OCO S02E03 - Being a caregiver and advocate for a donor recipient with Heather Lannon

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[00:00:00] Michelle Jobin: Hi everyone. I'm Michelle Jobin and you are listening to Time To Talk, a podcast for caregivers. This podcast is dedicated to helping family caregivers in Ontario. Through expert tips and resources, you will gain knowledge and validation for the ups and downs that come with caregiving. More importantly, you'll learn that you're not alone.

It's so important to take this time for yourself. We're glad you're here.

We are joined by Heather Lennon. Heather is the care and transitions facilitator for the aortic program, cardiovascular surgery at St Michael's Hospital. She is also an active volunteer for health-related charities and is passionate about sharing her experience as a caregiver advocate, researcher and donor family member.

Thank you so much for being here with us today.

[00:00:55] Heather Lannon: Thanks so much for having me, Michelle, I'm really excited to be here as well.

[00:00:59] Michelle Jobin: We wanted to create a space where Ontario caregivers could connect and share, and hopefully through our conversation today, we can all gain a little more insight into the special role and responsibility of a caregiver and specifically your particular experience as a caregiver.

And there might be people out there that also can relate to your experiences. So we understand that you Heather were a caregiver for your husband who was in need of a heart transplant. So could you tell us more about how you started caregiving and about how this whole situation came to be?

[00:01:33] Heather Lannon: Yeah, for sure.

I guess just to give a little bit of background on which I think will be helpful for the listeners and kind of frame the conversation. So my husband, Jamie was born with a congenital heart defect and, um, he had surgery at a young age to correct that and the plan then was that he would go on and live a normal life, um, went back and forth to cardiologists for checkups and, and that kind of thing all throughout his life.

And then when he turned about 30 started having a lot of complications, um, was in and out of hospital a lot. And coincidentally, this is around the same time that him and I met and started dating and we knew something was wrong, but we didn't really know what was wrong. And I think that happens a lot with people with chronic illness.

And I bet a lot of the caregivers or people that are receiving care would relate to that and say back and forth to hospitals, doctors, tests, that kind of thing. So that went on for about two years and we were living in St. John's Newfoundland at the time. And it really just kind of snowballed after that two years mark, where doctors realized that, hey, he's really in trouble and we need to get him to a hospital that can accommodate his needs. So we were sent to Toronto General here in Toronto, the resources just weren't available in Newfoundland for his specific condition. And, uh, they diagnosed him with severe heart failure.

So he was about 34, 35 at the time, which was quite a shock. I think a lot of us think of heart failure as like an old person’s disease, but he was quite young. And from that point on, we continued to come back and forth to Toronto for as long as we could. We wanted to stay at home in Newfoundland and that lasted for a couple of years.

And then finally the team here in Toronto made the decision that we would have to relocate and get the, uh, the be close to those specific care needs that he had. So we moved here for about three years while he waited for his transplant. And unfortunately, that transplant was not successful and he passed away in 2017.

[00:03:32] Michelle Jobin: Well, first of all, I want to say how sorry I am for your loss and also how generous it is of you to share your story with us and with others. And to also continue to advocate for those that are having similar experiences to what you and your husband had in terms of waiting for a transplant. And we appreciate so much you being here today for that.

Can you describe to us your biggest challenge in being a caregiver for your husband?

[00:04:01] Heather Lannon: Yeah, I think for me, the biggest challenge was I still am relatively young. When I met Jamie, he was 30. Like I said, that's around the same time he started having some complications and I was 25. So from 25 to 30, I think we kind of look at that as like you're becoming an adult and you're probably finishing university or college and starting, you're really starting your life.

And at that point in my life, I was thrown into taking care of someone. So I think that was really hard for me, especially I was watching all my friends get married, have babies, and, you know, start, you know, progressing up the career path. And I was kind of stuck in this position that I didn't really want or need or even ask for, but it just kind of fell upon me.

And I found that really difficult because you know, like most people in the early twenties, you have this kind of picture in your head of how your life is gonna, you know, the plan, everybody has a plan, oh, I'm going to, you know, finish school, I'm going to get this great job, you know, gonna find the love of my life.

