I was like, Oh my God, this shouldn't be possible.

Right? Like I can't use any of my core muscles cause I'm, I'm sitting like this. And like, you obviously just had the surgery. So I'm like, I'm not going to be like, they tell you not to lift anything. And singing is the, essentially the same thing with. And I was just like, my voice is popping. I was like, things are gonna be great.

Oh my God, like, if this is what it's like all the time, like, this is gonna be amazing. This is better than before I was even sick. And then I was like, oh, no, no, that was the prednisone. The dose has come down. I'm just like, no, no, voice is back to kind of where it was. Yeah. Yeah. So that was, I was like, well, [00:19:00] yeah.

And back to the kind of the mental side is, I think, I know one of the points we're gonna talk about is, is, you know, pre and post. And I think. Mentally, it's harder post transplant, and I, I know for some people, maybe they disagree. But for me, when I was on dialysis, it was like, just don't die. Right? Like, so it was like, just don't, you know, there's so many complications that could happen and like, just don't die.

And my family's like, yeah, don't worry about your career. Like one, I couldn't sing. Two, performing arts basically imploded. Yes, right. Because they're like, you couldn't do anything. You can't be in person. I was like, can't do anything. Right. And it's just like, okay. And I'm like, my voice doesn't record very well.

like I could just start doing it. Like I sing the way I sing because of the space you're trying to fill. And so I was like, well, yeah, I'm like, okay, lose weight and don't die. That was my thing. And then you get the transplant and COVID kind of goes away. And now you're just like. All right. You know, clock's ticking, like get your, get your move on.

And I'm [00:20:00] just like, okay. Well, you know, plus you have the prednisone, so I'd never had anxiety before. And now I'm just like, it's gotten better. I've learned to manage it and certain things, but that's, that was never there. Right. There was nothing. And now it's just like. On top of just general worries that you'd have being a transplant patient, then you're like, the medication is just fueling that.

Yeah. You're just kind of like, okay. Yeah. So yeah, that's one of the big differences for me is at least. Yeah.

**Candice Coghlan:** I, I agree with you. It is like, for me, dialysis was difficult mentally because you're stuck. Right? Like you just feel like you're kind of like in a waiting place and you're forced to just sit there and you're stuck, which when you're young, like I was 24, so similar to you, like it, it's just, you're stuck there waiting.

You don't have anywhere that you can go because your whole focus is like, they just say, like you said, just don't [00:21:00] die. Yeah, what we tell you eat, what we tell you show up when we tell you to show up and rest when on your off days and like take care of yourself. But in your head, you're like, okay, I do dialysis for this amount of time that day is gone.

So the next day you're like, how do I pack an entire day full of seeing people and doing things that I want to do? Because I have a little bit of energy from, from the dialysis. And then you're like, okay. And now I crash again and now it's back to, it's this weird cycle. Right. So for me, that was rough, but post transplant you're right.

Because you get all of these anxieties about, am I taking my meds on time? Am I taking them properly now going into the world of COVID like. Am I going to get COVID? How is that going to impact my transplant? And then even that

thought of, of rejection, like at the very beginning of my transplant, it's much better now, but I always used to look at my pills when I would set them out [00:22:00] and put them together and be like, this is the only barrier between me and going back on dialysis.

So looking at that sometimes would just be like, A mind twist to me because I was like, how are these small pills keeping me from that? Like it, it's hard to wrap your mind around the, all of like anxieties and the depression and like trying to stay positive because you do have this new kidney in you.

And it's almost like, here's your new kidney. You're healed. Go live this beautiful life now. Right.

**Ivica Balaban:** Oh man. Yeah, totally. I like. That's another guilt. Like, at the beginning you get guilt because you're like, okay, you know, this is so easy for me compared to some other people, right? Then you have to remind yourself, we're like, no, most of the people never have to be on dialysis and have this chronic disease, right?

And I think that's one thing that they don't, I'm not to say that they don't stress, but they don't really... I don't know how to explain, but [00:23:00] just the, the chronic nature of the condition, right? Yes. Like, they, they will say transplant is not a cure, it is a treatment. Yes. Which they're very clear about. But I think it's just knowing that you're always living with this kind of worry.

