Cancer Muggles & James Bond

Natalie: [00:00:00] I started with "Doc, give me the prognosis. How many years do I have to live?" Five to 10 years to having a real chance and managing my disease. And maybe even having the chance of seeing my daughter grow up.

Candice Coghlan: Welcome to Living Transplant. The podcast that takes you behind the scenes of the transplant program at Toronto General Hospital, and brings you open and honest conversations about the transplant experience. My name is Candice and I'm the Education and Outreach Coordinator for the Centre for Living Organ Donation.

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

Living Transplant will show you the world of transplant like [00:01:00] you've never seen it before.

Welcome back to The Living Transplant Podcast. Today I'm joined by Natalie, a liver transplant recipient who was diagnosed with stage four colon cancer the day before she gave birth to her daughter.

Natalie is a creative director from South Africa who's exploring the topic of the fragility of life. She encountered this exact theme when she was eight months pregnant. Feeling generally great until one day on a shoot she began having pains in her shoulder that were so intense she flew home and went to the emergency room where she was diagnosed.

Later we will be joined by her liver transplant surgeon, Dr. Gonzalo Sapisochin, whose innovative research is opening opportunities for patients to have living liver transplants to live longer lives, and for some people to be cured of their liver cancer.

Thank you so much for joining me and co-hosting this episode with me today, Natalie.

Pleasure. Thank you.

I'm wondering if you can bring us back [00:02:00] to that journey of your pregnancy and, what brought you to, the health news that you ended up getting.

Natalie: I remember it was the middle of the night, or at least it felt like the middle of the night. It was snowing outside. And I remember there was like snow shining through the street lamps. And a doctor came into the room and sat beside the bed.

And it was the first time I'd seen a doctor cry, which was quite intense. And she told me the baby was fine, which was a huge relief knowing that everything was great with her. But she told me that I had cancer. So eight months pregnant, sitting there, hearing in a hospital that you have cancer is, I don't know, I guess extreme.

[00:03:00] It's certainly not the thing that, that anyone who, starts a, pregnancy journey expects. And the, shoulder pain was actually transferred pain from my liver, which. Riddled with cancer all over it. And as, a baby grows inside you your organs get squished and moved around to make space for itself.

And this was actually pressing, on the tumors in my liver, causing the pain. So I think if it weren't for my daughter I, probably would've gone many more years without even knowing that I was sick, really. I had no clear external sides that there was anything really wrong with me.

Then after that She told me in the morning that they were gonna induce me and that I was gonna have my baby. And to top it all off the next day, they wanted me to have a colonoscopy. They wanted [00:04:00] to confirm the suspicions that the cancer had started in my colon and then spread to my liver, which was pretty common.

It was a lot to take in and I, think I felt pretty numb. And, it was strange. I guess I went from feeling that numbness to the next day feeling completely overwhelmed. Joy when, my daughter was born, and I remember her like laying on my chest for the first time just after she was born and in my head counting over and over her fingers and her toes and she was healthy and she was perfect.

And it was just such a relief. And it was quite a jarring difference of emotions between the one evening and the next morning.

Candice Coghlan: And quite a moment that this is a, moment of pure joy, that you have this beautiful, healthy little baby and that you [00:05:00] have to now face that next giant hurdle of what's coming.

Yeah. How did you, grapple with those two competing emotions

Natalie: I, don't know, I think I'm quite stubborn and practical when I wanna be for a creative, so I, just, said, well, this is what it is and, I've gotta deal with it. And, thank goodness for, family and friends and support.

Candice Coghlan: You got to introduce your beautiful baby girl to, to your family, but you also had to tell them what was coming next. How did you do that?

Natalie: Yes. Well, I remember we called them from the actual hospital bed. That evening, which was their morning in South Africa.

And I didn't really know what to say. This was just before I was gonna be induced. And Dave, my husband, thank goodness for him. He did most of the talking. [00:06:00] And I think telling my parents was probably one of the hardest things I've ever had to do. And now, being a mom myself I think being in a position where you're unable to help your child is one of the scariest things.

I think more, than being sick yourself. Is, just that lack of control. And yeah, my mom was on a plane the next day after she got an emergency passport and yeah she came to stay with us. She was actually, stuck in the country for a year because of Covid. And it was actually, it worked out really well.

She, had her own relationship with my daughter and she helped us so incredibly much. Covid it actually worked out well for one. Yeah.

Candice Coghlan: Yeah. They got to have that bonding time that they may not have been able to have without

Natalie: it. Right. Definitely. Yeah they, never would've if, it weren't for that.

Candice Coghlan: Wow. And as moms do [00:07:00] always jumping into action immediately when they know that their kids need them. Right? Yeah. I totally get it now, I get it. Right. Yeah. Yeah. I'm the same way. I used to question my mom's craziness of all the things that moms do until you become one yourself, and then you're like, oh, now I understand you.

And also, I'm sorry for everything I've done in the past, because you're an amazing human.

Natalie: Definitely. My mom's 70 something, and you never stop being a mom. No. Yeah. It's just, it's your title forever now. Yes,

Candice Coghlan: exactly. Yeah. Wow. Walk me back to your, diagnosis. What was the diagnosis for you and how did they decide to treat?

Natalie: I went for the colonoscopy and they confirmed it was stage four colon cancer. And so a month after Alice was born, I started chemo [00:08:00] which, was intense. And it was a chemo called folfuri and also an immunotherapy called Panitumumab.

And it, was incredible. They, reacted in an instant. I know many people are concerned about the state of healthcare in Canada, but I haven't had anything but the most overwhelming support and luck and help from absolutely everyone.

