

Season 4 Episode 4: Waiting for the Science to Catch Up

Candice Coghlan: [00:00:00] Living Transplant is a podcast that takes you behind the scenes of the transplant program at Toronto General Hospital, with the goal to educate, inspire, and fuel your passion about transplant. I'm your host, Candice Coghlan. Thanks for joining us for Season 4. In this episode, I sat down with Darrell Wallis, who spoke to me about his journey with hollow visceral myopathy, which caused him to grow up being unable to eat and living in and out of hospitals.

I'm He and his family had to wait for the science to catch up for him to have a multi organ transplant, including a liver, bowel, stomach, and pancreas, which gave him his life back. A few years ago, Darryl's son was diagnosed with the same disease and received a multi organ transplant, which was performed by Darryl's surgeon, Dr.

Anand Ganekar. Dr. Ganekar, whose practice focuses on abdominal organ transplantation, joins us to discuss the rarity of multi organ transplants.

[00:01:00] Innovations in organ preservation and stem cells. He speaks about the privilege it is to have the opportunity to restore somebody from certain death to almost a normal life, and the personal connection he has to the success of his patients.

Please enjoy. Welcome back to the Living Transplant Podcast. Today I am very happy to welcome Darryl Wallis to our podcast. Thank you so much for joining me today. Yeah, no problem. It's great to be here. Awesome. So I'm wondering if you can tell our listeners a little bit about yourself.

Darryl Wallis: Um, so I'm 37 years old.

It just turns 37 a couple of weeks ago. About 16 years ago, I had a multi organ transplant consisting of a new liver, bowel, stomach and pancreas. Um, and now I'm living a normal, healthy life. I'm married, two kids, uh, practicing pharmacists and just kind of happy to be here, I guess.

Candice Coghlan: So, uh, you talked a little bit about that transplant.

I'm wondering if you can, uh, bring us back and talk to us a little [00:02:00] bit about your journey with hollow visceral myopathy and, and how you were diagnosed and how this really began.

Darryl Wallis: Around the age of one year old. I was starting to have a few, um, kind of strange symptoms, so I wasn't really gaining weight. I was having a lot of vomiting, diarrhea, um, abdominal distention, bloating.

Not exactly sure what was going on. Um, so I'm from a relatively small town in Ontario called Sarnia, and the doctor here weren't exactly sure what was going on. So they, um, sent us to London where they had a bigger medical center. And there again, they weren't exactly sure what was going on, what was causing the symptoms, and so they sent us to Toronto to SickKids Hospital and similar kind of thing.

They weren't exactly sure what was happening, did lots of testing, lots of different studies as far as, you know, gastrointestinal transit and that type of thing, and essentially diagnosed me [00:03:00] with what you mentioned earlier, which is hollow visceral myopathy, which basically means that My GI tract, including, you know, stomach, bowel, um, all of that did not, A, absorb nutrients properly, and B, didn't move things through at an appropriate speed.

And there wasn't, and still isn't really a cure for that, um, but the solution at the time, and much the same today, was putting me on total parenteral nutrition, or TPN. That's essentially, um, just IV fluids and nutrition to bypass the internal organs and goes directly into the veins. And the plan at that time was, there is no cure for this, the only ultimate solution would be a transplant to replace the stomach and bowel.

And essentially the doctors told my parents, we're just going to try to keep your son Darryl alive long enough so that we can successfully do those [00:04:00] transplants. Because at the time, 36 years ago, they weren't really doing any transplants of that nature. Uh, any attempts ended almost, uh, immediately in either organ rejection or the recipient's passing away.

That's

Candice Coghlan: pretty scary.

Darryl Wallis: Yeah. Um, especially for, you know, my parents, I'm the fourth of four children. So, you know, they had a lot to manage.

Candice Coghlan: How did this affect you growing up, um, with waiting basically on this treatment?

Darryl Wallis: For me, in some ways it was normal. It was kind of all I ever knew was. you know, hospital life, um, admissions to hospital, missing school, you know, not being able to do exactly everything else that the other kids could do.

There were years where I'd spend 20 or 30 days in a row at the hospital, and that happened a number of different times. Um, so as far as, you know, growing up, it definitely had a big [00:05:00] impact on my say normal, you know, school life, work life, social life, those types of things. The biggest impact I think for me specifically was just not being able to eat.

I spent 20 years from the age of one until I was about 20 when I had my transplant, essentially not being able to eat. Um, and of course in our culture, eating and, you know, everything around that is a big social aspect of life. So that was difficult for me. Um, my parents generally did everything they could to make me, you know, not, not deprive me of anything and make sure I was included in, in everything that all of my siblings were.

