

Courage My Friends Podcast Series IV – Episode 4
Asking For a Friend...For All Our Friends:
Living Organ Donations, A Gift Beyond Words

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ANNOUNCER: You're listening to *Needs No Introduction*.

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COURAGE MY FRIENDS ANNOUNCER: COVID. Capitalism. Climate. Three storms have converged and we're all caught in the vortex.

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STREET VOICE 1 Everything is more expensive. I don't know if it's because of the climate crisis or all of this conflict but I have kids and I need to believe their future is going to be better and brighter.

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COURAGE MY FRIENDS ANNOUNCER: What brought us to this point? Can we go back to normal? Do we even want to?

Welcome back to this special podcast series by rabble.ca and the Tommy Douglas Institute (at George Brown College) and with the support of the Douglas-Coldwell-Layton Foundation. In the words of the great Tommy Douglas...

VOICE 4: Courage my friends; 'tis not too late to build a better world.

COURAGE MY FRIENDS ANNOUNCER: This is the *Courage My Friends* podcast.

RESH: What is a living organ donation? How can one put into words the enormity of giving a part of yourself to save the life of another? And how can you become a living organ donor for a friend or even for a friend you may never meet?

Welcome to *The Courage My Friends* podcast. I'm your host, Resh Budhu.

In our fourth episode *Asking For a Friend...For All Our Friends: Living Organ Donations, A Gift Beyond Words*, we discuss the need, the meaning, and the stunning success rate of living organ donations.

This special episode takes its inspiration from friend and guest, William Woolrich as he begins his search for a living kidney donor. William and Education and Outreach Coordinator for the University Health Network Ajmera Transplant Center, Candice

Coghlan, discuss the search for and ultimate gift of life through living organ donations.

William and Candice, welcome. Thanks so much for joining us.

WILLIAM: Thank you for having me.

CANDICE: Thank you for having me as well.

RESH: Lovely. And William, I want to start with you. So tell us about yourself.

WILLIAM: Well, I grew up in Toronto. I was born in India, but grew up in Toronto. We moved around a lot all over the city.

I studied at York University. Did my BSW at York University, and then my Masters at York, and then my Doctorate in Education.

I wasn't a particularly successful student at the beginning. In fact, I'm a high school dropout. But I went to university as a mature student and managed to make a career out of that from there. I'm a faculty member at George Brown College in the Social Service Worker program. And I also teach part-time at York University in the Social Work Program there.

RESH: You were also in Community Work, as well at George Brown College,

WILLIAM: Absolutely.

RESH: And Candice, you work with the University Health Network, Ajmera Transplant Center. So could you tell us about your work and a bit about yourself?

CANDICE: Absolutely. So like you said, I work for the Center for Living Organ Donation at UHN's Ajmera Transplant Center. And I am an Education and Outreach Coordinator for the Living Program. So I work with potential kidney and liver recipients. I work with living donors who are looking to donate either a portion of their liver or a kidney to someone else.

I work with caregivers. And then both of our amazing teams, our liver and our kidney teams, at the Ajmera Transplant Center.

And I provide education through the journey. So pre-transplant during those workups, and then post-transplant as well for people as they're going through this.

We'll talk about it later, but I have personal experience with this as well. So I know how difficult and emotional this journey can be for people. And so we're really here to help people find resources and information about their pathways.

I am a life-long learner. I love reading and gardening. I have a two year old beautiful little girl who keeps me very busy and an amazing husband. And we also have a three pound chihuahua who hopefully you won't hear today at all because we all work from home now.

But yeah, work in this space. I've been volunteering with kidney patients and with nonprofits now since back in 2008.

And I really love the work and I love the people that I work with. They're one of a kind and truly unique.

RESH: And the Ajmera Transplant Center, is that Canada's largest transplant program?

CANDICE: Yes, it is. It's Canada's largest transplant program and it's one of the largest in the world as well.

RESH: And you are also, I have to say a fellow podcaster. You have a podcast.

CANDICE: Yes, I do. So I am the host of the *Living Transplant* podcast that we host. All about the behind the scenes at Toronto General. So not just about living organ donation, but all types of organ donation.

RESH: Right. Now, just to add a bit of context here. This episode comes from a bit more of a personal place than perhaps some of our other episodes.

William, you are also a friend. And you are a colleague from George Brown College where we both teach. And you are very much the inspiration for this episode; because a couple of weeks ago you sent out an email to your colleagues about your current health situation. Would you mind telling us about what's happening with you? You know, some of what you were telling us in that email?

WILLIAM: Absolutely. I've had, kidney disease since I was a teenager, due to autoimmune disorder. Initially it was diagnosed as Lupus and more recently I've gotten a diagnosis of Anti Phospho Lipid Antibody Syndrome. That's kind of a... kind of a mouthful to say. But both of them are auto-immune disorders. You know, I've been stable for many, many years, but this past fall, my kidneys really started to deteriorate significantly. And as a result, I went on a whole host of medications, some of which had incredibly serious side effects, very debilitating side effects.