They needed to get my tumors stable essentially. My CEA levels were pretty astronomical. I think it was like over 3000 when they first tested my blood.

And sort of normal levels for humans in the body is like from north to four. It was incredibly extreme. So they reacted [00:09:00] really quickly. I started chemo. It made me incredibly tired, but also so did having a newborn so there were a lot of parallels with that.

But what I found from the chemo, I was incredibly lucky. My body responded really, well to treatment. I had the terrible side effects, hair loss paper, thin skin really that would like flake off all the time. Diarrhea, painful rash on my face that just came out in these terrible blotches.

It was awful. They told me that's the way it's working. I was like, great. I certainly don't look very good or feel great. But yeah, they assured me that it was working and my ca numbers, every time they did the blood work were were halving. Which was amazing. They used to call me their star patient,

I, couldn't ask for anything better despite all the [00:10:00] terrible side effects. I started with a doc, give me the prognosis. How many years do I have to live five to 10 years to having a real chance and managing my disease. And maybe even having the chance of seeing my daughter grow up.

There were a lot of sort of conflicting emotions that I was going through. That's great to have this incredibly beautiful little baby, but what if I wasn't gonna be

there for her? I, started getting a little bit more optimistic. And that's when they started talking about putting me onto a, HAIP trial.

It's a hepatic artery infusion pump trial. The, pump is like small hockey puck size sized device. And, it was inserted into my abdomen just under my skin so you could see it was a little bit bulging out and it fed chemo directly into my liver. Wow.

Which was pretty incredible. So I, felt a bit like a cyborg had it connected to an iPad so the nurses could tell how much like liquid they were putting in and how much was left.

[00:11:00] I just took the chance when I was feeling well to do like things that I like doing and I really like roller coasters,

So, so then when my brother was around in the summer we, went to Canada's Wonderland and I was like, oh, I wanna go on that ride. I wanna go on that one. It was one that like shoots you up into the air and then drops you and then I look at the sign on the side as Not, a good idea for people with pacemaker or other bodily implants, . I was like, ah, but I could just, try see what happens. . And my brother was like no, He's the responsible

Candice Coghlan: heer in you.

Natalie: I was like,? He, yeah. He was like I'm not letting you do that. I was like, come on.

And my nurse, actually, I mentioned it to her the next day when I actually went for treatment and she was like, ah, you probably would've been fine. I had this, thing inside of me, I didn't go traveling, so they didn't have to like, scan me and wonder if it was a bomb or anything.

Candice Coghlan: Right. .

Natalie: They, did [00:12:00] warn me actually that it would beep if anything would go wrong with it like nothing went wrong. But sometimes when I was lying quietly in bed at night, I could hear a tick, very faintly captain Hook, just having a clock inside me ticking

Yes. But yeah, that it was, I think it was just a crazy, experience and crazy adventure really. Yeah.

Candice Coghlan: And so you, did this trial with the HAIP pump, and what was the goal of that?

Natalie: It, it was the perfect device to feed. Chemo directly into my liver without giving me any other side effects. Okay. Which was incredible. So they could have a concentrated amount of chemo directly into there and hopefully ensure that it wasn't gonna spread anywhere else and potentially even reduce the size of the tumors even more.

Which, it did, which was [00:13:00] pretty incredible. They didn't see any new activity and some of them, they saw shrinking and some of them they said, looked completely dormant or like dead. Which was amazing. But I still didn't have. Enough of them there was still bits light lighting up every now and again on the CT scans.

So there was no way that my liver could be resected essentially in small portions for them to, remove all the cancer that way. So at the same time that it was inserted I had a Hemi colectomy where they removed a third of my colon, so they got rid of all the cancer in my colon as well, and then inserted the pump a bit of a two and one and this was September, 2020. So I had the pump for, a bit over a year. And then my transplant day was the 6th of December. And then they removed it [00:14:00] when I had the, transplant. I, had no need for it anymore.

Candice Coghlan: How did they decide that you were gonna be transplanted?

How did you get from the, chemo to that decision of let's find a, liver

Natalie: For you? I always say this, it sounds so strange for someone who had cancer to say they're incredibly lucky, but I, was I was. I was in the only province where they were doing this, pump trial.

And, then I get told by my doctors we want you to go have a chat with this guy. He's a transplant doctor and maybe, he can help you. He's also doing a trial. And honestly I don't remember much of the details. The first time I met him I was like, I had heavy chemo and baby brain fog at the time.

I do remember it was just before my first operation and it was quite a hypothetical discussion, I remember him saying, you're young relatively healthy, apart from the cancer, of course. Right. And if this operation went well and if you only had cancer lift in your liver, I would be a, perfect [00:15:00] candidate for the liver transplant trial that he was doing.

So that, that was interesting. I do clearly remember the, second time I met him, it was a few months after my operation and I'd actually gotten an infection in hospital. So I was there for 51 days. I was being fed with a tube of my nose and, I was skinny.

I was hooked up. Port morphine pump for a few months and I remember meeting him and I wasn't necessarily in the best mood to discuss being opened up again., essentially. Right, right. He was so, Dr. Sapisochin was so understanding and patient, but also brutally honest about the possible risks involved.

I think it's great for doctor to say we've got a miracle here. But, he was like, here's what we could do for you here. Here are the possible risks involved. Would this be something you would be interested in? And I said, look, I literally, I just went through quite an ordeal but I'll think about it and I'll do [00:16:00] whatever I need to do to be there for my daughter.

I went home and I started to recover and went back onto chemo again. And I, finally started to dawn on me that maybe there was a way that I could actually beat this thing. My husband I don't know how he stayed so positive. He, was like, we're gonna beat this.