So, um, they still made me go to school every day. Um, they still made me have a paper route. When we were eating dinner as a family, even if I wasn't physically eating, it was, yeah, you're coming to sit with us. You know, we're all spending time together as a family. Going on vacation was difficult, but they always made sure that that was something that we could still [00:06:00] all do as a family.

When we were camping, for example, that might look like. Hooking an I. V. pole or an I. V. bag up to, you know, a nail in the camper or a screw or, you know, outside at the campfire, just arranging it on a tree branch, like, they were very good at making sure that, um, I had as normal upbringing as possible.

Candice Coghlan: So, at what point.

Through your journey, did transplant come forth as a potential option, this multi organ transplant? It

Darryl Wallis: was always something that was kind of at the back of our mind, something that was going to be needed eventually. The concern with long term TPN is that it tends to cause liver damage, and if that's left too long, it can lead to liver failure.

And ultimately in that, that's what happened in my case, uh, I was when I had my transplant in sort of the end stages of liver [00:07:00] failure. So it was always a balance of trying to delay the transplant as long as possible, while recognizing that, generally speaking, people who are waiting for organs can wait years before those organs become available.

The risk of listing too early. Is that, let's say, when I was 10 years old, the risk of the transplant was much higher than the risk of staying on TPN and those longer term risks, along with that liver failure, you also have risks of, um, IV line infections, um, you know, bacterial infections, generally speaking, um, you know, bleeding is always going to be a risk with the central line.

So it's weighing that balance of not waiting so long that you would die waiting for a transplant. While still waiting long enough that, you know, the transplants were becoming more successful. So I was 19 years old when I got listed on the transplant list. I was at [00:08:00] school at the University of Toronto.

And for me, I was on the transplant list for about a year, little over a year prior to getting the call for the transplant. And at that point, there wasn't much of an option to say, no, we'll wait longer or anything of that nature. It was very much. You know, if it doesn't happen now, the outcomes are,

Candice Coghlan: are not good.

And you mentioned being at university, you are now a pharmacist. Did what you went through, did that influence your career

Darryl Wallis: path? I would say, uh, growing up the way that I did, which was essentially from the time I was a year old until I was 20 years old, I was hooked up to. Um, those IV feeds overnight for 17 to 18 hours a night every night, um, and it wasn't until, you know, maybe a year or two before my transplant where I can actually get a portable IV pump to be able to the house.

Prior to that, it was very much hooked up to the IV pole, [00:09:00] either in the house or in my room for those 16 to 17 hours. Which gave me a lot of time to study and learn, and so I was always very interested in the medical field as well, having spent so much time around nurses, doctors, surgeons, anesthesiologists, pharmacists, all of that, and pharmacy was a pretty good fit for me because it allowed me, you know, a little bit of the social aspect where you get to see the patients on a regular basis.

It allowed a fairly good work life balance where most of the work is left at work, um, and it allowed me to, you know, do something which involves things that I'm good at. So puzzle solving, um, you know, patient interaction, optimizing medication regimens, and then having all of the experience, you know, navigating the healthcare system and being in the hospital and knowing personally what that's like, I feel, um, helps me really connect a little bit better with my patients.[00:10:00]

And, you know, meeting them where they are and helping

them as

Candice Coghlan: well. It gives me, um,

like an immense amount of satisfaction. and that they're really working towards making things better for the person and not just the combination on a paper. Right. Exactly.

Darryl Wallis: That makes a big difference in healthcare. There is sometimes, um, a focus on, you know, the problem or the disease or the specific infection and whatnot.

And sometimes the actual patient, the actual person gets lost in that West to find the answer. Um, so keeping that, that person front and center is always beneficial, both to health outcomes and just, you know, like I said, meeting that person where they are and being able to, to see them as more than just their disease.

Candice Coghlan: [00:11:00] Absolutely. Going back to you're in university, you're studying hard, uh, you get this call and what was that like? How did it feel to be told, Hey, we have these four organs ready for you. It's time. It's time to come.

Darryl Wallis: So the call came really in the middle of the night, about 1 30 AM. It's kind of a difficult emotion to convey, I guess, cause it's everything all at once.

It's, you know, fear, it's apprehension, it's excitement. It's scary, right? To undergo this huge surgery with kind of a, an unknown healing period, be an unknown outcome. Um, but also there's that level of. Like this is what I've been waiting 20 years for this is the moment, you know, so yeah, nervous, nervous excitement I guess would be the easiest way to [00:12:00] describe it.

