

Charles & Dr Ross Final

[00:00:00] Living Transplant is a podcast that takes you behind the scenes of the transplant program at Toronto General Hospital, with the goal to educate, inspire, and fuel your passion about transplant. I'm your host, Candice Coghlan. Thanks for joining us for season four. In this episode, I got to sit down and have an intimate conversation with my friend, Charles Cook, an incredibly brave and vibrant person who is a heart and kidney transplant recipient.

After far too many close calls with death, Charles has implemented the life motto of keep banging. Later, we're joined by the one of a kind cardiologist, Dr. Heather Ross, who is highly decorated with awards like Canadian Geographic's Top 100 Explorers and the Order of Canada. She speaks to us about football, her childhood, testing our limits, and why the patient journey to her is more than just treating the disease.

Please enjoy. Welcome back to the living transplant podcast. I am extremely excited to [00:01:00] have a good friend of mine, Charles cook on today. Welcome Charles. Thank you for joining me. Thanks for having me, Candace. This is a great way to start off a beautiful Friday. Um, there's nothing that I love more than a good conversation with a good friend, you know, an exchange of ideas and information.

So let's get to it. So I'm wondering if you can tell our listeners a little bit about yourself. Sure. Uh, my name is Charles Cook. I am a 54 years old. I am the father of two fantastic young adults. They both live in Toronto, uh, one son and one daughter, Matthew and Chloe. Uh, they've been kind of my inspiration to get through all of the crazy stuff that I've been through and, uh, you know, born and raised in Georgia.

Uh, born in the city of way cross, which is my mom's hometown. Amazing. And can you tell us, uh, who is the guest who is joining us today in the background?

Our Myers [00:02:00] parrot. She isn't on camera or on, uh, the podcast officially, but she always has something to say. I love it. That's great. Thinking back to, uh, your time in Georgia, can you tell me a little bit about how you, you came to Ontario and um, what kind of spurred that, that move for you? We were looking to move, uh, Manager from the Athens restaurant back home to Florida.

He'd done a good job. So We need to find a replacement. So I got done my interviews that day Had lunch with the general manager of the restaurant said I

think you know out of this bunch that I interviewed today We're probably going to get somebody to be the replacement for the person that we wanted to move He said, all right, walk me out to my car, you know, have a good day.

I was supposed to go to Chattanooga, Tennessee the next day, called the regional manager and said, Hey, I'll see you tomorrow. We got some interviews set up. And then, you know, I started driving home, uh, didn't make it too far and I started [00:03:00] feeling funny. Uh, and I tried to pull off the road. To get into the media and just to kind of figure out what was going on and everything kind of broke loose.

I wound up having a massive stroke behind the wheel of the car. The doctor had told my wife that things weren't looking good. My brain was swelling up. You know, there was no movement, no sensation, all that stuff. He said, you know, prepare yourself for the eventuality of that. If he comes home at all, he being me, he's going to be coming home in a wheelchair.

Well. You know, like my mama said, you know, they don't know everything, you know, and 12 days later, I got up and walked out of the hospital under my own steam. So we decided the best thing that we could do as a family would be to put ourselves in a situation where when and if something happened to me, then she and the kids would be surrounded by the large support network available.

And that meant moving close to her family. And so you moved to Ontario. Mhm. At what point did, did things [00:04:00] change health wise?

Okay. So again, another thing we had made the decision to move the last weekend that I was in Georgia was Father's Day weekend in June of 2006. Um Wife and kids back at the hotel. And then we were going to go out and pick up some takeout, bring it back to the hotel. We were going to have dinner. So, uh, my dad was in the van.

My mom and I went into the restaurant, made the order. My mom and I walked out into the van and my mom said, Hey, they didn't give us our drinks. I said, okay, what did we order? I'll go back and get it. I go back in there and the host is like, didn't you just leave? I said, yep. But you guys forgot our drinks.

I said, Oh, I'm sorry. You know, I'll, I'll go get them. What'd you need? So I told her whatever it was. And, uh, she walked back to the back of the restaurant and turned to go into the kitchen to get the drinks. I saw her walk back there. And

when she turned, it was like somebody flipped the switch, [00:05:00] lights went out, I collapsed.

And then the next thing I remember, uh, servers walking up to me, kind of standing over me like, are you okay? And I didn't really know where I was. I woke up and I'm kind of like, this is weird. And I got up and I grabbed hold of the hostess stand to kind of steady myself. And I said, I'm okay, but it feels like I'm going to pass out, not realizing that I just come to from passing out.