And more recently I was hospitalized. I was at UHN in fact, for about a month.

And I was told that my kidneys had almost failed. They were you know, just limping along on the bare minimum. And I should think about the possibility of a transplant. And transplant waiting-lists for people who get a kidney from a deceased donor are extremely long. It's much, much shorter if one can find a living donor. And one way to

find a living donor is to really put the word out and ask people to consider a living donation.

Most people are born with two kidneys and you can get by just fine with one. And so really just sort of spreading the word that you are looking for a kidney is helpful in terms of finding that living donor.

And so I did put out an email. I have to say it was a little bit awkward, because I don't know... disclosing your personal health information to people, even among friends and colleagues, I find it personally difficult, but I thought it was also important to do so. And so that was what precipitated that email.

RESH: I mean, I would imagine there are so many soul-searching and difficult moments that you've been going through. You said it was just this fall that you got that news. Was this something you were prepared for? Not prepared for?

WILLIAM: I was surprisingly unprepared, I would have to say. Even though I've had kidney disease for a long time. It had been stable for so long, I'd kind of taken it for granted that it would stay stable. So I wasn't particularly prepared for it either personally, emotionally, or in other ways as well.

So I unfortunately had to go on long-term disability for the moment. And that you know, has an emotional as well as financial ramifications.

I've started peritoneal dialysis. And I've started getting training to do that from home. And it means whole lifestyle changes. It means diet changes. It means thinking about your future, thinking about the vision that you had for as you grow older and really changing that up. So it's been quite a roller-coaster ride.

RESH: Right. Could you speak a bit more to what dialysis is?

WILLIAM: Sure. Dialysis is an artificial means of trying to fulfill the functions of what your kidneys did. So cleaning out the toxins from your blood. There's two main forms of dialysis, hemodialysis and peritoneal dialysis. And peritoneal dialysis is done through a tube that's been installed in my stomach. And fluid is pumped into your body and that fluid removes some of the toxins and then that fluid is pumped back out of your body.

So that is mostly done... at UHN, at least it's done mostly at home. You get training for it, and I've been doing the training. And then you have to do it from home. And there's a whole thing.

You have to look out for infection. You have to keep track of huge amounts of supplies. It's kind of a big deal.

RESH: Yeah. Yeah. And as you said, that's part of the big lifestyle change that you've had to make.

Now, Candice, William talked about living donors being the better option. Why is that the better option? And why is there so much of a longer wait time for deceased donors?

CANDICE: So as William said, you do have to wait. Because there are so many people right now in Ontario and across the world who are waiting for organs, the need outweighs the supply right now. And so on average in Ontario, people are waiting two to six years depending on their blood type. If they're O blood type, they can only receive organs from O. So that group of people are waiting the longest. And there is a large wait-list. There are on average 900 to 1200 people who are waiting for an organ in Ontario.

And that takes a long time for one to become available that is compatible with you.

Whereas with living donors, they can step forward, they can go through a work-up process. In UHN, the average is three to six months that our goal is to have those living donors worked up.

And you can plan your surgery.

When you're getting a deceased donor, you're waiting for that call. You don't know if you're going to be healthy enough at the time to receive that call. You don't know where you're going to be when that call comes in if you're able to make it. But with living donors, they go through this very, very in-depth process to see if they're healthy enough to either donate a kidney or part of their liver.

And that generally takes under a year. So, you know, you're waiting sometimes a sixth of the time to get that life-saving organ. And we know that it's very difficult on the body to do dialysis.

I did dialysis for about 15 months. It can be very difficult. It's hard on the body to do these. There's other things that can happen while we're waiting.

On average someone dies every two days waiting for an organ.

And, you know, living donors are these remarkable angels on earth who step forward to go through this for us, and they're able to save people's lives by donating these. And it's filling this gap. That there is such a major massive need in Ontario and in Canada for organ donors.

RESH: Absolutely. And those are quite some numbers, and yet not impossible because we can totally end the wait-list. Right?

CANDICE: Absolutely.

RESH: But also is there an issue with people... I mean today we're talking about living donors, but in terms of deceased donors, is there also an issue with people maybe not consenting or people forgetting to, or just not checking off the box on their driver's license renewal something like that? Is that also part of it?

CANDICE: That's huge. So over 90% of Canadians agree with organ donation and they think it's an incredible thing. Unfortunately, in Ontario, only about 35% of potential registered donors have registered their consent. So, that puts a big question mark on it.

If people are going through this awful time in their lives when they have to make a decision like that about their loved ones, not knowing if they wanted to be a donor or not, that's a really difficult thing for your family to have to face.

But if you register your consent, if you talk to your family about your wishes, They know then when that time comes, what you wanted. And it's much easier to make that decision when they know, beforehand than to have to make that decision in one of the hardest moments of their lives.