We're gonna do it. And, I think I, I'm started then to realize like maybe, I was going to and then I started thinking about who, my donor would be, cuz I had to find a living donor. The, trial doesn't allow for, deceased donors. So, so you had to get a willing participant to essentially give you 60% of their and I, yeah, I started thinking about that and there was some sort of hope, I [00:17:00] guess in the back of my mind. Wow.

Candice Coghlan: That hope was that if you could find a living donor to donate their liver to you, that could potentially cure the cancer and you could be cancer free with this transplant.

Natalie: Yes. Incredibly, because up until then I hadn't heard the words cancer free from any doctor. It's, from going from stage four to being cancer free is it's pretty much unheard of. Obviously it happens, but it's yeah I, just, I didn't even, I didn't even think it was a possibility.

It was huge news. Yeah.

Candice Coghlan: When you were told that you had to go find a living donor, how did you go about doing that?

Natalie: I was incredibly lucky. I say again,

Candice Coghlan: Lucky. Yeah.

Natalie: But My, my family and close friends, the couple that I, I had told were, like offering up their livers, [00:18:00] oh, wow. Whether they were compatible or not. I, had people who really cared about me offer and that meant the world. And I know a lot of people don't even have, one person that they can ask.

And I know it's an extremely tough ordeal to go through there's the, option of putting out sort of social posts or, asking, strangers for help. And I'm lucky that I wasn't in the position where I had to do that. I eventually, gathered up the courage to ask my brother who I knew was the same blood type as me, because that's one of the requirements.

But asking to someone, even if it's someone you know, who will say yes. Yeah. To willingly get up, cut open and give you 60% of their liver is an incredibly hard emotional thing [00:19:00] to do. And I remember like crying on the phone to him saying, I know this is really tough for me to ask you, but could you give me your liver, and, yeah, it took me months to ask up the courage. But he, flew over from California and he underwent a huge batch of tests to see if he was a match. It's. Determined from body size, they have to be a similar body size to, the person they're donating to, health, to where the arteries are positioned themselves because they have to match them up in a similar place.

And, a couple of other things. But I guess it was also really nice. He got to meet his niece for the first time and they built box fors together and like a double story one, which probably wasn't like the best idea for one and a half year old to play in a double story box for, but she loved it.

And, we went to the beach and I guess it almost felt normal in some ways. Really lovely and a special visit. But in the [00:20:00] end unfortunately my brother wasn't a match. The, tests came back and his liver lobe was unusually small. And so, so they weren't gonna risk it, they, just wouldn't be enough to take so I know my brother was heartbroken actually, I think he felt it was some way he could make a real difference. And so was and then I, my husband just said, I'll do it. And I was like, what? And he made the decision to get himself tested.

And it was a long shot. He didn't even know what his blood type was, if he was even a match. And then he was a match. And initially we were like, we weren't even gonna consider it because just it would be too risky and logistically

difficult with Alice both of us [00:21:00] going undergoing surgery at the same time was quite insane with such a small child.

But he got tested, his blood type was a match. He, did all his CT scans. He went through the whole process and in the end they, used his right lobe instead of his left. He, they did like an opposite of what they usually do.

But he had such a great liver they, were like, it'll be perfect and, it'll all work out. It'll be a little bit more complicated for them. But they can do it. And yeah. So we said, okay, let's do it. Wow.

Candice Coghlan: You mentioned being a little bit nervous about the two of you being in at the same time, How did you deal with both of you going through this process?

Natalie: Yeah. Well as I said it Dave felt like he could finally do something for me, which was amazing. And, he just wanted everything to be over and done with. And me. I started drawing up our wills, [00:22:00] it's, I know it's, dark, but it's true. I, wanted to make sure everything was in place, in case anything happened. And I was conflicted and excited at the same time. And we, shipped both sets of our grandparents over. My parents and my brother took the first shift before the transplant and our stay in hospital. And then my husband's parents stayed with us for a month at home with a recovery.

We were really lucky, Alice had only just started to get an inkling of, the fact that mommy was sick. And, I remember her starting to say, chemo and things for the first time, which is like heartbreaking. And I was like, well, that's gotta stop and

So the grandparents came and [00:23:00] they spoiled her rotten with love and the parents were happy to supply it. And it worked out really well. Again, more, time with grandparents.

Candice Coghlan: Wow, that's incredible. You went through the transplant, your husband did well with, donating and, you accepted that piece of his liver well, and so were you cancer free then?

Natalie: Yes. I, didn't wanna believe it. I like intellectually I got it. But I think I only really I only really realized it deep inside after my, three month scan where they, were like, yes, you're still cancer free. And I was like, are you sure?? And they were like, yes you're cancer free.

And yeah I, don't know, some, sometimes I still don't believe it and other days it [00:24:00] feels like it never happened. And yeah. Yeah.

Candice Coghlan: That's quite the journey that your family went on from pregnancy all the way through to your husband, ended up being your donor. You're coming up now on your, almost your one year. Anniversary of the transplant. How has life changed from that initial day in the hospital to now?

Natalie: Well, I'm on immunosuppressants for the rest of my life. So I get sick very easily, which is tough when you have a daughter in daycare.

Yes. But as I mentioned sometimes, everything just feels so normal that I've forgotten. But the, small things definitely give me more joy like my daughters giggles or just the sun on my face or, I, just appreciate every little moment and I don't wanna lose that.

And [00:25:00] I think I'm more honest with myself about what I really want. I think maybe I used to, I dunno if I was a people pleaser, but I'd I'd do things that, that I was expected to do. I think. But, life is too short to to live other people's dreams. So, so I think I've been stronger to voice what I really want.