At that time, I was excited kind of in end stage liver failure very jaundiced extremely fatigued, you know, having trouble physically getting to and from classes so it's, it's something I knew couldn't wait it's something I knew was necessary, but still extremely scary. At that time, there were more successful transplants and most of the patients were having better outcomes and the technology and the knowledge base had come so far, you know, over the previous 20 years that I was confident in the surgeon, confident in the doctors.

Um, but still there's, there's a level of uncertainty there for sure.

Candice Coghlan: Yeah, that's, that's huge is to walk into something preparing yourself for the worst, but definitely hoping for the best and knowing that you're in, you're in good hands and you were in good hands. The, the surgery was as much as you could say a [00:13:00] success.

Darryl Wallis: Yeah. Um, the surgery itself went very well. Um, everything kind of fit in there as it was supposed to be. There were I got some expected complications post surgery. Um, they had to go back in and, you know, repair a few miscellaneous items over the following couple of weeks, I ended up being in the hospital for about two months post surgery, which was a relatively good recovery time.

At that time, I went home. I was readmitted to the hospital about a month later with. Essentially fluid in and around my lungs from a leaky lymphatic duct, I guess, but that kind of resolved on its own with a couple of months of TPN. And then, since then, I've had a relatively complication free period, which is.

We're about 16 years post transplant now, so.

Candice Coghlan: How long after the, the surgery, [00:14:00] did you eventually stop using the TPN? Yeah. So

Darryl Wallis: in the immediate post surgical period, they kept me on TPN for a couple of weeks just to allow the organs to kind of settle and heal. And then they put in a G tube, um, because I hadn't really been eating.

Well, at all previously, um, so it was sort of a stepping stone, so to speak, and I had me as well. Um, so that, uh, TPN to, to G2 feeds transition happened in those first couple of weeks. Um, you start to feed the bowel slowly to make sure that everything is working properly. And then you can kind of ramp up those calories to a full diet.

Um, so I was on YouTube feeds for. Just about a year post transplant had the ostomy reversed about 10 months post transplant, and I was starting to eat a little bit in that kind of 6 to 12 month period eat, you know, normal food, [00:15:00] you know, about a year post transplant. We were at that point where I don't get hungry I didn't get hungry I still don't physically get hungry, but there was no.

I guess physiological reason why I couldn't eat a whole diet by mouth instead of via the G tube. Um, so the decision was made essentially just to kind of take out the G tube and, and hope for the best almost.

Candice Coghlan: And what was that like to start eating food?

Darryl Wallis: Yeah, it was exciting. I can vividly recall, um, you know, a time when I was probably 8 to 10 years old.

It was likely around my birthday. I was likely in the hospital. Uh, and my mom asked me, you know, if you could have anything you wanted, anything at all, what would it be? Uh, and my answer always was just, I want to be able to eat. Like, I didn't want travel. I didn't want, you know, toys. I didn't want stuff. I just wanted to be able to eat.

For me, that was the ultimate goal. That was, that was [00:16:00] normalcy in my eyes was just being able to eat now, you know, post transplant, I was actually able to eat and I was living in Toronto where there were, you know, all of these multitudes of cuisines that I'd never been exposed to, never been able to try.

Uh, it was an exciting time for sure. Um, to be able to eat whatever I wanted, whenever I wanted with. You know, no, no concerns about any food getting stuck in my throat or, or vomiting or feeling unwell or, you know, getting admitted to the hospital for X or Y reason because of something I ate, it was, um, just freedom.

Yeah. Wow. The ability just to, to not be tied down to anything. So after school, you know, when I was younger, there wasn't an option to really, you know, plan to go anywhere or do anything spontaneously. Everything had to be very. Regimented plans, backup plans, you know, emergency supplies, all of that, [00:17:00] where now, you know, if my wife and I want to go away for the weekend or want to take the kids somewhere or want to travel, you know, get in the car and just drive somewhere, that's something that for the most part, we can do.

I'm sure we'll talk more about my son Owen in a little bit. But as far as myself and my wife, the level of freedom is almost yeah. Yeah, it's almost laughable to change between now and previously, like just, just the amount of stuff that I can do if I want to. Freedom is just hard to describe. It's almost like, um, night and day now versus pre transplant.

Like there's, there's almost no way to adequately describe the level of change and like the monumental impact that it's had on my life. From pre transplant to post transplant, I certainly had a good life [00:18:00] pre transplant. I was happy. I was doing the things I like to do, but at that time, it's almost would have been unimaginable to look at what I'm doing now and see that as a possibility.

