

S3E10 Transcript

[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 Centre for Living Organ Donation.

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

Living transplant will show you the world of transplant like you've never seen it before.

Candice : Welcome back to the Living Transplant Podcast. Today I'm joined by a remarkable woman, Maria Acero, who is a caregiver to [00:01:00] her husband, Luis. Later will be joined by Dr. Margaret Herridge, who is a Professor of Medicine, Critical Care and Pulmonary Medicine at UHN, a Senior Scientist in the Toronto General Research Institute and Director of Research for the Interdepartmental Division of Critical Care Medicine at the University of Toronto.

Thank you so much for joining me and co-hosting this episode with me, Maria. Mm-hmm. , thank you so much.

I'm wondering if you can bring me back to when you first met your husband. How did the two of you meet?

Maria : So we met in high school. We were 15 years old. We lived in Colombia in a place called Guajira.

So that's the, the region where we lived. And this was a camp for workers of a company. So my father-in-law, my dad work at the same company, and we ended up living in this complex that was only 200 houses or so. So we met at 15 years old.[00:02:00] He was a year ahead of me in his class. There were, I think nine people. And in my class we were six. All the families were very close together because there was absolutely nothing outside that camp.

So we spent not just the school time, but every holiday, every weekend, everything together, because there Yeah. You were confined to this place. So families were very close. It was fun. And, but you had limited options to, to do a stuff outside the camp and to meet other people and that, so, yeah.

It, it was different, but it was a lot of fun. Oh, that's cool. That's really neat. So his brother was also in my sister's class. Mm-hmm. and his mom was my friend's mom. So it, it was a very close relationship. Yeah. You already knew each other. Yeah. Oh yeah. Yeah. Wow.

[00:03:00] So, Luis , was diagnosed with autoimmune hepatitis at a very, very young age, when you began dating, did you know about his diagnosis? Yeah. Did he talk openly about it?

So we, we met when we were 15 and he had just been diagnosed mm-hmm.

so I knew that he was sick and he handled his disease very well. He was a happy person. He went to school, he kept his life going. So I guess for me, I, I always admire that, right? That he and his family would just keep going and having a normal life despite the diagnosis. And when I started dating him two years after, that's why I was 17 and he was 18, his disease was more or less under control.

So for us, it just meant that he had to take medicine every day. [00:04:00] He was more tired than I was, of course, because his liver wasn't working properly. So he would take like long naps and I wasn't, but in all honestly, didn't bothered me. We had a lot of fun and, and it never bothered me when we started dating more seriously.

I did have people from my family saying, Listen, this is a person that is, is sick, and you have to look to the future. Right? Like, it's going to, going to progress. There's no cure. It's just going to go downhill and you will be in this life forever. But it's not like it has stopped me or, or made me change my mind in any, in any way.

But I was always conscious that that transplant was going to come at some point in life. And when, when this was happening liver transplant was just a starting in Columbia. [00:05:00] So it, it wasn't a good outcome, right? Because it wasn't really a well established program or anything like that. You would have to go out of the country, which was an amount of money that we couldn't afford by any means.

So yeah, it, it was very complicated, but I guess we were really young and when you that young you don't think about that stuff, right. , So, Yeah. Right. That's how it went. You're in love and you decide to figure it out. Exactly How comes, Yeah. Right.

You two dated and you were living in this amazing community.

And then when did you two decide to get married?

So we did do things in the correct order to say it somehow. So he, because we lived in this close community, when you graduated high school, you really had to go to another city for university. [00:06:00] Wow. Cause there was no university in that place. So he moved to Bogota, which is a capital, and I started university there and I had a year to go.

When I graduated, I went to Bogota to, to apply for university and all that, and I got pregnant. So I went to a different city called Tali to live with my parents. And I did all my university in Cali with my parents and my baby. He was living by himself, but in a different city while he finished his university.

Right. Once he finished, then I, I moved to Bogota and we started living together and got married. So our son was already six years old. Beautiful. So we married in 1998. And then we lived there for two years and moved to Canada year 2000.

So you were going to school with a young baby and Oh yeah.

Wow, [00:07:00] Wow. And what did you go to school for? I did in the industrial engineering in Colombia, Columbia. Wow. So there, this is a five year degree. Mm-hmm. . So I, I did all, all of that with my son. I was living at my parents' place, so I, I did have a lot of help. Mm-hmm. , my parents were absolutely amazing at that time.

And then they helped a lot with the, with the baby. Mm-hmm. and we saw each other every summer, every Christmas, every holiday. Yeah. We, we did our best to keep that relationship going and to have him with our son at all times. Yeah.

And then you moved to, Canada in 2000, so why did you decide to move?

If you remember the nineties were a really bad stage in the Colombian political situation. [00:08:00] So the situation was dangerous. The drug cartels were at the peak pick and we decided this is not life for our son. This is. It's crazy. So he

had been here for six months or so studying English at the University of Ottawa, some point and really liked Ottawa.

And I was once in a trip and in one of those magazines in the airplane there was an advertisement for immigration to Canada. I said, Well, that, this sounds cool. Let's try it. And it just happened. Yeah, It just, yeah. We did all the process and we ended up here. So we moved here every year, 2000 we four suitcases.

Wow. And a lot of dreams and yeah, it was really nice.

Incredible. Incredible. And [00:09:00] you have stayed in Ottawa ever since?

Yeah. So before we moved he got a job at Nortel. Incredible. So thank God that's when we came here. He already had a job. Mm-hmm. . So yeah, we came here and he started working at Nortel and kept going all the way.

And he really never got laid off, just transferred from place to place, which was a . Yeah. And yeah, and I ended up doing my other degree. So now I did biology and biotechnology and a masters of science. Changing my career path altogether, and we had another baby. Mm-hmm. . . Yeah.

Candice : That's incredible. Wow.

That's that's quite the journey that you guys have been on as a family. And so through all of , these times Luis was generally healthy , and [00:10:00] managing well,

Maria : he was fine. It was something that hanged in our heads at all times.

Right. And he had these regular checkups every six months or so and did his lab works and his scans and all that. But really for us, it represented a pill or two every morning. Right. But he had what we considered a, a normal life. Good. Yeah. Now, after everything that happened, I can see how that was not a normal life because he has lots of more energy now and he's a totally different person.

And he's just, he's he's humor and he's energy and his way of doing things. He's way different now. So I guess that wasn't a normal life. Right. But because he had been sick from such a young age, It was normal for us. Mm-hmm. and it was good. It was a good life, right? Mm-hmm. , it just is so different now.[00:11:00]

Yeah. That's incredible. Yeah. You kind of morph your normal into what it has to be. Right. That becomes Exactly, that becomes your normal. Cuz it's all that you know. Exactly. You don't know what life is like outside of that. Exactly. Exactly. For us was absolutely normal.

Fast forward, you've been in Canada for 18 years and Luis was then diagnosed with a form of liver cancer.

What was that like for you guys and, did they discuss the treatment options or what did you have to do moving forward?

It was a huge shock. Mm-hmm. . I guess, I don't know. I guess it, it, it had always been in our minds, but I, it's something that you really like, never think is going to really happen.

Mm-hmm. . So we go for the yearly camping trip [00:12:00] every single year and we love it. And this is our thing. And when we were camping that year, he started having a fever and feeling really sick. But he didn't have anything else. No. Like cough, nothing. So, It never closed my mind that this had anything to do with his liver, because when you have a fever, it's like, okay, you got a cold right.

Or something. Right. But it was a really bad fever. He was really sick to a point that I, I one night was thinking, What am I going to do? Like within the middle of nowhere? Right? The closest hospital is like four hours from here. My goodness. So that was a scary. Then the fever went away again for no reason.

They just went away. Mm-hmm. . But when we came here, I told him, You know what, You have to go and get checked because that's not normal. Like, why would you get sick like that? And, and he went and then did his scans [00:13:00] and they founded the cancer. It was a huge shock. The doctor that was seeing him that day, so he called me at the office and said the results are in and the doctor wants to talk to us.

So I immediately knew, Yeah, this is not, But even before that, when he read, he says, Scans, I called my parents in law. This was December. Mm-hmm. , right? And I said, You know what? I think my gut feeling is this is not good. And I think that the diagnosis is going to be that he has liver cancer. And I would like that at that point.

You guys are here. So they flew in. Wow. And so we got the diagnosis and I was in shock. And [00:14:00] even the doctor that, that was seeing him that day,

that she had seen him for 18 years, at that point, she was in tears. And, and the diagnosis was the, the tumor is too big so you don't fit in the scale to be a candidate for the transplant.

However, I've remitted you to this person in Toronto to see what your options are.

so how do you take that? Right? Like, so yeah, we have spent entire December in Toronto going back and forth and, and looking at options and, and what we could do. What was the outcome? What? And then the solution was they were going to try a treatment to reduce the size of the tumor. So that hopefully would fit within those parameters for him to get into a list.[00:15:00]

But we had to be there by January 3rd or something like, So that was Christmas . Oh my gosh. Yeah, we told our children what had happened. My daughter was eight, nine years old at that point, so she was still very young. Mm-hmm. from the beginning. We tried to tell her things the way they were. Mm-hmm.

