

# S3E8 Transcript

**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 for and Donation. I'm also a 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 like you've never seen it before.

Welcome back to The Living Transplant Podcast. Today I am joined by a woman who loves with all three of her [00:01:00] hearts, Michelle Rambarran. Later will be joined by Dr. Michael McDonald, Director of the Advanced Heart Failure and Transplant Program, the Peter Munk Cardiac Center and UHN Transplant. Thank you so much for co-hosting this episode with me, Michelle.

**Michelle Rambarran:** Oh, you're welcome. Thank you for having me.

**Candice Coghlan:** Awesome. So I'm wondering if you can bring us all the way back and tell us a little bit about yourself before any of your heart issues began.

**Michelle Rambarran:** Sure.

So I was married in 2003. We were expecting a baby in 2005. I was very busy getting the nursery ready and getting ready to be a mom at home. And yeah, I was not expecting anything that was to come and so I was in completely shock with that .

**Candice Coghlan:** Yeah. Wow. And so in, in 2005 you had what is called a spontaneous coronary artery dissection.

And I've [00:02:00] read that, that condition can present itself as a heart attack, but it's often misdiagnosed. Can you explain to me first what that is and then what that was like for you?

**Michelle Rambarran:** Yes. So spontaneous coronary artery dissection is when there's a tear in the wall of a coronary artery, and that tear can cause blood flow to be restricted to the heart. A lot of people who have this SCAD actually experience chest pains or they can even have a life threatening heart attack. And there are some cases also when there could be sudden death. Most people who actually have this, don't have any risk factors for heart disease, such as high blood pressure, high cholesterol, or even diabetes.

**Candice Coghlan:** Mm-hmm.

**Michelle Rambarran:** So it was quite surprising for me as I was in the same situation where I didn't have any of these risk factors and suddenly faced with SCAD.

**Candice Coghlan:** Wow. And [00:03:00] so how did that present itself for you? How did you first initially feel that, or, or what was going on for you?

**Michelle Rambarran:** Yeah, so for me, I was at home. I was feeding my son. It was about five days after I got home.

**Candice Coghlan:** Wow.

**Michelle Rambarran:** And I felt pain in the back of my neck. I had difficulty breathing, some chest pain. And so when they called the ambulance, nobody really thought, "Oh, this 29 year old's having a heart attack right after just having a baby." So it took some time before they realized it was actually a heart attack.

**Candice Coghlan:** Oh my goodness. And so when you were diagnosed, you were brought to the, to the hospital to emergency. How did that process go? Did it take a long time for them to figure that out, or?

**Michelle Rambarran:** I think it did, because I think initially they were looking at maybe it's a complication from the pregnancy itself.

**Candice Coghlan:** Okay.

**Michelle Rambarran:** And then I think when they [00:04:00] finally got my blood work back, that's when they realized it was a heart attack. And that's when they prepped me and got me ready for at that time they were put trying to put in a stent.

I ended up in the hospital for about a month, and from there I was referred to UHN and I was able to meet Dr. Heather Ross. And that was my first introduction to her, and she was a great doctor who kind of explained to me my situation with my health condition and what to expect over the next little while. And one of the important things she said to me is, "the longer you prolong needing your heart transplant, the better for you."

And she suggested regular exercise and a healthy heart diet which I definitely did. I mean, I progressively started to do my treadmill for about an hour a day and then making sure my diet changed and listened [00:05:00] to what was good for the heart. And you could definitely feel it if I ate something bad like a pizza.

**Candice Coghlan:** And how did you manage being a young mom who was going through all of these health difficulties?

**Michelle Rambarran:** It was very difficult, like to first try to understand what was actually happening to me.

I was lucky enough to have my parents who were living with me help taking care of my son because in the first year I was in and out of the hospitals all the time. Right. I had my husband who was always supportive and whether it was being with me at the hospital or being at home with her son mm-hmm.

um, He was amazing in doing everything. And I had a lot of close family and friends who literally dropped everything. Took vacation after I had the heart attack. Came and spent time at my house to help my mom with my son and they took turns rotating doing this. And I even had a cousin who flew in for a week just to spend time and make sure that my son was okay.

And my mom had a break [00:06:00] because she was also stressed out with me in the hospital. Mm-hmm. . So it was a lot to take on, but I had a great support system around me who helped me through.

I find being a a new mom is, is hard on its own And then to add all of that on top of it, that's something that a lot of people don't ever have to think about.

So it's fantastic that you have that support network and you were able to meet with the, the amazing Dr. Heather Ross, who who is so remarkable in, in everything that she does as well. So you were able to exercise and, and eat. Right. At what point did Dr. Ross say to you that we're getting to a point where a heart transplant might actually need to

happen?

So, I mean, for me, I always remember things based on my son's age and , he just born and he was about two and a half [00:07:00] years old. So that's when she said it's time to go on a waiting list for a heart transplant. I had actually gone into the hospital initially they were planning to do an L V A D and it was changed to a heart transplant while I was in the hospital because the donor heart became available.

And it was actually the very first family day in Canada. So it's a day I will always remember .

For me personally, I wasn't thrilled about getting an LVAD. I had a two year old who was basically pulling on everything and I was worried that me having an LVAD would restrict how I would get to interact with them.

Mm-hmm. . And, and so when they decided that, oh there was a heart available, I was happy because I was already admitted into the hospital waiting for surgery.

That's a, a very quick turnaround that they would've had to do for you. What was that workup [00:08:00] process like?

I believe initially they had put me on a waiting list for a heart transplant. I think only because I was admitted in the hospital they were considering an L V A D mm-hmm.

But when they did put me on the waiting list for a heart transplant, there was a lot of things that was involved. We had to do blood work in which they were checking for kidney and liver function. . They were also testing what blood group and tissue type I was in order to determine the specific antibodies in my blood and I had to do an ECG, a coronary angiogram. A stress echo, X-rays. And one thing that I found was very interesting was all the consultations I had to do. So I had to do a dental assessment to make sure my dental hygiene was good because there was some restriction on what you could do from a dental perspective after the surgery.

I met with the heart transplant surgeon in advance and I [00:09:00] also met with the transplant team and also a social worker, which I found was actually very helpful for me to talk through some of my emotions. As great as my family and friends were to talk through everything, there's certain things that were just running through my head that it was great to talk to a social worker about.

Mm-hmm. .

I think that's one big thing social workers and, and, and the peer networks that, that we can use as patients to reach out to people because. There are some things that as transplant patients we go through that we can't talk, like you said, we can't talk to our family and friends. And also maybe sometimes we don't want to scare them with our fears or we don't want to ask embarrassing things to our family and friends and Google's not always our best friend and finding results.

Yes. So, so you're right. Having, having a social worker or those people out there [00:10:00] who have been through it is just so important to, to

have. Yeah. Yeah. I, yeah, I agree. Like I think also keeping those emotions internally, it can cause an outburst, like for me personally, by keeping some of that in.

I remember my poor husband, we had gone out for dinner and we were at Jack Astor's and I think I finally just broke down before the waitress came. And in my head, all I was thinking was, he's not even gonna remember me as his mom if something were to happen now. And he was, at this time, this was pre going on the waiting list, so he was on less than a year old.

And there's a lot of those fears that you have within you about who's gonna remember, are they gonna talk about it? I'm gonna miss all these events and milestones and your child's life. And it's a lot to deal with. Mm-hmm. . Wow.

And that gravity of, [00:11:00] of this situation and that's a lot to put on a 29.

Were you 29 or or 30 at this time? Yeah, I

had just turned 30 in the hospital. There was a time when I didn't think I was gonna live to see my son's first birthday. And I just celebrated my son's 17th birthday and I'm incredibly proud of him. I'm, I mean, I love all of my family for everything they've done.

And. Yeah, I look forward to seeing the rest of these milestones. You always have that hope that, again, you're gonna be that one who beats the stats. So. Exactly. I feel like I'm gonna do it this time, .

Oh, wow.

And all of those things that you have to go through in such a young age to, to deal with that thinking that your life is gonna be one way and then there's this giant fork in the road that you've been forced to take and all of these things that, that we [00:12:00] have to deal with as young people going through the transplant process.

Where friends and family may be doing some things that are completely different. And they don't have those big, heavy thoughts on their backs, and we would never want them to either.

Yeah, I, I remember when I first met Dr. Ross, even the way she talked to me about the heart transplant, I mean, she was very frank and one of the things she said was there isn't a heart sitting on a shelf waiting for when I would need it.

That would be a match. And so listening to you're waiting for a hard transplant, there's no guarantees. When I found out, I mean, I had only spent five days with my son at that point. Mm-hmm. . And I also learned over the progression with the, my treatment that because of my age, there could be a possibility that I would need a second transplant.