RESH: Yeah, absolutely. Now William, so you are now on the living donor wait list, correct?

WILLIAM: Not yet. I have to get worked up myself. And so we're starting the process right now.

CANDICE: There's no living donor wait list. There is a deceased donor wait list. And then he would get worked up for that. And then you would have to find your own living donor. So there's actually no living donor wait list.

RESH: Oh, interesting. Okay. Thank you for that.

So William, who could be a donor for you? I know you're being worked up, but right now, do you know of any specific criteria?

WILLIAM: I'm not sure. I think the blood type has to match. But other than that, as Candace was saying, there's a whole medical work-up that has to be done both on me and the potential donor before they decide whether or not there's a match. And there's a long list of questions that have to be answered: Do they have a past history of kidney disease, for example. That might be an exclusionary criteria.

There's a lot of medical questions and a lot of time and effort that goes into determining whether or not someone's a match.

RESH: And Candace, do you want to come in on this? Does the person necessarily have to be a relative? Does there have to be an exact blood type match or compatibility at least? Could you speak more to that?

CANDICE: That's a great question. A lot of people think that they have to be a blood relative, and actually we see so often that they are not.

So living donors can be anyone. They can be relatives, of course. They can be friends, acquaintances. Many people find their living donors by making appeals - similar to yourself, William - by posting on social media. You never know who your donor is gonna be. And we see that more and more, that sometimes a colleague or you know, a university friend from 15 years ago, steps forward.

You have to start with a Health History Form. So that is the first step that if someone wants to become a living donor, they fill out a form on our UHN website that goes through their health history and their medical information.

They have to have proof of their blood type, so they can get that either if they're a blood donor, they would have a card or they could get that from their family doctor. And then they would go through that list and then they would submit that. And that's the first step to seeing if somebody could be a donor.

Generally, if they're a healthy person, if they look like a good candidate, the living donor team would then reach out to them and have a phone call all about the process and discuss some of that health history information in depth.

Some of the things that would make someone not a good candidate would be, like William said, if they have kidney disease, if they have a history in their family. Diabetes is often a question as well, because that's one of the leading causes of kidney disease.

So they'll go through all of those things with the potential donor. And then they will go through a very extensive work-up process, including blood work, urinalysis, as well as different type of medical imaging as well.

So, even if all of that blood work and everything looks good, they're also gonna wanna check out those kidneys. So to do an ultrasound and see what those kidneys look like, if they're good for transplant. And then they'll go through things like stress tests.

And really the whole process is to make sure that this person who is stepping forward to do this incredible thing is going to be healthy enough to do that. Because we want to make sure that the donor is going to be able to live a very healthy, really unchanged life from donating this organ.

RESH: So speaking of blood type, William, what is your blood type?

WILLIAM: So my blood type is O positive. Unfortunately as Candice mentioned, that's the longest wait list group. But even if someone who's listening is considering organ donation, even if you're not O positive, I invite and encourage you to consider organ donation anyway. There is a paired matching program where

person A donates to person B who we don't know, and person B donates to person C. So that there's a kind of a round robin of kidney donations.

So even if you don't match my blood type, you might match someone else's and then someone else can donate to me.

RESH: Right Now until Williams message and of course preparation for this interview, I have to admit that to a great deal of ignorance on all of this. And still this is very much learning for me as well. And I'm sure it is for many of our listeners and for many people, until it actually comes home.

And I've been listening to your podcast, Candice, the Living Transplant Podcast.

CANDICE: Thank you.

RESH: And I have to say... well, I have to say, if you're looking to not only have a deep and really comprehensive understanding of the transplant process, but also if you want to reinvigorate your faith in humanity, listen to that podcast. It is...

CANDICE: Oh, I agree.

RESH: It is so real and it is so very beautiful.

CANDICE: Thank you.

RESH: So, Candice, you, you hear these stories all the time, but could you please speak to the meaning of this act of living organ donation, for those on both the giving and the receiving end.

CANDICE: It's pretty hard to put into words. But people who step forward to be living donors are saving our lives.

As recipients we are doing everything that we can to stay alive and to stay healthy while we're waiting for this incredible gift of life. And dialysis, yes, it gives us extra time while we're waiting. It is life support, but it is not a good way to live.

It's really hard on our bodies. It's hard emotionally. Many of us take off work because it is such a toll that is taking on our body.

I was a crash start on to dialysis when I was 24. And you know, you just don't expect that to be your life. So while you're waiting, it can be the worst, darkest, hardest days of your life. And to have somebody step forward and say, Why not me? I'm gonna try, I want this person in my life.

Or I have this organ and I can live a very healthy life without it. I'm gonna donate.

It's almost impossible to put into words what it means to us.

In the simplest terms, I guess it means life and freedom and an opportunity to have a second chance.

RESH: William, I wonder if you could come in on this as well. What does that act of giving mean to you?