Candice Coghlan: Yeah, it's hard to Imagine what that was like to not have to have all of those backup plans or to know exactly in a very, very small example for me, knowing when I was on dialysis, knowing where the closest hospital was, or knowing, um. You know, making sure that I had certain things when I, when I left the house now, post transplant, it's, do you have your little pack of pills with you and that's it, right?

Do you throw them in your backpack and off you go? And it's, it's a very small thing for me compared to what, what you've been through. It must feel like. You've had two lives almost like your, your pre transplant life and your post [00:19:00] transplant life. So your wife and you met during your freedom phase, I'll say, and, uh, you guys got married and you have two beautiful children together.

At what point did you notice a change with your son, Owen's health?

Darryl Wallis: Um, probably about a year old. Um, so prior to having our and I had had tons of genetic testing, um, both sort of on a personal curiosity level and Future planning level. Nobody in my family had had anything like this. No uncles, aunts, you know, grandparents, cousins, nothing like this had ever happened in my side of the family or Jamie's.

It was very much like a question mark as to what, what led to it, what caused it, was it genetic? As I said, I went to Mount Sinai, I had some genetic testing [00:20:00] there, as well as at UHM at Toronto General. Thank you. And there, there was no indication that it was genetically transmitted, my specific version at that time and, you know, around the one year mark when Owen was just a baby, he seemed to be having similar symptoms to what my parents had described me.

So, you know, he was a little bit distended, a little bit of vomiting, didn't seem to be eating as much as he could or. Or should have been, uh, weight gain had sort of slowed, um, we saw a few doctors in Sarnia, doctors in London, and they were all sort of like, no, like, it doesn't really look like, you know, what you had, and then just kind of kept going.

Eventually we went to SickKids and at that time was much more distended and much more like my presentation. More genetic [00:21:00] testing, etc. Um, and eventually determined that there was a not not necessarily a new gene but one that's more associated with aortic dissections and aortic kind of Widening, but also in rare cases has been associated with polyvisceral myopathy, and we both share that gene.

So he was diagnosed around a year old, and when he was about two years old, he had an acute septic episode, and he lost his entire small bowel and most of his large bowel as well.

Candice Coghlan: Knowing what you had been through yourself and, you know, going through all of the hospitals and going through that medical world, how did you guys prepare for what was to come for Owen?

Darryl Wallis: I wouldn't say it's, it's something that you can never really prepare for as much as I kind of [00:22:00] knew what it was like, and I maybe I'm a little more optimistic. Generally, it's different when it's Your child, instead of you, I know when I'm in pain or unhappy or doing things that I don't want to do, um, you know, as an adult, I know how hard that is as a child.

It's that much harder. And as Owen's dad, it's, it's one of those things where you can't help them the way you could, if you know, they fall down and they scrape their knee, those kinds of are difficult enough.

Did

Candice Coghlan: he have a very. Similar pathway that you did with treatment wise with, um, feeding and, and surgery.

Darryl Wallis: Similar. So when he had his septic episode at age two, um, at that time, when they took out most of his bowel, they put in an ostomy. and started him on [00:23:00] TPN at that point. Um, so in some ways, you know, similar as far as timelines go, the difference for my case was that I had my entire bowel my whole life until my transplant, and that helped to mitigate some of the liver damage caused by the TPN for him with TPN.

No bowel at all, no opportunity for nutrient absorption outside of the TPN and lacking that, you know, internal organ system. Um, he started showing, you know, signs of liver disease a little bit earlier, uh, because without his central line, you know, he wouldn't be able to maintain hydration. He wouldn't be able to survive longer than a couple of days.

The risk for him, you know, longer term and shorter term were much higher. Uh, he wouldn't have necessarily done better longer term without a transplant. Um, so we made the decision around the age of four [00:24:00] to list him for transplant. Uh, he was at that time and, and even right up until his transplant, he was, you know, healthy, happy, um, running, jumping.

He, he never really stops moving and never really stopped. He adapted extraordinarily well to, you know, having that central line, having the ostomy. Um, you know, hospital visits he doesn't necessarily enjoy, but SickKids Hospital does a great job at making the kids feel comfortable there. Um, so yes, he's had his share of hospital admissions and uncomfortable procedures, but like I said earlier, I am very good at trusting the process, and he's very good at just being a kid, so he doesn't let a lot keep him down, you know, if he has the option to get out of his hospital room and run around like he's going to get out, run around with the IV pole, or he's going to pull out of his life, right?