Yeah. You have to keep coming for blood work every two weeks. Mm hmm. Like, we know it's been over a year, but you just got to keep doing it. We got to make sure, which is great, right? Like, don't find anything right quick, but... It's kind of like, okay, like, please let that, right. Let that let off. And so like the way you're saying, like you said, like you have this new kidney, like get out and, and, and go.

And I kind of feel the same way. Definitely. Right. Like they're like, my family's like, Hey, you got your voice back. Like get working. And so at the moment I kind of feel like I'm in this catch 22 where do I keep going with singing? Cause like my voice is back and, and like, I, I can do it. Or do I just let it go and go to something else and really be able to use my time?

I'm kind of grappling with that right now. And so I'm just [00:24:00] trying to figure it out, but it's, yeah, it's just, you get under this pressure where people are like, all right, like get going. And I was like, yeah, I would, but it's a bit more difficult. So yeah. The

**Candice Coghlan:** best advice that I was given from a transplant recipient friend of mine was now that you have the ability to do.

Whatever you want, because physically you're treated, it's time to choose what you want to do with that extra life that you've been given. Right? So if, if the things that you're doing in your day to day are not giving you the same amount of joy that they used to just trash it and move on, like find what it is that you really love to do.

**Ivica Balaban:** Trying to like, I really want to do it. Yeah. And so like I have, I have one audition left. Hopefully I get an audition for the COC chorus and I can see kind of then what I could do. And plus there's the life, not the life, you're kind of a liability and you're afraid of everything. Cause my doctor was like, yeah, sure.

You can perform anywhere. And [00:25:00] like for me, so I just got COVID and I got it in the one event where I was singing and it's just also people, even employers think about that too. Right. So yeah, you're going to compromise and. They're like, well, you're going into a profession that's like, I mean, singers generally are, I don't want to say germaphobic, but are fairly health conscious because they know, you know, you get a bug and you're, you're done, right.

But it's, yeah, that's something I'm, I'm, I'm kind of struggling with, but I'm working on. And I think that's one thing that I didn't anticipate when I was on dialysis. So Right. When I was on dialysis, I was like, everything will work out, you know, I'm gonna and now I look back and I'm like, maybe I should have spent that time because the one thing with dialysis is sure you don't have, you can't do as much.

But if you're thinking of switching, that's like the perfect time, right? Because you, you have all the time you're sitting there for. Hours, you can start learning something new, doing

**Candice Coghlan:** something. So I'm wondering if you can tell our listeners just a little bit about what this transplant [00:26:00] has done for you and your life.

**Ivica Balaban:** You come back to normalcy, right? I think people, when they're sick and then they get it, they're hoping for like, oh my God, it's, and it's, it is, it's amazing, but it's again, it's. It's hard because you, that's, it's so good of a feeling that you, you quickly forget what dialysis was like and what being sick was like.

So it's, it's a little bit more difficult to compare sometimes. And then you remember and it's like, no, I used to wake up and I couldn't be right. And I, and I, you know, I couldn't do anything. I, I have to be like, I could drink half a liter of water a day and they'd be like, Hey, you know, keep it off and you can't eat this candidate and like now I kind of stick to a similar diet that I did when I was on dialysis, but I think it's, it's a lot easier, right?

It's easier to stick with it. If you're allowed to indulge, I can have some cheese. I can have some, whatever, but yeah, for me. At least I think the biggest thing was with the singing and like my career was, I think the thing that was most affected, right. I think it obviously my family drew together, [00:27:00] so that was great.

And, and I tried to keep most people out of it because I didn't want to do anything too crazy. But it gave me the opportunity to at least go out on my own terms and try my best at my best. Right. It wasn't like. I was cut short because of the disease, but the fact that I got my voice back, I could at least try again, whether it works out or not is undetermined, but I had that.