I is my very personal opinion that kids deserve that. Mm-hmm. just, just to know what's happening. Right. And to be prepared for what can happen and know the options and know why you're doing what you are doing. So we told her what was happening. We told her we were going to Toronto for at least a month, so my parents know were here, thank goodness.

Mm-hmm. She could stay here and keep with her life. And he went to Toronto. We stayed there for, I think it was like a month or [00:16:00] something like that. And he had his treatment and then he was putting the list in March. Wow. Or something like that. Yeah. And then that treatment was successful in, It was successful.

It was very scary. Yeah. Very, very scary because of the, like the side effects of the treatment and, and all. And even he needed preparation, right? Like you, he needed to hold his breath for so long, for example, to, to let the machine do a job. And he had to be absolutely still mm-hmm. , but he couldn't hold his breath that long.

Oh. So we needed training, so Wow. So we, we literally trained for it, like we got the, this snorkel and, and, and trained him on how to hold his breath because he [00:17:00] couldn't. Wow. So that was a scary Yeah. And yeah, we whole, like, we held training sessions on how to hold your breath that along and, and try to, to try to repeat what the machine was going to do because he was very nervous.

And I was telling him, if we practice at home, at least you know what you're going to expect. Right? If you practice here waiting like 25 seconds or something and you only need a team the feeling. And even when I'm feeling that I don't have breath, I can still hold it, I don't know, like five seconds more or something.

But you need to know what's gonna feel like. Yes. So we need that that I think worked out. So problem solved. But the problem is it wasn't only not to breathe, it was you had to hold your breath, you had to have your lungs empty. Right. So you will take a huge breath and then release there and then hold it. That's hard. So that's even worse.

[00:18:00] That's hard. It's not like you had it. You, you lungs are empty. Okay. So that, I think that was scary and that was hard. Mm-hmm. . But it worked out and, and then he was put on the list. And then the other bad moment that we had is he was put in the list and he was told he could have a living donor.

Mm-hmm. . And then we had someone that was a candidate and, and everything, and then they called to say, No, you're not a candidate for the living anymore. Mm. I think that was one of the low moments mm-hmm. that, that took a lot of hope out of Yeah. Out of our minds. Mm-hmm. . So now we were waiting for that a deceased donor right.

Which in my mind was very, very hard. It's just like you're hoping for someone to honestly die so that [00:19:00] you can get your liver right. And that was really hard to handle in my mind. Mm-hmm. . Mm-hmm. . So I am a very religious person and that didn't sit well on my, How do you pray for that? Right. Like Right. How do you pray for someone to die so that your husband can get their liver?

Yeah. That didn't sit well with me. Yeah. So that was hard. Mm-hmm. . And then we received the call in December, so it was a full year of waiting mm-hmm. for that moment to come. Wow. Yeah. While you were waiting practicing and, and doing different tests and making sure that, that he was comfortable, did you have to go back and forth between Ottawa and Toronto that whole time?

A lot of times, yeah. We, we went, we traveled so many times to Toronto. I [00:20:00] think that we have drive driven the, the 401 in every situation with rain, with snow, with sun, with winter, with everything. We did a lot of planning on that year. Mm-hmm. , we. Yeah, I think that both of us have always been very logic and a structured people, so we planned our life a lot in that year.

So we try to secure that. Sophia, my daughter, had a, a normal life so she could keep her as sports and, and his school and everything like that. We went to a nutritionist and completely changed our diets. We have always eaten very healthy. My mom is a nutritionist and his mom is a nutritionist, so we used to eat healthy.

Right, Right. But we, we had a, a nutrition from [00:21:00] the cancer foundation and she, she guided us to how get foods that we give him more energy during that time. So he had a lot of proteins, a lot of fibers, all that. So we completely changed our diets, not just his, but I'm a firm believer that this is a team effort.

So all of us ended up eating what he was eating. No salt or whatsoever. It was a family. Yeah. Commitment to this. That's amazing. My family did the same thing when I went on dialysis. Yeah. They all, they all switched what they were eating. Yep. So it was just a house that was a safe. Exactly. Right. Exactly.

It made it so much easier for me to, to stick to the needed. Right. Yeah. I think it's the only way, like if, if someone is eating something different, like, I don't know. I couldn't, like, I felt it was just mean eating something [00:22:00] that he couldn't eat. So Yeah, we changed our diets. We made it the best out of it.

The, so pancakes became full of fiber and oats and stuff. , right? Yeah. We got a lawyer, we organized all our finances, everything that, that was hard and all our wills and all of that. But it's something that I feel like you need to, right? Mm-hmm. . So we, that we found where we were going to live in Toronto and when things happened, we had a list of hotels.

We made a list of what are we, what do we need to do the day that they call mm-hmm. . So we need to call this person, we need to drive here, we need to fix that. Everything was planned. Yes. , We had a that for D situations. That was the year. Yeah. Wow.

And. The call came that there [00:23:00] was a potential liver for your husband.

How did that all start with the first liver transplant?

So we got the call around, noon on, that must have been December 13th. We were at work. So we happened to work on the same building. Different companies, but the same building. It's very convenient. Yeah. So he, yeah.

So he called and said, I just got the call. So we have to be in Toronto by midnight. So we, we had some time. So we came home. We had decided in advance that the day that we were going, all of us were going mm-hmm. cause our family commitment to this. So we called my son that was at work and told him, Yeah, we're leaving like at two or 3:00 PM So scheduled the stuff together and we see you at went to pick up my daughter at school, came home, got [00:24:00] our, because I had a list of, what do I have to put in the, So we packed our bags, we made the calls that were in the everything.

And I think like at 4:00 PM or so go to Toronto. Then found the hotel. We had hotel, hotel, everything organized and then went to the hosp. Oh. Before we left the hotel, we took a lot of family pictures. It, it was almost Christmas, right. So the hotel was beautiful, beautiful decoration. So we took a of family pictures there called my parents in-law.

They were in Colombia, so they had to fly to New York and start driving. Wow. Here. So his brother lives in New York, so his parents were going there and then driving from New York with his brother and his wife here. And [00:25:00] yeah, we went to a hospital and he ended up having his first surgery. It was the next day. Mm-hmm. his parents weren't here when he went into surgery. It was like 10:00 AM or so. And, and they, he went into surgery and then in his parents and his brother arrived when he was in surgery already. And it, it took a really, really, really long time.

Mm-hmm. like 10 hours or so. But we were fine. It was part of the plan, right. That I, that part I had imagined it was going to be that way. Mm-hmm. , So I remember it was just when Disney Plus had launched, so my daughter had a, an iPad and I think that she went through an entire catalog that night and we Yeah.

That was plans. It was fine. It was okay. He was super happy when he went into the [00:26:00] transplant. It was like, I, I, it always felt like getting him to the transplant is the goal. Right. If we get that transplant, we made it. Right. Right. So that was a super happy day. A super happy situation. More than a scary or anything is we made it right.

This is it. We made it, and it's a happy situation and we're done. We're fine. Right. Like, this is it, It never, ever, ever crossed my mind that something was going to go wrong. So I was prepared for everything up to that day. Not for what happened. Like, not even once I know that they tell you things that go wrong, I, I totally get that, but it just never crossed my mind.

Like, it, it just, I had a goal that was getting him transplant and that was it. I'm done like it. Mm-hmm. . [00:27:00] Yeah. And so that transplant goes, goes relatively well and he wakes up from surgery and what is that recovery like?

He was perfect. Mm-hmm. , he, he woke up, he had tons of energy. He was chatty, he was happy.

To the point that my sister-in-law said, You know what he's doing awesome. I'm just gonna go home a few weeks early cause it was Christmas. Mm-hmm. , they have kids to see my kids and his brother stayed for a little more days, but everyone thought this is perfect, right? Mm-hmm. , however, from the beginning, from, from even the, the day one when he woke up, I, I felt something is off.

Like, I don't know, it, it, it didn't feel [00:28:00] normal to me. Mm-hmm. that he was so happy and so chatty and so excited. Like it wasn't him like it, it was something different, something off. I always thought this might be just the pain medications, right? That he's in this happiest state. But in my mind, that was something not right.

I, I can't explain it. I told my son and I, I told my best friend, like, there's something really, really weird. Mm-hmm. , you're just your intuition. Yeah. Like mm-hmm. . Yeah. There was something off. And then my son had to come back to work and he was coming back on a Friday so that my could go home.

Mm-hmm. and he will stay with me in Toronto. And when his brother left, like at around 7:00 PM he was perfectly fine. I said, Okay, bye. [00:29:00] Thank you so much for coming. Merry Christmas. Then my son arrived and I told my son, Okay, I'm going to go to a hotel. I'm gonna have a nap and, and come back. And you stay here.

Mm-hmm. , this might have been 8:00 PM or so, and at 11:00 PM he calls me to a hotel and says, Mom, you have to come. Said what happened? He was perfectly, he's not fine. Hes walking around, running around the hospital trying to leave. See? What do you mean he's running? He can't even walk. Mm-hmm. . So no, literally, you have to come.