And what else changed? Well, my, my husband doesn't buy me birthday presents anymore. And I said, oh God. He said, well, I gave you a liver isn't that good now, and he made the, he was like, some, couples get like matching tattoos we've got matching scars.

Yeah. I think, and we're all stronger. We're all stronger for it I think that's, it's brought us even closer, the whole family, even though we, live so far [00:26:00] away from each other. We're, so incredibly close.

Candice Coghlan: That's beautiful. What's your favorite thing to do as a family?

Natalie: Oh man. Like a sleep. .

Candice Coghlan: Yes. Right. With a toddler. Yeah. Do

Natalie: You feel that's a big one. I think, well, in summer it was chasing down the neighborhood ice cream truck. Yes. I used to, do that with my dad when I was little. So it was really cool to, just see it from, my daughter's eyes. Yeah, handing over the money, getting an ice cream, just what do you mean trucks go around giving you ice cream.

And that was incredible. And I guess in winter Dance in the kitchen together spontaneously. It sounds cheesy but we do sometimes. Yeah. So those are some of our favorite things.

Candice Coghlan: [00:27:00] Those are the, fun things to hold onto, right? Yeah. You're in the process of, creating a new art installation that centers around your journey and the cancer patients journey. Can you tell us a little bit about that?

Natalie: I'm not even sure why I started doing it but I'd collect every one of my hospital bracelets. I received after every chemo session, every MRI, every doctor's visit and hospital stay.

I felt like it was a, record of the time I'd spent fighting. I, just, I dunno why it was a take. I just couldn't get rid of them. And then later I thought it might be quite interesting to collect other cancer patients, hospital bands and create an installation out of them. And arrange them in the way that you'd see marks on a prison wall.

You'd have four down, and then one across the days that they'd basically and [00:28:00] so from a distance you'd just see a wall of these, marks essentially crossing off fives. But when you look up close there, you realize they're actual hospital vans representing one less day on earth are spent getting chemo treatment, radiation, whatever it is, in order to gain sort of one more day with people they love.

And, I'm hoping to display. Somewhere epic on a giant wall and just hoping that it'll be a very powerful statement for human resilience, essentially. This is what I'm hoping in my mind. I just need to convince people to give me hospital bracelets now. So, yeah.

Candice Coghlan: Yeah. I think it's it.

Like you said, it's epic and it's such a beautiful mark of that resilience, like you said, and the strength and the bravery of what people go through when they're fighting through these [00:29:00] every single day. To have those moments with their family and, to get through that time to get to the other side of it where then maybe they can be standing in front of that wall.

Natalie: Yeah. And I think even if you don't get through it per se it's everyone's journey is different. And I think everyone is resilient in that

situation. People say like how, did you do that? You're so strong. I just, you're human. You wanna survive.

You, you, every, you just do it. You just do it. And, if there comes a point where you can't, that's okay too. I cannot judge anyone's journey. It's a tough thing to go through. But I, like the idea of having some sort of reminder of. The days that we have spent and other people have dedicated to cancer patients to, to make their [00:30:00] lives better.

Candice Coghlan: Do you have any advice for people who are going through the cancer journey or to loved ones who are supporting somebody who has been recently diagnosed?

Natalie: Oh man, that's a tough one. Yeah, it's a good one and a tough one. For both the loved one and the person being diagnosed you're not alone. You may feel you're alone. You may feel you don't wanna be a. Burden on anyone. And I, was the same. I wanted to show I was strong and I think the biggest thing I learned was to be humble and accept help.

And, it's okay to ask for help. And there is always someone who wants to help. Even if you don't have family. There are support groups, there are government programs which we are [00:31:00] lucky, to have enough, a lot of in Canada. But there's, always something. There's someone online, there's talk to someone, get someone to help you.

There'll be a meal train. There'll be someone willing to help you clean your house. I think yeah we, need to know we are not alone. And I think, and then just on a side note, for, young cancer patients, follow the cancer patient on Instagram as in the cancer patient and there are lots of great memes Cancer Muggles will totally not get, and you will show them to your spouse or your friend, and they will not get it, and you will laugh. And, it's just a special community and they've got some really good discussions that they have in their story section.

And and I think in [00:32:00] that way you even feel you're not alone. You're like, I thought that was only me. That person is also dealing with that. And, I think having a sense of humor makes everything more bearable. And that's, what I try to do during my journey. Amazing.

Candice Coghlan: And I love that you call people who have not had cancer. Cancer, muggles. That's too funny. Yeah.

Natalie: There's a whole lot of language, for, young cancer patients. That's great.

From, scan anxiety to cancer, muggles to, there's a bunch of them and it's yeah.

It's, great to know you're not alone. It's, important.

Candice Coghlan: Is there anything else that, that you'd like to add that we didn't talk about?

Natalie: What else could I add? I'm one of the lucky ones. My story could have gone incredibly differently.

I, have some survivor guilt I know some people in a very similar situation to me with young kids. And their cancer [00:33:00] is, not going away. Its spread too far that they weren't given the opportunities I was given with the trials that I was on. And it's hard seeing them go through it.

And there's only so much you can do and be friends with them and tell them that you're there. And it's tough also with my cancer there's a real possibility of it coming back especially in the lungs. But I, just try and appreciate today. I'd love to say I try and be happy every day.

You can't always be happy. But you can always appreciate something or at least be curious, even if the day turned out terribly be curious about what you did and learn something from it and look forward to the next day, even if you dunno what's gonna happen.