I had that agency back to at least be able to try it. I remember it was okay for a while. Like, I could still sing on my off days and it wasn't terrible. And then it got to a point where I was at my brother's house and the neighbors were singing happy birthday in the backyard. Anytime I hear happy birthday, I'll, I'll, I'll jump in, whatever.

And I, I jump in and I go to sing and I go to sing like, Happy birthday! And my voice just died. Oh. And it wasn't even high. Like I just, it was, it wasn't even a crack. Like I don't even know what happened. Something imploded. It was just the worst thing I'd ever done. And I was so, I was like, oh my God, I can't even sing happy birthday.

This is not good. And then the first [00:28:00] thing I woke up when I got my transplant, initially, I was worried because of the intubation. Right. I was like, cause they say it could, something could happen, but like, I knew I was a good hands cause they're like, they already knew I was a singer when I was, I was going to ask them to be like, oh, you know, I know you can't really do anything, but it would just be careful when you're doing it.

Like, we know you're an opera singer. It's okay. And I was like, wait, I didn't know how you knew that, but okay, cool. And I woke up in the room, I'm like, I'm already kind of loopy and I'm already singing and it's already fine. And I was like, holy crap. Oh, this is great. And then there was also that there's the

eight, if for anybody who's been to UHM and the Monk building, that those, that elevator atrium in Monk on any floor, this is the seventh floor, has the greatest acoustics anywhere I've ever been.

Like any church, it doesn't make any sense, but I'd go, I was there for a while, so I'd be walking as much as I could. And every time I passed by, I just let it loose. And I was like, okay, everything's back. That's so cool. You don't really realize it. Cause it's the one thing was. Singing was effortless before I was like, if I wanted to sing, when I was on dialysis, it took all of my strength [00:29:00] to even just get some stuff out.

Right. And I had to be on and off day. I had to have had good clearance. Right. I had to have, you know, eaten well, slept well, all this stuff. Right. And this was just like, you could have put me upside down and like, you know, doing it like whatever. And I could have just sung anything. Right. That's just, it just comes out.

Right. It won't stop. So I think that now for me, it was huge. Right. I had that back. That's beautiful. That, that kind

**Candice Coghlan:** of sense of identity. This might be putting you, you on the spot and you can say no if you want, but can you say happy birthday to you? Like, can you sing that for us? Just this one line.

**Ivica Balaban:** Happy birthday, happy birthday to you.

Like that. That's so fun.

**Candice Coghlan:** Yeah. Yeah. Oh, that sounds so much better than our birthday, happy birthday

**Ivica Balaban:** song. Yeah. That's, that's my job in my family. I started singing a little louder, so it kind of drowns them out. Yeah. But if they're singing well, I'll sing quieter and let them sing.

**Candice Coghlan:** That's amazing. That's so fantastic.

I'm [00:30:00] wondering if you have any advice for, for specifically young people who are living with kidney disease or who are recently diagnosed, or even people who are post transplant about what you've been through and, and what you could share with them.

**Ivica Balaban:** I think the biggest thing for me, I think it's a lot of the psychological and mental side of it.

The physical side, you can't really do much about, right? You kind of try and stay active as much as you can. You'd be surprised what you're actually capable of doing. Like I said earlier, like I, I was able to do a half marathon and I'm not in particularly any good shape. Like I'm. You know, average at best and I was able to do it.

So the mental side, find a support system and lean on it as hard as you can, like, cause you're going to have to, there's no, as strong as you might think you are and, and. As you know, resolute or indomitable spirit. It's going to, it's going to hit you. Right? Like, it doesn't care who you are. Right? So, find people.

This is, [00:31:00] you know, before and after. I think for me, it was even more important after. Because when you're on dialysis, it's basically You know, feel great, go to dialysis, feel tired, sleep, repeat, right? So there's, you don't really have time or the capacity to do much on, on, in terms of you're not afraid of as much.