And I knew that from the start. Mm-hmm. [00:13:00] but is you don't really think of that gravity of all that information that's coming at you. You're still stuck on the, there's no guarantee of a heart transplant. Right. So, yeah.

**Candice Coghlan:** Wow. So when you. Got that work up. You're, you're in the hospital and you're ready to go.

How long was that surgery that, that they performed on you?

**Michelle Rambarran:** I believe the surgery was about five hours. Mm-hmm. . And I personally I remember my mom telling me actually that the time went by so fast because my son was there and entertaining everybody,

But at the same time, there was also the surgeon who came out and talked to my family and gave them updates and stuff. For my family, they were comforted in knowing that. Mm-hmm. for me personally, after that surgery, there were

certain things I remember, there's certain [00:14:00] things I don't because you're on so much medications after it that sometimes you're hallucinating and yeah, I do, I do remember opening my eyes and seeing my husband and thinking that, please don't leave me and I'm not sure what's gonna happen next.

And he had been there already for, since the night before, because as soon as I heard I was getting the transplant, I was like, I wanna see my son. Like, yeah, I wanna spend as much time as possible. Right. So yeah, it was, it was a lot .

**Candice Coghlan:** So they came to the hospital the, the night before to visit you.

**Michelle Rambarran:** Yeah, so I had actually found out probably around one o'clock in the morning. My mom, because I was in the hospital and I'm not sure if so the protocol was, I think they called the cell phone number that's there for the donor for the person who's waiting mm-hmm. . And so my mom had answered the phone at home and she had called me, but also the nurse at the hospital had mentioned it to [00:15:00] me and I just said I want you guys to come as early as possible.

So I think they came around four or five o'clock in the morning. Wow. And yeah. And at that point I was starting to be prepped. I had all my IVs plugged into me and but I wanted to see my son one last time not knowing what would happen next. Mm-hmm. .

**Dr. Michael McDonald:** Wow.

**Candice Coghlan:** And so you went, you went under the surgery was successful and when you woke up post transplant, Other than the the large amount of pain that you were probably in from the incision.

Did you feel any different once you could finally feel those feelings?

**Michelle Rambarran:** Yeah. I definitely felt stronger. Slowly I progressed to, from sitting up to walking and before I left the hospital, I felt pretty independent. Being able to do the basic things like eat your [00:16:00] food, take your meds, go to the washroom alone.

Mm-hmm. . So I felt like I was ready to go home and I didn't have to worry about my chest pains. I didn't have to worry about slowness with my breath and tightening feeling when I was walking. So it felt great. I felt like I was ready to go back home and see my son .

**Candice Coghlan:** Well, yeah, I bet you were just antsy to get outta the hospital.

Like the second they said, off you go running to the doors. So what was life like with your, your son and your husband in this new heart?

**Michelle Rambarran:** For the first year it was what most transplant patients experience. We had a lot of clinic appointments. I had a lot of biopsies and blood workup that we had to do.

This went on for about a, a year and a half I think, at. When there was a lot of appointments mm-hmm. and but over the years, [00:17:00] like, I mean, I felt great. I mean, I didn't have any issues. For the most part, I didn't have any rejection with my heart, which was amazing. And my two year old at home really prompted me to be active.

Right. So Right. I was running behind him we were going out and playing in the yard and things that I couldn't do even from just carrying him. Right. Some, a simple task that's carrying your child was not allowed when you were waiting for that heart transplant. I had to wait for someone to put him on my lap to hold him.

Mm-hmm. . So it was very different. And finally I felt like there was hope for the future. Yeah.

**Candice Coghlan:** Wow. My nephew when I was, a crash start I spent a lot of time with him and he was about three or four years old at the time. And similarly, like I had before before dialysis with my tubes, I picked them up all the time.

I roughed house with them. I would jump in pools and all of these things. And then that all [00:18:00] came to like a screeching halt, right? And I remember that was one big thing of why I wanted a transplant too, is I wanted to be able to be active with, with my nephew again because he was such a light in my life.

And, Thinking about all of those things that we take for granted before, we have these kinds of situations that are just so beautiful that we're able to do. And I'm wondering, do you have any favorite things that, that you do with your son? Was there moments post transplant that made you so elated that this was your new life?

**Michelle Rambarran:** So when I would feed my son and he would sit in his high chair, I would play some music and we would dance. So I would spin him and because I couldn't carry him right. So we would still spin in the high chair and he would dance in his seat and I had to make sure he wasn't eating so he would choke[00:19:00]

But it was a lot of fun to see him smiling and laughing. And over time that progressed from the high chair to me actually being able to carry him and dance. And that was a lot of fun for me and

**Candice Coghlan:** for him. Yeah. Oh, that's awesome. And so your heart transplant worked incredibly well for, for almost 12 years after that point.

When were you told that there would be a potential that you may need your second heart?

**Michelle Rambarran:** Yeah. So I mean, I always knew in the back of my head that I, I, there was a possibility I could need a second heart transplant. Mm-hmm. . But you always hope that you're the one who's gonna beat the stats and not needed and do well because you do see a lot of people who've been with the first heart transplant for 30 years and 40 years.

Right. And so you hope you're one of them. For me, when I realized I was starting to get sick again [00:20:00] was I was just walking home or actually I was going to the ghost station after work and climbing the stairs at the train station, I just suddenly was completely out of breath. I actually had to sit down as soon as I got up and just wait for myself to catch my breath and feel like I was not lightheaded again before I could move and literally get on the train again.

And That's when I suddenly thought that, okay, there must be something wrong. So when I reached out to the hospital, that's when they were saying that they're noticing some decline and that I would probably need a second heart transplant.

**Candice Coghlan:** Wow. So that must have been quite shocking to go through that, that process again.

And this was close to, to Covid, wasn't it that you, that you ended up having your [00:21:00] second transplant?

**Michelle Rambarran:** Yes, definitely. So I was only a couple months. It was only a couple months into Covid when I got the call. I was actually very lucky

to even get a call because during Covid initially they had put a hold on all transplants, right.

So I, I believe when they lifted that hold, I was probably one of the first few to receive a transplant. And it was a very different experience because of all the restrictions at the hospital. I got the call at home I came to the hospital with my son and my husband, but I had to say goodbye to them at the Elizabeth Street entrance of the hospital and doing all the pre-work up before the surgery I was sitting there by myself through all of it.

We had to do a covid test, make sure it was negative. And by the time it was almost like a full day had passed before I actually went in. Wow.

**Candice Coghlan:** So you had to say goodbye to them and, and [00:22:00] go in by yourself, all by yourself and do all of this on your own. Yeah. That's terrifying. And you know that, that we, we don't hear as many stories about.

Patients who have had their transplants through covid and what that was like. We've talked to some people who are post transplant. You know about the isolation and the fears around covid that transplant patients have. But we, we don't hear a lot about the inner workings of having a surgery at the height of, of the pandemic.

Can you talk a little bit about what that was like too? To receive a transplant during the pandemic.

**Michelle Rambarran:** So at that time, I don't know that mandatory masking and all of the protective gear was in place because it was still pretty early in Covid. Mm-hmm. . So I remember them saying, because I asked if I need to wear a mask, and I remember them saying that, no, it's not mandatory for a [00:23:00] patient, but the, the nursing staff and everybody else had to wear it.

And I have to say from the transplant floor and all of the nurses there, the care was incredible. These are people who are. In an environment where you're seeing a lot of covid patients and here they are taking care of you right after a heart transplant and they still have their bubbly personality and they're encouraging you to become more independent and start walking and you know they're still there for You As you're learning new things about what happened in the surgery and the procedure and there's a lot of information coming at it at you mm-hmm. and for me it became very overwhelming without anybody else, so. Right. Having those nurses and there great personalities there for the support was incredible.

Mm-hmm. .

**Candice Coghlan:** Was there, outside of Covid, was there anything that was different [00:24:00] from the first time around?

**Michelle Rambarran:** For me it was very different. I feel like I was older now, the way I dealt with the surgery and the recovery was a lot harder than the first time.

I felt like I bounced back immediately after the first transplant, and with the second one, it was far from it. I don't even remember anything for probably the first week and a half. And the first thing I remember personally was waking up and not really recognizing that I was in a hospital and I had had a transplant, but what I did see was Dr. McDonald at the foot of my bed. Then, then only I realized, oh, I'm going in for a biopsy and then only click that, oh, I had my transplant. And so seeing some recognizable people that are comforting to me, it was, it helped, [00:25:00] but Very different experience overall. And I don't think I covered as quickly the second time around as I did with the first.

And there were some complications in the surgery that contributed to it, but there were also some things afterwards that had developed that I didn't expect. Mm-hmm. .