WILLIAM: Well, it's hard to put into words Resh. I think Candice said it beautifully. It's a gift beyond words. As Candice said, the dialysis takes a tremendous toll on you in a number of different ways.

And to have someone donate something, part of themselves, that would allow you an opportunity to really have a life that's much more in keeping with the life that many people envision. It's really hard to put into words.

And to go back to what you were saying earlier, Resh, about still learning. I feel like I'm still learning too. I'm learning new things every day as I go through this process. You know, it can be quite intimidating and frightening at times.

It's a process that I'm still going through.

And I have to say, since we're talking about it, I've had some support too from the Kidney Foundation in terms of talking with peers and people who, like Candice, have been through this, that's been tremendously supportive as well. And just hearing about their journey.

They have a family support network where they're able to provide emotional support through families who have been through that sort of experience.

RESH: So it's a very comprehensive support network.

WILLIAM: Absolutely. That's where I found my peer support. They reached out while I was an in-patient in the hospital to find out what they can do. They hooked me up with someone who had been through dialysis and received a kidney transplant, we had a long conversation on the phone. He was able to reassure me and tell me what life was like and that it wasn't all bad and that he was able to find enjoyment and he was able to go camping while on dialysis and all these things I didn't even know were possible. So that was huge.

RESH: It sounds like you're part of a new community.

WILLIAM: Yeah, I'm still new at this, so I'm not sure if I'm a full-fledged member of the community yet. But, absolutely. It means a lot to hear about people who have been through this and have managed even on dialysis, even before a transplant,

have managed to work through this and are having a fulfilling life even as they move toward the goal of a transplant.

When you're on dialysis, things can seem very dark. And hearing about people who still find enjoyment in life is incredibly meaningful.

RESH: Absolutely. And Candice, you are a full-fledged member of this. You've been through this process. Again, you really understand this because you've been on this journey yourself,

CANDICE: For sure. So when I was 24, back in 2008, I was diagnosed with kidney disease and kidney failure out of the blue. So, I do have a rare gene deletion that was unknown my entire life and it caused my kidneys to slowly fail.

We thought I just had a really bad flu and did some blood work.

WILLIAM: Right.

CANDICE: And in the evening, very early I was called by the lab and they told my parents, you know, make sure that she's okay. Go wake her up and bring her to emergency right away.

RESH: Wow.

CANDICE: And so it was a whirlwind and I started dialysis. Within 24 hours I was on hemodialysis. I did that in center for about five months.

And so hemodialysis is the other kind of dialysis, which takes your blood out of your body and cleans it in a machine and then puts it back. And it also takes fluid off of your body as well. That's one of the symptoms of having kidney disease, is our bodies aren't able to process that. And so I did that for about four and a half hours, three times a week, in hospital.

And that really wasn't conducive with the lifestyle that I wanted to have at that age. So I went home to do peritoneal dialysis, similar to what William is training right now. And, my, at the time, three-year-old nephew used to tell people that it was like a dishwasher for my organs. So the water would come in and it would wash them for me, and then when I would wake up in the morning, I would do it at night. You know, I would have clean, clean dishes or clean organs to go away for the rest of the day.

So, I did that for about 15 months, and through that time my mom was being worked up to see if she could be my potential donor. And we were very lucky that on September 9th, 2009, she donated her kidney to me. And since then, I have had a very remarkable life, I'll say. I've volunteered in this transplant community. I've worked in the transplant community, in a couple different roles.

You know, it's not a community that you wish somebody could be a part of. But once you're in it, it's a community that you're very grateful to be part of. Because it's a lot of very brave, compassionate people who have been through this and they want to help you through it.

So anyone who is listening, who is feeling alone or feeling like they need connection, like William said, there's places like the Kidney Foundation, which has incredible support groups.

There's a program called the Transplant Ambassador Program that I used to work with, who connects people with people who have had transplants and people who have given.

So there are a lot of networks out there as well as online. There's the Canadian Transplant Association, you know, many, many places.

I can send you links. You can always put them into the description as well for people to reach out to.

RESH: And we will be doing that. So we will put all of those links in the show notes for this episode.

William, where you've talked about how things can certainly get dark at times like this. Where do you find comfort? Where do you find joy?

WILLIAM: Well, I've been doing a lot more reading. Reading was difficult for a while there. There's a surprising relationship between your kidneys and other organs, like your heart and your brain.

And so one of the things that got affected was my concentration. So even a two hour movie was too much for me for a while. But since I've gone on dialysis, my concentration has improved and I can enjoy reading again, as well as, you know, watching movies. And I really enjoy spending time with friends.

My drinking is fairly limited these days for

RESH: I can imagine. Yeah.