We're going to live happily ever after. And I don't think that's exactly how things turned out, uh, in my situation. So I struggled with that for a very long time and really felt a lot of times that my life had been taken away or my goals or my dreams have been taken away, but feeling very guilty about that because here was Jamie obviously fighting just to stay alive.

[00:05:23] Michelle Jobin: I think you touched on two really important things, there. One that often we think of the role of caregiver as being someone usually later in life, taking care of someone, maybe even later in life. So we don't think of this traditionally, although we should, because there's many, many people that are in your situation, as something that a young person experiences.

So first of all, it's so wonderful to have you here to share your story and that side of things. Cause I think it's an important thing for people to understand. And second it's that push, pull, that guilt that a lot of caregivers feel. It's not that they do not want to help the person that they are helping and they, it's not that they don't want to be providing care, but it has a massive impact on your life as well.

And it's okay to have those feelings. Because it's a complex series of feelings, I'm sure that you've described, that you went through. Do you feel that that's something that it was initially hard to discuss?

[00:06:18] Heather Lannon: Yeah, absolutely. And I never ever talked about that part of it while we were going through that.

It's only been after and I still don't feel great talking about it, but I think it's a really important piece, like you said, because, you know, I think many people feel it, many people who are providing care you know, there are days you just want to scream, like pull your hair out. And the physical part of caring is difficult enough, but in Jamie's case, and I'm sure a lot of other people who are dealing with chronic illness, there's an emotional mental piece too.

And Jamie became very, I would almost say depressed because of his illness, which I think is completely normal. If a physician tells you you're in a life or death situation, you're going to be angry. You're going to be depressed. You're going to be resentful. You're going to be, all these things. So I think sometimes we think caregiving and we think that physical, you know, helping with bathing or meals or taking the doctor's appointment, but there's this huge mental, emotional piece that I think sometimes we forget the caregivers dealing with that piece too.

[00:07:20] Michelle Jobin: Absolutely. And I think it's incredibly important to actually eventually at least, or whenever it feels comfortable to speak those things out loud, even if it's just to someone else you want to confide in. And I think our listeners will appreciate the validation for the feelings that they might be having, because everything you're going through is important as well.

So we definitely think it's a valuable thing to talk about that piece of the puzzle. We understand that you ended up relocating, as you mentioned from Newfoundland to Toronto, to be closer to your husband's medical team. And I think this is also something that a lot of people perhaps have to experience. How did your, you and your husband come to that decision?

And, and can you talk a little bit about that experience?

[00:08:00] Heather Lannon: Yeah. And I get asked this so many times, how did you decide to come? And, um, you know, I'm actually gonna kind of quote Jamie because we used to get this all the time and he'd always say. It wasn't a decision. There was no decision. It wasn't a choice.

It was, I stay in Newfoundland and die or I go to Toronto and have at least a chance. And you know, his point of view was always, you know, if you were in a situation where you were going to live or die, you would do whatever you could to stay alive. You know, I think people sometimes picture it kind of like, uh, we sat down and had a conversation about it.

Like that did not happen at all. It was more, we need to save his life. Let's do it. And I think a lot of people would do that. Like not actually consciously even think about it. And maybe if you were later in life, you would debate if that was, you know, I'm close to, you know, 80, 90 years old, do I really want to move and uproot my life, but when you're 30, I think you will do whatever you can to, to stay alive.

And that's kind of what we did. We never ever talked about it. We just said, yeah, let's do it.

[00:09:07] Michelle Jobin: But in doing that. And of course it's the decision or not a decision at all. It's of course it's the journey that you go on, but you're also both removing yourself from your community. So that is an additional challenge, perhaps.

Can you speak to that experience at all?

[00:09:23] Heather Lannon: Yeah. So there's so many things that you remove yourself from. So your livelihood, both of us were working and had jobs in Newfoundland. You have to think financial-wise, what am I going to do when I get to Toronto, Ottawa, wherever it is you're going. Your support system is likely wherever you live, whether that's family, neighbours, friends, or whatnot, that's going to be miles away.

And yeah, your whole life is in one place and you're moving to another place. So that's really challenging. And that interesting, I think we're going to get into it later, kind of sparked the idea for the Ph.D. And that's what I actually studied was these people who relocate and how that impacts their, you know, their care and how they they do.