**Candice Coghlan:** So you found out as you were kind of waking up, what was going on? Did you have memory of, of who you are, who you were?

**Michelle Rambarran:** For me, like I remembered who I was. I didn't remember that I had the surgery initially. And I personally don't remember anything from the first week and a half other than my hallucinations. I remember the hallucination, but I, I only did some pieces of it and But for the most part, I don't remember what actually happened afterwards.

I do remember one of the doctors telling me, the cardiologist actually [00:26:00] saying that he spent a week treating me and coming up and following up and making sure I was great. And at the end of all of it, I called him Stella, who's my nurse practitioner, and had been with me since the beginning, . And he said everybody around them laughed , because I had called him Stella.

And at this point I I didn't even remember any of this. Wow.

**Candice Coghlan:** Yeah. So uh, kudos to Stella as well because she obviously made a big impact for her to be remembered, right?

**Michelle Rambarran:** Yes. Yeah. She has over more than over 12 years .

**Candice Coghlan:** Wow. That's amazing.

**Michelle Rambarran:** Yeah. And then slowly they started to tell me what happened with the surgery, and that's when I had realized that, oh, there, there were some complications in the surgery itself.

And what ended up happening was I also needed a val replacement along with the heart transplant. Wow. And For me, what they had mentioned was that [00:27:00] in the middle of the surgery, they had realized that there was an issue with the donor heart. And so my surgeon and the team that was there had to come up with a solution quickly.

And that's when they realized they had to do the valve replacement. And I'm grateful for their quick thinking and doing the solution. And looking back, I'm feeling great now, but initially it was a, an uphill battle. . Mm-hmm. .

**Candice Coghlan:** Wow. And so I have to ask, this is a maybe a, a strange scar question, but do they use the same incision, like the same scar to, to do the second transplant?

**Michelle Rambarran:** For me, they did yes, they used the second, the second transplant was with the same scar. And one of the things that Dr. Cusimano did was also removed my defibrillator that I had implanted. And so that was great because I mean, I didn't have to come back for another surgery to remove it. Right. So I was glad that everything that needed to be removed [00:28:00] was taken out and sold back up

Yeah. Wow.

**Candice Coghlan:** And so after that week and a half, when you, when you came back, was there anything that prompted you to click in? Was there a moment that you remember, okay, this is where I am and this is, this is what's happening.

**Michelle Rambarran:** So after the biopsy, I was looking around and when I was talking to the nurse that was there, it clicked that, yeah I had the transplant.

I mean, I couldn't move at this point. It actually ended up happening that I had some issues with my kidneys and I needed dialysis as well. So, so initially after the transplant I had been going through dialysis treatment as well and I think my

kidneys to just had gone into shock and over the about a week or so, I think it started to come back to normal.

And now they just monitor it to make [00:29:00] sure that it's not bad. Mm-hmm. as it was. And also some of the things I developed was I had developed diabetes, From some of the medications, like the Prednisone. Mm-hmm. . And so I had to go through the process of learning how to check my sugar, give myself my insulin.

So yeah, it was quite a few things that happened and I even got to the point where I almost didn't wanna know what was going on. I almost said to them like, if happening, don't tell me. It's too much information for me. I don't wanna know . Yeah. To what you have to do.

**Candice Coghlan:** overload, right? Yeah. It's a lot to handle.

Yeah. And so how long did you have to do dialysis for?

**Michelle Rambarran:** From what I remember, maybe it was about a week and a half. Mm-hmm. . And after that I, I was able to sit up and get some fluids in me on my own. And it started to help and they, they reduced the [00:30:00] amount of dialysis and then gradually was.

**Candice Coghlan:** Wow. And, and the diabetes are, you still have, do you still have to monitor that?

**Michelle Rambarran:** I do, actually. It wasn't, I thought that it would go away. It did reduce for a while. Mm-hmm. my dependency on the insulin. But yes, I still have my diabetes and I am still on a form of medication. Hmm.

**Candice Coghlan:** And so that that transplant, how long did it take for you to eventually be able to leave the hospital and, and go home?

**Michelle Rambarran:** I believe it was over a month. Wow. Before I was able to go home. Mm-hmm. . And I was looking forward to going home, but at the same time I was a little nervous because it took a while for me to be able to actually walk in the hospital and see myself in a mirror. And I was shocked when I looked at myself like I didn't recognize who I was looking at with all of the medications. My face had [00:31:00] just gotten so big and round and I couldn't recognize me when I looked at it, looked at it. And so I felt like I had to warn my son and my husband that I don't look the same as when you dropped me up.

And you just need to be prepared for it because I don't think I've ever been so puffed up like this before. Mm-hmm. I don't think my husband believed me until he finally saw me. And then because I had mentioned this to both of them, they tried not to stare too much and I basically had to say, Okay, let's stare, get it over with.

And this one on

**Candice Coghlan:** I had a, I had a similar instance. My husband and I worked together when we were just dating and we worked at this community center and we had family Fridays. So bunch of families from the community would come and bring potluck food and one of the moms was looking at me and kind of side eyeing and, and then she she came up to me and [00:32:00] asked like how, what the surgery was and how I was feeling. And then as politely as she could she just kept doing this and was like, What happened to your face,

I said, It's the medication. Like I, I have what they call a moon face now from, from my medication. But I was shocked as well. I went from, I think I gained almost 30 pounds in the first three months of, of using my prednisone. And my face was, my face is still much rounder and chubbier than it, than it was pre.

But very, very round. And you, you can feel. That you feel puffy too. It's such a strange feeling with those high doses. Yeah. And then eventually they, they lowered my prednisone and I, I've tapered off quite a lot, so I've lost some of that, that moon face. But it is shocking to see [00:33:00] yourself.

Post transplant?

**Michelle Rambarran:** Yeah, definitely. For me, I definitely had that moon phase and I think I was just so stressed when I was in the hospital being by myself in Covid and not having that family support with me throughout that I had the first time around. Yeah. But for me, I actually started to lose my hair and Oh wow.

I actually lost the majority of like, it started probably. Three months after mm-hmm. the surgery. And they probably progressed for a couple, maybe two or three months to the point where I almost lost everything. And, and maybe about two months later it started to slowly grow back. But I was in shock that I would even lose my hair because something like that never even happened the first time around.

Right. So Right. For me to deal with the moon face and then my hair loss, I was so glad we were in Covid and I didn't have to see anybody . Right.

**Candice Coghlan:** Yeah. Not many benefits to Covid, but , [00:34:00] but once in a while. Yeah. Wow. And so how long did it take once you were home, that you started to feel a little bit more like yourself again?

**Michelle Rambarran:** I would say probably almost two years this time. Wow. Because of the amount of things I think initially that happened. Mm-hmm. . And so I, I mean, I felt like an old lady. I was walking with a walker in the beginning and I felt very dependent on it too. Mm-hmm. . So, I mean, I went through similar things like the biopsies and be blood works and all of the other tests and clinic appointments, but my recovery to be able to be self-sufficient, I think mm-hmm.

Was a lot longer with everything. Mm-hmm. .

**Candice Coghlan:** So once you got to, to feeling better I know you're, you're very active in the Heart Links support program and thinking [00:35:00] about us patients, I feel like connecting to other people who have been through something similar is the best medicine that we can have because there's nothing better than having somebody simply say, I understand, and you know that they understand.

Can you tell us a little bit about that program and, and what spurred you to get involved in it?

**Michelle Rambarran:** So for me, I joined Heart Links the first year after my first heart transplant. And I had heard about this potluck that was happening at Christmas, which would invite all of this doctors, the surgeons, the nurses.

So I thought it would be a great opportunity for me to see them thank them again. And but Heart Links basically a support network. It is targeting specifically heart transplants and their families and caregivers. And they do a lot of other things like speaker events. I mean, during Covid they had a number of [00:36:00] sessions on the Covid vaccine what it means to be immunosuppressed and moving around with Covid.

So it was very helpful. They also had other activities, like I mentioned, the potluck. And because of Covid and not being able to do some of the stuff that they had traditionally done, that's when the hard things, virtual step challenge kicked in. And that was an amazing activity because we were surprised to get so

many people who just wanted that comfort of knowing other transplant patients who are still trying, trying to get active.

Mm-hmm. while still being isolated cuz of covid, right. So mm-hmm. And I think I, I agree with what you mentioned earlier, is that it's great to be able to talk to a, another heart transplant patient or for my family to talk to another caregivers because they have similar experiences. And sometimes when you go through things, you look at it and say, is this normal?

Like, am [00:37:00] I feeling the same things that other transplant patients are feeling And mm-hmm. and sometimes you hear the side effects of me medications, like you just mentioned the moon face, and it's great to know that other people went through the same thing. And it's it's, you get that sense of comfort talking to somebody who's really experienced it.