Whereas when I was after transplant. I found the Kidney Foundation has transplant, you know, peer support groups. I think just talking with anybody who understands it. So, you know, speaking with you, Candace mm-hmm. . Yeah. Take every opportunity you can and cause as much as people wanna sympathize and wanna understand and wanna help, unless it's happened to you, like it's, it's very difficult to, to really help people, so, mm-hmm.

finding other transplant recipients, whatever it is, doesn't have to be kidney. You know, I, I, one of the best things that happened to me was I think when I was four or five months out, this was on, I had an Instagram account just for my singing and you know, it's, it says I'm a transplant recipient. So I was able to [00:32:00] meet other younger transplant recipients and we had a group and it was so different because it's, we can talk about our problems and so reach out on social media or anything like that.

I think. They're the most, we're the most welcoming people you're going to find and understanding, right? A lot of people are like, okay, whatever, but like, oh, you're one of us, right? And you're in this new kind of, I don't want to say tribe, but they get it. Other people get it. And they can, even just talking, I find even today has been very therapeutic.

Just being able to talk and know other people get it. Other people understand. Other people have been through it because you will feel like no one else understands anything that's going on. Yeah, nothing's better than just letting it out and talking and finding those

**Candice Coghlan:** people who get it. That's really good advice.

Thank you. And so now we have our amazing Margot. I should have called you magnificent Margot, maybe, right? Thank you so much for joining us today. We're really excited to have you. And I know that this is [00:33:00] only. A month or a little bit, little bit more than a month now after your retirement. So we're excited to get, to get to hear all about how retirement is now.

I'm wondering if you could introduce yourself to our listeners.

**Margot Mitchell:** My name is Margot Mitchell. I have been a social worker in the transplant program at Toronto General Hospital University Health Network since 2001. I'm recently retired. I worked most of that time with the kidney transplant team, but also because the social workers there cover each other, all the organs in transplant, including Liver, who also has A living donor program.

**Candice Coghlan:** Fantastic. And so what drew you to social work? What made you want to get into

**Margot Mitchell:** that? Oh, we're going back a long way. I became aware of that as a young person, people were approaching me with [00:34:00] problems and I didn't know these people very well sometimes and I didn't feel very well equipped. To support them in with their problems, and I became aware of liking the idea of being able to help people, but needing to find out how to do that, acquire the skills and knowledge to do that.

And then I came across. The profession of social work and I was drawn in at that point and it's a, it's a very good choice. It's, you work with people who are endlessly interesting, inspiring, and it's been a good run. Yeah.

**Candice Coghlan:** Wow. And so thinking about that, that run, what has made that career so meaningful?

**Margot Mitchell:** Yeah, I think I've always worked in medical [00:35:00] social work and. I started off in oncology for the first 20 years and there's a very robust need. Mm-hmm. . Um, as Avi Aviche was just saying, a need for people to tell their stories to be heard.



I think that's the least of the role for sure. It's a baseline kind of, um, Commodity, if you will, that we can offer and we do help guide people through the medical, the institution or the process, help them if there's knowledge gaps, we do try to connect them with other people who have been through it. If that seems to be a need that they have, there's always [00:36:00] a role.

And the longer you're in something, and you've heard from many, many, many different people who are actually going through it, the more effective you are as a conduit to help people prepare as much as possible, to adjust as much as possible, to get the most out of their medical treatment, and to live as full a life as they can while they're waiting for treatment, perhaps while they're going through treatment.

And reach out into the world again after their treatment and so they can live their

**Candice Coghlan:** lives. And, and we've talked about it today, that whole idea of the emotional and psychological aspects of being diagnosed with something and, you know, going through that diagnosis to treatment, to, you know, either dialysis or, or a transplant and that whole journey that we go through.

So, and you go [00:37:00] through kind of. These waves of, you know, you, you feel like, okay, I can do this now. This makes sense. I'm in a survival mode where I'm going to do this every day. And then you get waves where, you know, it's difficult to just get out of bed in the morning, whether it's, you know, after a diagnosis or during treatment or even post transplant, and I wonder as a social worker, what are some of those?