Candice Coghlan: That's beautiful. Thank [00:34:00] you. We talked about this remarkable person that came into your life who is here on the line with us now. . I'm wondering if you can introduce him

Natalie: for us. Sure. Oh big, ask. Dr. Gonzalo Sapisochin is an associate professor of surgery at UHN, multi-organ transplant and h pb, surgical Oncology Division of General Surgery.

And he also gave me a new liver. So welcome Dr. Sapisochin. Thank you.

Candice Coghlan: I'm wondering if you can tell us a little bit about yourself.

Dr. Sapisochin: As Natalie was mentioned I'm a transplant surgeon and also a pary surgeon. I've been in Canada now. I was talking with some of my colleagues yesterday.

I couldn't believe it. I've been here for nine years now, and I came from, Barcelona, Spain for some training. We came for two years and we've been nine. I specialize in, dealing with liver [00:35:00] malignancies. Primary liver cancers. Like hepatocellular carcinoma or cholangiocarcinoma.

But I also specialize in, in metastatic disease or spread of, disease to deliver like colorec metastasis. And I have a a strong research interest in in advancing science in the knowledge of, these kind of cancers. And especially on a concept called transplant oncology, which is actually utilizing transplantation to treat patients with either primary liver malignancies for or secondary liver malignancies.

So I dedicate a lot of my time, obviously operating patients, but I also I dedicate a lot of my time in, doing research and I have a medium to large research team with a lot of young individuals that are very enthusiastic and, we have different research projects going on any given time.

Out of work I'm very into sports, so I'm really into cycling, so I cycle a lot [00:36:00] as much as I can and really into sports. And I'm a father of two, two kids that are very busy. And yeah, it's a little bit of a summary.

Natalie: What made you interested in transplantation in the beginning and specifically liver transplant?

Dr. Sapisochin: I've been asked that before and it's I've, thought quite a bit about it. So my, both my parents are doctors, but they're actually both psychiatrists and they do pure psychoanalysis, so not really close to surgery.

My, my grandfather was a surgeon in Argentina and he actually was at the time, and this is when he was operating in the fifties liver surgery is not that modern actually. Liver surgery has been with us probably for 40 years. And at the time they were he was starting to do some liver, a biliary surgery.

And since I was a kid, I knew I wanted to be a doctor and since I. Kid I actually knew I wanted to be a surgeon first, a cardiac surgeon. But then when I was [00:37:00] in, in, Madrid, my third year of medical school, I joined as an intern. It was called, at the time, a surgical unit. And it was one of the surgical units in Spain that were doing more liver transplants.

That was a very famous surgeon now retired. And that was the first time I saw a liver transplant. And I clearly said, "Well, this is what I'm gonna do. This is unbelievable, and this is exactly what I wanna do." And that was in, in my third year of med school. And then I started focusing on, that and I couldn't it's actually absolutely fascinating, right?

A liver transplant or an organ transplant. The first time that the blood goes through the new organ again, and the organ kind of becomes alive again. It's something that, it's extremely unique and obviously it also really attract me the, how much you help people.

It's, you really impacting lives in a way that it's really, strong. The impact [00:38:00] is, brutal in someone that has either organ failure or has a incurable cancer. So I think those were the both the, reasons I, got into this.

Candice Coghlan: Thinking about that liver transplant that kick started all of it, you were also part of the first study in North America that showed living donor liver transplants were viable for people who had controlled their colorectal cancer and liver tumors.

Can you describe to us, what is done to help those patients to get to that point where they could have that transplant?

Dr. Sapisochin: Yeah, for years people especially in Oslo in Norway has thought, have thought that as we do in surgical oncology, we know that patients with, liver cancer, when, you know, when the cancers are obviously confined to the liver.

The only real potential for cure is the combination of systemic therapies. But surgery you there's, real no real therapies. Even though [00:39:00] the world of, immunotherapy is really changing, there's no real therapies that cure liver cancers or, metastatic disease to deliver.

So we know that the only option is to remove these tumors. And even though we do very advanced surgery, and there's a lot of things we can do with the liver delivery is a fascinating organ that regenerates, it's the only organ that regenerates. And that's actually something that's absolutely fascinating.

There's many patients that we can't operate. So the thought was, if the only way of curing these patients is removing the disease, and the only way to remove the disease is removing the whole liver. And you can't live without a liver. Why don't we start doing transplants?

And this started happening in, in Norway, the issue in Norway. And I actually know that the people there very well. They, have a, very interesting problem that is that they have a surplus of organs, so they have more organs than patients in the waiting list. Wow. Which is certainly not the problem we have in North America or in many other countries.

So in Toronto the only way to be able to do this is with a living donor. And, we are thanks to many of my [00:40:00] partners and, senior colleagues that started this amazing program many years ago, we have the benefit of being able to offer living donation in this setting. So we put together, we, are one of the only programs doing this in North America.

And with other two programs we, put together through serious demonstrating outside of Oslo that this could be done safe. And that this could be done and, actually help patients. So the way these patients are selected, it has to be patients that have disease only in the liver.

Obviously if the cancer has spread outside of the liver, this is not a possibility and they have to be very stable on systemic chemotherapy. And that's a way of testing the tumor biology. Right? So if the tumor is controlled with systemic chemotherapy, and in, in some cases, in Natalie's that she had direct therapy to deliver through a pump it's a way of, controlling the biology of this tumor that tells us that these tumors are not gonna spread after the transplant. And those are the candidates we're looking for this [00:41:00] possibility.

Natalie: You probably answered this question but any sort of other criteria you need to meet to, to have a living donor transplant as a patient.

Dr. Sapisochin: Yeah, so in this setting the, criteria we utilize, so these are patients with, spread from the colon cancer.