Mm-hmm. .

**Candice Coghlan:** Absolutely. And so during Covid. I know for me, I was afraid at the beginning I was, I was even afraid to go outside for walks because I, I just didn't know who I would see during my walks or who I would encounter. And it was just a very, very heightened scary time. And I am now, this year I'm 13 years post transplant.

So thinking. Thank you. But thinking you were, you were months [00:38:00] into your transplant at home through Covid. Were there things that you did to stay connected? You talked about the the virtual programs and, and the STEP program. Were there things that you got involved in that kind of helped with that isolation?

Because I think even now, as much as some of us have had five five. Vaccines. Some of us have had Evusheld, but I think there's still some fear out there for recipients because we're immunocompromised of what we can do and where we can go. I guess this is a very long way to say. Do you have any suggestions maybe for transplant recipients of things that they could do to stay engaged with the community?

**Michelle Rambarran:** So for me, like what I noticed was as we were attending these virtual events or step challenges, we did see some friendships build up and there is some groups that would do the step challenge, but then there were other people who [00:39:00] would just go for a walk in the park. And there was, you're right, there was a different level of comfort with different people in terms of how to get out in the community and interact because of their covid comfort.

Mm-hmm. for me personally, initially I would do my exercises at home. I had my treadmill and that was my primary thing. But I think attending some of these speaker events, hearing the doctors reassure us that we can still do things in the community. We just need to take some steps to be careful, right?

Like, wear your mask, make sure you're vaccinated and when I saw some of the transplant patients and how they were doing with Covid, it gave me some sense of relief that it doesn't necessarily have to be that extreme depending on the steps you have taken to protect yourself and get out in the community. Right. So you can still go out.

It's just making sure you're being careful. Like, I mean, I have hand sanitizers and everything around me, [00:40:00] and my mask is in my purse, my cars, my pockets, everything again . So I'm always prepared for that kind of protection of myself and my family in order to make sure that we can do the things slowly, start to do the things we used to do.

Mm-hmm. .

**Candice Coghlan:** I read an article about you and which you said that you tell your family that you love them with all three of your hearts, and you've talked a little bit about how your family supported you through this journey. But I'm wondering if there was anything that your husband or your son did throughout the journey that helped you get through this?

**Michelle Rambarran:** So I remember my mom specifically saying to me, What do you want from me? Like, what do you want me to do? Because she felt like she couldn't sit with me in the hospital, right? Cause my husband was there. So I just said, Take care of my son. And she did. Like, I mean, my mom was the one for the first month who was doing the middle [00:41:00] of the night feedings and waking up in the morning and dressing him up and giving him a shower, a bath, and all of that stuff was my mom.

And she was a great support to me throughout. And with my husband, like he was the one where he was always taking me to my emerge. Like, I mean, I always felt sick. It seemed to be at 11 o'clock at night. And so my husband would take me to the emergency. He would sit with me until like two o'clock in the morning when if I say, Oh, you're being admitted, and go home.

A few hours of sleep and then get up, sit with my son for a bit, go to work and do it all again. Right. So it's, it's the fact that they kept pushing and doing things and not once did they ever complain about doing all of that for me. And I had, I

personally had a lot of support around me from, like I mentioned before in my family who literally dropped everything to come and take care of my son [00:42:00] initially.

And people who would offer to come and clean my room and clean my house and pick up groceries for me. And these are people who didn't even live close to me. . Wow. So, I mean, I really appreciated all of their support and I could never thank them enough for everything they have done for me.

Mm-hmm. . Mm-hmm .

**Candice Coghlan:** And what is one of your favorite things to do as a family now?

**Michelle Rambarran:** So we do like to go on vacations. I mean, after my first transplant, we've, we finally went on our first vacation, which was to Hawaii.

**Candice Coghlan:** Wow. What a place to go.

**Michelle Rambarran:** I know my doctor said, You can go anywhere in Canada, in the US. And I'm like, Hawaii is in the US. I'm going there. . That's amazing. They suggested Alaska, but I was like, No, I don't wanna be cold. . Yeah, . And, and then we ended up going to Disney. My [00:43:00] son and he had an amazing time just to see the smile on his face when he saw the characters. And we went to Austria for a wedding and I finally went back home to see my family in Sri Lanka.

And some of the non-Canadian and US places were. I had to ask, is it okay for me to travel here? Are my meds stable? Am I stable enough to do that trip? And so it was great to be able to finally get out and do something like that. After my second transplant, I finally did, we did go on a trip to California and that was the only one so far.

But you know, now that Covid is settling a little bit mm-hmm. and we're getting more comfortable with flying. Maybe another trip will happen next year. .

**Candice Coghlan:** That's awesome. That's fantastic. My, my daughter is, well, she's 19 months now, so in July we went to Halifax to go to a family reunion. My husband's his family is from that area in [00:44:00] Nova Scotia.

And so she just, The time of her life on the airplane waving to everybody and smiling and putting stickers on everything. And then two weeks ago we went to

Banff for a conference so she had her second flight. So she's seen close to both ends of Canada now in under a two year lifespan. So I always laugh and say the kid's seen more of Canada than most people that I know, but but it's so much fun to be able to do these things now that we're transplanted, right?

We have the opportunity to, to go see what we wanna see and, and participate in, in whatever we we wanna do. It's, it's amazing.

**Michelle Rambarran:** Yeah, it definitely is to be able to go out and travel and just feel normal again. Right? Like, just feel like everybody else . And I don't think people appreciate that when we say it is that they haven't had so many things restricted.

[00:45:00] So to just feel normal and do the everyday things, it's great.

**Candice Coghlan:** And I, I agree with you even. I love going grocery shopping late at night, and I, I, I missed that so much during Covid. My mom would actually bring groceries and put them on our porch for us because we were nervous to go out into the grocery stores, and we didn't even know if we had to sanitize all of our groceries at the beginning, all of that stuff, right?

So we were so nervous. And so that's kind of like one of my small joys. Now that seems like a chore, but to me, I just, it's quiet and I like walking through the aisles and slowly doing my grocery shopping and having those tiny little things back that other people may not may not appreciate as much , as we do as transplant patients, right?

Mm-hmm. , definitely. Yeah. Yeah. So, I'm wondering most of us or all of us live with the gratitude for the [00:46:00] amazing gift that we've been given from our donors. What do you do to honor your donors and their families?

**Michelle Rambarran:** So I definitely still pray for my donor and their family because as much as I'm grateful for my heart I recognize that somebody has just lost a loved one and I, I hope my prayers have helped them to deal with that loss and know that their organs are living through somebody else and it's given them a second chance.

But one of the things we do to honor our donors is we actually, my husband, my son and I pick about five charities that we donate to, and we do this every year around Christmas time. And my hope is that somehow maybe the research that we support or maybe a food bank that we've helped will actually reach my donor and his families, right?

Maybe my donor would've wanted to do [00:47:00] something like this and hopefully, Somehow it touches somebody .

**Candice Coghlan:** Wow. That's beautiful. I love that. Yeah. That's incredible. I'm wondering if you have any advice for people who are going through something similar either in heart failure or going through a transplant journey or living with a chronic disease perhaps that you could share from, from your personal journey.

And then also anybody who you've met through all of your amazing volunteer work too.

**Michelle Rambarran:** So I would say is don't give up. I know it can feel like the road is hard ahead, but have some hope because that hope will get you through what's to come. And for me personally, I took advantage of different things that was available to me at UHN Hospital at Toronto General from asking all sorts of questions for the transplant team, just so [00:48:00] that I felt ready and that my family felt ready for.

What was coming ahead with the surgery and post-surgery. I also took advantage of speaking to a social worker again and talking to my emotions and you don't have to be afraid to be able to say what kind of help you need. And like I found for me, my transplant team reached out to whatever specialist I needed and got me the support that I needed to make sure I was ready and in the right state of mind also for my surgery and in my recovery.

Mm-hmm. . Yeah.

**Candice Coghlan:** Oh, that's great advice. Thank you. Thank you. Awesome. So is there anything else that you want to mention?

**Michelle Rambarran:** So for me, I'm just thankful for the people who were around me, within Toronto General, within the UHN hospital my family and friends, my donor specifically, and also their [00:49:00] families.

There's never gonna be something that I can do that will ever repay it. Right. But I hope that they know I'm grateful. I'm grateful for the donor who decided to be an organ donor. I'm grateful for the family who accepted that decision so that I could have this opportunity despite of their feeling of loss.