But yeah, it is challenging and you know, more and more people need to, you know, maybe not relocate, but they're travelling great distances to come to, um, you know, if they're here in Ontario, they might be coming to Princess Margaret for cancer treatment or they're coming in. One of our bigger hospitals for cardiovascular care.

So, you know, that puts that extra stress and extra burden on a person who's already dealing with a very serious illness and, you know, just trying to stay alive.

[00:10:30] Michelle Jobin: That's incredible for me, even with my father who is receiving care and he only lived an hour away from Princess Margaret, there were still even times where we had to find a hotel room or things like that.

So definitely have experienced, you know, a microcosm of that, of just having to sort of figure out how to rearrange your life, to be closer to care. On that point, because it is such a huge change to go through on top of an already stressful situation, and you've been through the experience of moving and relocating to an entirely different province to be closer to a medical team, do you have any advice for a caregiver that is going through a similar experience of needing to relocate in order to be closer to their care recipient's medical team?

[00:11:17] Heather Lannon: Yeah. You know, advice. It's always, it's always an interesting one because I think every, every situation is so different, but I guess I'll share things that I kind of learned that I found helpful.

And I think we touched on it a little bit and one of the most difficult things for me was that I lost every bit of social support I had, they were way back in Newfoundland and I was here. So I think one of the best things that people can do for themselves is try and find some kind of a support network. Um, and support can look so different for different people.

So I was lucky. We had an amazing medical team look after Jamie who cared for him, but we're also very concerned about my wellbeing and checked in with me. So that was helpful. And then, within transplant, it's not just an illness, it kind of becomes a community. So, you know, I ended up meeting a lot of other carers who, um, had people who were, you know, waiting for a heart transplant, waiting for liver transplant, waiting for other transplants.

And they were probably the best people to connect with because they really got it. Whether they had relocated or not, they knew what my day in day out looked like. And, uh, you know, that was a great support, even just a phone someone's and say, listen, I need to get out of here and get a coffee, can we just like meet for 30 minutes?

And, uh, I felt really safe, I guess, in that space. Cause like I had said before, there were so many things that I'd never ever say out loud or talk about because I was thinking, you know, wow, how could I say, oh my God, Jamie is driving me nuts, and I'd actually like to divorce it right now. When here he is trying to stay alive long enough to get a transplant.

But I could say that to those other people who were experiencing the same thing. So definitely finding, you know, a community, um, whether it's, you know, other people that are in similar situations, you know, hospital community, even just, you know, someone that you can hang out with that has nothing to do with hospitals.

Sometimes it's nice to just break from that completely and, you know, maybe join a book club or a running group or something that's just for you that maybe has zero medical focus or caregiving focus, just so you can kind of turn your brain off that space for like even an hour. I would find that very, very helpful.

[00:13:35] Michelle Jobin: That's all great advice. And, and you did touch on the fact like, like you said, even if you don't relocate from a different community, what you're dealing with is so specific that your original network might not really be the people that you need necessarily at that time. And you also touched on the fact that your medical team, your husband's medical team, was also checking in on you, but how do you feel that maybe if that's not the case, how a caregiver or patient can better advocate for themselves when it comes to navigating the healthcare system. And I also should add the layer on that, you've come from Newfoundland to Ontario. So you have a particular unique perspective on our healthcare system here. So can you speak to any of that at all?

[00:14:15] Heather Lannon: Yeah, I think, um, I was at a real advantage.

My background is social work. So, um, and, and I, I used to tell Jamie all the time, Jamie, you were so lucky you've come equipped with your own social worker. So I had that kind of inside knowledge of how to navigate systems, which I don't think the average person might have. As someone who's, you know, done courses and gone to school and study things, I really kind of relied on knowledge is power. And I just tried to learn as much as I could about the test Jamie was having, his condition, the medications, and I felt that kind of gave me confidence to advocate because, you know, I'm in a room and I'm sitting down with doctors and they might be talking about, oh, you know, he has atrial fibrillation and we're going to try and ablation procedure and if that doesn't work and it's like, I don't even know what these words mean. So I felt like that equalled the playing field a bit and gave me more confidence to you know, advocate and speak up and say, I don't feel comfortable with that. Or, um, could you explain more even just asking questions I think is super, super important.