So the colon, the primary tumor has to be resected. So and usually we have to wait at least six months. And as I said they have to be controlled. They have, they can't have disease outside of the liver. And currently we're only doing living donors given the gap we have in Ontario between the number of organs and patients in the waiting list.

So patients have to have an available living donor. But that, that, those are the main criteria.

Natalie: Yeah, I was one of those lucky ones. .

Candice Coghlan: Yeah. What would be the benefits and risks of having a living donor liver transplant for people like Natalie and other cancer patients?

Dr. Sapisochin: Yeah. I'm talking specifically about colorectal liver metastasis and they're still under investigation even though there's [00:42:00] more and more data coming from actually other centers besides Oslo and the Oslo data is being updated, that this seems to really impact in the survival.

So from, in terms of benefit, as I was saying removing all the diseases, if it's only in the liver, seems to really benefit patients. And even though we don't have data still comparing transplantation with the standard of care, which is chemotherapy, even though there's a trial in France looking into that, it seems that if you try, if you extrapolate, which is not something you know perfect to be done, but if you extrapolate what is the outcome of patients only on systemic chemotherapy compared to transplant, it looks like the benefit of transplant is there.

Obviously this is a very big operation that can be done to everyone. Patients need to be healthy. There's definitely a risk for the recipient because these are one of the biggest operations we do in the abdomen. But in general in, in Toronto, we have a long experience with over I think at this point, over 1200 or 30 cases of living [00:43:00] donation.

We're the largest program in North America, so it can be done very safely, and we can never forget that. There's also a risk in the donor, which is obviously our main concern. It's a healthy individual that's doing becoming a hero. If he or she was not a hero already.

And there's definitely a risk in the donor. The risk is, small that's something that we obviously. Hugely into account because at the end of the day, we're removing around 60 to 70% of the liver in the donor. But usually these, donor do very well and after a week they're home and, don't have major, problems.

Natalie: Amazing. It is amazing. Heard this so many times and it's amazes me every time. Yeah. Yeah. And then I'd just like to know are there any sort of long term impacts to someone's health? You know me, whose undergone chemotherapy as well as part of this? Yeah

Dr. Sapisochin: I

[00:44:00] think I think it's the long term outcome is, obviously hard to know because there's no that long term follow up in patients that had chemo and now have immunosuppression, et cetera.

Obviously, as we were talking before, we're always, worried that the tumor may come back, but obviously the more the years pass, the less that risk is and we think that we can actually treat many of the patients once the tumor comes back. I think the main risk is obviously the body doesn't like external drugs and chronic immunosuppression impacts many organs, et cetera.

However, I would say that it's I haven't taken them, so I'm talking about what patients say, so maybe now that you would be better. But in general, these drugs are well tolerated. And I always say I, I had a patient back home in Barcelona that became a friend. And he was doing triathlons after a liver transplant.

He, and he was actually pretty good and he would be really good at cycling, running swimming. And so I think [00:45:00] most patients after a liver transplant have a completely normal. Live with a very, high quality of life, in most cases.

Candice Coghlan: Can you talk about those immunosuppressants that are needed?

Are the immunosuppressant therapies any different in somebody who's received a liver transplant because of cancer versus somebody for another reason?

Dr. Sapisochin: So that's a, it's a good point. So as there cancer immunosuppression, there's always has to be a balance between our body.

Like we know from, from, cancer biology, that. Our body always is fighting against pre-cancer cells, and the body knows how to find them and destroy them before they become a cancer, et cetera. And obviously if you're decreasing your immune system with immune in immunosuppressants, there's a risk that the cancer may actually come back earlier, et cetera.

That's been really shown in, basic science, in laboratory data. There's not a lot of data, real good data in, in in patients and in, in, clinics, [00:46:00] but it makes sense. So what we try and do in patients transplant with cancer is to decrease the immunosuppression as much as we can.

I think we've learned in the last 20 years to be less scared about rejection and, be able to have lower levels of immunosuppression and, and, be less worried

about rejection. So I think that's one of the things we try in, patients for cancer is minimizing immunosuppression.

Candice Coghlan: We talk about living donation. I know how incredibly beautiful living donation is and the impact it has on our lives. Natalie is amazing proof as well of what it does for us, but do you have an idea with all of your work that you do, why those rates are so low and what we could do to

Dr. Sapisochin: Increase that?

Yeah. Well I'm gonna, actually, I don't know if I can do this, but I'm gonna challenge you that it's, low in Canada.

I think actually, so it's depending what you compared with, right? Like our rate of, living donors in the liver transplant setting, it's around [00:47:00] 20 to 25% of the liver transplants we currently do are living donors. Okay. And that compared to other centers in the Western world, we are actually the largest program and we have the largest proportion.

So this is actually high. In the Western world, obviously it's it's very different than in Asia. In Asia, most transplants are done with living donors. But I think your point is very well taken in, the sense that we still have 30% of patients that never make it to transplant and die while waiting.

So I think that is where. I think programs like ours need to educate about the importance, and I think we've been getting better at showing one data. So we've done many studies showing that if you have a living donor just not for this indication, but for our indications, the chances of you surviving since you need a transplant are higher because your chances of, dying while waiting obviously decrease.

And and I [00:48:00] think education of, the population is key by doing science and, research and demonstrating with data and then by educating people. So that's why this program is, so important.

Natalie: How do you ensure that patients like me going through all of this, not only just survive, but have a good quality of life and thrive afterwards?

Dr. Sapisochin: Yeah. There's a lot of education that goes into it and, programs to, educate the population. I think one of the things is that again, as I was saying in the beginning transplant works and patients actually feel very well after a liver transplant, right?