I'd had a defibrillator pacemaker implanted in my chest after the stroke. Structures were, if you ever feel like you got therapy, which is a shock, then, um, You know, you're supposed to call the office and then they can read it and let you know what was going on. Wednesday, I go to the doctor's office and, uh, the technician's there.

She puts the little like metal donut over my chest where the defibrillator is and, uh, you know, hits the computer and it starts printing out stuff. And she said, Oh, you had [00:06:00] an episode. All right. And then, uh, she said, you went into VFib. And he sat down in front of me and just started shaking his head. And he said, I never thought this would happen.

And he said, um, you know, if we hadn't put that defibrillator in you, we wouldn't be having this conversation right now. Cause you'd be dead. And so once you settled, I'm, I'm assuming you found a cardiologist here to take, take good care of you. And happened to be, um, my mother in law's cardiologist. was able to take me on as a patient almost immediately.

2009, I went into full fledged heart failure. And, uh, he said there's three outcomes, artificial heart, heart transplant, or death. He said that my plan is once you turn 40, I'm going to start sending you down to Toronto General. Because they do the heavy lifting on end stage heart failure, and we know how this thing is going to end.

And that is how [00:07:00] I wound up going down to TGH. That is how I met our next guest, Dr. Ross. And so when you met Dr. Ross, at what point did she tell you? That it was time for you to be put on that heart transplant registry. Ooh, Candace, um, kind of getting goosebumps. Cause this is all coming back. Went to Toronto general for a regular checkup.

Saw Dr. Ross. She said, and I'll never forget it. You know, Dr. Ross is just so straight up and that's what I loved about her. She said, I got some news for you. And then you're not going to like it. She said, uh, it's time. And, uh, I was like,

okay, you know, we knew this day was coming. We used to know what was going to be today.

And then she said, um, I'm going to admit you and, uh, we're basically going to go from there that like, like to be told that. This is it. You have no prep. You don't get to go prepare yourself. [00:08:00] You're here now. And this is happening. I guess I was in such shock or whatever, um, about the severity of the situation that it was just.

you know, what's the next thing I got to do? Okay, I'm not going home. I have no clothes with me or anything like that. We got to get, you know, just the basic necessities taken care of. I'm gonna get checked into the hospital and then we'll just kind of see where we go from there. By that time, I had been kind of in and out of hospitals enough that it wasn't scary.

And I really did consider Toronto General is my hospital away from home. You know, and, uh, it really became that leading up to that transplant. What was that like? What was happening during those hundred days? Oh, man, it was, uh, like I said, I was prepared for, okay, now it's time. You know, we're going to put you on the list and then you wait.

What I wasn't prepared for was, and they weren't prepared for either. And they being the team on the heart function team, which Dr. Ross was [00:09:00] ahead of was that. My heart had been so bad for so long that my body learned to compensate for it. And what had happened was the pressures, the filling pressures, they call it inside my chest were so high that they couldn't safely give me a heart transplant.

I wouldn't even be able to be listed. But the reason they didn't send me home was because they didn't think that I was going to live long enough if they let me out the door to come back for a follow up appointment. So they had to keep me, you know, where they could monitor me. And all of this I learned kind of after the fact, you know, we had a plan.

It's like, we're going to go in there. We're going to get this thing. It's going to keep you alive. The pressure is going to come down. Then we're going to, you know, put you on the waiting list. And then we go to surgery and pretty much everything that could have gone wrong, did go wrong. Um, I died twice on the table, uh, after he, you know, opened up my chest, he had to do cardiac massage twice to bring me back from flatline [00:10:00] that was rough, but I'm still here, you know, you know, uh, I made it and, uh, through a lot of prayers and support from, from everybody.

Was there something that you held on to or something that you did? During that time that helped you get through those, those days or something that, well, you know, I have the motto keep banging, um, which I got really through life experience, um, Just that mindset that life's going to put obstacles in all of our paths, our jobs to keep banging at the one directly in front of us till we knock it down.

Then we move on to the next one. Monica basically was there with me every day. You know, she basically put her life on hold

to take care of me,

something that she did not sign up for. And I've always said, you know, um, we talk a lot about the caregivers. [00:11:00] If life is a play, I've always had the proper role in this play. I've been the patient in the bed. I know what I can take. You know, there's nothing short of something that kills me that I can't handle.