So he's, uh. Yeah, he's a ball of energy, for sure.

Candice Coghlan: And [00:25:00] then when, when he was listed, how long did it take until he received his transplant?

Darryl Wallis: Uh, so for him as well, it was about a year, a little over a year that he was on the transplant list. He just had his transplant in July of last year. Um, so we're about six months, six, seven months post transplant.

Now, no major setbacks prior to transplant, aside from, like I said, you know, you've got your... Typical hospital admissions, um, you know, line infections were still a concern, you know, not really being able to get the central line wet, and he had the G tube, so had to be a little bit careful at school and sports.

He doesn't let anything keep him down, so he just thinks that he's able to do whatever he wants, whenever he wants, and to some extent, that's it. That's true. And yeah, he's just extremely resilient.

Candice Coghlan: So what was the process like, um, [00:26:00] when you received the call that Owen's organs were there and that it was ready and it was time for his transplant as

Darryl Wallis: well?

A difficult decision because, you know, if we had said no, this This isn't the right time or we think we'll wait like there's no telling what tomorrow would bring or next year it could be five years before we get a call for another option. And with that, with his disease and with the prognosis like there's no telling, you know, next week you could get a line infection and need to transplant that and so regardless for anyone waiting for organs it's never, it's never an easy decision to.

Thank you. When you get that call to say, yes, we're definitely going to do it. There's that apprehension of, you know, are we making the right decision as parents? Are we putting him in a [00:27:00] situation where, you know, he could have a negative outcome, things could go poorly. But I just kind of look back to, to my hospital journey and always trusting the process and trusting the doctors.

Even for me, you know, 16 years ago, the transplants were becoming more and more manageable. We'll say, uh, and over the past 15 years gone so much better. And the 1 thing he did have going for him is he was so healthy. He is so resilient. He is, uh, such a fighter. Like, we were, we weren't necessarily, um, overly concerned about him coming out You know, with a positive outcome, it's just, you're never really sure what's going to happen.

We knew it was the right decision, but it's still hard.

Candice Coghlan: So he went through the process, he had the four organs [00:28:00] transplanted as well, and it was a success as well?

Darryl Wallis: Yes, so, um, he was in the hospital as well for a couple of months post transplant. There was some... You know, setbacks as expected, you know, blood work not looking exactly right and, you know, but as far as his physical recovery, he was, you know, ready to be up and moving within a couple of weeks and day eight, he was up out of bed and, you know, he didn't take long before he was back to his relatively normal, crazy self.

He's back home now. He just had a surgery to have his ostomy reversed, uh, G tube put in, so he's not on TPN anymore. He's starting to eat by mouth a lot

more. He is still getting some G tube feeds as well, but as far as, um, progress, like he's hitting all of the landmarks that he's supposed to be hitting.

He's doing everything he's supposed to [00:29:00] be doing. He's due to go back to school next week. He, yeah, he's great and things like that. So he's, we're trying to, much like you would, you know, a baby just learning to eat, um, trying a little bit, the food, you know, a little bit of different things every day, just so he gets to learn what different tastes and textures and all of that are like,

Candice Coghlan: Wow, it must be a.

And interesting and joyful journey to re experience food again, through, through his eyes as well, that you got to go through that journey of the, the world opened with all of these foods and tastes and, and now that's happening for Owen as well.

Darryl Wallis: It's great to see, um, when he was younger, you know, a year old and two years old when he wasn't really eating, it was, it's harder, right?

Because. [00:30:00] You want as a parent to feel like you're feeding your child and giving them what they need. Um, and he just didn't seem to either want to or be able to really eat any significant amounts of anything. And so now, you know, sitting with him at the table or, you know, packing his lunch for school. And then when he gets home asking him what he liked and what he didn't like it.

It's just fun.

Candice Coghlan: So I'm wondering if you have any advice for families who are going through a process that, you know, they have a child or a sibling or a parent who's living with chronic disease or has to go through this transplant process of what you've learned through your journey and Owen's journey.

Darryl Wallis: For a lot of medical families, us included, day to day, it's just hard. You know, you've got possible appointments, you've got restrictions on what you can [00:31:00] do, where you can go, you know, who you can see gatherings, you know, the pandemic has been difficult for a lot of people. And then, like I said, focusing on those positive moments so did I spend a lot of time in the hospital as a child.