WILLIAM: For obvious reasons. But spending time with friends. I enjoy nature, so going for walks in the park, whenever I can. I'm looking forward to spending a little bit of time if I can, doing day trips out of the city. You know, because I'm kind of relearning a little bit my energy to walk, I've had a lot of muscle wasting and atrophy because of my illness since the Fall. And so walking became extremely difficult and I was using a cane for a little while.

But since the dialysis I'm hoping to get even better and doing some physiotherapy as well, I'll be able to walk for longer distances and enjoy being out on trails and with my wife and with my kids and with friends and colleagues.

So yeah, those are the kinds of things that I've enjoyed in the past, and I'm looking forward to enjoying them in the future.

RESH: We have the weather for it. So

WILLIAM: Finally!

RESH: Finally! The timing is great for all of this.

WILLIAM: Exactly. And we have earned that nice weather.

RESH: Absolutely. Absolutely.

Your kidney Candice came from your mom. And from what family and friend donors have said on your podcast. Many of them they said, well, there was no choice. This is a necessary act of love.

CANDICE: Yes.

RESH: What about for people who do not know the person in need of the transplant. Because it seems like there's a different type of love that's there. And I wonder if you could speak to that.

CANDICE: Yes. We have a very large community of anonymous, non-directed donors. So these are people who have no connection to the recipient at all. They don't know them, but they decide to step forward out of the goodness of their heart, and they donate either a portion of their liver or a kidney to anyone who is in need, who would be a compatible match to them.

There's a couple ways that they do it. For kidneys also, they can donate into the Paired Exchange Program. And this is a program that happens through the Canadian Blood Services; where if someone has a donor who is a healthy, great candidate, but they're not compatible with their recipient, they can go into this "chain" we call it, and they can swap kidneys.

So non-compatible matches can go in and there's an algorithm that happens about three times a year that matches people across the country with donors. And so these anonymous donors can also donate into that pool. Which means not only is someone getting a kidney, but it's taking someone off that wait-list as well.

And so these anonymous donors, when we talk to them, many of them say, "Why not? You know, I'm healthy, I'm able to give, I didn't know about this. I didn't know it

was a possibility that I could do this before. But now that I know that I can, I want to do this." And what greater gift can someone give than the gift of life and, and the gift of opportunity?

And many of these anonymous donors are the most humble people you will ever meet. And very understated about what they've done. And actually we have several donors from our program who are double anonymous donors, so have donated a kidney and a portion of their liver to somebody they'll never meet potentially.

RESH: Wow. And again, as William was saying, it's sort of, I mean, to steal from the, the blood donation motto where they say, "It's in you to give."

CANDICE: Yeah.

RESH: You can live a perfectly healthy life with just one kidney or a portion of your liver, right?

CANDICE: Absolutely. They go through such a vigorous testing process that the people who are donating are extraordinarily healthy and they go through multiple tests. And we have had many people who have stepped forward and gone through the process. And, sometimes something is found that they didn't expect, and it has also saved their lives. Unfortunately, they're not able to donate to a loved one. But they wouldn't have known that there was something there if they hadn't gone through this process.

So, yes absolutely it's in you to give and we have many people who step forward who want to be a donor to their loved one and are unable to. And they say, well, what can I do now? And I always tell them, what we need the most is advocates. You know, it's really hard, as Williams said, to share our story and to be this vulnerable about our need.

And so if there are people out there who would share our story for us and put the word out there and let people know what our needs are; it's a lot easier to have to answer questions than to put our story out there ourselves as well. And so we always say, living donor advocates are also saving lives. And people can volunteer. They can donate blood. There are many things you can do if you can't be a living donor. And register your consent to be a deceased donor.

RESH: Absolutely. Candice, again, you're Education and Outreach Coordinator with the transplant center and there can be myths or misunderstandings around donations and what it is to be a living organ donor or deceased donor as well. What are some of the more common myths or misunderstandings that you find that you need to dispel around this? Because, as you said, it can be a frightening thought even.

CANDICE: Living donation definitely is. It is just that that's possible. So we find that a lot of the public doesn't know that you can donate a portion of your liver. Many

people have donated over 60% of their liver to someone and it grows back. So that's kind of a really cool thing that not a lot of people know. And it grows back very quickly. Generally within three months these donors have a full liver again.

And then people who donate a kidney, they're able to live a very healthy life with that one kidney. My mom is going on 14 years now with her kidney, and she's still incredibly healthy. And other than taking a look at her scars or if you did an ultrasound, you wouldn't know that she's donated a kidney.

So, knowing that you can do that, that's a big thing.

We launched a campaign called Great Actions Leave a Mark, back in September, and it's all about living donors and all about living donor recipients as well and the life that we have post-. So people can check that out at greatactions.ca.

And then with deceased donation, we'll also hear things like, "Well, I don't think I can donate because I have this problem, or that problem."

And we tell people, you know, the best thing you can do is register your consent. Tell your family that you're interested in being a donor. And then let the doctors decide what healthy organs that you're able to donate.