But I don't know if I could sit there, if the roles were reversed, and see her in that bed, somebody I love and care about, and not be able to do something to help them. You know, but she found the strength, you know, and she stayed with me. I told her, you know, you gotta be crazy. You didn't sign up for this and the crazier that the ride has become, the just tighter she holds on.

And I tell her now, you know, I hope you never come to your senses because you get out of here, you know, and. You know, quick as a flash, but she's still here and that's why we're sitting here talking today. And hopefully somebody that hears this, you know, can identify and say, Hey, if that guy can do it, then I can do it too.

Cause I'm just a regular guy who happened to have had, you know, a bunch of crazy stuff happened to me. And from the beginning, I [00:12:00] just said, I'm not going to quit, you know, just bring it on. I'm going to keep banging. You kept banging through all of those things that a lot of people would have probably given up.

You know, level one or level two, um, you know, thinking about video games as you keep getting higher and higher, you know, they finally get to the big boss, which is this heart transplant. Right. And so how did that happen? The other thing besides being down in CVICU for almost eight weeks with that

blood caused my kidneys to run dry for too long. They wound up dying. They thought that. Right after surgery, we'll put this dude on dialysis, that'll jumpstart

his kidneys. Hopefully they'll come back on their own, and they never did. So... When I wake up and realize, you know, kind of where I am after the surgery, I [00:13:00] don't know how long it was down in CVICU.

I kind of looked and, uh, there's an electrical cord hanging out of my belly, uh, which runs to a machine called a wall unit, which is plugged into the wall, just like a lamp. And, um, that was weird looking, but. That was what I had expected. You know, in that eight days prior to the surgery, they said, this is what an LVAD does, this is how it works.

It runs on electricity. I'm like, okay, all right. But then I looked down and there's these two tubes hanging out on my chest and they're clear. They got some red stuff in 'em, and they're going to this machine. I'm like, what's this red stuff? It looks like blood. Is that my blood? What? What's going on here?

They said, unfortunately, during surgery, you lost your kidney function and now you're on dialysis. So, LVAD, dialysis, phone rings on Friday. Mr. Cook, Toronto General, [00:14:00] we need you to come back in for further testing and observation. We've been following your blood work. There's a substance in your blood called L.

D. H. That keeps going up and up and up. We need to figure out why and back to the hospital over the course of about a week. They figured out through process of elimination after a bunch of different tests. The only thing that could be causing the increase in the L. D. H. Was the LVAD itself, because LDH spikes are created when a large amount of red blood cells are broken down at any one time.

So it seemed like the LVAD was malfunctioning. I'm like, this thing's working great. I feel better than I have in years, you know. But the only way to find out if that is what it is, is they need to take it out and physically examine it by opening it up. And, uh. To do that, it needed to be replaced, which required another surgery.

So after the a hundred days, I was out for three weeks, had to go back for a week of testing, and then after that, we were in may I have LVAD two, I get to do it all over [00:15:00] again, had the second LVAD surgery that went off. you know, with flying colors. And Dr. Badiwala did that surgery again. And, uh, before he left, he opened up the device in the OR and took a picture of it with his cell phone so he could show me.

And it was literally like a big glob of reddish grayish junk that would have gummed up the works and would have stopped the OVAD from working. I would have died. So if they hadn't caught it when they did again, we're not sitting here, you know, talking to each other after the second LVAD that kept me alive, you know, long enough things were working well, we redid the testing three months later, and all the pressures that come down, like, uh, they thought they would.

And I remember like actually being on the exam table and Dr. Ross came in and said, Yes, yes, you know, your pressures are down, we can put you on the list. Again, you know, just, just, she was there every step of the way. You know, it was, I never felt like I was alone. I was always part of a team and she was [00:16:00] my partner.

She was the head of the team. They put me on the list and they tell me that I'm going to, you know, expect to wait two to three years. My blood type is O positive. O people wait the longest because we can give to anybody. You know, we can only accept, Oh, ourselves. So I said, okay, you know, I got this thing down.

I'm doing my LVAD. I got my dialysis going. Um, now I'm on the list. I can, I can, I can live with this. Phone rings, Toronto general, Mr. Cook. We think we have a heart for you. Why don't you come on down? I'm like, there's no way this is nine months later when they told me it was going to be two to three years.