I think it took me two minutes to get dressed, call my parents in law, come to my room and stay with my daughter. And I run the hallway, like, I think took me three minutes from the hotel to run to there. [00:30:00] And that's the image that I found like completing disoriented person. Mm-hmm. . Yeah. All of like in three hours.

This is, that was a shock mm-hmm. . How did this happen? In three hours and, and it was just down here from there.

What was going on physically that was causing all of this? What was the progression from you getting to the hospital?

This was December 20th. That day was December 20th.

And what I found was he, he really wanted to leave the hospital, which made zero sense. Like he's mm-hmm. He was perfectly fine when I left. He was very aggressive. Mm-hmm. He started not recognizing people and not even remembering anything like his, [00:31:00] his kids, for example, he was confusing my son with his brother in his mind.

At no point was my daughter, like, he was like back in time or something like, And then his liver started just not functioning like the, the, the liver labs were beyond bad. Yeah. So that was December 20th and he just went downhill, like super, super, super fast. He never stopped recognizing me for some reason.

Mm-hmm. . But everything else he did absolutely out it. And then on the 22nd at night, they told me that the only chance was to get a second transplant and that we had 48 hours to find another liver. Just thinking, what do you mean, [00:32:00] 48 hours? We spent a year. Mm-hmm. waiting for this. And he said, No, it's 48 hours.

And he's number one in the national list. So there's your hope, right? Like it's not just within Ottawa, but it's just the, the complete country. But even so, if we find that even in, in 48 hours, his chances of survival at 20%

Yeah. And then they found the liver. The next day and got his second transplant on December 23rd.

And the transplant that they found you, had to make some tough decisions about that as well.

Yeah. So the doctor came and said the only liver that I have is not his blood type. Mm-hmm.[00:33:00]

but at this point is the only choice. Right. Right. So it would be really, really hard and, and, and you would have to get also you the spleen remove mm-hmm. . But it's the only option. But you need to say, Yeah. If you want to go that route or keep waiting or, or what do we wanna do? Yeah. Well, by all means.

Mm-hmm. like 20% sounds a lot better than nothing. Right. So, Yes, go ahead. And then he, the, the surgeon also came back a few hours later and told me, I need to sure that you understand what the situation is and repeated everything. Like he's a non-compatible, we have to remove the spleen.. His chances are so on.

And I said, Well, but [00:34:00] nothing has happened. Right? Like from the moment that you came like three hours ago, we are talking about the same mm-hmm. , he said, Yes, yes. I just, I just need to make sure that you understand what I'm saying. Mm-hmm. . Yeah. Yeah. By all means. Go ahead. Wow. Yeah.

Candice : They went through with that transplant and Luis got that liver, how did that second liver do for Luis?

Maria : So that recovery was really, really, really hard. I kept thinking at that point. They always tell you that the, if you are really healthy when you get to a transplant, the chances of survival are, are very high. Right. And, and of you recovering well.

But he was really healthy when he went into the first one, but he was super, super sick when he went into the second one. So I had that in my mind. I, Yeah. Mm-hmm. . So it took a month or so for him [00:35:00] to start showing like, Okay, this is, this is going well. Mm-hmm. right. But the first weeks or so were very, very hard.

He was in the ICU then. He was in a step one, He couldn't sleep at all. So that didn't help in any way to recover his mental state. Right. , he didn't remember anything. He, for a long time he wouldn't speak.

That was a really hard part for him not to speak. He was just looking at you like, like if he was listening to you, but there was silence to speak back. Mm-hmm. or to say anything. That was a really, really hard moment for me and for my kids. I bet. But the doctors kept saying, Just give him some time.

Right. Before the surgery, the only question that I had made to the [00:36:00] doctor was, is his brain intact? And he has said yes. It's, I said, Okay, then you go ahead. But if his brain is not intact, he wouldn't have like to keep going that way. Mm-hmm. . So when he started not speaking, that was my question to the surgeons, like, Okay, you told me.

Mm-hmm. , his brain was fine. Right. And they were saying, Yeah, yeah, let's just giving him some time and if if he doesn't improve, we will do another scan

or something that hopefully it came back. And then when he started speaking again, he didn't remember anything. So I had to like practice with him every morning how the, the nurse would do the rounds before the nurse would come, I will do this practice sessions and your name is, and these are your kids and you kid, and today is that date and all that.

And little [00:37:00] by little he got it Somehow he knew that he needed to remember those things. So he would pay like really close attention to what I was saying and try to say it in advance to the nurse coming like he, I don't know, it was weird. Like he didn't know anything, but somehow he knew that he needed to remember those things.

Mm-hmm. , that it was important for him to answer the questions correctly when the nurse came. Mm-hmm. . And when he would answer correctly, he showed like he was happy, right? Like mm-hmm. So somehow he understood that that was important, right? Mm-hmm. . So yeah. That, that was a really, really, really hard stage. I, I think I was prepared for physical illness, but not for mental illness.

Mm-hmm. . So that was a shock, a complete shock. I wasn't prepared for that one. Mm-hmm. . But little and little. To improve a little, and then, then it's better. And then they take one line out [00:38:00] and one that out and you see like, ok, we're moving in the right direction. Mm-hmm. and yeah, we spent 42 days at Toronto General.

Yeah. I felt like I lived there. And then we moved into rehab at a hospital from the Salvation Army in Toronto. And that was really, really good for him. The physical therapy was amazing and yeah, it was like a, a slow return to, to leaving outside the hospital. Mm-hmm. , you can imagine that after leaving all that, you're so nervous.

Like every time there was a lab work, I honestly was like so, so scared. The half an hour or so that it takes for the results to come back. Mm-hmm. . So I think that hospital was like, give that transition to relax. You know what mean you're [00:39:00] okay. Like, you, you can keep going. Yeah. Normally then we moved to a friend's house.

In Toronto here is my friend from work. Her parents were away in Florida, so we lived in that house for another month, I think. Mm-hmm. and then came back to Ottawa. Full of dreams and happiness and a week later we got to go back cuz he got sick again. That was another low blow . Mm-hmm. , Seriously, after all this, we left at home a week.

Mm-hmm. . So we went back and he had to have some procedures done and then we came back and the next year was full of issues and then secondary illness and full of trip to Toronto. Yeah, it was, it was a really hard year. You, [00:40:00] but now life is really good. So I, I think you have to be patient and go with the flow and make the best out of each day and things get better.

Mm-hmm. just have to be patient. Mm-hmm.

Candice : we've talked a couple times now, one thing that I always admire about you and everything that you've done is having those small goals of this is what we're gonna accomplish today. How did you get through those days?

That's a long time to be supporting somebody who's first, not, not even. The person that went into that surgery. Right. You're, you're caring for someone who doesn't know where they are and is, is very confused and in a really intense place. And then moving back into trying to find a normal life.

Maria : I think I, as I said before, I, I've always been a very logical and a [00:41:00] structured person, so I, I do things step by step. Like I, I have these little plans for everything. Mm-hmm. , and as I told the, the nurses all the way there, this, I have one job and is getting him better. Mm-hmm. like, this is what I'm here for. I have nothing else to do with my life then to get him better.

Right. So I had plans every day. Today I'm going, for example, for the physiotherapy, the physiotherapist will come like once every day. Well, what if I do this 10 times per day? Mm-hmm. , this is gonna work. I can do this. So I got the physiotherapist to teach me what I have to do and I did it every day, every hour or so let's do this.

So that keeps you occupied, right? And, and, and that gives you that sense that I'm doing something to make this better, not just sitting here waiting, right? Mm-hmm. he wanted to [00:42:00] have more protein so I can go and buy the highest protein milk in the market. I'm gonna. Or he wants today to eat this, I can cook it and bring it back and, and the practice sessions with the stuff that he wanted to remember.

I have nothing else to do. I can sit here and repeat that over and over and over until he remembers. Mm-hmm. . So just that sense that you are doing something and that you have a plan. And I don't know if this is mentally healthy or not, but I, I just didn't give a space in my mind to think how things could go wrong.

Mm-hmm. , maybe it's not healthy or anything, but that's what I did. I, it just, I, I didn't have a space in my mind for bad situations. I just had a plan. I have to do A, B, C, V and E today. Mm-hmm. , this, this is what I'm going to do. This is what we're going to achieve. [00:43:00] And that's what I would go and do. Yeah.

And, and then you, you feel good because you're not thinking, Okay, my goal is to get out of this hospital and have a normal life. My goal is for him to be able to put his shoes by himself today. Right. Right. And he did it. Ok. Mission accomplished. I'm happy today. Right. And tomorrow is going be the shirt, and I dunno, I feel like that's easier than, than to try and think how it could be way better.

Mm-hmm. companies now. Mm. Wow.

Candice : How are you? How's your family and how's Luis doing now?

Maria : Oh, he's doing amazing. Yes. He's doing so, so well and we have discovered that he has all this energy . Yeah. So, so we can do a lot of his staff. And he seems a lot happier than what he was before [00:44:00] and a lot more social.

He was never a, a very social person. Never since when I met him when he was 15, and now he is, and I'm wondering, well, maybe he didn't feel healthy enough or, Right, right. Like, Yeah. Even like my parents and my brothers that have known him from 35 years ago, they see him now and said, he's so different. And yeah.