Things that you would maybe sit down with somebody and, and help them and, and cope with that kind of traumatic incident that's just happened because really a diagnosis and an and an organ failing is, is very traumatic and it kind of comes in in waves. It's not often all at once or we're all at the end,

**Margot Mitchell:** you know, there's that phrase that we hear so often one day at a time, but.

When we just say the phrase, it doesn't necessarily get us to a place of dealing with things. It's really [00:38:00] parsing out what that means to each individual and getting through each day. And as you mentioned, there can be some days where people may feel, all of us may feel that we just can't face the day, but then you can say to yourself, you can take on a self inquiry as to what does it mean to get through this day.

What do I have to do today? Do I have to attend dialysis? Do I just have to watch my fluid level? And, oh yeah, I'm going to be, those people are coming to visit and they always bring that food I can't have. So what are the essential things I have to do? to get through this day. And tomorrow may be a better day.

Let's see what tomorrow brings. You think about the whole of time stretching out in front of you, trying to deal with all of that. It can be very overwhelming, just too much to get through. So I would often have [00:39:00] people tell me what one day at a time means for them. It's going to mean something different to everyone.

It's also going to mean some, for the same individual, it's going to mean something different each day, perhaps. Good information is foundational to people being able to take care of themselves, no matter what the condition is. They have chronic condition of any kind. It may be kidney failure, liver failure, but also after transplant, we would consider having a transplant, a chronic condition.

where people have to self manage and take care of themselves. And I, I put so much emphasis on self management because when people are able to take care of themselves and follow the medical advice, they're probably going to feel. as well as they can feel in their situation. And when [00:40:00] you're feeling better, you can cope better when you're feeling that you have enough energy to meet life's demands.

I have a friend that used to say when I feel equal to the task and not every day you feel equal to a specific task, or maybe the task is getting through the day, right? But it's when you're feeling your best because of your own efforts, and maybe dialysis is part of what helps you to feel better than you're more able to cope.

And when people are able to fit a few more things of their regular life into their day, then that's, that's a quality of life.

**Candice Coghlan:** I remember When I had just, I decided to switch from hemodialysis to peritoneal partway through, and [00:41:00] so I had, well, you'd remember the feeling of having your, your catheter here, and then I also had just had surgery to have the peritoneal catheter in my abdomen.

So I was like. How am I going to wash myself for the first little while you find creative ways with tape and, and, uh, Ziploc bags. Right. But I remember I have

very unruly hair as well. And, uh, my mom said to me, you know what? Don't worry about that. Will it make you feel better if I wash your hair one night?

And just that simple act like she, she washed my hair for me. She dried it. She styled it. And I just felt like a whole new person. Just those simple tasks. Sometimes when you're on dialysis are really tiring. So it was just a tiny little thing that. It made it easier for me thinking about those, those tasks, like you said, of what can we accomplish and maybe there's somebody who can [00:42:00] help you with those tasks too, if, if you don't feel up to the challenge.

Yes.

**Margot Mitchell:** And having those people around that are kind of listening and really have an empathy for what you're going through can be so valuable, even if they're there. Not stepping in, but kind of watching out and ready to step in if needed because people struggle sometimes to find that balance and caregivers can struggle to find a balance between being there for somebody and letting that person achieve whatever they can achieve.

Nobody enjoys. Being what they might call a burden. Um, I wish we had another word because for someone you love, no one's a burden. It's just the wrong word. Yeah. But it's a strain perhaps and having that person just at the ready who you know is in your court. [00:43:00] is really, really important. The other person that I always think is a good support person is what I would call the challenger.

People talk about having little cheats where they're maybe ignoring the rule for to do this, usually small things and very often they've talked with their team about it and these little cheats are okay. If the cheats went on and on, Or if the cheat was after transplant when people aren't taking their medication, then that challenger is a person who this, the recipient, the transplant recipient knows is in their court, but is willing to say to them, Look, what are you doing?

Take a look. This isn't safe. I'd like to see you do your best. And to try to challenge What's going on with that person and see if they can help get them back on track. There's so [00:44:00] many different roles, the support person plays, it's hard to kind of capture all of them.