I literally sat down on the bed and said, is this call for real? Are you telling me the truth? And they said, I assure you, this call is legitimate. I am telling you the truth. You need to get down here as quickly and safely as possible. And, uh, it was a Saturday and, uh, I hung up the phone and I was kind of like, okay, you know, all cool.

But then I called Monica at work and, [00:17:00] uh, I had to leave a message cause she was in with a client and I'm like with the receptionist, I said, I need to speak to Monica. You know, it's literally a matter of life and death. She's like, okay, I'll take a note. And she slid it under the treatment room. And then a few minutes later, Monica called me back and I was like, just, we just got the call.

I gotta go, you know, I wasn't cool anymore. And then, uh, hung up the phone with her. And, uh, I said, you know, if we'd had like a nanny cam or something, then we could have made a million bucks off of America's funniest home videos. Cause I didn't know what to do by the time we get there. I'm thinking

that we're about to experience a dress rehearsal, which is what they tell you, you know, that you can expect to get the call.

And sometimes we'll call you down and for whatever reason, you're not right for the organ that day. The organ is not right for you. You wind up going home without your new organ. That's what I was expecting. What I wasn't expecting was for everything to go through on the first shot, which it did. [00:18:00] The next thing I remember is waking up in recovery, you know, and I had somebody else's heart in my chest.

And that was my thought was I kind of opened my eyes and looked around and I was like, I'm alive. Thank you, God. You got me through another one. Then I remember thinking I'm alive because I have someone else's heart now. And I've said this so many times. I've never felt so thankful, so humble and so unworthy all at the same time.

And I broke down and I started crying like a baby because I couldn't think of a single thing that I've ever done in my life that made me worthy to receive such a precious gift. Me versus anybody else, you know, that was, I was supposed to be waiting two to three years and I got this in nine months and I couldn't understand why.

And I was like that for weeks, you know, um, just every time I thought ran through my head and I really got to the point where I was, I'm going to need to seek professional help if I can't get, you know, [00:19:00] this under control. And the way that I finally got right with it was I, you know, the wee hours of the morning I was in our bathroom, our en suite and crying again.

And I'm like, man, you know, just. Just try to get ahold of yourself. The thought came to me that, uh, and what I actually did was I wrote an email to a group that I belong to called Life Donation Awareness Association. They were the first people I'd ever talked to about transplant. They found me because they did an article in the local paper about me, you know, living on my LVAD waiting for a heart transplant and several people in the group had gone through the same thing.

They've been LVAD patients and then gone on to receive a transplant. Um, I wrote the email just saying, Hey, have any of you guys ever experienced these feelings? You know, this kind of guilt, this depression, this, you know, uncontrollable crying and that. And I didn't send it because I was talking to myself in the mirror and I just said, [00:20:00] think about the person who donated their heart.

I tried to get into that mindset and to me it had to be an individual who with their final wishes wanted to do something to help somebody else have a chance at a better life. I became the beneficiary of that goodwill, somebody they didn't even know. And to me, that was the ultimate form of paying it forward.

And so at that moment, I said, I'm going to live my life to honor my donor and their family by doing whatever I could to pay it forward for all the patients coming along behind me. And That's it. That's what drives me. Now. I'm trying to pay for not only the gift of my heart, but the gift of my kidney as well.

Two gifts that I've received that I can never pay back that I can only pay forward. And that's what I'm trying to do. That's that drives me with everything that I do now post transplant. And that's why we're sitting here talking about this. I'm going to have you pause there and we'll, uh, [00:21:00] we'll say hello to Dr.

Ross because she has joined us. Hi. Hello.

How is everybody? Good. How are you? I'm good. Thanks. I'm good. I'm wondering Charles, if you want to introduce Dr. Ross. Sure. You know, I've called Dr. Ross the queen of my heart function for years. And, uh, that's the only title that she goes by in my book. She is the boss, Dr. Heather Ross, and in your words, Dr.

Ross, I'm wondering if you could tell us a little bit about yourself. So, my official title is, uh, head of the division of cardiology at the Peter Monk Cardiac Centre, scientific lead for the Ted Rogers Centre for Heart Research at Peter Monk Cardiac Centre, the Loretta Ann Rogers Chair in Heart Function, the Pfizer Chair in Cardiovascular Research, Professor of Medicine, uh, at the University of Toronto.