So really just, you know, and it was just Google, it wasn't, I didn't go out and like buy expensive textbooks or take a crash course in cardiology. Like just Googling the names of procedures or meds or whatnot. So I had at least some knowledge of what they were talking about when they'd come in and, um, you know, spew is the only way I can describe it.

Cause they had just, I don't think often doctors, nurses, medical staff think that, Hey, this person has like no knowledge base of what I'm talking about. They're just going on and on in their own terms and languages. Um, I thought that was really helpful for me.

[00:15:57] Michelle Jobin: Oh, absolutely. I think I think what it is is every profession has its jargon.

Right. And so. Uh, we get tripped up in that amongst ourselves, but when, when it's doctors and nurses dealing with patients, I feel like the stakes are a lot higher in terms of the person on the other end, really understanding the situation. So that's great advice. So you touched on your Ph.D. before, so in your Ph.D. research, you made findings about the connection between home and the heart transplant journey. So can you tell us a little bit more about how your idea or your research question for your Ph.D. came about and your findings for it?

[00:16:32] Heather Lannon: Yes. So, um, the research project or the idea to do a research project obviously came from, um, me and Jamie's own experience. And what had kind of happened, and it happened very naturally. I had no intention of doing a Ph.D., but, um, I always journaled, I kept journals. I've kept journals probably since I was five years old and, uh, interesting enough in social work, we, we recommend journaling many times to clients and patients and people as, as like a stress relief and getting their thoughts and feelings out on paper.

So I actually journaled the whole transplant experience. So I had, I don't know, 6, 8, 10 of these you know, uh, documented, uh, handwritten journals that I had kept the whole time. And the idea had already been, I'm going to turn this into a book or I'm going to do something with it, but then, you know, um, we started, I started thinking more and I was like, I really want to help people.

So how can I help people? And then the idea came to turn it into a research project, which led to the Ph.D., but the whole idea came about just meeting patients in the hospital. It really blew my mind how many other people we would meet in the hospital that were, um, come from aways, um, you know, you, you just bump into them, you know, down in the Starbucks line, getting a coffee, you hear them talking, especially if they were from Newfoundland, you'd pick up the accent right away.

And Jamie and I started thinking like, if we've met this many by chance, how many more are there? There has to be many more. We're just in one hospital. What's at other hospitals, other locations. And, uh, that's how the idea came to be. And the whole connection to home kind of came about because every single one of these patients wanted nothing more than to go home.

And, you know, I, I knew there had to be a connection. There had to be a connection between the moving for medical care and the home. So, uh, the project ended up being about 20 qualitative interviews with patients and caregivers, because I wanted the caregiver perspective as well, with individuals who relocated for heart transplants from all across Canada.

And the findings were basically that home is, is where the heart is. And I use heart more as an emotion or a feeling than a physical structure. And home is about, you know, where your loved ones are. Where do you feel comfortable, where you feel safe and that you can kind of make home, wherever you are, as long as those factors are there.

So I was able to pull out, I mentioned the medical team, how good they were to me. A lot of people had that same feeling that, you know, having a medical team that made them feel safe, made them feel like they were at home. Um, you know, finding a community, whether that's other patients and caregivers, whether that's a hobby group, whatever that might be that made them feel like they belong.

And that that was a feeling of home. So that's kinda how it came about. In addition to studying the 20 patients and caregivers, I also opened all those journals and studied myself, which is a very interesting thing. And you talked about, you know, saying some of those things out loud, I never ever thought that those journals would ever be public.

So, um, that was a little bit scary, but I think pulling those really important things out will benefit, the kind of like the greater good and people will realize that it is okay to have those maybe selfish thoughts that we like to kind of keep close.

[00:19:54] Michelle Jobin: What do you wish people knew about the transplant experience?

[00:19:58] Heather Lannon: Um, transplant is, you know, I like to say it's magical because it really is a magical thing where giving somebody an opportunity to live, we're giving somebody, the phrase we always use is the gift of life, and that's what we're doing. We're giving them an opportunity to, to have another lease on life. So that whole kind of notion of rebirth and being reborn and surviving when maybe 50 years ago, this whole transplant concept didn't even exist.

People just died. We didn't think or know that you've been taken an organ from one person and put it in someone else. Um, so I think in that sense, it's magical. It's definitely a unique piece of medicine that I think is just really remarkable. Obviously, not everything works out like in, in my case. I still think it's a very interesting, very visionary kind of area of medicine that I think will only continue to evolve and grow as, as time goes on.