Yes. Does Owen now have a lot of hospital appointments. Yes, but there's, there's people you meet at the hospital where you know you have those

connections with there's. You know, activities that he gets to do only at the hospital, there's volunteers there, there's moments of joy within, you know, that kind of darkness, so to speak, um, and just focusing on that is important because everybody, regardless of whether they live with chronic disease or, you know, have lots of possible admissions and all of that, everybody in life has moments where things are going well and moments where things are not going well.

Um, and just appreciating those times where things are going well, even if [00:32:00] it's, you know, something as simple as us and the kids going for ice cream, like it doesn't need to be a vacation in Hawaii. It doesn't need to be climbing Mount Kilimanjaro. Just, um, taking time to appreciate the simple things in life.

Candice Coghlan: Thank you. Is there anything else that you would like to share with the listeners that you think that we maybe didn't touch on?

Darryl Wallis: Obviously I'd like to promote the idea that organ donation is important, right? Um, you know, and I know, and most of our circle know that, you know, the choice to, to donate your organs, um, is a difficult one, but it's something that can have such a huge impact on the recipient.

Yes, of course. Um, but also their family, their friends, their community, you know, it's the type of thing that, you know, it's one small action, but that can [00:33:00] snowball into. You know, having huge impacts on the world as a whole. Uh, so for me, for example, I've now been a pharmacist for 13 years and, you know, throughout that I've had the opportunity to help hundreds, thousands of people, you know, on their individual health journeys, make them healthier and, and happier for their family and their friends and so every positive experience I've experienced or I've had a part in.

Is solely due to that one organ donor and when you factor in that one organ donor can help eight different individuals, um, the amount of impact that that can have is almost immeasurable, especially for for Owen. Right? Like, I can't imagine what his donors family kind of is going [00:34:00] through and, and has gone through and how difficult of a decision that was to make.

It's, Just so incredibly generous at the most difficult time in most people's lives and family's lives at the end of life. It's there's so much going on and it's such a difficult time and to be able to make that decision to donate those organs and to save lives. Um, I'd like to think brings some level of comfort to those families as well.

It's

Candice Coghlan: so incredibly important and so many Canadians. agree with organ donation and agree with being organ donors, but they haven't registered their consent or talk to their families. So it's so important for people to hear journeys like yours and Owen's as well to see the actual impact of [00:35:00] what organ donation can do.

Because like you said, who knows how many lives have been touched because That donor decided to donate their organs to you. I might throw you under the bus here, Darryl. Why don't you introduce Dr. Ganekar because, uh, you have a connection. This

Darryl Wallis: is Dr. Ganekar. He did Owen's transplant surgery in July of last year, uh, and then conveniently he was also involved in my transplant, which was 16 years ago.

Candice Coghlan: Welcome Dr. Ganekar. Dr. Ganekar is also the associate professor of surgery at the University of Toronto and multi organ transplant program at the University Health Network. Thank you so much for joining us today. It's a

Dr. Anand Ghanekar: pleasure to be here. Again, thanks for the invitation.

Candice Coghlan: So I'm wondering if you could tell our listeners a little bit about

Dr. Anand Ghanekar: yourself.

I'm an abdominal transplant surgeon. Uh, my, my practice is mainly focused in, uh, abdominal organ transplantation, mainly liver [00:36:00] transplantation and kidney transplantation. I spend quite a bit of my time. Um, I do a lot of, uh, doing living donor operations, meaning, uh, procuring kidneys and parts of the liver from from people who are willing to donate to somebody else.

And I also do pediatric transplantation, mainly liver transplantation and much less commonly, uh, intestinal transplantation, which is. Uh, how I was involved in, in, uh, Darryl's, uh, uh, case and, uh, Owen's operation more recently.

Candice Coghlan: So I'm wondering, you talked about your, a couple different journeys you've been on as a surgeon.

What led you to become a surgeon and specifically in transplant?

Dr. Anand Ghanekar: Obviously we spend, uh, quite a long time training in medicine and, uh, uh, we see lots of different [00:37:00] I have lots of different experiences. Um, although I enjoyed many things in medicine, I think, uh, surgical specialties offer us an opportunity to combine both medical knowledge as well as technical skills.

And so that, that's what led me to, into surgery. And then once in surgery, I think I was, became excited. about, uh, transplantation because it's quite unlike any other discipline. Uh, often patients with organ failure are some of the sickest and most complex patients that, that we have in a hospital. And, uh, transplant surgery gives, it really provides, uh, quite a challenge in terms of trying to help people.