Amazing. That's fantastic. But at the end, at [00:22:00] the end, uh, that's a, that's a, a mouthful, but what I would say is, uh, I am, uh, a, a woman seeking To partner with patients to enable the best possible care. Uh, that really has been the goal. That's been the journey all along. It's how do we partner with our patients?

How do we better understand the patient journey? How do we understand some of the issues related to disparities and accessing care? How do we actually address, uh, how do we truly understand the patient experience and the, and, and what matters to patients in terms of quality of life. That's amazing to hear

from a patient perspective that that is, you know, at the forefront of everything you do and how did you get to that place?

Does that thought process come from, you know, way back as, as a child or, you know, is this something that's come to you through the years? So [00:23:00] there's no, there's no, uh, docs in my family, uh, the, um, but you know, for whatever reason, I remember very clearly my mom asked me when I was, uh, was a kid, you know, what do you want to do when you grow up?

And I was like, I want to be a doctor. Didn't have a way to explain why just knew it was always what I wanted to do. And then I had a couple of pretty significant experiences. One was when I was an intern and, uh, my grandmother had a heart attack. My patient, my parents were out of town. And my grandmother had a heart attack and I was the, I was the next of kin who was most readily available.

And I remember there we were in the emergency room and she'd had a large heart attack was suffering from acute heart failure. And the doc in the emergency room was sort of, we need to intubate, we need to, uh, we need to do these other treatments. And, and I was my, my grandma, my grandmother doesn't want those done.

Uh, her express goals are not to do [00:24:00] those things and I, I was there and, and, uh, and, and the emerge doc was amazing. Listened. Uh, we got my parents on the phone. My mom was the formal next of kin went through all the appropriate processes and I was able to be there and hold hold my grand mom's hand when, when she died of acute heart failure.

Later in life, my father developed a coronary artery disease and heart failure with preserved ejection fraction. And so I was able to also witness the impact that it has. So, you know, those are 2. Important things that happened, uh, one very early on, probably helped, you know, push to push me towards cardiology.

I was already a cardiologist when my dad started to develop issues. And, and then of course, there was the major moment, uh, on Vincent when, uh, I developed high altitude pulmonary edema, which gave me tremendous insights into what, [00:25:00] uh, patients feel. Um, I had Deal with it for about 20 hours, and I found that overwhelming.

Um, but wow, did it give me insight into how a patient feels day in and day out? And that can go on for days, months, years. That was a true, a true experience. And I think it, it made me realize, uh, again, how important. It is to understand

what the patient experiences and what patient priorities are. And so thinking about that experience that you had at that high altitude, some people who may be listening may not know how, how you would have gotten up there.

Can you tell us a little bit about test your limits and how that came to be? Sure. So, uh, an amazing doc out of the Montreal Heart Institute by the name of Dr. Michelle White. A beautiful patient, uh, has a beautiful patient by the name of Sylvain Bedard that many people [00:26:00] will, will know his name. And, uh, they, they did Mont Blanc in, uh, was 2002.

And I said to Michelle, you bastard, you didn't invite me, you didn't invite me. Uh, what's that? Uh, and so, uh, he, he was planning a trip to Bolivia in 2004 and he invited me. And, you know, the running joke, which is, which, uh, which I always like to say is he said, hey, Heather, how would you like to come down and climb a mountain with 13 guys on Viagra?

Um, and I'm like, what could be better? Uh, and that's, that's because Viagra is used for altitude, but, uh, Bit of a joke there, but, um, and Sylvain was, uh, uh, was the heart recipient on that trip. And that's when I first met Dave Smith again, uh, you know, just really no words to describe how incredible these 2 men are.

Um, and I really enjoyed the experience, but when I [00:27:00] came back, um, I thought, uh, and meeting with somebody who's been a major supporter of the program, I thought, could we do something? Bigger, uh, in terms of, uh, raising awareness and also fundraising, because at the time, uh, the mechanical, uh, heart or left ventricular assist device that, you know, Charles has talked about wasn't funded.

Right so we had to figure out a way to buy those devices to save lives and, uh, this was before it was funded to provincial funding. So philanthropy was how we did it. And so when we thought about the big test your limits trip to Vincent, it was really around raise awareness and raise and raise funds for people with advanced heart failure research or mechanical devices, right?