His personality is so different now that I think that he's feeling so well. We, we have taken vacations in which he can hike mountains, like we have done six or seven hours hikes. Oh, wow. And he's totally fine. And then that was not even a plan ever. Right. Like he's so, Yeah. No, is he's really good, thank goodness.

Candice : Mm-hmm. . Wow. That's incredible.[00:45:00]

One thing that comes through. Over and over when, when we talk is your dedication to, to family and having this be your family's journey, not just one, one person's journey.

And I'm, I'm very grateful that, that I have an incredible family that supported me through this whole journey. So from the recipient side of things it's amazing to have that support. From the caregiver perspective, why did you decide to

make this of Whole Family journey rather than maybe separated , and keep it apart from everyone else?

Maria : I would never like for someone to not tell me what's happening. Mm-hmm. . So I, I thought it wouldn't be fair to my children to not know what's happening. Mm-hmm. , I think that [00:46:00] in my mind, I always thought if he God forbid dies, it would be better for my daughter to have, live that process than to get a shock at once.

Mm-hmm. , that was my very personal opinion and that's what I, did. She lived the process. And somehow she knew that that was a possible outcome. Mm-hmm. And the night of his second transplant, I did talk to her and say exactly that he could die today. It was a really hard conversation, but I felt that was what I would like for someone to, in my case.

Right. Just tell me what could happen and what could not. Mm-hmm. , my son is an older person. See, he's a grown up. So he was in many ways my support so he was going to be [00:47:00] involved anyways on what's happened and, and how things were going. My parents-in-law had, we haven't been seeing him, them that often because they live in Colombia, so I thought it was only fair that they could have spent some time with him before the transplant came.

So they came and stayed with us for months and have that chance to spend that time with him. But honestly, for me, we were the support for him, but for me, family wasn't my support because I, I felt like I need someone outside and I have this friend that had a, a child with leukemia. And she's been my really close friend, but she was my support.

I don't know, perhaps because

[00:48:00] this, this sounds really harsh, but I didn't need anyone to tell me how sad things were and how bad things could be and, and cry by my side. I needed someone really, really strong by my side. And she's that person. She's the person that will tell you, How can I help? What can I do? Like, Right. Yeah. No, not remind me of how sad the situation was.

Just how would, can I be helpful? What, what is it that you need? So, mm-hmm. . So she was always my support. I think it's important to find what is it that you need and who can give that support to you, right? Mm-hmm. .

Candice : Absolutely. And it's now my, my great pleasure to introduce everyone to Dr. Margaret Herridge. Dr. Herridge is the professor of medicine, critical care and pulmonary medicine at the University Health Network.

A senior scientist in the Toronto General Research Institute, Director of Research for the interdepartmental Division of [00:49:00] Critical Care Medicine at the University of Toronto. She is also a caregiver and advocate for her husband Rob, who received a living donor liver transplant. Welcome, Dr. Herridge .

Thank you so much for joining us today. Thank. Nice to be here.

Maria : Hello, Dr. I was wondering if you can tell us what inspired you to go into a field of critical care and pulmonary medicine?

Dr. Margaret Herridge: Well I am a critical care and respirology specialist here at uhn.

I've worked here my entire career. So actually I've been looking after transplant recipients for my whole career I was a respirologist first and then I did additional training in critical care and I did both for many years. Now I just do clinical critical care.

So I'm working here in the Toronto General [00:50:00] ICU where a lot of our case mix are transplant recipients lung transplant recipients the more complicated liver transplant and kidney recipients occasionally. And occasionally complex heart transplant patients. I like looking after complex patients.

And I really enjoy the challenges of communication in that setting as well and working in a very large interprofessional team. So I would say that's why I like doing critical care. And I am an outcomes researcher. I study outcomes, our group studies outcomes after critical illness, both ironically in patients and caregivers.

So all of this was our group's research focus for many years prior to experiencing a lot of [00:51:00] this ourselves.

Candice : And we will have an upcoming episode with your husband but I'm wondering if you can talk a little bit about your journey from being a professional in this world to actually experiencing it yourself.

Dr. Margaret Herridge: Well I, I guess what I would say is we're all just people at the end of the day, , I mean, we have professional roles, but all doctors become patients, doctors become caregivers.

And I think these roles really disappear when you have. A very personal involvement in I either have a loved one who's getting sick or you're sick yourself, or you're becoming a caregiver. I mean you have a knowledge base as a physician mm-hmm. , so you have that. But I mean, the emotional effect on [00:52:00] you and the impact it has on you, either as a patient or as a caregiver, it matters more just I think to contextualize as a, as a just a person.

Mm-hmm. much less as a physician .

Rob was really an entirely healthy person. He's a transplant surgeon himself.

So, I mean, there's all these levels of kind of irony here. , mm-hmm. connection. But he's a urologist and he does kidney transplants at St. Michael's Hospital, and this is a very large part of his career. Mm-hmm. . So he's a very busy clinician. He started out as a basic science researcher. We both trained in Boston for a few years.

And then he evolved into more of a surgical educators. So he's a very he's very modest, but he's a very decorated surgical educator at the University of Toronto. Mm-hmm. . So he is totally [00:53:00] well working, very hard and busy. And then he took our daughter, who's a student at McGill, or he was visiting her when she was doing an elective in Singapore.

And they decided to take a day trip and went to a market to buy some fruit actually, because they were gonna go to an elephant petting zoo. And I guess, Rob was rummaging around in this barrel of bananas and actually he got bin by a snake and wasn't a poisonous snake, but it was a snake bite.

And then he got a really bad cellulitis or very bad skin infection. It was just about a day or so before he was coming back to Toronto. So he didn't see a doctor in Singapore, cuz I think he thought it wasn't gonna be so bad, but it became this really pretty raging infection, tracking up his arm and he was really getting sick and I pretty remember being pretty shocked by the state of his arm when he came home.

So he went on [00:54:00] initially an antibiotic and it wasn't effective. And then a subsequent broader spectrum antibiotic. And unbeknownst to him, he developed a very severe antibiotic reaction called Stevens Johnson Syndrome

and he developed this unbelievable, sort of thick, generalized severe rash. Rash isn't even the right word.

It's sort of this thick inflammatory skin response. And enlarged lips. He got very sick with this and had high fevers, night sweats. This went on for months. He saw physicians, people thought it was maybe a serum sickness type of reaction to the antibiotic.

They said, Don't worry, it'll get better. The natural history is this should settle down. But it really didn't. And he became sicker and sicker and sicker. And of course he's just determined, hardworking sort of person. [00:55:00] And I think with the alarmed with the information that it probably should get better, just kept going to work.

But it was clear to me that he was getting very, very sick. And and I began to notice that he was becoming a little bit jaundice and he was getting slightly confused. Not in a really, not in a way, I think that people noticed it worked so much, but I was noticing just little things that were, it seemed unlike him, things he might say or and as he got sicker and sicker, I began to notice more and more that he was actually confused. Hmm. And then he recognized that and spoke to the people at St. Mike's and said I'm sick. I don't really know what's going on with me, but I really need to take a, a time away from work because I'm really, I'm not.

Okay. And I, that was right. He wasn't. [00:56:00] And then he had more and more testing and realized that actually what had happened with the Stevens Johnson Syndrome, and this is a rare but published complication, is he had developed liver failure. And so obviously he remained off work.

And then all of the, Hi, we have three children who our sons were teenagers at the time, our daughter or young adult. And we were, myself and all the kids were evaluated to see if we'd be eligible for to be donors. And none of us was. And this was also its own difficulty, um mm-hmm.

and so I would say that was very hard on, I found that very difficult. I, I really wanted to be able to donate [00:57:00] to Rob. Mm-hmm. yeah. Mm-hmm. . Yeah. And I think the kids found it even worse actually. And I think that they still think about that. It really troubled them to not be able to help their father in that way.

But no one was a suitable donor. So then we began the process of trying to spread the word and, and waiting. And I think the waiting was excruciating

because there was so much uncertainty. Rob initially was pretty sort of, he was sick for sure but he was more stable. But as the waiting period went on he began to have some complications.

He had a couple of GI bleeds. A couple of months before he was transplanted, he had a very significant GI bleed. [00:58:00] And the other thing is that I, I needed to keep working through this because he wasn't working and he has his, had his GI bleed and was hospitalized when I was on call in the ICU and it was just the loss.

Yeah. And I was so worried, cuz I, I know, I know about all of this and I could see that he was beginning to decompensate mm-hmm. and we didn't have a. and a lot of people came forward. A lot of people think very highly of Rob in his community and so many people, trainees, so many people came forward colleagues, trauma urology, trainees, friends, and just for whatever reason, no one was of the right candidate.

Maybe some people had new medical conditions that were diagnosed as part of the transplant workup. There was a lot of that. [00:59:00] Mm-hmm. . And then this colleague of mine who I'm very friendly with, but were not close friends came forward. Mm. And part of the problem for me is that I'm just not tall.