Um, Get better by, by bringing both quite cutting edge medical care, but [00:38:00] also very demanding, technically complex procedures, then, uh, you know, we have the opportunity to restore somebody from certain death to almost a normal. Life. And, uh, that's very special. It's a, really a privilege also. It's, it's probably the only field in medicine where we deal in nowadays with such a precious resource.

And that is, uh, In the form of donated organs, whether they're from a deceased owner or a living donor, there's no replacement for that.

Candice Coghlan: Darryl and I talked about this, you know, for, for us recipients, you're, you're right. We, we go into that surgery. On, on the verge of death for some of us and within mere months, we're given this incredible new lease on life.

And, you know, Darryl talked about his, his freedom that really, you know, that organ donation provides us. The ability to have these [00:39:00] incredible new experiences and, and live life and as a healthy person and it's remarkable that, that, that journey for, for surgeons happens in within a few hours and it completely changes our lives.

It's amazing.

Dr. Anand Ghanekar: Well, you know, even though we do these operations all the time, I mean, I, I still find it pretty incredible, you know, and have to pinch myself, uh, you know, when a kidney comes to life and, and starts making urine and, uh, or, you know, a liver starts producing vial and the. You know, all the,

or, or the intestines, you know, when we restore the blood flow and they start, uh, peristalsing and, uh, you know, doing their thing, you know, it's, it's, it's pretty amazing to see and, uh, all of our predecessors have discovered or made, made so many advances to make this, uh, possible the way, the way that we're able to do it today.[00:40:00]

Candice Coghlan: So I am a single organ recipient. I have a kidney transplant and, uh, I'm wondering if you can discuss the aspects of surgery and care for multi organ recipients, because I, I know the logistics behind doing a multi organ transplant must be. Multiple teams and a lot of organization and I was wondering if you could talk about what that's like to be part of a transplant with multi organs.

Dr. Anand Ghanekar: Rarely, we've had, uh, situations where we will retrieve. A living donor kidney and a living and part of the liver from a separate living donor on the same day and implant both of those in a single recipient. They're not as complex as the kind of multi organ transplant that Darryl and Owen received. And the reason for that is that what they had is multiple organs.

from a [00:41:00] single donor, but they were all transplanted together. So as a single, what we call a cluster. So we didn't transplant the organs all in, like we didn't have four different organs, uh, separated and then put them all in separately. And that's something that's quite unusual, um, because there are not that many people that require simultaneous transplantation of all of those.

abdominal organs. What makes this, uh, uh, complex is a number of things. Often patients who require this type of transplant have had quite a lot of surgery before because the conditions that necessitate this often, often have required them to have multiple abdominal operations before and that can make doing the transplant surgery quite difficult.

The other issue is that patients who need this type of transplant often wait for a long time. Because there aren't [00:42:00] many donors, deceased donors, where all of these organs are in perfect condition at the same time, and where we can, you know, things are optimized so that we can actually achieve this type of transplant in a relatively short period of time, because the intestine is relatively sensitive to disease.

Thank you. What we call the cold ischemia time or the time between when it's removed from the donor and when the blood flow is reestablished in the recipient. So if there's a donor, for example, in Vancouver, uh, you know, just

the time involved. Would, would make it difficult to achieve that in, in a, you know, and get a good result.

So often we have to have a donor that's relatively close by and, and then again, in perfect, you know, where the organs are in perfect condition.

Candice Coghlan: I have a couple of questions for you about, about your research as well, but I'm wondering [00:43:00] Darryl, if you have any questions, uh, while we're chatting about the surgery and that kind of process.

Darryl Wallis: One thing, um, I guess that my question is, you know, do you as a surgeon feel like you have enough follow up with your patients in, I guess, a personal level?

Because I know, um, you're there and you're doing the surgery and you get to see those organs. Start. Um, I know with you and I, it's kind of special because you were involved in my surgery. And so now you're able to see me 16 years later, but more so in the context of Owen. So, outside of that, um, do you, you know, do you follow up or do you not not spy on your patients?

But, um, do you get to Yeah. Do you get to know about your, your patient's outcomes

Dr. Anand Ghanekar: from their surgery? That's a great question. Um, I always [00:44:00] joke with patients that they, uh, that the less they have to see of their surgeon, the better. It means they're, you know, it means they're doing really well. You know, we keep very close track of how people are doing when they're in the hospital.

Obviously most surgical problems that are going to arise, uh, arise early, you know, after in transplant surgery anyway. The, you know, the kind of major surgical problems if they're going to happen, happen within the first few weeks of a transplant. Uh, and so we are quite attentive and, uh, keeping a close eye on things during that time.