Like that was really the purview of test your limits. And so, in, in thinking about it was like, well, we got to do something big. We got to grab people's attention. So, uh, going to the Antarctic and [00:28:00] climbing Vincent, which is 1 of the 7 summits or IE, the tallest mountain on its continent, uh, 7 summits, uh, probably will be an attention grabber.

Right? And that's what we did the challenge, of course, is that many of these things are limited by issues related to weather and we were delayed getting started by just over a week. But the back end of the trip was a fixed date. And so all the rest days that you would plan into a climb. Where you climb high sleep low as part of your climatization, all of those days were lost because of, uh, because of bad weather.

So we ended up on the mountain with a 7 day window. And no rest days possible. Uh, and, uh, you know, the key things that lead to risk of altitude is exertion rate of ascent, uh, ability to to acclimatize. And we had, we had none of those. And on the summit day, uh, where we were making the bid for the [00:29:00] summit at about 200 vertical meters, we could see it.

It's in sight. Uh, myself and one of our other climbers, Dr. Pat Murphy, uh, our sats were in the sixties, our O2 sats were in the sixties and it was deemed to be unsafe at that point, Dale was fine. Wow. Uh, speaking to how he is a, uh, just a true team player and understands that it's the journey. And not the destination, he said, we go up as a team, or we go down as a team, we had 2 guys, he could have gone up and summited.

I have no doubt he would have and the 2 docs on the trip that were there for safety. Needed to turn around, but we went down as a team and we got back to the summit camp. And unfortunately, over the course of that night, I got sicker. Normally, what would happen as you descend as you would start to get better.

And Pat did, uh, but I unfortunately got much sicker. And, uh, in the middle of the night, my saturations were in the 40s, [00:30:00] uh, which is a climber emergency and we, uh, we mobilized and Barry and Dale and I climbed down, uh, Dale carried my pack. Yeah. It's it's still a very emotional thing and again, puts you in the perspective of a patient of what it feels like to almost die.

And I, I, uh, I've never forgotten that feeling. I've never forgotten Dale's help getting me down the mountain and, uh, this is. 16 years later, so you can see it still has an impact. Mm hmm. Um. But down the mountain, I got and, uh, recovered I did and, um, and that was the birth of Test Your Limits. And, you know, we, uh, we, we decided to do some, uh, low altitude challenging trips since that time.

So, uh, North Pole, Greenland, we, uh. [00:31:00] Traverse Greenland, uh, skied across Greenland. That was just under 30 days. Um, most recently we cycled the dumpster highway. Uh, we've done nine trips. Uh, we've raised over 3 million towards research. And, uh, some of the early, uh, devices that we were

able to pay for through philanthropy, we were able to make the case to the ministry for funding.

Based on our results, so, uh, you know, in every way and and, uh, on a most personal level, uh, test your limits has been life changing. And I think, uh, yeah, I don't, uh, it's hard, hard to put in words, but, uh, a truly, a truly life changing experience and brought me much, much closer. I think to understanding, um.

That patient journey. Yeah, you can, you know, hear it in your voice and see how, how touching [00:32:00] that, that was for you. And I think for a lot of us transplant recipients. Once we get that new gift of life, we metaphorically feel like we can climb a mountain and some of us obviously to, um, but you know, that, that transition from what it felt like prior to, to the life that we're given after is just, you know, so life changing.

And, and I've talked to a couple of different doctors about. You know, not just treating the disease and treating the person and not having transplant as this end point, but rather having it as, is this the best treatment for the person? And what is our life going to be like after that? I'm thinking about that.

Um, you know, focusing on the quality of life that you've talked about, how do you have those conversations and, and how do you figure out what the best [00:33:00] treatment would be for somebody who is in end stage failure to make sure their quality of life is the best, whether it's an LVAD or a heart transplant or deciding not to.

Have treatment. So the only way I know to have those conversations is openly and honestly. And I, you know, when I, when I speak to trainees, I, I tell them some of my key principles to these discussions are, uh, never be in a rush, take the amount of time that is required. In the moment, uh, don't be hungry don't don't have turn your pager and phone to silent.

Um, you know, there's always somebody else in the chain who can answer, you know, general emergencies, right? Or if you're in a situation where you're covering for emergencies, then that's not the right time to have the conversation, right? If you can help it, because it is really important to take the time that's needed.