[00:20:56] Michelle Jobin: I wanted to move on to, what you're doing now in terms of work.

Can you tell us about your work as the care and transitions facilitator for the, our aortic program, cardiovascular surgery at St Mike's?

[00:21:11] Heather Lannon: Yeah, that's a mouthful.

[00:21:14] Michelle Jobin: It is, but it's a good one. It's a good one. Please tell us more.

[00:21:18] Heather Lannon: Oh, it's funny. I took this role on in August, so I'm just there close to six months now.

And, uh, I graduated with my Ph.D. on a Monday and I started this job on a Tuesday. So, uh, it was, uh, kind of a whirlwind. I knew I wanted to do something with hearts I was like, I need to do something with hearts. I want to do something that's very patient-focused. So not like a research where you're kind of behind the scenes, but more you're right there in the trenches with the patient.

And this opportunity just came up at the most perfect time. And basically what I do is I am the, I like to kind of call myself the tour guide, the, uh, the go to the, the person who walks the journey with the patient and the caregiver. So when they're referred to our program for surgery, these people usually know they have a condition they've seen a cardiologist and the cardiologist has said, you likely we'll need surgery.

They come to us and, uh, we meet them in clinic and then I kind of stay with them throughout that whole journey, organizing their tests, you know, making sure they're all ready for surgery, answering their questions. Um, I'm kind of their main point of contact. The person that they pick up the phone and kind of, you know, I'm freaking out, um, you know, I'm feeling a little lightheaded today.

What should I do? And you know, or I'm so scared. Um, I'm going to have open-heart surgery, am I going to die? Like that kind of thing. And then I get them ready for surgery and then send them off. And then we follow up with them after surgery. So it's, it's kind of a neat position. I don't think the title really fits.

Nobody really knows what a transitions facilitator is, but I like to kind of just describe it as that person who walks the journey with them. Um, and they could be having, you know, surgery for an aneurysm, they could be having surgery for, um, you know, a leaky valve. Uh, a variety of reasons. They could be in heart failure, they could be experiencing, um, you know, shortness of breath, chest pain, palpitations.

It could be anything. So it's a, it's a wide variety, but, uh, it's definitely, um, a privilege to kind of go from, you know, the point they come to us until they're cured. They're there done their surgery and walk that path with them.

[00:23:25] Michelle Jobin: I like your version of your title, the person that walks the journey. I think that's great.

And do you find this incredibly rewarding?

[00:23:32] Heather Lannon: It is really rewarding. Um, you know, they come, like I said to see us in clinic and clinic, you know, if anybody has gone with a loved one to clinic appointments at a hospital, it can be very intimidating. It can be very scary. You're probably seeing 2, 3, 4 doctors, nurses, maybe you're doing blood work, having x-ray and other tests.

By the time you're done those clinical pieces, your head is usually swimming and you're really overwhelmed. And, uh, we've decided when I started, that's the point where I would go in and sit with the patient and their loved one. And, uh, it's almost like the closer, but they end on a, oh my God. When I get in, you can see almost that physical reaction of I'm so overwhelmed.

Am I going to die? Oh my God. I didn't think I needed surgery, now I'm finding out I need surgery. And you know, I really liked that I'm that last person who goes in and I don't always tell people about Jamie, but in some cases, just sitting there and saying, I know exactly how you feel right now, I've I've been there,

I had a loved one who had heart issues. Um, you know, let's talk about it. I think that's, you know, really a nice piece. And then they leave feeling very ha you know, decompressed, not that high anxiety tension-filled, oh my God, all this information was just dumped on me. So again, no, it is totally rewarding. I, you know, I like to define it or say, I feel like I get to help like 10, 15 Jamie's every single day, which is really nice.

[00:25:07] Michelle Jobin: That's really nice. And, and I no doubt that they and their caregivers feel, feel less alone and more empowered. And sort of on that note during your caregiving experience, because this is a big piece of the puzzle in terms of mental health of the caregiver, is there anything that you would do for yourself when you felt that your own mental health was suffering?

Or is this a realization maybe that you've come to after the fact.