Mm-hmm. . I'm thankful for the nurses and doctors and surgeons who, who helped me through everything, including that solution with a valve replacement

and thinking on their feet. Right. And maybe that first 10 day part where I didn't remember anything. I'm thankful for them because I, I don't remember it, but I'm sure there were nurses who were there to take care of me.

Mm-hmm. , and I appreciate it. And I remember nurses when I was going through dialysis who would cuddle me with towels because I was so cold. And [00:50:00] just checked on me constantly to make sure I was feeling okay. I mean, eight hours of dialysis was all lot at the time. Mm-hmm. . And I, I will always be grateful

**Candice Coghlan:** How is your son now? How does he feel about his mom going through this remarkable journey?

**Michelle Rambarran:** I think it's hard for him sometimes because yeah, he's always had a mom who's been sick. And I think it's challenging when you know that you have a parent who's sometimes going in and outta the hospital and having issues and not in the beginning we didn't tell him everything cuz he was quite young.

And then later on is when he started to understand actually that I had a heart transplant and what it actually meant. So I think it's a lot on him to digest. Mm-hmm. . But, but he's been great. I mean, he's thriving, he is doing well in school and he's definitely an extrovert, more [00:51:00] talkative than I am.

And , he might disagree with that comment, but

but he's doing that. Supportive.

**Candice Coghlan:** I've gotta ask You we have a far way to go until we hit that teenage years. But do you have any advice for, for me as a, as a mom who's living with the transplant on either you know how to manage talking about that or even just day to day?

**Michelle Rambarran:** Yeah. I'm no expert on teenagers. I'm still learning as I'm going , but for me, I've always had a very open dialogue with my son in the sense that if he asked me something, I'm gonna tell him the truth. I'm not going to like, make up cute words and things like that. So I was very open and honest about what the experience has been like. What the surgery was like. I think as a teenager they'll go through some times when they wanna talk to you and sometimes they want you to leave them alone. . [00:52:00] Mm-hmm. . I'm definitely experiencing that part of it right now. And I also have to understand to give them some space.

**Candice Coghlan:** That's good advice.

Hello, Dr. McDonald.

**Dr. Michael McDonald:** Hi guys.

**Candice Coghlan:** Thank you so much for doing this for us.

**Dr. Michael McDonald:** No, my pleasure.

**Michelle Rambarran:** Dr. Michael McDonald is an associate professor for the division of Cardiology.

He's University of Toronto, medical director. Advanced heart failure and transplant program at Peter Munk Cardiac Center and UHN transplant. His clinical efforts focus on advanced heart failure transplant and implantable device therapy. But on a personal note, I first met Dr. McDonald as a fellow, working with Dr. Heather Ross in clinic. And after my second transplant he was the first person that I recognized when I was alert, and it gave me a lot of comfort to see a familiar face who had respected and trusted for a long time.

[00:53:00] So, welcome Dr. McDonald's.

**Dr. Michael McDonald:** Thank you very much for, for the introduction and for the, the personal note as well.

**Candice Coghlan:** Can you bring us back and tell us a little bit about what interested you in becoming a cardiologist and what really inspired you to specialize in transplant as well?

**Dr. Michael McDonald:** It's a good question and, and it comes up, particularly say with a lot of junior trainees and, and learners, and you get an opportunity to have one on one conversations with people often at early, very early stages in, in their career.

And, and it, it kind of causes you to reflect a little bit and think about where you were once upon a time. And what I often say is I, and I think this is how I came to my career choices, is usually a combination of the subject material that interests you. And I was interested in, in human physiology, even going back to my undergraduate days.

And and the heart, [00:54:00] it's it's sort of the only organ that continuously moves. And and I, there's something inherently fascinating about that to me and

understanding the, what we call the hemodynamics or the, the fluid dynamics of the heart. So there's the, that whole idea of the subject material being kind of interesting and, and a focus to really drill down and, and want to learn more about and, and and lean into, so to speak.

And then there's the, mentorship side of things. As a lot of learners go through their, their journey, you try to project yourself onto the characteristics of your role models and your mentors. And you kind of sit maybe and it's, it's on an elective or on ward rounds in the hospital or an lecture somewhere, and you kind of latch onto the characteristics of people that you want to emulate someday.

So I, I think I came to it through a combination of those things I was inherently interested [00:55:00] in, in the heart. And then and then I really latched onto some of my, my early mentors and really thought, Geez, if I could only have the skills that those people have someday, I'd be pretty happy with myself.

So, so that, that's kinda where the fascination comes in. And then when you fast forward through the course of training, you have decisions to make about what kind of area. Within, say, cardiology or any specialty for that matter. But in my example, cardiology, trying to figure out what area wanna focus on in particular.

And looking after patients with advanced heart disease. When I was a, a resident after medical school, one of the things that I always was a little bit hooked on or wanted to know more about was the what next piece. So if somebody's very sick and you exhaust your usual therapies or treatments there seemed to be this corner of cardiology that addressed, Okay, what's [00:56:00] next and what next?

What's next for some patients are, is a is a transplant. And then that starts, it's almost like one door closes and another door opens and it's a very different Entrance, you're kind of entering into a new phase of a patient journey and you get to follow along for that part of the ride as well. So that was part of the fascination for me, was just sort of hanging on to the, the journey and figuring out, okay, what next can we offer and how do we how do we make people live well and live long?

**Candice Coghlan:** Amazing.

**Michelle Rambarran:** So, cardiovascular disease is the second leading cause of death in Canada and the leading cause globally, who is most at risk of heart disease and failure.

**Dr. Michael McDonald:** So, so heart disease is as a, a broad term, and probably when we think of it most commonly, or most familiarly, we think of it in terms of coronary artery disease or, or heart attacks.

And the people that are [00:57:00] most at risk for that. There's often factors that we can identify and, and there are newer factors that are harder to identify, specifically family history and genetics. We think that depending on, on your family and the type of genetics that you carry, you may be more or less at risk for developing coronary artery disease, heart muscle disease, or other types of heart disease that could ultimately lead to, to what we call heart failure.

Conventionally, or, or normally we're, we're pretty familiar with the, the big risk factors. The risk factors of high blood pressure that's not well treated. Tobacco cigarette smoking. Diabetes, particularly if it's not well controlled and high cholesterol. And those are things that are, are quite modifiable.

You can't do much about your family history, but you can do much about your cigarette habits. So we really try to aggressively counsel patients to control their risk [00:58:00] factors, minimize their their chance of developing heart problems at a, at a younger premature age. And again, there's always things that are within your span of control and things that are outside your span of control.

And, and of course you can have heart conditions and heart disease despite all, all the right lifestyle and risk factor, control elements that you can, that you can manage on your. So there are emerging risk factors we recognize at a population level. So in addition to the ones I mentioned, there's the, the other healthy lifestyle aspects.

So old fashioned kind of boring diet and exercise, but we know a little bit more about diet and a little bit more about exercise. And what we've sort of been thinking and preaching for many years is in fact turning out to be quite true, That if you do eat a, a healthy type of diet, it will prevent cardiovascular disease in [00:59:00] the future.

At a population level. Same goes for at least moderate amount of exercise. If you can keep your arms and legs moving somehow you're, you're more protected or low doing everything you can to lower your risk of developing

heart problems in the future. So, so that's who we think is most at risk for the common types of heart disease.

I, I will say that that some people develop heart muscle diseases or cardiomyopathies for reasons that we actually don't have a good handle on. Sometimes we do a deep dive and try to figure out why the patient in front of us may have presented to us now, particularly at a younger age with heart conditions or heart disease.

And and it remains a little bit elusive as to exactly why that happened to a, to a patient and not another person who may have had the same kind of lifestyle risk factors and genetic background. [01:00:00]

**Candice Coghlan:** Hmm, interesting. So you talked a little bit about those preventative measures about eating healthy and exercising.

If you are having a progressive heart failure or you're living with heart disease on top of those things, are there things that can be done to slow that progression?

**Dr. Michael McDonald:** Certainly, and, and this is where the medications and what we call multidisciplinary management come into play. So if we focus, those are sort of two synergy synergistic aspects.

So the medication piece is to say that once you've identified we'll use the example of heart failure, which is kind of the, the condition we're focusing on. For today. Once you've identified a diagnosis of heart failure, you can dramatically change the prognosis by the addition of, of a number of different medications that have [01:01:00] been proven to improve life expectancy and reduce the chance that someone's gonna get sick and require hospitalization.

And we have about four or five key medications that do that, that change the natural history of of heart disease and heart failure. And so much so that in the current era, We're now starting to think of this in terms of a condition that can be put into remission in some cases, because we do have patients that develop heart failure and on appropriate therapy within a fairly short period of time can, can improve dramatically and really change the trajectory of, of their condition.