Make sure you have [00:34:00] the, the data. As good or as not so good by that, I mean, the quality of the information, not necessarily what it means when you're having the conversation. So make sure you have as many pieces of

information as you can to be able to give your best valued opinion about what the different options will look like.

Because you can't ask somebody to decide if they don't have the information. And sometimes we don't. And if you don't say that, this is the best information that we have on what your life would look like. Um, and what the, what the potential risks are, what, what the information tells us about what the quality.

Of your life will look like, and what your survival will look like. In my experience, different patients put different value. On [00:35:00] quality and quantity, and it is my position. It's not my position. To say, what's right, it's up to the individual patient. And so over my career, I have met patients who've chosen not to.

Have a transplant and and I don't understand I don't understand that position. But it's, it's not my decision to make, um, my, my role is to provide the best information. And then when asked to give my best recommendation based on based on that information, right? That's actually how I see my role. I really do see this as shared decision making.

It is, I, I, you know, I think, I think having a partnership with your patient is important in every aspect. Of medicine, but I think this, there is no better case for where it matters the most. Uh, and we're shared decision making [00:36:00] is just so vital. So, looping back to, you know, those early days of, um, test your limits.

You talked about, um, the research that you were really passionate about getting funded and. Those research interests that you have. I'm sure they've changed over the years. Um, what are some of those things that you're currently interested in with research? So, so we've been really building out, uh, in the digital health space.

And I think it's, uh, you know, technology has always been a big part of advanced heart failure. So it actually, it seems in many ways like a natural evolution. If you think about how much technology has advanced life expectancy and heart failure. And transplantation, right? Uh, through, uh, implantable devices, defibrillators, uh, gotten smaller implantable monitoring devices, patch technology, um, mechanical circulatory support and in all its forms.

And, uh, I think we [00:37:00] become really interested in how we can leverage digital health, uh, to improve. Access to equitable care, recognizing that there

are tremendous inequities and disparities in health care delivery. Despite having universal health care, we clearly identify populations of patients. Who are not getting access to high quality care, whether that be because of where they live or or whether that be because of what they look like.

Uh, so it is there are massive disparities in the communities. So black indigenous and persons of color. Uh, this is well recognized, but. It's been well recognized and nothing's been, you know, I shouldn't say nothing's been done. Many things have been tried, but we, we still haven't seem to have really, uh, changed it as much as we need to.

And we have a lot of work being done [00:38:00] looking at how digital health. Uh, and digital health tools could could improve that 1 of those tools that we've developed to something called medley, which is a remote patient management platform, uh, or program that leverages, uh, rules based expert system, which is a type of artificial intelligence to help manage patients.

And it's now health Canada. It's been for a while health Canada approved as a class 2 medical device. And we've had more than 1500 patients go through the medley program. And we did a look back. We did a look back based on, um, you know, recognize Canadian markers of, of, uh, social determinants. And we're, we're really overjoyed to see that.

Based on, uh, markers of marginalization, we do actually reach communities and [00:39:00] individuals that are in the lowest quintile, uh, on marginalization. respected markers of marginalization within Canada. Amazing. Now that is a way for us to say, Hey, you know, and, and they, and they, they do benefit from Medley. Now the question is how do we more proactively work with communities?

To try to improve access to equitable care. So, uh, we have been working with the Winnebago area health authority, which is an indigenous community along James and Hudson Bay, a number of coastal communities, um, uh, with a. Hospital and moose factory, and we've been working with those communities. Using a community based.

Participatory approach, so what does that mean? That means asking the community if this is important to [00:40:00] them. And if it is important to them, asking the community in a respectful way to partner. To try to develop tools that are relevant to the community, which is gets us back to this idea of. What matters to the individual patient into the community and not.

What does somebody at a ivory tower think is important to that community? So, I think for, you know, there's so much coming technology is so disruptive. What we want to do what we want to make sure is that there's lots of technologies that are commercially available. Uh, right. But what technologies are medically relevant.

And in what circumstance, and in what community and. And if they are relevant, and they do work, how do we make sure that we can have that be a sustainable. Approach, so I [00:41:00] think when I think about, uh, you know, where the future isn't and remember covert, we were going here already. We've been working on medley for a decade.

So we've been doing a lot of work in this space for a while. But when covert happened, the expression that's been used is it pushed us 10 years in 2 weeks. So, and we had to immediately move to a more virtual or digital environment in order to be able to provide care because there just wasn't access having.