Or we hear, "They might not save me if they know that I'm a registered organ donor."

And that's a big one that we get. The doctors who are working on, you don't know if you're a registered organ donor or not. That is all through Trillion Gift of Life Network. So if you go in, if something terrible happens to you, they're gonna do everything that they can to save your life. And no if, ands or buts about that. Their job is to save you and to keep you healthy.

So those people who are working do not know that you're a registered organ donor. So those are a couple big ones that we get about both of those sides.

RESH: So that's interesting, some of those myths. And what you said about scars, Hey, scars are cool. I mean, those are the, the marks of life.

CANDICE: Exactly.

RESH: So, there you go. William, what about you? I mean you're just now engaging in this process. Are there some myths or misunderstandings that you had or that you find yourself needing to dispel? Because even as you're going through this, hey, you're educating the rest of us too. I mean, even that small, that brief message to us was quite an eye-opener.

WILLIAM: Well, I think Candice spoke to many of them. You know, it was only through going through this process that I recognize that there are people that aren't

relatives that can donate an organ that will save your life. I didn't realize that. And in fact, going back to the peer support, hearing some of the stories of people who received donations from strangers. It really was, to go back to what you'd said earlier Resh, about sort of reinvigorating your faith in humanity.

CANDICE: Yeah.

WILLIAM: You it definitely does that to hear about people's stories and how a complete stranger donated part of their body to save your life. It really is heartwarming. And I didn't even know that was really much of a thing before I started going through this process.

I was also doing a little bit of reading about the policy implications of where some of these wait-lists come from? And Candice could probably speak to this better, but it's my understanding there are places in the world where it's assumed that you will be an organ donor unless you indicate otherwise.

Whereas here, you have to opt-in. And I think that changes the wait-list for those places dramatically.

RESH: That's interesting. So, Candice, is there advocacy around that, that it's not an option, but it is a mandatory thing that could happen here?

CANDICE: Yeah. So what we call it is "presumed consent". And so rather than it being mandatory, what it is is that everybody is a registered organ donor. And you have to opt-out of that program, rather than opt-in.

As we've seen with the stats, you know, the majority of Canadians believe in organ donation, but they just haven't registered their consent.

Nova Scotia just passed that recently. So Nova Scotia is the first province in Canada to have presumed consent. So now in Nova Scotia you are a registered organ donor unless you opt out of the program. And so there has been conversations across Canada about what is this gonna look like in Nova Scotia? And how will it change their wait-lists. And how will it change how that province is providing care?

RESH: So Nova Scotia is sort of the guinea pig right now?

CANDICE: Yes. We are all watching.

RESH: We're all watching. And then of course, this is the, the land of universal healthcare. And I'm wondering if there is any move or if we're just waiting on Nova Scotia, but we do have universal healthcare, the Canada Health Act, and we're always talking about the ways that we can improve that. So is there any discussion in terms of organ donations and the CHA?

CANDICE: I'm not sure about that actually. We would have to chat with our policy makers on that front. But, I think right now we're all watching Nova Scotia. There are many countries in the world who have presumed consent.

Spain is one of them and they have very high levels of organ donation as well. And I think it more speaks to the culture around it as well. So, looking at Spain as just an example. The culture of giving an organ donation, it's normalized. So those rates can be higher because it's not just about presumed consent, but it's also about having conversations within the community and it being normalized. That this isn't something strange that somebody has donated an organ, or that, you know, somebody's person if they passed that they have that legacy. That they have saved several people's lives or that they've donated tissue as well.

We know that one organ donor can potentially save up to eight lives and over 75 more with tissue and bone donation as well. So I think it speaks more about the culture that we can create in Canada with organ donation. And take away some of those stigmas that we've talked about. Take away that fear about organ donation as well, and really make it a normalized thing that everybody knows it is the gift of life and what better thing to do with a legacy of yours, right?

RESH: Right. And everybody deserves health and life and all of that. Because one of the misconceptions that I know of is that sometimes people can think, well, you know, people who need organ donations probably were engaging in unhealthy lifestyles or they're of a certain age or something like that.

But, you know, as you've both said, this can come totally out of the blue. Candice, you thought you had the flu, it turned out to be this. William, you're probably one of the most health-conscious people that I know. And either way, it doesn't matter whether you were living a healthy lifestyle or not living a healthy lifestyle, everybody deserves to live, right? So,

CANDICE: Yeah, absolutely. I think that's one of the big things that, you know, people assume that your organs have failed for a certain reason. And I think you said it fantastically that there are all different types of people who are experiencing organ failure from babies up to people who are in their late stages of life. It can be anyone who's affected by this. And even for those populations of people who have organ failure because of something that they've done in their life, everybody, like you said, deserves the ability to have a healthy life. And if you're able to give that gift either while living or deceased, what a beautiful thing to do.