I think patients as, time goes by, realize that that they're back to normal and, feeling well, and this, obviously doesn't, it's not, it doesn't happen in days or, months. It probably happens in maybe years or, at least at least many months.

But I think patients actually themselves feel [00:49:00] really, well. And obviously in someone like, you, there's always this nerve wracking moment of doing scans every three months and getting to those scans and making sure there's no recurrence. And it's the anxiety around those, three months.

And I think what we do is to try and help the patients go through that journey that we know is definitely very stressful for the patients it's also stressful for the teams when we're waiting for those scans. Absolutely. So,

Natalie: Yeah guys care just as much as we do.

So and, I like that and I think, you know that, I agree there's totally that scan anxiety, but knowing that you guys every two months you're monitoring me and if anything does happen, We'll be able to sort it up. You won't be catching it years down the line. And I think for me, that's quite a big relief, especially when I'm trying to reduce my stress as much as possible.

So, so thank you. Yeah.

Candice Coghlan: And [00:50:00] thinking about those scans and follow up for, all transplant patients, but for your patients specifically, is there and, I know you might not have long term data, but is there a, rate of success for having these liver transplants for cancer patients?

Dr. Sapisochin: Yeah, the data we have, again it's, relatively limited because as I tell patients now, when I see them in clinic, like there's probably. I don't know the numbers. We don't have them we're working on, or international registry, but I don't think there's more than 130, 150 transplants done in the world for this condition.

So it's really new and rare, we know with the data we have is that now there's 10 year survivals with no recurrence, meaning patients that were transplant more than 10 years ago, the cancer never came back. They're alive with and they're cured. Right. So, but that proport obviously the numbers get smaller because we don't have enough, follow up and enough data.

I think that it is, [00:51:00] reasonable to say that the chances of being alive five years after a transplant like this nowadays for this condition for colorectal

metastasis is probably around 60 to 70%, and the chances of the tumor coming back is probably in the same range in the 60 to 70% range. I think what's important that we were just discussing is that we follow the patients very closely, and in case anything was to pop up, We would probably aggressively deal with it, meaning that depending where their recurrence is, we would treat it surgical.

Candice Coghlan: And I know we don't like to throw around the word cure often, and people sometimes will ask me as a transplant recipient, well, is your kidney disease cured now that you have a transplant? And it's, not a cure it's a different form of treatment. Sure. But when, you're transplanting patients who have liver cancer, is this a cure for that cancer or would you say it's more of a treatment that is a long term treatment?

Dr. Sapisochin: It goes to the definition of, cure. [00:52:00] I, think that obviously for the condition we're talking about today, colorectal metastasis, I don't think we have an answer yet. We do have patients there's literature of patients that are cured, but curing cancer is obviously a very big word.

But I can tell you that for other cancers that we transplant, like Hepatocellular carcinoma, which is primary liver cancer, I think there's now very good data of median survivals of 15 years with no recurrence. And I think that is cure. So we'll have to see. We've learned obviously the, cancer we transplant most is primarily rare cancer er carcinoma.

And now we have very long term data of patients that are cured. And that's the, when we transplant patients with metastatic liver disease, the goal of the transplant is clearly cure, even though, again, it's hard to define cure in this setting.

Natalie: I, might have mentioned this to you when we chatted last time. I was just curious how many patients you've. You've operated on since my [00:53:00] transplant a year ago.

Dr. Sapisochin: I think when we did your case, I can't remember if you were our case number four or five some anyway, we a total of seven, so I think after you would've done either two or three. So we definitely did a case, we did a case like less than a month ago, but then we did a couple of cases. We did another case like ng, I think probably three after years. Okay. Yeah. So we've done a total of seven and we have three more that will happen very soon, hopefully in the next three months.

Since we've started, I see a candidate for this, at least a candidate a week. Wow. Not as Natalie was saying at the beginning, not every patient is, a candidate and, then some were able actually to operate and resect, which is something that we sometimes thought with, Natalie at some point.

It's, a difficult disease to decide. What I can tell you too is that our own data and others support [00:54:00] that when patient have a lot of disease in the liver, even if you can take it out, probably there's gonna be more data showing that transplant is better. So I think what's gonna happen, and I, I'm fortunate enough that I've become a key opinion leader in the topic.

And I go around the world giving talks about the topic that more and more this is happening in most places around the world. There's more data coming out, there's more evidence that this works. And I think if we had this podcast in five or 10 years, I think we're gonna see that this is a clear indication.

And there's actually already discussions here in Ontario with the government and the possibility of u of utilizing DC donors for, this indication, given that there's more and more data showing that this is a good very good outcomes for this these scarce organs.

Candice Coghlan: How would that impact a cancer patient if they have to wait?

Dr. Sapisochin: So that's, obviously a very smart [00:55:00] and excellent question, and that's why living donation is so, so good in this setting because with living donation, you can plan the chemo, you can plan when to stop the chemo.

Natalie: Fascinating.

Candice Coghlan: You are part of the International Society of Liver Surgeons, which sounds like a really cool, like James Bond, like society.

Dr. Sapisochin: That's actually pretty fun. You're right. .

Candice Coghlan: I'm wondering if you can talk to us about that society and any of the innovation and research that's, happening either at UHN or around the world.

Dr. Sapisochin: Yeah, so it's, not James Bond, but its fun, it's a fun group of surgeons. It's, a society that was, is built between the Korean, a Korean group

and, a group in Turkey. And it's basically a group of individuals that are, we're all doing similar things and trying to advance science in, in the field of transplant [00:56:00] oncology organ transplantation and, surgical oncology.