I'm not short I'm a taller woman, but my husband's six foot two. And I this was one issue. There were other reasons our sons couldn't donate, but for my daughter and me, we, we could have, but we were just not big enough there. The graft wouldn't have been big enough, mm-hmm. , we would've been small for size and that David Grant, who was looking after Rob, initially the prior head of the liver transplant program, and I know I've worked with David.

Mm-hmm. he said, Marg it's, it's just not safe not safe for you to do this. And there'd be a risk that it just wouldn't be an adequate organ. And then we get into all sorts of complications. We need to wait. And so Marie, who's a Respiriology colleague of [01:00:00] mine at St. Mike's, who's six feet tall and a very athletic, she's a, a really an elite athlete.

She's a biker. She, she's a long distance bicyclist and a very serious athlete came forward and unbelievable.

Maria : Mm-hmm. . I think that what you're saying is it very important for people to know that sometimes you find help in that, in the person that you, least expect that is going to provide his help. So it is very important to spread the word. In our case, my husband couldn't have a living anymore. It had to be a

deceased person. But yeah, someone that we would've never expected to come forward. This was the wife of one of his friends, which we had seen maybe twice in our lives. And yes, as you said, yeah, we, we were conscious with them, [01:01:00] but not really friends. And right away she came forward and said, Yes, I, I can do this.

I will do this for certain, and, and I'm forever grateful. Like, even though she couldn't donate I, I would've never expected for her to come forward. Mm-hmm. . So I, I, I think that that's something that gives you hope to know that if you spread the word and you keep asking people that you will never think of will come forward and help you.

Dr. Margaret Herridge: Mm-hmm. , that, that was of comfort to me. Mm-hmm. . Yeah. Thanks so much, Maria, for saying that. It's just so true what you say, and there were so many people who after Rob got his transplant, Told Rob and said I tried so hard, but this was the reason I was turned down and I wanted you to know that we tried and, and some of these people, I just, we were both shocked by it.

Yeah. And [01:02:00] of course, deeply moved by it too. Like we just had no idea that they would have been willing to do that or to put themselves forward like that. And Yeah. It, it is really, it's so true what you say and talking to Marie and I guess Marie and I, as I say, we're always very friendly with each other, but we're both very busy people and we always say to each other, We would totally be great close friends if we only had the time to cultivate it.

We all, I think, have people like this in our lives, right? Yeah. Yeah. But Marie always says to me when I'm, I don't know, sometimes I just email her in a day because I'm thinking about it, or I'm thinking about Rob, or there's some situation in the unit. I'm professionally constantly looking after patients like this, that I'm thanking her.

And, and she writes back to me and she says, Marg you [01:03:00] just always need to understand that it was good for me. I was, I got a lot from this too. So I appreciate the thanks, but also thank you and Rob for allowing me to do this because it was meaningful for me and my family, and I think that's incredible.

Mm-hmm. . Yeah.

Candice : When we go through these situations, whether we have a lot of notice or if it's an acute case there's a loss of sense of control and we don't know what

to do with ourselves and either as a recipient or as a family member or a loved one.

I'm wondering if you can talk a little bit about what you did to feel like you had some control over this situation when you were going through this.

Dr. Margaret Herridge: Well [01:04:00] it was, the loss of control was extremely difficult . I think for me, because Rob was off work. I mean, I, I love my work anyway, but I mean, I really, I coped a lot by immersing myself in my work.

Mm-hmm. , I mean, obviously I was helping Rob at the house too, but when I was at work, it just was a bit of a mental health break for me to just sort of go, Okay, Rob's, I left Rob at home today. He's fine. Kids seem okay and I just now need to try to compartmentalize this. I need to go to work and just sort of only focus on whatever it is the unit, my research and it, it's gonna create a bit of a, a relief from the worry and the uncertainty about where we're headed.

And that's how one, one strategy. [01:05:00] Mm-hmm. . I also I really try to focus on how I could help Rob tangibly because it wasn't helpful for me to sit around the house and worry with him like not helpful. Mm-hmm. . So what Rob did, and this was Rob's idea, but I really tried to help facilitate it was, We both knew the better the more functional he is, the better surgical risk he'll be.

So Rob decided he would just take up walking with a vengeance, like create walking as his job. Cause he's used to being a very, very busy person. That he would just get up in the morning, get dressed, get changed, and he would sort of walk almost all day. So it was during the winter. So he discovered the path downtown underneath all the business buildings.

I don't know if you guys mm-hmm. know about that, but the streets were [01:06:00] too. Like, it was just sloppy. And I think we were both worried maybe he'd fall or whatever. I mean, he wasn't that debilitated or frail, but why borrow trouble? Mm-hmm. . And so I drove him to the entrance to the path at the Eaton Centre every day when I wasn't in the unit.

And we'd sort of get up and that's what we did. I'd drive him down, I'd say goodbye. And it was like he was going off to work . And he Yeah. Did the path. I tried to just encourage him, He'll tell you also what he did, but he became a regular at the St.

Lawrence market. He went shopping every day. The people, the merchants there became his friends. He knows everyone at the market before through this period became friends with a lot of the people. And it just became sort of like his job because he needed routine. And so we sort of did that. I'd drop him off and then he'd do his kind of job that day.

And then he'd call me if there was an issue or whatever, and then [01:07:00] I'd go to the hospital and do what I had to do. And I think for each of us, it was a way to distract, to bring structure and to try to cope with the waiting and the uncertainty, which really was brutal, honestly, was really, really hard.

That loss of control and not even knowing if this was even gonna work out that maybe at the end of this he was actually gonna die because we had to look at that. I'd be interested. Maria, what did, what were your strategies?

Maria : Yeah, I, I think I, I totally agree with you. I kept my life as normal as I could because I thought, as you say, if this is the end, there's no no help in just having a really sad year.

I'm doing nothing and, and crying the entire year. Yeah. If there's not going to be a good outcome. So let's keep life this year because we are still okay. [01:08:00] Right. We're waiting, but we are still fine. Yeah. So we kept our life as it was. I kept working. He stayed at home for some periods of time and then returned to work.

I made it my mission to not get life asleep through. So if he was depressed that day, I would call him several times, get him to go walking, get him to eat, get him to not sleep all day. Just do stuff like, I don't know. I took a lot in the sense that I'm not going to, to make this year, the saddest year of my life.

If this is going to be the last year, it's going to be a good one. So yeah, so we, we planned a lot. We, I made a point to go on holidays and to go for hiking and to go, If, if we were going, for example, for the drive to Toronto, I will make a point to stop at a lake mm-hmm. Or something [01:09:00] mm-hmm. and go look at Thes and walk around the mm-hmm.

So just make it at least a little bit enjoyable. Mm-hmm. though, we knew that the trip to a hospital was not exactly a good thing. , but, but we had some fun, I made a lot of plans least so I, I plan every day because that gave me that sense of, I still have this in. I am going to plan what he's going to eat, when he's going to walk, when he's not going to walk everything, I am going to plan what my daughter is going to do.

So that, that gave me some, some, some sense of control because on in my difference with your case to the doctor. Right. So you knew medically what was happening. I am a scientist as well, and I a biology and bio technologist, uhhuh. So I have some idea of how mm-hmm. things work and I, when I got the results from the lab work, I kind [01:10:00] of know how bad it's or how good.

Yeah. But I don't have the full understanding and that was hard on me. I need to understand things. I need to know what's happening. And, and I didn't have that, that was the hardest part for me, not not having a full understanding of what the situation was. Mm-hmm. . So I tried to control every minute of my day to not allow bad thoughts to come into my mind and to not be both of us depressed at the same time.

Right. Yeah. So yeah, we, in many senses, we were one support for each other at different times during that year, but I totally agree with you. That year of waiting was brutal. Like it was, it was the worst. Yeah. Thank you.

Candice : I agree with you.

Totally. And I'm wondering if you can speak a little bit about how you advocated for Rob and how you supported him through that journey of telling [01:11:00] people what was going on.

Dr. Margaret Herridge: Well we had this discussion, I remember vividly with David Grant and David saying, Okay, now you've gotta find a donor because Mar and the kids are, are, can't, like, they're not eligible. Mm-hmm. . And and so we said to David, So what do we do?

Mm-hmm. . And he said, Well, you need to reach out to your community. I go, Well, how do you do that? Mm-hmm. , He said, Well different people do different things. I said, Well, like what? Give us some ideas. I mean, I have no idea what to do. Mm-hmm. . And he said you've got different networks at work or in the community or whatever.

I would just start reaching out. So I think we both felt kind of overwhelmed by this. Yeah. David said, and, and [01:12:00] Robert, it can't be you. It needs to be Marg because you need your advocate. To drive this it, you need someone to reach out on your behalf. It just, it's just the way it needs to be.

It's how people would welcome the information. We armed with basically no information. I mean, truly, I think this is what Rob and I would want to help the transplant program formulate a plan for help caregivers or patients with, is that

we, we really, I mean, we know lots of people, but we just had no idea how to begin what to do.

And so we just bit by bit started we started first with kind of extended family. Mm-hmm. and close friends. I created an email message with a very brief story of what had happened and what was going [01:13:00] on. And included in that story was the link to apply to be a donor to fill out that initial screening form for donors.