And we're starting to see some cases that we would consider into remission. And we're still, we're at, yeah, we're scratching. It's fascinating. We're scratching this surface about what those patients look like, who they might be,

what kind of characteristics they have that would, that would've told us that they [01:02:00] would have such a, a staggeringly positive outcome.

Even for patients that don't go into or don't improve dramatically, I would say we know that we can still dramatically improve prognosis. Even, even if the measurements we're taking or the tests we're doing are showing that the heart is sort of not in a recovered state, but it's still dysfunctional. We still recognize that the prognosis can change on medical therapy.

And of course, how do we get patients on the right medications at the right time? It takes a village the conventional model of coming in and seeing a prescriber, say a physician having a visit to be pay for parking, get a prescription for your medication, go home if you tolerate it well, we'll see you in a few months and we'll, we'll sort of change the medications around.

You can imagine that that leads to some inefficiencies. Mm-hmm. and a lot of people are really trying to figure out, okay, how do we make this [01:03:00] more patient centered, patient friendly, and frankly more efficient? And that's where the care team that comes together and we try to build better systems. We're always inventing or iterating and tweaking the model.

But if we can develop a better or more reliable system of care, we can get more patients on the right medications at the right time. And then once medications have had a chance to do their thing, we have other interventions. We treat electrical problems of the heart, which are called arrhythmias. We treat those con confidently.

We can treat leaky valves with procedures and interventions in ways that we may not have been able to treat before. We have a whole number of of tricks up our sleeve that at the right time we can deploy to try and change the, the trajectory of of illness wherever possible.

**Michelle Rambarran:** So one myth that is often assumed is that cardiac arrest and heart attacks are the same thing. Can [01:04:00] you describe these myths and maybe talk to some of the common heart myth.

**Dr. Michael McDonald:** No, that's, that's a good question, Michelle, and I'm glad you brought it up because it's, it's definitely true. We throw these terms around almost as if they're interchangeable.

And then when you hear about it in the, in the popular media, you can get kind of confused pretty quickly. And, and what's makes things even more confusing

is that there is some truth to the fact these are interrelated. So I'll try to, I'll try to, to explain Cardiac arrest is usually the cause of an, of an electrical problem in the heart, or an arrhythmia, something called ventricular tachycardia or ventricular fibrillation.

And so when someone has a collapse, that is the most common cause. And, and that's why these AEDs are automated. External defibrillators are strategically placed in public places where if you can, if you can put pads on a patient that collapses, they'll [01:05:00] identify the electrical problem and and potentially shock the patient out of it, which can be life saving.

Now what causes those electrical problems are, are varied. One of the causes is a heart attack, and that's where sometimes the terms get confused or, or used interchange. We're probably just not being very precise with how we're explaining things. So certainly we have electrical problems that can lead to a cardiac arrest or a collapse.

We have coronary artery problems, which is to say heart attacks and and blockages in the main arteries that supply blood to the heart. And if that happens, then you have injury or damage to a big a big portion of the heart muscle, which can then in the future, lead to weakened heart muscle function and the syndrome known as heart failure.

And so we've, we use the terms heart attack and, and [01:06:00] heart failure and cardiac arrest because they're related and one can lead to the other. But in fact, they are, they are strictly speaking different things. Any heart condition if it's left untreated, will eventually cause the muscle functioning of the heart, the core activity of the heart, which is to act as a pump and squeeze blood around the body.

Any untreated or longstanding cardiac condition that impairs the heart performance can lead to the heart failure syndrome over time. So when we're teaching it in, in school, we often say that all roads can lead to, to heart failure.

**Candice Coghlan:** Interesting. Thank you for that. And you've talked a little bit about how to prevent some of these things from happening and then even when they do happen, how to manage them so that p patients can even potentially [01:07:00] go into remission.

I'm wondering, In that world what would be a reason that someone would need a heart transplant? And when would that time be that would be optimal for that patient to have a transplant?

**Dr. Michael McDonald:** Yeah, you're, you're hitting on the, the core question, and this is something that we struggle with week over week in our, in our team meetings with my, my colleagues and we, we discuss at what point are we gonna offer the best outcome to a patient by, by activating on a list for transplant, if that is in fact an option.

So really the fundamental issue. For, for a patient is, will we offer a better length of life and quality of life with transplant than if we just continue on with the medications? We know that some patients will progress in their journey. Their heart failure will progress and get worsen. And if [01:08:00] we identify when that's happening, particularly if somebody is not functioning very well, they have a lot of symptoms, particularly if they have to get admitted to hospital a whole bunch with fluid in the lungs or, or difficulty getting rid of excess water.

If we see signs and symptoms of heart failure that are hard to control with, despite the best efforts of the medications and interventions and surgeries and procedures, if we exhaust all of our options and, and the clinical situation deteriorates, then it comes to a point where if we're able to offer a transplant that that's no question that will, that will.

Afford somebody the best prognosis, the greatest length of life and quality of life. The challenge in, in transplant medicine is, and has always been, is there's never been enough supply to match the demand. So we look at number of patients [01:09:00] that could potentially benefit from a transplant every year versus the number of transplants that are actually performed at our center or across the country or internationally.

And there's a real mismatch there. And that's where some of the excitement in transplant has been recently is really looking at expanding that donor pool and using the technology we've got and, and some of the science that we've, we've. We've learned about in the last several years to expand transplant as a viable option for more and more patients.

It is still, despite the wonderful progress we've made with medications and devices over the last 10 years in particular, transplant is still by far the best therapy for a failing heart.

**Michelle Rambarran:** Wow. So is it common for heart transplant recipients to need either a second heart transplant like I received, or another organ transplant?

**Dr. Michael McDonald:** The short answer Michelle, is in, [01:10:00] I think this's not very common. No, no , no. It's, it's not about about two or 3% of all heart transplants are redo transplants or second transplants. The most common reason, and people may be wondering if you have a, if you have a new heart, why would you need why are there problems or why would you ever need a second transplant?

And that's largely because in some patients, they can develop narrowed or pinched arteries within the transplanted organ. Over time. We believe that that is related to the immune system getting overactive and kind of causing some inflammation and scarring in the arteries that supply blood to the heart.

So it's a form of coronary artery disease that is really unique to a number of our transplant patients. And over time, the treatments for that are getting better. Our understanding of that process is getting better, but it is [01:11:00] still the most common reason that a transplanted heart will become dysfunctional.

And the, and the reason that patients may need to be considered for a second heart transplant. By the time we think about it and consider whether that's a good option, whether that's a viable option, whether patients are still strong enough to undergo another transplant surgery, you get right down to it.

It's only about a couple of percent of all of our transplants that represent redo heart transplants. So, so rare indeed. ,

**Candice Coghlan:** you're a rare gem, Michelle. I sure are.

**Dr. Michael McDonald:** Yep. . Yeah. That's more ways than one. And Michelle, you asked about needing other organ transplants too. It's true that that in some patients there they will develop kidney dysfunction in particular after after solid organ transplant.

And that's largely related to some of the medications we use to suppress the immune system and prevent [01:12:00] rejection. One of the main effects of that is to be, is to cause some kidney injury or, or strain on the kidneys. If you combine that with other risk factors for kidney disease, say high blood pressure, diabetes or hardening of the arteries, atherosclerosis, if you look at the, that combination of risk factors, progressive kidney disease becomes a problem for some patients after transplant and we're very mindful of that and, and very attentive when we're making decisions about what kind of medications to use.

But again, despite our best efforts, some patients' kidneys really deteriorate and it is, it on occasion will need to look at a kidney transplant late after a heart transplant as well. I would say that happens rarely, but, but perhaps more commonly than needing a second heart transplant. Yeah.

**Candice Coghlan:** Yeah, and this might be a question for a, a nephrologist, but thinking about as a kidney transplant recipient [01:13:00] myself, when I, when I talk to other organ recipients, some of them have had those issues with the medication affecting their kidneys.

So as a kidney recipient who's taking those medications for the kidney, how does, how does that impact? Is it the same? Regardless of what the organ is, the, how the medication impacts that, that kidney,

**Dr. Michael McDonald:** It's similar. It's the same, but different. How's that? How's that for an answer? So perfect.

Yeah. . Yeah. So, so the medications do indeed have the same expected side effects mm-hmm. , however depending on what type of organ transplant we're, we're talking about, the amount and timing of the different immunosuppression medications might be quite different. Right. So the immunosuppress immunosuppression taken by a liver patient would look very different than the immunosuppression.

At least the medications taken by a heart transplant recipient and, and a kidney transplant recipient may [01:14:00] be different yet. Right. And so part of, part of the experience of, of our kidney transplant colleagues is they're really good at identifying that balance because if we don't suppress the immune system, we can get some, some injury to that kidney.