[00:25:33] Heather Lannon: Um, you know, I get asked this question lots of times too, and I always kind of find it interesting because I always thought as someone who practices in the area of mental health, I would have been, you know, knowing the signs that I was like getting close to burnout, or I was stressed that I, you know, use all these techniques and tools that I would tell patients and clients when I saw them. But when I was in the situation, I feel like I had blinders on or something because none of it even dawned on me that I was as stressed out as I was. So I always got share a story. I laugh at it now, but at the time it really wasn't funny. And I was going along, you know, I think we'd been in Toronto, maybe three, four months at that point, Jamie was in and out of hospital.

Um, you know, having some very serious complications. He went into cardiac arrest at one point, like it was very touch and go and we were renting an apartment. It was a furnished apartment. And I went home that night from the hospital, completely exhausted and was preparing dinner for myself. And, uh, they didn't have a cheese grater in this apartment and whatever I'm making required grated cheese.

And I literally sat on the kitchen floor and sobbed and sobbed for hours over the cheese grater but it was not about cheese grater. It really wasn't. And, um, after sitting there for over an hour crying, I had enough, uh, insight to say, I need to phone someone. So I phoned my mom and, uh, you know, it's, it is funny now it was like, I don't have a cheese grater she she's like, okay. I think she thought I was, you know, going off the deep end, but that turned out to be a really great thing. Because after that, whenever I would be chatting with my mom or my sister or whoever I told the story to, they would say, are you getting close to a cheese grater moment? And that was kind of the clue to, okay, you need to step back and do something for you. And yeah, that could be, you know, I learned just the little things, like I had said before, even if it's a 30-minute, I need to go for a walk. Um, you know, there would be times I would just leave Jamie in the hospital and say, I know you're safe here. I just need to go.

And I would just walk around the block a couple of times it wouldn't be anything extravagant, but it would just be, you know, fresh air, sunshine, collecting your thoughts, that little bit of exercise. Um, It could be treating myself to one of those super fancy Starbucks drinks or something, or, you know, going and getting my nails done or my hair cut or something that made me feel good about me.

I found that was really helpful, but letting people know that you were struggling, which I think, you know, all of us like to put on this, uh, superhero kind of persona that, Hey, I'm so tough and strong and everything's great, but yeah, the cheese grater. And we still use that phrase in my family today. Just to check in and say, Hey, you doing okay?

You know, who is it? You looking for a cheeseburger or?

[00:28:22] Michelle Jobin: And it's even as a professional, it's really hard to know when you're in it, you don't always see it, right. Even you yourself as a professional. So it's hard to see what you're going through when you're, cause you're just putting one foot in front of the other every day and just trying to get through.

So I think all of that is great advice that our listeners might be able to step back and take a look at that, are they close to that kind of moment and what they need to do with themselves and those little things that make you feel more like you, those are all really important. You spoke about how, you know, transplant is such a specific thing and such a specific community.

Do you have any advice just to sort of wrap up today to someone who is currently caring for someone who is on a transplant list or in need of a transplant?

[00:29:06] Heather Lannon: You know, I think if it's a caregiver, just telling them, you know, you're doing a great job because I think a lot of times we internally do that talk where, oh, you know, I'm not doing enough.

I could be doing more, you know, I'm not good enough. And I think just, you know, telling people to keep going, you know, stay hopeful. Um, you know, even if things don't turn out the way you thought they would, I still think that something beautiful and positive can come out of it. You know, obviously I wish Jamie was still here, but I look at all the things that transplant has still brought me, even though he's not, you know, I ended up the Ph.D., I've gone and talked about this in so many venues.

And, you know, I really feel that the more we talk and the more we connect, we're really going to help each other and support each other. So definitely stay strong, advocate for yourself and find those connections. Cause that's, what's really important.

[00:30:02] Michelle Jobin: We appreciate your knowledge and experience and perspective so much.

And we thank you for being here today, to speak with us about all.

[00:30:12] Heather Lannon: Thanks so much, Michelle, it's been great chatting with you.

[00:30:14] Michelle Jobin: It's been really great chatting with you as well.

Thank you for listening. We hope you enjoyed this episode. You can access more details about support services on our website, ontariocaregiver.ca. Until next time I'm Michelle Jobin and you have been listening to Time To Talk, a podcast for caregivers.

We hope you have a wonderful day.