RESH: Now we sort of have two ends to the story of living organ donations right here. Candice, you've undergone a successful transplant. You had a beautiful baby not long ago. William, you are now, just entering this process of going through an organ donation, a living organ donation.

What's life like for you right now and also, it's not just your life, but there are so many people who are involved in your life, friends and the family.

William, you're a father, you're a husband, you're a friend, a colleague. So what is the impact on your family, your social unit right now?

WILLIAM: Well, it's, it's quite sort of tumultuous. There's so many unknowns when you're going into this process.

As I said, there's an emotional adjustment. There are financial implications because, as Candice pointed out, sometimes working is quite difficult. There's endless medical appointments. There's that unknown or finding out, will I be eligible? How will this work? How will I stay as healthy as I possibly can in this interim because there's so much to learn about. About peritoneal dialysis and trying to stay healthy while you're on it. So it all kind of takes a toll, both on me and on my family, as you said.

I'm married. I have kids, one's in university, one's in high school. And trying to keep everyone's spirits up is a full-time job in and of itself.

You know I think my family at first was quite shocked, especially my wife. We weren't prepared for this. So I've been stable for so long and, to hear the news that my kidneys had deteriorated so, so rapidly and so dramatically, was a shock. But my wife and friends and colleagues also really, really stepped up to support me in ways that I found surprising and incredibly touching. It was quite overwhelming to be quite honest to see the degree of support that I received from colleagues, from friends, and most especially from my wife and from my kids. Both emotional support, trying to support me in days where my health was incredibly bad, where I could barely get out of bed where ... well, to be perfectly blunt... I honestly didn't think I was gonna make it.

RESH: Wow.

WILLIAM: And that the emotional support that they provided me throughout that time, was huge. And of course, the instrumental support that people provided me, people bringing food. My wife making food, doing errands, bringing things that needed to be brought, arranging for deliveries. It just goes on and on the amount of support that all these folks gave me was huge. And I don't know how I could have done it without them to be honest.

RESH: I guess this is one of those moments that you don't realize perhaps how much you are loved and how much you mean to people until you see that outpouring of support and love and concern.

WILLIAM: You're right. I don't think I realized it. I was quite moved by it. You know, so much so that I really didn't know how to thank people, if that makes any sense.

RESH: Yeah. Yeah. Were they with you when you found that your situation had worsened, was this something that you had to tell your wife and or your kids? How do you deliver that news?

WILLIAM: Well, my daughter's 20 and my son is 17. And we felt it was important to be transparent with them and honest with them. But you know, we did have to think about it for a while. How do we break it in the end? We just ended up trying to be, sort of, matter of fact about it.

We didn't want to scare them or alarm them, but we were matter of fact about it and honest and blunt about what the news was and what it meant. And understandably they were concerned, but they did the same thing that other folks did. They were supportive. They did all they could to help out around the house, for example. To support instrumentally as well as emotionally. I mean, they're amazingly caring and mature young people. And so they really stepped up when we asked them to step up.

It was again, lovely and moving to see how they responded.

RESH: Oh, that's amazing.

Now this is again, one of those ultimate acts of humanity as you've well, both of you have said. And Candice, you mentioned the *Great Actions Leave a Mark* campaign that is now an annual event. Is that correct? And could you tell us a bit more about that?

CANDICE: Sure. So we launched the Great Actions Leave a Mark campaign in September of last year. And what it is is it's photos and videos of living organ donors and recipients. And it spans across Canada. So we have images and videos of people from British Columbia all the way out to Eastern, Canada, which we will be launching this living donation week.

And the goal is to raise awareness about the incredible act of living donation. To inspire people to learn more. And also for people who are waiting to see that there are incredible people out there who are willing to step forward to be living donors as well. And it's truly a gift of life. And we wanted to showcase the scar.

Often scars are seen as something negative. And myself, I have had so many surgeries and, you know, two types of dialysis, and sometimes those scars can be difficult to love. But the one thing about living organ donation is it really is that mark of love, as we've talked about.

That every time I'm able to look at my kidney scar, I can think about my mom and the incredible gift she's given. And so we showcase those scars as that mark of opportunity. And many people talk about what that scar means to them. And so really trying to raise awareness about what living organ donation is and who organ donors are as well.

So they're all different ages, genders, socioeconomic places that people are coming from, different geographic locations. There is not a profile of a living donor. They are

just amazing people stepping forward. So people can take a look at the campaign @greatactions.ca and they can see all of those amazing stories across Canada.

RESH: And that's a great point. William also spoke to this, that this is not a group or a community that you plan to be a part of, but eventually anybody can become part of this community and it is such a remarkably diverse community as well. I've certainly been seeing that.

And it also tells you about the success rate because again, it gives a lot of hope. So what has been the success rate of living donations in Canada?

CANDICE: So for living donors at UHN we have 100%, success rate for survival.