And yet if we overdo it with some of the medications, that can also stress out. The kidney and, and they're really quite expert at juggling that and figuring out in which way to to direct their their medication treatment plan.

**Candice Coghlan:** Amazing. Thank you. That was always a question in my mind as I've been talking to other organ recipients of, of what happens there.

So that's great. Thank you. I have a friend who prior to her heart transplant, she had an L V A D and she would laugh and say she was gonna plug herself in at night to charge up. And I didn't know anything about it until I had met her.

I didn't know that that was even a possibility. And even when she made that joke the first time, I was like, [01:15:00] Are you being serious? You plug yourself in. Like, what, what is happening here? So I'm wondering if you can describe to us what an L V A D is and what it's used for and why a patient would have something like that.

**Dr. Michael McDonald:** Certainly L V A D stands for left ventricular assist device, have really been a revolutionary surgery or, or treatment for advanced heart failure. Really over the last 20 years. That's been the greatest period of growth and essentially, and, and L V A D replaces the pumping function of the main pumping chamber of the heart, which is the left ventricle.

It's long term LVADs require surgery. So it's open heart surgery as we conventionally think of it. Mm-hmm. and the pump is, is. Literally sewn on or attached to the left ventricle. And there's a, there is a tube or cannula and the blood that is sucked out by the pump from the heart [01:16:00] is ejected through that tube or cannula into the main blood vessel of that supplies and distributes blood to the rest of the organs called the aorta.

And that is controlled by a cable that comes outside the body, usually around the belly button, and is attached to a, a controller, which is sort of about the size of a, an iPhone. And and that's powered by two batteries. So people walk around during their day to day with their, LVAD attached to a couple of portable batteries. And indeed, at night they, the batteries are, are charged and they are plugged into an AC adapter or plugged into the wall, so to speak. And these, and these pumps are really marvels of technology and can and can take somebody from being critically ill in hospital even dying from advanced heart failure and then give them their function back and their quality of life back in a really really staggering way. [01:17:00] It's sort of to be seen to you'd have to see it to believe it in, in many cases. So why, why do most people not know what that is? Well, it, the truth is there's still relatively uncommon interventions.

Again, it's a little bit like transplant where if you look at the number of patients that could potentially benefit from, from a transplant or potentially benefit from an LVAD, only a small proportion will ever undergo surgery To have an L V A D, the most common reason that a patient would need an lvad.

Is as a bridge, at least in Canada, as a bridge to transplant. So if we identified that somebody needs a transplant, but maybe their size or their blood group or their immune status would tell us that, you know what, This person's gonna wait a long time on a wait list for, for an organ, a suitable organ to, to be available, then we would often consider an L V A D as a bridging therapy.

And patients can live [01:18:00] several years, in some cases on LVAD support while they're waiting for a, that perfect organ to become available, That perfect heart to become available there. They're again, they're not, Cures for heart failure. They, they, in the same way that dialysis is not a cure for kidney disease, but they replace the organ function.

They do have their issues and patients have to learn and be taught how to manage this really sophisticated piece of technology to maintain circulation and to keep their, and to minimize the risk of complications. So patients can still run into trouble with infections and, and blood clots. And so that, those risks all have to be managed with the technology.

So again, it's a really transformative option for a minority of patients who are, are sick enough to need it but well enough to make it through a big operation, a, a big surgery. [01:19:00] So it's finding that sweet spot for when someone. Not too sick, but, but certainly not too well. And, and when we can replace the heart function better with technology and, and machines than we can with medications.

**Candice Coghlan:** Fascinating. Thank you. Yes, .

**Michelle Rambarran:** Yeah. That was a lot of great information. Mm-hmm. . Mm-hmm. .

So an exciting innovation in the heart world is xeno transplantation or transplanting animal hearts into humans. There was a recent study in which a pig heart was successfully transplanted into a baboon who lived longer than two years.

Could this be the, a possibility in the future? And if so, what would that do to the transplant world? Yeah,

**Dr. Michael McDonald:** I, Thanks Michelle. This is a really, really exciting area in, in transplant medicine. It was sort of kicked around as an idea back in the early days, say 30, 40 years ago when people were trying to figure out how to, how to make the, the whole transplant [01:20:00] medicine work.

But, but as our understanding of the immune system and the genes that control the immune system has evolved, people are really taking this into, into a revisiting this as a viable option and not just animal to animal. But in the last year there was a very high profile case in the United States where a genetically engineered pig heart was transplanted into a, into a person.

And and that individual lived for I believe over three months close to four months and eventually died from a. Probably probably died from overwhelming infection and and rejection as well. So it's very similar to when heart transplant human to human was first being pioneered back in the 1960s and trying to figure out how do we cope with this cope with the immune system and, and what's the [01:21:00] science behind that and, and what medications do we need to use to get this just right.

So it has a tremendous amount of promise. One of the ways that the science has advanced is is by being able to knock out genes or edit genes that are responsible for making that organ look foreign. Mm-hmm. . So in, when you transplant a xeno transplant or animal organ into another animal or a human our immune systems are designed to recognize that inherently as foreign because they recognize proteins and sugar molecules on the, on the animal cells and they attack it. And with some of the technology and scientific advances, they've been able to knock those off the, off the animal tissues and and make the immune system more agnostic to it.

And in other words, more tolerant of that foreign foreign entity or that [01:22:00] animal entity. It's not perfect, but it's certainly a, a giant leap and it remains to be seen if we. As a community, perfect this and make it a viable option. There are other concerns. Animals carry different viruses than humans.

And so that's, that's historically been one of the big concerns about using animal organs, even if they're genetically modified for for human transplantation. And I don't think that story's fully been, been written and we have to understand the impact of of some of those infections. But I think it's a proof of concept and we're in the pioneering days of that.

And it remains to be seen whether this is gonna be a viable option in the next five years, the next 10 years, or are we still looking 50 years into the future before this is a, this is viable. But you can imagine that would transform transplant medicine and it would certainly solve the fundamental problem of a supply demand mismatch for our patients.[01:23:00]

**Candice Coghlan:** I was really excited to get to listen to Massimo Mangiola from NYU Langone at the CST Banff conference. And he was talking about the immunology behind the pig organs. And he talked about how they did two kidneys and, and two hearts very successfully. And listening to the way that those scientists are approaching it as well and the researchers are approaching it is we often talk about our big goal of ending the wait list.

How it's this very big pie in the sky goal, but something that we always kind of look to of what are all of these things happening in the research world that can contribute together to helping patients? And it was fascinating to hear. That they, they would like to target highly sensitized patients first because there are people who [01:24:00] may wait 10, 15 years or may never get the transplant.

And this might be an option for them to start down that path. And then thinking about Other people who are doing research in looking at our anti-rejection medication and how we'll be able to eventually, potentially lower that or have a smaller doses of it. And then people who are looking at at UHN we've got the research about creating a universal blood types and all of these things that are happening in the background that we don't hear about as patients

**Dr. Michael McDonald:** I, I totally agree. I think you, you highlighted some of the key pieces, which is a lot of progress is made by pulling on different threads and coming at this from different angles.

And so eventually you make progress and, and things don't always work. And it takes long cycles of research and [01:25:00] unsuccessful experiments before. Hit on something that really looks promising and, and sort of reinvigorates everybody's enthusiasm for, for one approach over another. So it's, it's really interesting.

We benefit from being part of a huge program at at UHN the Ajmera Transplant Centre is, is one of the biggest transplant programs in the world. And, and by volume, the biggest in, in North America for the past several years, doing well over 600, 700 transplants, solid organ transplants a year.

So you can't help but attract world leading research and expertise and clinical experience. And we all, we all learn from each other. I'm, I'm amazed at how much I learn from my non heart transplant colleagues because they have so much depth of experience and so many good ideas about things. So I really think you hit the nail on the head with your [01:26:00] comments.

Mm-hmm.

**Michelle Rambarran:** That was a lot of good information because as a patient, like you said we don't always get access to it. Mm-hmm. and hearing that innovation is amazing. Are you able to tell us a little bit more about what are some of the innovations or research being done today at UHN?

**Dr. Michael McDonald:** I, I think if we, if we focus on the, the heart program, which is near and dear to me, of course.

You know what? We look at it, our program has grown in terms of the number of clinicians and people doing research, the number of trainees that come to our program. So over time, we are, we're kind of growing and with that comes more in. And we have innovation on the pre-transplant side or the advanced heart failure side, and we have some innovations on the, on the transplant side.

And it comes down to pulling on different threads. As we were, as we were saying, we're looking at how do we expand the donor pool. [01:27:00] We are poised, and I hope, I hope we can do this in short order to join some of the, the handful of programs throughout the rest of the world that are now using DCD donors to expand the cardiac donor pool.