**Candice Coghlan:** And you were nodding your head when, when she mentioned the word burden.

**Ivica Balaban:** Yeah, well, I, I recently read a quote about, you know, burden and it was that, I mean, I think all of us go through that. We feel like a burden and the person said a burden is something you're saddled with that. You don't want to keep doing and you're not. And the fact that someone's there taking care of you, helping you, they've chosen to continue to help you.

They're not saddled. They're not, you know. They're actively doing it. So I think that's the difference, right? You're certainly, yeah, it's not ideal, but it's not something that they are, you know, fighting against. They want to help you. So that just popped in my head as soon as the word burden came up.

**Candice Coghlan:** I think we often forget that.

The people that we love want to help us and they often don't know how either. [00:45:00] Right. And, and for some of us who might be more stubborn than others, we might not be able to express our needs either. I wonder Margot, if you have, um, any advice for, for those of us who have difficulties asking for help, because I think most of us would agree.

We don't want to ever ask for help because. We're already feeling like we're asking for too much, right?

**Margot Mitchell:** Yeah, you're right, Candice. That is a, a huge thing people have to negotiate. It is very hard in our individualistic and very independent culture to ask for help. I think, though, I think when there's an understanding between the person needing help at times and the caregiver that the caregiver would give a signal, it doesn't have to [00:46:00] be asking for help.

It might be an agreed upon word that they've agreed upon. So, in public, you could just bring that word into the person would know, for example, if a person's at a social event and getting really tired. And instead of announcing to the room that they're tired and they need to go, there might be just sort of a discreet word that the caregiver.

So there could be those secret signals, but mostly I encourage, I encourage people to put things on the table. And for the caregiver to say, I really want to be there for you. I don't know, as you said, Candace, very wisely, they don't know how to help. And I need your. To let me know when you need that help, put it on the table and if the recipient can come to some sort of understanding, it's not [00:47:00] acceptance, but some sort of understanding that this person wants to help and to let them in.

When they really, really, really need it, not before. I always tell people who are ready to go to surgeries, like donor and recipient, there's going to be pain. There's going to be, the recipient is already feeling that what the donor is doing is really, really, really amazing. They don't want to see them have any pain.

There's going to be pain. And when you're first, when you can't see each other because you can't go to each other's rooms initially, you're going to be seeing each other on a video screen like this. You're going to see pain in each other's faces. So don't put the energy into trying to hide it. Just know that there's going to be pain.

and know that we're treating it and know that trying to put on a brave face for that other person takes a lot of energy and it doesn't work in the end. [00:48:00] And so putting cards on the table there again and being patient with one another. I know you don't like me helping this way, but I can see that you're so tired and I really want to do this for

**Candice Coghlan:** you.

One thing that we talked a lot about was that guilt that a lot of us transplant recipients have in many different aspects. I'm wondering if, if you've experienced dealing with that, that post transplant guilt and, and any advice you'd have for, for those of us who are still struggling with it.

**Margot Mitchell:** Yeah, guilt is part of life, isn't it?

And it can crop up. I think we're all good people and it can crop up. In ways that takes by surprise what you mentioned, the guilt of being on dialysis and getting a [00:49:00] transplant relatively quickly over somebody who doesn't have that option, you know, for a living donor to come along and get somebody either prevent somebody from needing dialysis or having them on dialysis a very short period of time.

Does. Everyone involved, everyone affected by this disease, a good, a good deed. It's, if you're getting off of dialysis and not being on the waiting list, then the person who does have to be on the waiting list, who doesn't have that choice, is going to get their transplant so much sooner as well. And so there is, um, one could look at society and say that, and realize that there's, inequities to people who are successful in their lives, [00:50:00] in their careers, who have a better financial situation, to know people who are also successful in their lives, have a stable financial situation, who can take that time from work.

There's a safety net for these people if there's complications. And there, there is a difference in The who comes forward for a living donation. These are people who can.

And there again, there is perhaps a privileged group of people who are able to receive a living donor. And if all those people were on the waiting list, it would be very, very much longer list.

**Candice Coghlan:** So, thinking [00:51:00] about that whole process that, that the 2 of us have been through with, with having a living donor, one of those pieces was that psychological workup or the psychosocial part of this, that, that now you're laughing about.