There's actually gonna be a meeting in, Istanbul, and there's a lot of innovation there. What, many people are starting to do is to do is, utilize with disease organs we can actually split organs or split livers in two.

So it is to utilize a small proportion of liver, way smaller than what we, for example, utilized in, most living donors like Natalie, where we utilize 60% of the liver here is probably like 20% of the liver. And transplanting this in a way that its auxiliary transplant without removing the other liver, waiting for that liver to regenerate and then removing the deceased organ.

So this is something called rapid procedure and it's a combination of some, it's a combination of utilizing the concept of transplantation and the concept of liver regeneration. So it is [00:57:00] utilizing both and manipulating the body to grow what we want and not grow what we don't want. And then weeks later, removing part of, the disease liver.

So it's actually a very interesting concept. It's all very innovative. There's probably, again, there's probably been. 15 cases done around the world. And it's gonna be a group of individuals discussing this. It's a very interesting group and a lot of things happening the group actually created I think six or seven research or study groups. I, actually lead one in living donor liver transplantation and it's actually looking at outcomes of, living donor liver transplants for Hepatocellular carcinoma around the world.

So it was like an open study and there's been groups from all around the globe participating. So lots of very interesting things happening in that group.

Natalie: I, guess maybe, it's too heavy [00:58:00] and just tell me if it is, but how do you, deal with it every day? How, people come in who, who are hoping to be part of your trial who can't get in, and how, do you, tell them no? How do you put someone else's life in your hands and give them a new liver and be confident enough to do that and know they're gonna survive.

I just, I like, every time I think about it is I could not have your job, and I'm glad there is someone like you. But how, do you do it every day? Yeah.

Dr. Sapisochin: It's, a fascinating job. I wouldn't change my job for anything I do, but I think you're getting to a point that we also go through a lot mental stress and it's key to be able to separate things as [00:59:00] much as you can.

And some of us are not as good as others to separate things, and I'm, not great. I think what's worked for me is one is, to be very honest with patients. I am very, honest and I find myself in situations where patients come to my clinic where no one has really told them anything, even though they've seen a lot of doctors previously.

And I'm very honest, and I think that's important. And I think, when, things go badly and we think about all the Sadness that goes, as you were saying, of telling someone no you also have to grab us with people like you and think about all the beautiful stories that there are there and all the people you can help.

And then my cope mechanism is, exercising. That's my that's where I release tension. And I couldn't live without that. Right. And that's why I'm probably that obsessed with, cycling, because that's a bit of my that's [01:00:00] my way of releasing stress. And probably that's, that's how I, cope.

And we all find different coping mechanisms because it's definitely stressful and, hard and the surgical piece, I'm sure you will do it. It's just a matter you get used. You just get used to operating and it's and it's, beautiful actually. It's, be nice.

Candice Coghlan: Unfortunately my coping is baking. Yeah. Which means there's a lot of sweets in the house.

Dr. Sapisochin: Well, that's okay. Yeah. But for me sports is like meditating. For me, like cycling is like meditating actually.

Natalie: I just wanna say thank you for, caring and thank you for giving me my life back.

Dr. Sapisochin: Yeah. No, those are very nice words.

Natalie: So I appreciate it.

Candice Coghlan: I've got one question for [01:01:00] both of you and I'll start with you, Natalie. And this is what I call the really hard hitting, difficult journalistic question.

If you were a tree, what kind of tree would you be?

Natalie: Oh my goodness, if I were a tree I guess it would have to be something indigenous because my father he's a naturalist and gets rid of invaded plants for a living. I have a, silver maple that I'm looking at right now outside in my garden.

And apparently it's one of the oldest in the neighborhood. And part of our contract with our landlord was that we weren't allowed to chop any trees down. And it was actually one of the reasons why, we decided to, to rent the place because it's it. It's huge. It's got musk growing on [01:02:00] the side of it.

It's a pain when all the leaves fall down and you have to fill up like 12,000 bags. But it keeps us shaded and, it's peaceful and when the wind blows, it's like sways gently and it just goes with things and, I wanna be that tree. I just wanna have some peace and quiet and go with the wind and enjoy the sunshine.

I'm. That's

Candice Coghlan: beautiful. And what about you?

Dr. Sapisochin: I had the, I guess I had the two minutes that Natalie was talking to think about it, so I had a little bit more, more time to think about it. You know what, I think I would be one of those California sequoias. That are like high tall and you can see the world from up [01:03:00] there.

I, when I've been there in those national parks, it's just unbelievable how I'm sure that what happens up there only they know. But I'm sure it's, absolutely fascinating. As Natalie was saying, that heights just dealing with air up there and wind up there and rain up there and birds up there.

So I would be a, yeah, one of these Californian red sequoias.

Natalie: That's beautiful.

Candice Coghlan: And thank you so much Dr. Sso. So, so grateful for your time and for all of the work that you do. Natalie is, incredible proof that, you're, saving lives and not just for the one person, but also for the family and for, their friends and their communities. So thank you for the incredible work that you do every day.

We're so grateful.

Dr. Sapisochin: Thanks for having me.

Candice Coghlan: And thank you Natalie, for being so open and, vulnerable and sharing your journey and for educating other people [01:04:00] about making sure that they're on top of their health as well. And I'm so happy to know that you're coming up on your anniversary and that things are, going well.

So we'll definitely have to celebrate that too.

Natalie: I know, I was actually talking to my husband and I was like, what are we gonna do? It's my one year anniversary of it's a free, I was like

Dr. Sapisochin: definitely celebrate it.

Candice Coghlan: Absolutely. Yeah. I bring you a slice of cake.

Dr. Sapisochin: Yes, exactly. Bring me a slice. I would love that.

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