And basically as we heard that fewer, like so many people came forward, but we heard from them that they couldn't donate. They'd been turned down. We had friends of my elderly parents it was like, they, they can't donate, but they wanted to apply any all of these sorts of things.

They say, Well, they just told us immediately that we can't donate, and I'm a very healthy 88 year old, and we're going, well, we're so touched by this. Hearing more and more that people wouldn't be eligible. We just expanded the envelope a bit and then began to expand it through professional circles.

And just [01:14:00] more extended friendship circles. It got, got outside of close friends. Now we're in sort of more acquaintance circles, neighbor circles and the enlarging circles and professional circles. And for sure, this is how Marie heard about it. I asked permission for my colleagues if they would be willing to send it all the information out to colleagues.

Not just at the UHN but across the UofT T. I'm part of national networks in critical care across networks. I mean, we just spread it more and more and more and more as we heard more from our friends or people who knew us that they couldn't do it. Wow. And it became almost like I'd be interested in Maria's perspective and Candice yours too, like from your mom.

Like [01:15:00] that also became a major source of kind of structure and distraction for me. Mm-hmm. , I I was working at the general with doing what I usually do to Maria's point, trying to maintain some sort of routine after the fact. Everyone told me I looked like a wreck. But anyway, in the real time people go, Oh, you're doing so great, Marg.

Right? But anyway and after the fact it's all over. People said, Oh my God, we were so worried that you were here at work and you look terrible and exhausted and so stressed out. But anyway, you go through you, you, it helps you, you go through it. But that became another focus for me. It became my job then I'd get

up really early before work and I'd send out emails or I'd fielded emails or I'd say to people, What's your community?

Would you be comfortable sending it to your community? Mm-hmm. , I'd say to Rob, who haven't we thought of yet? Who we have some sort [01:16:00] of connection to who you think might be interested and bluntly eligible because there were so many people who were so kind, but they're just, they were too young or they have medical problems themselves, or they're just too old.

Mm-hmm. . And so it became a little bit like that. I know a lot of the urology trainees put their names forward. Wow. And they spread through the urology cuz Rob was the program director of the U of T urology training program. So he trained people he is the program director for about 10 years.

Right. And so, and they think the world of him and so they, that sort of network took, its on its own network of younger people who would be lower risk donors and maybe more eligible donors. But that's how we approached it. But [01:17:00] I think that's something that we'd love to help the MOT with because it's, that was really hard for us.

We did not know where to begin. And David had some good advice, but it was kind of, I don't mean like, I'm not being critical at all. I mean, I just think the world of, of David and the team, let me tell you, and as a colleague too, cuz I work closely with him as a professional colleague.

All of the team, I think so highly of them. But it wasn't specific like, Mar you need to do this, this, and this. And I just going, I, I feel overwhelmed all over again about now what? But I'd be interested in what you guys, how you guys managed that. But that's what we did was just sort of ever enlarging circles as it became clear to us, we needed to spread a very, very broad net and use any kind of connection that we had or our connections.

To work. Right.

Maria : I think [01:18:00] that in our case, it, it was different, but in a sense we were even more at lost because we didn't grow, grow up in Canada. Mm-hmm. , we have zero family here. Mm. So even though, so to, as you said, you started with your family. Right. But if we start with that, that means we were catching this net in a different country.

Those people that would volunteer would have to come here and get tested. Oh yeah. Mm-hmm. and then go through a transplant here. And this is just, one fact

is a ridiculous amount of money mm-hmm. that, that we can't afford and these people can't afford. Right. So yes, people can have the best intentions in the world, but if you go to our realistic scenario [01:19:00] is absolutely difficult and almost impossible for someone to come from another country and go through this processing here.

Mm-hmm. . So that has scared me a lot. I was completely as lost, like they said. Yes. Cast a wide net. And I was thinking even if I send it to the entire population that I know in Canada is not even close to being a white mm-hmm. . Right. Go to your community? Well, I, I don't know, like what my friends from work like, I, I was really at loss with that and so I, I went almost the same route.

I said, Well, the only thing that I can do is write this email. They're my story. Gave the link and send it on Facebook to all my contacts and see what happens, right? Mm-hmm. . So we did, because you're desperate and yeah. Whatever you are [01:20:00] doing is better than doing nothing. Mm-hmm. . So I did that and what I discovered is that there's really good people in the world.

Yes. Like people that has nothing to do with you and just hear this story and say, Yes, I will do this. I will totally do this. Yeah. Send me a papers and I will fill them up. And we had several people volunteer people that none of them were close to us. Mm-hmm. . So there was no one that I would say, Oh, of course this was, I dunno, a close family member or a, or a friend from all my life.

No, just people that at some point in our lives we have known, or friends of friends that had volunteer, even a person. Was a friend of someone that my mother-in-law knew all of [01:21:00] them volunteered and send papers to, to Toronto for the investigation. And at the end, my husband couldn't receive a living to transplant.

But my message with that is even if when you think that this is overwhelming and you have these really small network, send it out and, and rest confident that there's a lot of good people in the world that just do it because it's the nice thing to do and just volunteer and come up. It doesn't have to be anyone that you know for your entire life or is your family or anything like that.

Just have that faith that someone will come out. But you really need to send that email and don't, don't feel like overwhelmed of sending it. Just ask for help. It's what you need to do. Just send that email and, and wait and something will happen and people will come out and, and some will happen. It's that same feeling that I have that I was thinking I don't know [01:22:00] anyone.

Like what do you want me to do? Like I don't have a huge network cast. Yeah. I don't have social work networks. I live with my family. We are four, I know 10 people at work and my husband knows another 10. And that's about. So, Right, like you feel really, really like when they tell you Yeah. Cast that wide net.

I was thinking I can't, I dunno that many people. Yeah. So even in that situation, just do your best and send that email then I don't know, someone will see it and then just come and volunteer.

Candice : I say it often, it's one of the most unique situations in healthcare that we are placed in as a potential recipient for an organ is your best quality treatment is a living donor.

But you have to go find your best treatment and there's really [01:23:00] nowhere else in healthcare that you're sat down and you're said, you're told this is your diagnosis, this is your health plan. This is the best possible treatment that you can have. But you have to go find, You'll do it. Exactly. You go find that and we'll take care of it once you find that, but you're at a loss.

In all other aspects of our care, we're provided the best quality treatment by the hospitals and by our doctors. Yeah. But in this situation, we have to rely on the altruism and these big hearts of people to step forward and give us the best quality care. So it's, such a unique situation that people are placed in and having to go and find somebody, it feels overwhelming to think Absolutely.

That you have to go out there and, and find a donor yourself.

Yeah. Yeah. For sure. Mm-hmm. . That's exactly right. So how are you and Rob and your family doing now post-transplant? [01:24:00]

Dr. Margaret Herridge: Well, I think I think that we're all doing very well. Mm-hmm. Rob's very healthy. He's working hard, he's doing well.

I think that it's, it's taken some time for our kids to work through what happened. I'll just be honest. I think that's been hard. And I'm not sure the kids have completely unpacked all of that. It was very, very scary for them. And as I alluded to at the beginning, I think it was just really terrible for them to not be able to really help in a tangible way, mm-hmm. . Mm-hmm. . And I think they still it's not rational, but [01:25:00] Harper some guilt about that, even though no one was felt to be an acceptable donor and it was really hard for them. Mm-hmm. . I think they Rob and I recently both had Covid for the first time and Rob

got it from a patient of his, and then I got sick from Rob and we were pretty sick, but we were home.

And I just see the the fear in the kids completely. Is he gonna, Sick again. I, I'm so, I'm frightened Mom. Is he? They go, you, you'll be fine. , but is that okay? Well cuz it's true. Basically. I mean, it's a good assumption. I mean life is uncertain. Right. But it's a good assumption that I'll be fine.

Mm-hmm. . But [01:26:00] just to see the fear resurface right. Reminds them of a time when they were so afraid of losing him and and it just comes back, are, are you sure Dad's okay? I'm just calling you. I don't want dad to think that I'm being weird or extra worried, but is he okay?

Mm-hmm. ? Yeah, he's fine. Okay, good. I was really worried. I'm really worried. So I think that it had a very big impact on our children and and they're still processing that. But I I think sometimes we. Think enough, like we think now we're sort of, it's good we're turning the lens on the caregiver. And I think about this in my own research program on outcomes, but I think we really now need to include in the lens the children. Because the children are part of the family they're caregiving in their own [01:27:00] unique ways too.

And they're worried in their own ways too. And I think sometimes we're not, cuz we're all worried, right? Mm-hmm. and the caregivers focused on the loved one who's sick and you're worried about losing them. What's going on with everybody else? Yeah. Or the kids are being stoic because they don't wanna add to the caregiver's stress by saying for me, mom, I'm completely stressed out.

It's very hard to concentrate at school. I actually don't even wanna be here in school right now. You know what your natural reactions, because the level of anxiety and worry is so huge. And I just think it's it's over three years now that Rob had his transplant, almost three and a half actually.