I do actually. Keep track of, you know, uh, who I actually in my records have a list of everybody I've done surgery on. And, and that's part of a, also just kind of an internal quality control as well. You may have noticed surgeons take [00:45:00] things very, take things very personally. Uh, you know, if something doesn't go well, it's, it's our handiwork that, you know, was involved there and, uh, it's not like prescribing a medication.

where the medication needs to do the work or, or, you know, it's, it's a very personal connection we have with our patients. And so we do get pretty invested in, in how things go after the surgery. That's part of the part of what I think is different in surgery compared to what some of the other types of medical specialties is a very deep and personal connection with.

With patients, once you've operated on them.

Candice Coghlan: Yeah. Yeah. Your, your actual hands have been part of what makes us better and what has healed us. And that's a very personal connection to have used your, your hands [00:46:00] to have done something for us like that. So. You know, there, there's a lot of incredible innovation that has come out of SickKids and UHN.

And I'm, I'm wondering in, in your field, if you can talk a little bit about that technology or, or any of that innovation, because as Darryl said, you know, when, when he was diagnosed, it was kind of a wait until the technology catches up to. Have, have his transplants. Are there things that are going on right now at UHN that you're really excited about in, in that regard?

Dr. Anand Ghanekar: I think the way you could look at it as things that might come bear fruit in the short term, and then there's things that are a bit, say maybe five to 10 years off and then things that might be. Decades in the future to give you an example. Uh, that's relevant for Darryl. Uh, and Owen, you know, [00:47:00] years ago, the TPN, the intravenous feeding, uh, that patients with intestinal failure would receive was quite different than it is now.

And, uh, you know, it was just tiny changes over time, new formulations. And what we've seen is, is that the, that many of the old ways of delivering this were very hard on the liver. And so many patients with intestinal failure would eventually develop liver failure. And, and that was the main reason that they required multiple organ transplants.

It wasn't because the liver failed by itself. It was because the liver failed as a result of the TPN. These days, it's very rare for us to see liver failure in patients who have intestinal failure because there's been so many advances, small advances over time in formulating these TPN solutions so that they're not as hard on the liver.

So these days, [00:48:00] We're doing far fewer multivisceral transplants because of TPN related liver failure. I'd say in the next five years, there, there will likely be some major improvements in the way we're able to preserve

organs, uh, donated organs. So some new approaches that are being developed that are already being used in Europe, for example, which, which will likely be implemented in, in Canada and, and, and in North America.

Thank you. Which will, should actually expand the availability or the ability to use some types of particularly livers and potentially kidneys that we currently don't use. And that, that may be a big, big step forward in terms of increasing the pool of organs available for, for transplant. I'd say in the kind of longer term, there's really a big push these days in cell therapy.

So, uh, [00:49:00] uh, the idea of. Of growing cells, uh, outside of the body, you know, in a tissue culture, uh, that could be then infused into somebody to correct the pancreatic function. So for diabetes, for example, or liver function with hepatocytes. It's now, but there's starting to potentially be some real clinical application of this, uh, which might be on the horizon in the next decade.

I'd say. And then beyond that, I think this idea of bioengineering organs is there, and that's kind of the next step after the cell therapies, that if you can grow the cells, well, maybe you can put them into some sort of 3D printed scaffold or something like that, and then actually have a functioning organ.

So, I think those are kind of the pie in the sky things, but [00:50:00] there are some. Some, some concrete steps being made in those directions, which are very exciting.

Candice Coghlan: That's a good answer that we wanted to hear.

Dr. Anand Ghanekar: It makes it all worth it. I can say it's, it's, uh, you know, just to see Darryl and see everything that. That he's accomplished, um, you know, it's really inspiring.

Candice Coghlan: Well, thank you so much, Dr. Ganekar for being on our episode today. We're so grateful for your time and everything that you do and everything that your team does, uh, we wouldn't be here today without, without you.

So thank you so much for being part of our life and being part of our, our episode today. Thanks very much. It's

Dr. Anand Ghanekar: a real

Candice Coghlan: pleasure. And thank you so much, Darryl, for joining and talking about your journey and also Owen's and being so open and vulnerable with us today. We're very grateful for everything that you've shared and all of your [00:51:00] incredible advocacy work with Increasing awareness about organ donation.

And we'll say it again. If you haven't registered your consent, please go to be a donor dot C. A. And you can always reach out to us as well. If you have any questions or or fears about that process, because there's a lot of us who, uh, who would be very happy and excited to talk to you about that. So thank you so much, Darryl.

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