**Ivica Balaban:** Well, no, and just because my, my, my brother, when he did it, he was like, Oh, I'm going to mess with them. Right. And so. When he did the psych evaluation at the end, he's like, I get paid for this. Right. And I was like, man, no, no, no. He like, they knew he was joking, but I was like, I was like, you're just lucky.

The person had a good sense of humor because otherwise I'm like, please don't

**Candice Coghlan:** say that poor social workers having to listen to us,

**Margot Mitchell:** some people say. Did I pass at the end of our discussion? Did I pass? No, there's still the written exam.

**Candice Coghlan:** Oh my goodness. Yeah, it's, it is. You think that it is like a [00:52:00] pass or fail, right? Do I get past this? But, you know, thinking about that workup for us, is there something there that would make somebody not approved either as a recipient or as a donor? throughout that process.

**Margot Mitchell:** When social work does the social work assessment, whether it's for the donor or the recipient, it's about readiness for transplant.

And probably the first part of that is, do they know what They're getting into. So even though we anticipate success for transplants, there can be complications and some donors and some recipients just don't have the same experience that they had hoped for, that we had hoped for. Right. So, acknowledgement that that can be the case is important, and there are some certain, a number [00:53:00] of items we'd like them to understand might be a.

common complication or a worrisome complication. Um, so there's this whole process called informed consent and the person proposing the treatment, the doctor, is really responsible for that informed consent, but all members of the team contribute to it. Uh, donors and recipients contribute to it. They've been reading, they've been talking to people to find out.

What are the things I need to know? What's this really going to be like? There's manuals to read and they can be kind of technical, but really talking to peers is really very helpful. Um, so there's the information piece. And so if people don't know things, we can help to fill in the gaps. If there's a lot they don't know about, if they're confused about something, we might refer them back to their doctor for further discussion, just to round out their understanding of an [00:54:00] important issue, or what could be an important issue.

There's the Willingness for donors, there's got to be that willingness, of course, lack of coercion. Uh, we joked before, but we are listening for that. Right. And most situations where it's family are straightforward. There can be very, some very complex relationships as well. And the social worker would spend a lot of time with that person to really parse out what's going on, making sure again that that donor is giving willingly.

And what does willingly mean? Well, for most people, it's pretty straightforward. But again, in those complex situations, it can require a lot of discussion. And that's

**Candice Coghlan:** so complex, family dynamics are, are so important when you're going through something like this. [00:55:00] And I'm wondering for, for yourself, did you find that you had any changes with your brother post transplant or with anybody else in your family?

**Ivica Balaban:** I find that it's been actually quite good. I think if anything, we're closer, certainly because my brother and I aren't quite alike. Like my oldest brother and I are very much alike. Whereas my middle brother, well, this brother, we shared a room for like 20 years. So we're kind of opposite. Like we're, you know, but I think it's been okay with my mom.

It was, it was interesting because she's been. Like, you'd think that I was the most sick person in my family, but my mom, like, she's way past me, right? She's had two strokes, breast cancer, heart attack, diabetes, like everything, right? So, she knew what it was gonna be like for me, but I think at the same time it was like, knowing when to, you know, communicating when to...

When I needed help when it was like, listen, I'm just going to talk for like an hour and like, you just have to sit in the same room. You don't actually have to say [00:56:00] anything. Just she's like, yeah, cool. No, I get it. Yeah. The dynamics haven't changed all that much. I mean, my brother always jokes with me. He's like, you owe me your life.

And I was like, it was true. I'm like, you're just stating a fact. Right. But, but it's, it's, it was never, never like that. Like my family, we're. We're all about access service. Like we're not physically affectionate, no words of affirmation. None of that. It's just like, you need this. Okay. Right. It was never like an issue.