And he's been entirely well, like, it's unbelievable. Even to me, I just go like, I, he's entirely well [01:28:00] mm-hmm , that's awesome. But you know, it takes a long time for the kids to have. Ability to look at something that was so scary and painful mm-hmm. and to begin to process it fully and to integrate it into, yeah, this happened to the life of our family and it was really terrible and incredibly scary and we all were anticipating Rob's death because we had to be realistic about this as a possibility.

I was having a lot counseling, trying to prepare myself for this, to be honest, as he was getting sicker and sicker, I had to, I had to prepare myself for how I was

gonna deal with that. I mean, I don't think you can, but I was trying to look at it because I had to look at it. So I think [01:29:00] we're all good, but I think the kids are still continuing to really unpack all of this because it was a pretty major traumatic life event for them.

Mm-hmm. . And of course, they're so happy about what's happened, but the, the fear and the trauma and the moment is a real life event and it has a really important impact that requires you have to work through it. Mm-hmm. . But I'd be interested in what you guys think about that. That's what happened in our.

Maria : In our case I was going to ask you, how long ago had that been? Because in our case it's going to be three years this December. Wow. So similar timeline. It's a, it's a similar timeline. Right. My daughter was nine at the time, and my son was in his early twenties. I [01:30:00] honestly think, and I'm not doctored, but I honestly think that I have post traumatic stress disorder.

Like, I, I still, there's little things. For example, I, I can't go to the Delta Hotel in Toronto. Like I, I step inside and all this anguish comes back. Mm-hmm. like you all this feeling like I can't be there. Like I don't want to stay there. Yeah. And the very few times that we've gone back to that specific hotel's, like everything comes back's awful.

Like I, so that's for me, and there's little things like, there's a sweater that I wore because I only had brought, the one hoodie in my bag, so I wore that hoodie for 42 days or so. I can't put it on like, I, Yeah. I gave it away. I hate it. Like I, I can't have that sorted on. It's just, I understand. [01:31:00] Mm-hmm. And I think it's silly, but, but it's not like I, it's don want it.

I don't wanna see it anymore. Yeah. So little things like that, I, I, I, I hope with time they would go away. Right. But it's just those, I don't know that feeling like Yeah. Mm-hmm. , and for my kids, I think we tried to keep life for our little one as normal as possible, but of course it wasn't normal. Right. She, she was completely aware of what was happening.

And I think that she grew up a lot in those, in that time. Like, she's like three or five years passed on her life instead of just one. Mm-hmm. . And one thing that I, I noticed is, as you said, like that fear that he's going to get sick again. So for example, with Covid, this was the 11 year old that had that mask sealed to her.

Like she wouldn't take it off ever. [01:32:00] She was the one playing basketball with a mask on and everything with a mask on. Cause she was terrified of bringing COVID home. Mm-hmm. . Yeah. Totally. So I'm grateful that she

needs that, but in my mind, that's sad, right? Like, I know mm-hmm. me. Yeah. But that's the case for him.

She wouldn't bring, COVID it home. Like, so she, she has spent two years with that mask on her face, like,

Yeah. So I understand. I, I think that even though things are really good now, like it's, it's a really, really good life. I don't know how long it's gonna take for that to go away. Mm-hmm. . Mm-hmm. . So I'm, I'm, yeah. It's I'm absolutely grateful that life is really, [01:33:00] really good now, but it's something that happened and will estate there for a long time.

Dr. Margaret Herridge:

Yeah, I because I mean, ironically it's, so my, there's so much irony for me because I really do research in this area.

Mm-hmm. and I and I study caregivers. I mean, this is the other after critical illness, which is a traumatic life event and just like what we've all been through and so many of the caregivers, I mean, so many of the patients, but so many of the caregivers do have symptoms of PTSD or major depressive or anxiety disorders.

And it's, it's a well established literature. I follow these people, those are the studies that I do that follow up long term follow up studies. And I know these people and I follow them and I'm not, I mean, I guess this is public, so I guess people will know that I've actually have a lot more in common with them than maybe they even appreciate it.

But I'm [01:34:00] routinely referring people for counseling. Mm-hmm. because people do have ptsd. And the symptoms you're describing Maria absolutely. Are symptoms of ptsd. Absolutely. Yeah. And I have some of them myself. Mm-hmm. and it is with traumatic memory, it really does require this integration into.

Acceptance and integration as a life event. And it never goes away. But the, the interference and the the emotional trauma, you know how it, it interferes sometimes out of the blue unpredictably right there. Triggers mm-hmm. that goes away with treatment and counseling the memory. Well, it's always a difficult memory, but it's part of a life.

Right. And, and then you can kind of begin to move forward. And I think time does heal, but sometimes I think sometimes it does require specific therapy [01:35:00] because PTSD is very treatable. Mm-hmm. and I definitely have had counseling myself to deal with some of these things because I like to destigmatize counseling and mental health issues.

I went into counseling when Rob was sick because I really had to try to be in intact for the kids as much as I could be, even though that's who's fooling who I was really struggling. And then kind of in the aftermath trying to process everything. And, and I've really encouraged our kids to pursue it too.

Mm-hmm. . Yeah. And I, because it was a big deal and we can't go, Well, Rob's fine now. Everything's fine. It never works like. Yeah. If I could resonate to what Maria's saying about her daughter masking mm-hmm.

like, I worked all through Covid mm-hmm. and the ICU here at the general and along all through [01:36:00] the time when there was no one woman was vaccinated and all the patients were, There's a very high mortality here in the icu. In the general, At the general. And I mean, I moved into our basement for months.

I was kind of scared I would get it, but not, not nearly as scared as your daughter Maria to bring it home. Mm-hmm. . And I just said, Well, the last thing I'm, I do, I'm never bringing this home. I would, I lived separately from Rob for a couple of months.

Wow. And I just we weren't in the kitchen together. I was masked in the house. I didn't overlap any clothing. It's like, I worked during SARS too like no clothes came to my house. I, I immediately showered when I came home, I wore a mask and we had no contact with each other Really?

For months. Hmm. , I was so afraid of that. So I know what you mean. I just thought if he's like, now he's well and then he dies from Covid, cuz I brought it [01:37:00] home. I'll never be able to live with myself. I never be able to deal with that. Right. I think that was the case. He was, was terrified. Terrified of bringing Yeah.

Same. Mm-hmm. . Totally. That's probably my biggest fear being an intensivist during Covid, ironically. Mm-hmm. was just, I cannot make Rob sick. Mm-hmm. . Mm-hmm. . So Margaret, going back is, you were talking a little bit about your, your research with, with caregivers Yeah. And, and that Yeah, that's right.

Candice : Ironically. So. Yeah. Yeah, yeah. And, and you're, that's really crazy. The support that you, you recommend to, to caregivers and families. Yeah. I really do. Can you talk a little bit about some of that and we know that there's, there's not a lot of resources or support for caregivers and, and families who have survived [01:38:00] critical illness.

Can you, can you speak to that?

Dr. Margaret Herridge: There isn't, Yeah. I mean, I think one thing that our group is really trying to establish is a real continuum of post ICU care for patients and families and children. It's really on my radar. The kid piece, the children to create continuity, but also to help with a lot of things that the MOT program has a lot of resources for rehab and mental health.

So, but still that, that this doesn't exist for. ICU. We really tried to build a network so we can advocate and facilitate, but I'll tell you, even during, we did a big covid follow up study after covid ICU as to study. Our group is just finishing right now. And there's such severe mental health issues in the patients and the families.

And really in our research program is [01:39:00] advocating for , cuz everyone have that for sure, but even more so mental health support. Mm-hmm. , because the additional trauma for Covid and the caregivers was, the caregivers were banned from the bedside and the icu, so they couldn't even be part of the journey.

There was that extras, like separation trauma too. Like people, It was terrible. Yeah. So not only were they traumatized like we all were because they felt out of control or Candice, your, your husband or your mom or you mm-hmm. I'm sure they've told you similar, like you're hearing similar, I'm sure similar stuff, right?

Mm-hmm. , I mean, There's no one who looks after the caregiver or the children. And people really need mental health counseling. And what I try to do in clinic when I talk to the patients and the caregivers, cuz they often come in together, is to, is to normalize and destigmatize the mental health piece because it's normal that [01:40:00] everyone has been through a traumatic life event.

And that changes your life, it changes you, it changes your fearfulness, your sort of fear thresholds. And you need help with that to, I mean, the memory's gonna always be the memory, but need help with that so it doesn't interfere with your ability to live your life. And and I really try to normalize it.

I mean, I haven't, it's not really appropriate for me to be sharing my personal experiences with my patients or caregivers. I mean, it's, it's not, it's, it's inappropriate. Well I guess I'm doing this now. A lot of people watch it, but it's a boundary. It's a professionalism boundary issue. It's not appropriate for me to do that.

I can do it in this forum, but what I'm saying is, as a p. And as a researcher who does work in this area and understands the literature and my own experience, I mean, I, we really need [01:41:00] to be looking after people so much more after the event, regardless of the outcome of the family member. Like of the patient even if it's incredible.

Right? And, and Maria and I and you, Candice, I mean, we're all so fortunate to have had these incredible outcome experiences so far, and yet the trauma of the event lives on in US because it was a traumatic event and it was really unbelievably scary with a loss of control and fear of death, which was real and possible.