So what is a DCD donor that is, that stands for donation after circulatory death. Historically, we've only accepted heart donors from brain dead donors or neurologically dead donors. But what's changed is some of the technology to support hearts that come from patients whose circula circulatory functions have ceased.

In other words, they've passed away or died in a hospital setting, and we are then able to use the heart and and reanimate it, so to speak, on commercially available devices, assess the function of that heart, whereas we never would've been able to have that before because the technology hasn't allowed [01:28:00] it and the science hasn't allowed it.

Reanimate the heart, figure out if it's going to be suitable and then perform a transplant. And this would be a huge leap forward for our own program because there are really just a small number of programs throughout the world that have been able to champion this and take it on. And we have the technical expertise on the surgical side and on the research side to, to start doing this very soon.

So I think that's going to really make a huge bite out of our wait list and, and has the potential to be one of those transformative things. So that's hugely exciting. And and what we're learning from other centers that do this is that the outcomes are very favorable. In other words, they're as, as favorable as their conventional way of doing transplant.

and and that that whole enterprise is called Ex vivo transplantation. The idea that you can take a heart and put it on a machine and look at how the heart [01:29:00] performs on that machine and, and also transport it over greater

distances before making a decision whether it would be suitable for use in one of our recipients.

So I think not only do we get access to more organs that way, but we can also access different geographical reaches of the country, so we could attract an organ all the way out for, to British Columbia or Newfoundland for example. Whereas right now we're not really doing that because because the organs can't, can't be on ice and perform that well after about three or four hours.

So that's gonna open up a, I predict, anyway, I, I, I'm excited about this cause I think that's really gonna change the game for us as a program. One of the leaps forward from a couple of years ago was we started routinely transplanting organs from donors that had hepatitis C infection. The reason for that is we now have curative therapies or antiviral treatments for [01:30:00] hepatitis C.

So it's, it's it would never have been conceivable before if to transplant an organ from a donor that had Hepatitis C virus infection. But now it's, it's quite routine. We just treat patients preemptively so that they never get infected with the Hepatitis C virus. And it, it works spectacularly well.

So these are all innovations that are in the near term that are gonna expand that donor pool. And the other thing that that is always front of mind is, okay, once we, once we've performed a transplant and, and successfully had had someone taken off our wait list because they've received an organ, then the new journey begins.

And how do we make that really positive and empowering for patients? And how do we translate that into better long-term outcomes? So one of our, our colleagues is doing a, a neat randomized trial where patients will get digital health prompts and digital health [01:31:00] advice after they go home from hospital.

About managing their, managing their transplant because as as our patients know very well, it's overwhelming. We keep hearing about how overwhelming it is to learn about all of this. It's like a full-time job just to understand what your roles and responsibilities are as a, as a new patient, a new transplant patient.

So with digital tools to help support that journey. We think we can lead to better outcomes in terms of patient patient comfort and, and literacy and understanding of their condition reduced medication errors, risk of infection, risk of rejection. And over time, we can use we can use machine learning and

artificial intelligence map is to identify the real problem areas, the real hotspot for for when patients are about to get in trouble.

Cuz we always want to intervene early and [01:32:00] prevent a problem from happening before waiting to the problem until the problem arises. And then we have to, we have to get aggressive and, and treat it. So we've got some nifty things in the pipeline that are both going to, I think, increase access to to transplant in the, in the heart transplant world and also improve longer term outcomes as we understand medications that biology and and patient self care on a, on a whole new.

**Candice Coghlan:** Wow. I mean, listening to to that, it makes me definitely as a patient feel much more secure in the hands that we're in, that all of these changes are happening innovation wise. But then there's also these things that are happening right now. So if we're, we are transplanted patients now, there are other things that can support us through our journey because hopefully, Michelle and I talked about this.

Hopefully our transplants last [01:33:00] incredibly long. We're one of those that are celebrating our 50 and our 60 year kidney and, and heart anniversaries. So we won't have to think about ex vivo or, or xeno transplant in the future. But learning about how we can manage what we have now, I think is, is very important.

**Dr. Michael McDonald:** . And I think that's one of the exciting things about seeing our program grow is that we've got these, these really bright young minds that are coming along.

I've got some exceptionally talented colleagues that have all these ideas and, and they're really good at making this, this happen. And, and it can't happen in isolation. You need a, you need a team and you need some structure and organization and that whole, the, the adage that it takes a village is really true.

But but you need people to populate that village. So it's wonderful. We've been, been able to grow the program with with really talented colleagues.

**Candice Coghlan:** That's awesome. So, I, I have two [01:34:00] things before we leave today. One of them I, I like to, Google, but also go on social media and, and read comments from patients and family members when there's a research article posted or something about the work that's being done with people.

And so I found some posts about patients of yours who had written things about you. So we wanna read you a couple just to let you know what some of your patients have have said.

**Michelle Rambarran:** Dr. McDonald is a doctor with lots of heart. He truly cares for his patients and our help.

**Candice Coghlan:** Dr. McDonald is one of my son's doctors. He has an incredible bedside manner and makes us feel like people, rather than just numbers in a system, we feel seen.

**Michelle Rambarran:** You joined my care team a few years ago. My heart is seriously challenged, but with some amazing tech and tremendous skill and experience, [01:35:00] I'm able to keep on trucking. Thanks Dr. McDonald for the Heart Clinic.

**Candice Coghlan:** So those are some of them that we pulled from social media, and I know you guys don't do this for that reason, but you don't get to hear those as often as we, we wish that you could. So we wanted you to, to hear some of those from, from your patients who you've treated.

**Dr. Michael McDonald:** Oh my goodness, thank you. That it, it continues to be the most humbling, humbling job a person can do.

Thank you for that. Mm-hmm. .

**Candice Coghlan:** And before we leave, I have one question that neither of you know about. If you listen to the podcast this is gonna be sprung on you, but I hopefully this will come as a surprise. I'll start with you, Michelle. If you were a tree, what kind of tree would you be?

**Michelle Rambarran:** Tree so I think I would be one of those hydrangea trees. The dwarf kinds, I think it looks beautiful. It's full of greenery, it changes with the [01:36:00] seasons and over this experience, I definitely seen changes in my level of care, the treatment I received, how I progressed. So that would be my tree.,

**Candice Coghlan:** Beautiful. I love that. And what about you, Dr.

**Dr. Michael McDonald:** Oh my goodness. I, I, I didn't see that question coming, right, ? Yeah. I, I thought, ok, what's the prettiest tree I can think of?

And that, that's like a, a Cherry Blossom, but I don't really want people standing in front of me taking pictures that's not sort

I honestly, the first thing I thought of was, was one of those birch trees in, in northern Ontario. Cause it looks like it's been whipped a thousand times, but it, they, they, they're pretty hard inside and, and pretty sturdy. So so maybe I'll take that as my answer. That's

**Candice Coghlan:** awesome. That is actually always my answer as well, so, Oh yeah. I spend my summers up in, in the Kawarthas as a kid, and to [01:37:00] me, I just love the birch trees. I think they're beautiful and, and you're right, they look like they weathered a storm and they look strong even through the winter. So I just, I love those birch trees as well. So I love, I love tossing that question on people because it's the last thing you think that I'm gonna ask, right.

**Dr. Michael McDonald:** No, didn't that coming? Yeah, I,

**Candice Coghlan:** So before we leave Dr. McDonald, is there anything else that you would like to share with our listeners that we maybe didn't?

**Dr. Michael McDonald:** I think we, we've covered a lot and it's an overwhelming topic when you think of the, the patient journey. And I think none of this is possible without the, without the patients and the people who are living the experience.

And so I'm delighted that, that the patient voice bubbling to the surface where it belongs and and that you have outlets and, and opportunities like this one. I, I, I can't tell you how [01:38:00] much I appreciate the invitation. So, so thank. Amazing.

**Candice Coghlan:** Thank you so much. Thank you, Michelle, for co-hosting this episode with me and for sharing your journey with us.

All of the people who are part of Heart Links , and the heart World, are lucky to have you as an advocate and a friend. And Dr. McDonald, thank you so much for sharing this amazing work about what is being done with your team and at UHN and the innovation happening in the heart world.

I think it's very exciting for, for us patients to be able to hear all of that. So I truly appreciate both of your time and thank you so much for joining me today. Thank

**Dr. Michael McDonald:** you.

**Michelle Rambarran:** Take care.

**Candice Coghlan:** Don't forget to subscribe to Living Transplant 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](mailto:Livingorgandonation@uhn.ca). And for more information on living organ donation, [01:39:00] you can visit us at [www.livingorgandonation.ca](http://www.livingorgandonation.ca).

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