So, and it's kind of the same way now. Um, anytime he's like, he's like, yo, if you gain weight, like I'm going to get you. And I was like, look, I don't want to gain weight either. I'm like, I get it. Right. But he's okay. Like it's his, his personality is the same and it's the dynamics are, yeah. If anything, we're closer, which is

**Candice Coghlan:** just kind of nice.

That's fantastic. And we talked a lot about how important that, that peer support is too, whether it's through formal mentorship programs, like the kidney foundation or just informally through, through Instagram. [00:57:00] I'm wondering Margot, if you have any insights into what you think about peer support and the importance of that for, for those of us going through these.

**Margot Mitchell:** Journeys. Peer support is unique and can offer people what health care providers just can't. Um, I mentioned before that manuals, the information we give to patients is often quite technical, but what does that mean in their daily life? You know, that's what peers can offer and peers can say, here's what happened to me.

And, you know, when I talk to recipients, candidates who have talked to people who've had transplant before. They take away two things, either success, sometimes failure, but also a, an appreciation for what [00:58:00] everyday life might be like, what it's really like to take the pills, what it's the importance of the blood work, how they get their lives back in degrees, perhaps, but they get their lives back.

And one thing that I find that peers can really offer. Is a sense of how full life can be after the transplant that it's not just about the blood work, not just about the pills and going to appointments. People can be athletes. Like Vita, they can



get back to their career singing. They, I often point them to the transplant Olympics and they kind of perk up and they say Olympics, what do they mean?

I said, well, sometimes it's about the three legged race, but other times it's very challenging competition competitions. And then I also point them to. What a [00:59:00] heart transplant recipient had done was mountain climbing in Antarctica. With his cardiologist, not because he needed a cardiologist, but that was her interest as well, and I can talk about this because it's out in the public domain, and so on, but I do encourage them to explore that kind of thing.

In some way, whether it's Transplantolybics website, talking to other people who have had transplant and who have gone on to go to travel, have family reunions, have a career, get back to the gym, but to take on, and they're encouraged if they haven't had an active lifestyle, that that might be an important thing to talk to their peers about as well.

But it's something that no healthcare provider can really offer if we haven't. Going through that experience and [01:00:00] You know, you always have to caution people that that's one person's experience, that's not necessarily going to be your own. Yes. I think most people have the sense that that's the truth of it, you know, and hope, it offers a hope.

I recall a story from many years ago where a person who needed a liver transplant actually met up with a mentor. Who had had a transplant and that the person who was needing it asked if they could touch the person who had already had the transplant. And somehow for that person, it was really reassuring that whatever they felt when they touched that person, they felt real.

They felt just like me, just like something. It was. really therapeutic. So the peers can offer that sort of thing. It's invaluable. [01:01:00]

**Candice Coghlan:** Well, thank you so much, Margot, for joining us and talking about your incredible career and all of the advice that you have for those of us who have gone through this. I know that the UHN team definitely misses you, even though you've only been gone a few weeks and it'll be difficult to replace you.

Because you are one in a million for sure. So thank you so much for, for sharing and for all of the incredible work you've done over the years for all of us patients, it's remarkable to have someone like you in our corner. And for you Avitsa, thank you so much for joining me today and for sharing your story so openly.

**Ivica Balaban:** It was my pleasure. I think the PR, like anything to share a story and to show, you know, things get better and what it can do. I think I'll do anything I can. I'm

**Candice Coghlan:** wondering if, if you have one final thing that you'd like to sing us out with, or just say goodbye or something fun. Goodbye!

**Ivica Balaban:** I can do that. I don't [01:02:00] want to do too much.

**Candice Coghlan:** Thank you so much. So much fun. That's fantastic.

We hope you enjoyed this episode of the Living Transplant podcast. If you did, please leave us a review and share with your friends. Don't forget to subscribe to Living Transplant wherever you are listening today. If you have any ideas for podcast episodes, you can reach out to us at livingorgandonation at uhn.

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Special thanks to Lead Podcasting for editing this episode and for production support. Thanks to Paula Neves, our advisor to the show. I'm your host, Candice Coghlan. Thanks for spending your time with us.

Now I would like to leave you with Avicii singing a beautiful piece called Amor Ti Vieta, one year post [01:03:00] kidney transplant, enjoy.[01:04:00]