That's I, I'd love to see and help with that because we're really on a mission to do that for the post ICU patients and families and children. And we're all really talking about similar kinds of trauma and traumatic memory that requires treatment actually. And they're very specific treatments for these things.

There's very specific treatments for PTSD [01:42:00] symptoms and we actually have a PTSD super expert at Ryerson University. Well Toronto Metropolitan University currently, who is actually a national expert. I work with her and we have, there's a lot of expertise in a lot of help, but I think we need to create more like normal pathways where, you know, I just always say to the patients and families, it's normal to feel this way.

And I normally just suggest having counseling because that's something I just expect. You might need, May I organize that for you? I just try to normalize it instead of are you okay? I mean, it's just this sort of under current of judgment or you should be okay. Or you should be grateful.

Everything should be fine. Cuz your loved one is fine. It doesn't work that way. And I, I obviously cuz I study this, [01:43:00] I read about it, I think about it. I, I think that's an important focus that we could really help a lot with going forward.

Candice : That's amazing. If somebody wanted to learn more about your research or, or find some of these programs or, or resources that were available, where could they read more about that?

Dr. Margaret Herridge: I'm happy to supply some of those resources. Candice to you. Mm-hmm. and chat more with you and the MOT group offline. Wonderful. A lot of the lung transplant programs have been in other research studies. Our group's done because they've spent longer times in the icu.

And same with some liver transplant patients. Mm-hmm. . Mm-hmm. . So I've actually looked after a lot of transplant patients and families also, ironically, not just in the unit, but in follow up, [01:44:00] right. I know it's a bit un unusual for sure. Mm-hmm. , but happy to share some of those thoughts and resources, like for sure.

Yeah. Amazing. I think this is a message that our group and other groups are trying to message for adults who've been through critical illness or a major medical event in their lives, that we really need to also think about families the caregiver, the children, everyone who is cuz we don't get sick in isolation.

Our whole family gets sick and so we really need to look after the whole family. A hundred percent. I couldn't agree.

Candice : Is there something that you would wanna share to caregivers or to family members who have been through this journey that you think would help them from the experience that you've had?

And maybe I'll start with start with you, Maria.

Maria : I think that I'm conscious that [01:45:00] everyone goes through this in a different way and it's different for everyone. But what I think helped me and my journey was that I made it like a plan. I have to get my husband through his transplant and he's going to get well.

And that's the only thing that is in my mind. And I'm going to plan for that and, and I'm going to work through it. And we lived every day trying to make it at least a bit a happy day, right? So trying to enjoy the little things in every day. And if, as I said, if we were going to a hospital appointment, then we will stop at the lake and have.

A nice moment mm-hmm. in that day and have these little things that you enjoy every day and, and go through your process and enjoy it and, and find

[01:46:00] something to hold onto. So I had my faith, I prayed a lot. Mm-hmm. , but I know that that's not the case for everyone. And that that's totally fine. But that's what helped me.

Mm-hmm. , I found that that was of comfort to me specifically. So I prayed a lot, I had my faith. I, I enjoyed little moments every day. I found some space for me that was, I walked a lot, . I had these walking patterns. I even walked the stairs at Toronto General up and down the stairs every single day, many times just to relax and, and have some physical exercise.

And that helped me to sleep, which was very important because then you get physically tired of walking the stairs so you can actually sleep. Mm-hmm. . Yeah. So I think it's important to find a little space for you. It's important to enjoy little things every day. [01:47:00] Make it a happy day, at least a little tiny part of your day needs to be happy and also give yourself some space to break down.

Hmm. And. So I think that you're a better person once you have a good cry. . I totally agree. my friend told me, just go have a cry in the shower. No one will notice. Mm-hmm. And that was one amazing piece of advice, . Mm-hmm. . So I used to go in the shower and have these really, really, really nice cries and come out of there feeling really good.

Like, okay, I got it all out. I have this energy again to keep on with my day. Mm-hmm. . So you are the support to your patient, but you are also human. And you need to break down and have these little cries , and feel better and relax a bit and have a, that bad [01:48:00] moment and be okay again.

Candice : Beautiful. Thank you Maria. And for yourself, Margaret.

Dr. Margaret Herridge: Thanks Maria for saying that in a lot of the strategies for sure. I observed as well. Mm-hmm. I think the routine we both talked about. Mm-hmm. , I didn't mention, I mentioned Rob's walking. I also did walking too.

Interestingly, I didn't mention it, but it's a good, it's kind of you, it's contemplative, right? You can process, but you make yourself tired. The sleep is a crucial thing. Mm-hmm. trying to observe some routine so that the routine can anchor the day and you feel like you're getting, you're just got some structure that keeps you going because it's so difficult to keep going.

Mm-hmm. and a focus whatever that focus might be whatever your work is, whether you work within the home [01:49:00] or outside of the home, just

trying to do something that's productive, that also feels like you're not just in the waiting place. Candice, as you said, which is, is terrible. Like it's intolerable.

You need to feel that something is moving forward even though the global issue is uncontrollable, that you can control some things and move those things forward. I think what you said was really important and powerful. I really agree with Maria. I did a lot of crying in the shower too. A lot of private crying.

I'd cry a lot of my office at work cuz I was, I have privacy here. I'm by myself. Mm-hmm. so that I didn't, my children didn't see me crying cuz that really terrified. Hmm. And and same with Rob. It wasn't helpful for Rob to see me crying even though I know he knew I was , [01:50:00] but also the space to be real.

And that's why I sought counseling because I could say whatever I wanted to this person, I could tell her how frightened I was. Mm-hmm. . Yeah, yeah, yeah. And I could kind of leave it there. Mm-hmm. . So yeah, that's what I did. I didn't wanna burden my friends with it too much, or my sisters or my parents or elderly.

And they were absolutely terrified. And so they would look to me because I'm the doctor. And that was the other burden that I found very difficult. I didn't really talk about this here, but that was very, that was sort of a burdensome thing. Mm-hmm. . But anyway they looked to me to be the strong person and I knew that, so I couldn't unload on them.

Mm-hmm. . And so I needed a place, as [01:51:00] Maria said too, not just like to cry. Crying is very helpful if you're inclined to cry. , I don't know, not everyone. Mm-hmm. is sort of, I'm really okay to say that. I do that too. I, I cope in the ICU that way too in my office sometimes. But I needed to see a counselor. This happened to be a psychiatrist, a friend of, a colleague of mine who's a psychiatrist at uhn.

Mm-hmm. to just be very, very real. Mm-hmm. and to say all the stuff that terrified me and to just get rid of it once a week in a very safe space and no one else could hear. And that helped a lot. And I think a good strategy too for if, if that works for you. I really agree with Maria. Different things work for you gotta kind of know what works for you and try different things.

Mm-hmm. . But once you find what works, it's, it's [01:52:00] just keep doing it. Mm-hmm. .

Candice : So I have one final question that I like to leave on a positive note Margaret, I'll start with you. If you were a tree, what kind of tree would you be?

A tree? Yes. . What? Oh my God. You like to put people on the spot and end in a, in a silly way.

This is hard hitting journals to answer that question.

Dr. Margaret Herridge: Okay, I'm gonna hedge the question a bit. I'm gonna be two trees . One tree is because we have two of these trees at our house. One tree I would like to be is a Japanese maple, because it's architecturally beautiful. And it brings joy because it's can I say I'm not trying to be a beautiful tree, but I'm just gonna say, Yeah.

I would wanna be that tree [01:53:00] because it brings a lot of joy because there's almost, there's almost a sort of a artistic, kind of creative element to this tree. And I, I love it. I love looking at it. Mm-hmm. . So I like the sort of creativity or the joy that, that natural beauty brings.

Mm-hmm. . But we have a lot of very, very old, old oak trees on our property that are like 80 years old. Mm-hmm. . And not a lot like too , but they're big and they're solid and they're stalwart and they're strong. Mm-hmm. and they kind of anchor the property. So I think I'd like to be a bit of each. Amazing.

That's beautiful. And yourself, Maria.

Maria : I actually, I had before [01:54:00] Dr. Herridge said I thought about the oak tree. Mm-hmm. , but now if I had to pick another one just the name escape me in this beautiful moment. Is this tree a willow tree? Yes. And I would be a willow tree because it just goes with the flow, right? Like if the leaves just move with the wind and, and I like hold relaxed and, and, and laying in the ground and just giving a lot of shade.

And I think that's part of what I, I think we should do. Just go with the flow and withstand the situations and go with the flow and be happy and be shaped for everyone. Yeah, that's what I would be.

Candice : Amazing. Thank you so much to both of you for sharing your incredibly touching journeys and for being so vulnerable with me today and for discussing all of this.

I think [01:55:00] everybody can learn something from both of your journeys and I'm so incredibly grateful for your time and for sharing today. Thank you so much for being with me today.

Thank you. Great to chat with you. Nice to meet you, Maria. Nice to, to hear about for meeting you if they're having done. Really nice to meet you.

Yeah. And thanks Candice for, for offering the chance to speak about our experiences. We appreciate it lot. Thank you. Thank you so much.