So living donation is a very, very common surgery now. It happens quite often. We have over 200 kidney or kidney, pancreas transplants that happen every year at UHN and almost a hundred living that happen at UHN. And over a third of those are living donors. So about 200 transplants that happen a year for kidneys and almost a hundred for liver.

And a third of those are living donors that have stepped forward.

There are risks to donations, similar to any surgery. However, they're so common now that these living donors are able to often walk out of the hospital within three to five days and many of them are back to work within four to six weeks.

It's an incredible thing that people can do. There are risks just like anything else, but we have incredible success rate at UHN and across the country. So, if it's something that people are interested in doing, they will go through a very intense process to make sure that they're healthy enough to do that.

And not just physically, but also the mental side of things to ensure that they are okay to do this on all fronts.

William talked about the financial impacts to recipients. There's financial impacts to donors as well, but we make sure that any expense that the donor is going to have going through this process, that that is covered and taken care of as well through the PRELOD program in Ontario, and we have lots of resources through the center to support donors through their process.

RESH: So there's a great deal of resources, there's a great deal of support. Again, another surprise for me is that the surgery itself, you know, you're not laid up a week or two weeks in the hospital. You can return to a normal life fairly quickly. That's really something.

CANDICE: Many of our donors have said to me, it's a few weeks to months out of their life of being uncomfortable, to give somebody their entire world back.

RESH: Yeah. That is a powerful way to look at it. Absolutely. The ultimate gift of life.

So to summarize, you do not have to be a relative. There are so many people who are on this list. Just anybody who is listening to this podcast, you can register. And again, right now, Candice if somebody is listening to this podcast and say, you know what? I wanna be part of this amazing community, what would be the first step that they would need to take?

CANDICE: So they should go to UHN Transplant and take a look at that Medical Health History Form and take a look at the surgery manuals. I would suggest that they go to our transplant library where they could look at all of those different resources to see what this process would look like. And then they could also register for one of our free webinars that we do every Tuesday at noon. They're on Eventbrite. And you can just pop in and learn all about living donation and what it is like to be a potential donor. You can learn about all the tests and everything that would go into being a donor and really just look into more information. There's a lot of information out there.

You can always connect with us at the center as well. They could reach out to livingorgandonation@uhn.ca and we can answer any questions that people would have.

RESH: Lovely. And they can donate from anywhere in the country to anywhere else in the country. Correct?

CANDICE: Exactly. We have people from all over the country who donate at UHN. We also have people who are out of country donors as well. That process is a little bit more in depth due to visas and things like that, that they have to work through. But anywhere in the world people can step forward to be donors.

RESH: Okay. And William, the last word to you. So you again, are in need of a kidney transplant. You are just starting in this process, but what do you want to say to listeners of this podcast?

WILLIAM: Well, I would say what Candice had said earlier, that even if you aren't a match for me, you might be matched for someone. And, you know, I can't describe the gift that you would be giving to someone that you may not ever meet. And that said, you have managed to save their life. I mean, how many of us can say that, that we managed to save a life somehow. And this does that.

So I really, really encourage people to get involved. Have a look at it. Look at the resources that Candice just mentioned, that you're going to post, Resh on the podcast. And really consider it. Because it does mean the world to someone. And I think that it provides that sense of altruism, a reward even to the giver as well.

There is a feeling that someone can get, that I'm sure is indescribable from having to save a life.

RESH: Absolutely. And with that, thank you to you both, Candice, so lovely to meet and speak with you. And William, my friend, an absolute pleasure as always.

And the next time we speak, maybe we'll have a new friend who has connected with you to become your living donor, which would be awesome. So thank you to you both.

CANDICE: Thank you so much.

WILLIAM: Thank you. Thank you very much.

CANDICE: And William I wish you all the best in this journey, and please feel free to reach out if you have any questions or anything I can do to support you.

WILLIAM: I'm very grateful. And I should say that the folks at UHN have been absolutely spectacular. So I'm, I'm very, very grateful for the time and expertise that they've provided me.

CANDICE: I'm very lucky to be part of that team. That's for sure.

RESH: Great team, great community. And again, listen to the Living Transplant podcast, as well as Courage My Friend's podcast because hey, we're all in all of this together.

WILLIAM: Absolutely.

RESH: So thank you,

CANDICE: Thank you,

WILLIAM: Thank you.

RESH: That was William Woolrich, friend and faculty from George Brown College and York University in Toronto, and Candice Coghlan, Education and Outreach Coordinator for the Center for Living Organ Donation at UHN's Ajmera Transplant Center and host of the *Living Transplant* podcast.

If you are interested in being a living kidney donor for William, or being an organ donor, for anyone awaiting an organ transplant, please visit the show notes for this episode on rabble.ca. Needs No introduction There you'll find website and email links to the University Health Network, Ajmera Transplant Center, and you can also download the *Living Donor Transplant Program, Donor Health History Form*.

This is The Courage My Friends podcast.

I'm your host, Resh Budhu. Thanks for listening.

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