Learned many more lessons are accelerated things as we come out of coven. We want to make sure that we. Uh, double down on, uh, on the space and how it can hopefully, hopefully improve, uh, equitable access to high quality care. That's the goal. Charles, I'm going to ask you to unmute for a minute, um, because I know you've done a lot of work with the ACB organ health channel, and I'm [00:42:00] wondering if you have any perspectives from what you've been doing, volunteering with that group and you know, what we've been talking about.

Oh, definitely. Like, uh, Dr. Ross said, there is a large disparity and kind of what I think about all the time is. I've had a great outcome, you know, because I've had great people on my team, including Dr. Ross. Um, but I don't want to be the exception. I want my care to be the story that's told for everyone.

So whatever we can do to equal the playing field. That's what we're doing with ACB organ health. You know, that's why I got involved. So I'm wondering, I'm going to, since you're, since you're back now, I'm going to throw it over to you and see, do you have any questions for Dr. Ross? Oh, before I do a question, can I do a comment first or a couple of comments?

Well, Dr. Well, Dr. Ross, I got to say this, um, two of the most important [00:43:00] things, um, from the day that we met with our relationship and you're. Still the same 10 or 12 years later. And it's been fantastic listening to you talk this morning. Uh, one is that you were real, you know, from the first day that we met, it wasn't like, Hey, Mr.

Cook, you know, patient X, Y, Z number one, two, three, you were your Charles cook, I'm going to learn about you. And I'm going to talk to you as a real person, not as a doctor to a patient. And I always felt that we were a team. Um, the second thing is. You knew how to talk to me as a person. I know that you had probably a hundred patients at the time, but when we were together, it was like, it was just me.

I never felt that you were distracted or you had to run and do something else. So you talking about that, I can vouch for you practicing what you preach. You're not just saying it I'm living proof. I guess as far as questions go, you and I are both, you know, pretty avid football fans. My [00:44:00] team is out of the playoffs.

The Atlanta Falcons are home watching, you know, along with everybody else. How do you think your Ravens are going to do this weekend against Cincinnati without Lamar? So, you know, my, my dad is, is watching he's, he's really angry that the Washington commanders aren't then that would have been his first choice followed by Green Bay.

So, uh, he, you know, he's over. I am. I am totally agnostic to the, to the playoffs. While we're on the topic of football and we have a cardiologist with us, um, you know, from, from your perspective that it just kind of sent shockwaves to a lot of people thinking about this young guy who was hit, went down and had no knowledge of any heart issues prior to that.

Yeah. So I, I, uh, I was actually watching the game and when I saw it, it was immediate to me that it was cardiac in nature and not, uh, [00:45:00] and not a concussion that's he behaved exactly as a cardiac arrest would. So the first question you ask yourself is, did he have structural heart disease and we recognize that there is, there are categories of diseases that.

Increase the likelihood of sudden cardiac death, um, in in sport, which is why there's been more and more statements around screening people who engage in significant, uh, or especially professional athletics. So, you know, as a professional football player with the Buffalo Bills, I'm fairly certain he would have had some screening done, which is pretty, pretty typical.

But the extent of the screening is uncertain, right? And you can screen normal on an ECG and potentially still have some evidence of structural disease. So I'm not advocating that everybody have a cardiac MRI. That's not what I'm saying. But the [00:46:00] first instance, uh, in Damar's case would have been to, will

be, I think, for them to formally evaluate him for underlying structural heart disease.

The next is that there is this extremely rare. Uh, situation that can happen where you get, um, trauma, uh, direct chest trauma at exactly the wrong millisecond of time in the cardiac cycle. And it is, it is, uh, it is completely wild. Uh, should that stop people from engaging in athletic activity? Of course not.

Well, thank you so much, Dr. Ross for joining us today on the podcast. We really appreciate you being here and absolutely everything that you do for, for our patients and, and our community as a whole. Thank you so much. My absolute pleasure. You guys take care. It's great to see you. You too. Keep banging. [00:47:00] We hope you enjoyed this episode of the Living Transplant podcast.

If you did, please leave us a review and share with your friends. Don't forget to subscribe to Living Transplant wherever you are listening today. If you have any ideas for podcast episodes, you can reach out to us at livingorgandonation@uhh.ca or on social at [givelifeuhh](https://www.facebook.com/givelifeuhh). For more information about Living Organ Donation, you can visit us at www.livingorgandonation.ca.

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