

Living Transplant Season 4 Ep 11

Candice Coghlan: [00:00:00] Welcome back to the Living Transplant podcast, season four. In this episode, I sat down with Afsana Lalani, a cat lover and nursing graduate who made an appeal to find a living liver donor to save her life. We talk about being young and living with a chronic illness, facing death, and how a supportive community can make all the difference.

We are later joined by Dilshad Lalani. Yes, you guessed it, Afsana's mother. Thank you. a caregiver and a pediatric nurse practitioner. She speaks about the family journey in supporting someone on the transplant waitlist, being an emotional support and what it was like to be a nurse practitioner living through the process with her daughter on the verge of death.

Please enjoy. Welcome back to the Living Transplant Podcast. I'm so thrilled to have Afsana with me first, and then we will have her, her mom joining us, Dilshad, in a little while. Thank you so much, ladies, for joining me today. [00:01:00] Thanks for having us. Thank you and it's my pleasure. So I'm going to start with you Afsaneh.

I'm wondering if you can tell our listeners a little bit about yourself.

Afsana Lallani: Yeah, so I'm 24 right now. I live in Toronto. Alone with my cat, and I just graduated university in a nursing program this past June. And I used to play ice hockey growing up as a kid, but then when I was sick, I had to stop. So I picked up yoga and more painting.

I also work in research and other health roles where I am a lived experience advisor. Okay. Or a lot of different health, um, organizations like PSC Partners, which is a liver disease organization.

Candice Coghlan: Incredible. And so, you know, you, you touched a little bit [00:02:00] about, um, yourself without going too deep into it. Um, you mentioned liver disease and, and supporting people, um, within that community.

I'm wondering if you can bring me back to just before your diagnosis and, and tell me a little bit about how you were feeling and what led you and your family to go and, uh, get some support. So I was feeling pretty

Afsana Lallani: tummy sick, I would say. When I was 16, and I've always had a very picky eating habit growing up and a lot of issues with trying to gain

weight because I'm underweight, but it's just because of a fast metabolism, so these tummy pains were really new to me.

I'd never felt them before. And I was extremely exhausted all of a sudden, so I thought maybe hockey was too much at that time, or school was just really stressful and pressing, but the [00:03:00] exhaustion never went away and neither did that tummy pain. So, I ended up catching the flu one weekend when my parents were out of town.

And that tummy pain came back in the middle of the flu, and it was so painful to the point where I couldn't move. And that's when I knew something was wrong, and I needed medical help. So as soon as my parents got back to town, I was like, I can't do this, let's go. So we went to the ER, and that's where my workup began with a lot of blood work, MRIs, liver biopsies, that's the kids.

I definitely knew immediately at the ER that something was wrong, and my numbers weren't normal, how I was feeling wasn't normal, and so clearly it led to a diagnosis eventually of PSD or primary sclerosing cholangitis. Which is a really rare autoimmune liver disease. And [00:04:00] unfortunately it has no cure. So when I got this diagnosis, I was kind of scared and I didn't know what this disease was.

The internet said I had 15 years to live, but that wasn't reassuring and that there was no cure. So I really thought I only had those 15 years, if anything. But I was also a little bit happy that I got a diagnosis in the first place. Because we were going through these pains and these hospital visits so much that getting the diagnosis was a relieving feeling that I had more answers now and that I wasn't going crazy thinking that something was wrong with me when nothing was.

There was something wrong.

Candice Coghlan: And so 16, you find out that you're diagnosed with this rare autoimmune disease and what you're in hospital with your family, you know, you're a busy young person. How did you guys, [00:05:00] you know, shift gears and, and I guess get into the mode of this is our diagnosis. This is what we need to do to move forward.

And when did you find out that a transplant was the option to, to survive?

Afsana Lallani: Well, when I got the diagnosis and I was told there was no cure, they did tell me that there is a chance I could get a transplant down the

road if it does come to that, but I was reassured by my team in pediatric care that you may not ever need one.

And it's very unlikely that this situation would happen to me, but it did happen to me and I did hear that news when I crossed the street into adult care. And my doctor saw that I was getting sicker and I was deteriorating and my quality of life was going down. So they made a referral to the transplant team at that point once I [00:06:00] exhausted all treatment options.

I had to go through all that exhausting treatment options steps first, so a lot of medication trials and treatment options that I continuously just didn't respond to, so I had to go through the transplant pathway, but I actually ended up going back to my doctor. When the transplant team said it wasn't time for me, because I wasn't sick enough.

Which is interesting, because you have to be sick enough to get a transplant, but if you're being referred there, it must be that you are sick enough. So that was another hurdle our family had to kind of go through and persevere for another year and a half before I did get that second referral back to transplant to go through the process fully.

But leading up to transplant, dealing with my health as a family was very different than our [00:07:00] usual lives at that time, I think. I mean, I tried to take the illness as something in the background of my life. It became the foreground of my life later, and I did go to university, but I factored in, factored in the point that I am sick and I need to stay near a transplant center.

That may be something down the road. So I chose a university near my transplant center and near my family for the support I needed. And my dad even switched his job so that he would be working at home or more locally and then in the evenings whereas my mom worked in the daytime so that at least one parent would be around to help take me to appointments and go to different like procedures and even if I was just feeling sick someone had to pick me up from school at that time it was high school so it was a huge [00:08:00] adjustment even my sisters didn't know what this disease was, it's just this monster living with us now.

So as a young

Candice Coghlan: person, you know, we, um, we expect to go through certain things at certain phases, you know, going through your high school career, dating, um, you know, the acceptance into university, all of these kinds of

milestones that you go through between that. Kind of 14 to 21 age. And it's such a critical time in our lives.

And how did you balance trying to stay a kid, but then also, you know, accepting this reality that you're living with a chronic illness?

Afsana Lallani: I think that I accepted it pretty early on. I already had one chronic illness from a toy arthritis for my entire life. So getting another chronic illness seemed like another badge to wear at that time.

And I didn't let it define me. That's

Candice Coghlan: [00:09:00] amazing. And so when you got to the point where they said, okay, we're at that, that tipping point of you are sick enough that you need a transplant, but you're still healthy enough to be able to go through this surgery, your, your family, um, Stepped up and and tried to see if they were a match and, um, we've discussed unfortunately there, there wasn't a match within your family.

So how did you move forward to look for a living donor while you waited on that deceased donation list?

Afsana Lallani: It was a little disheartening and I didn't know what to do. But eventually I came to the idea of this social media public appeal campaign, which I started on Facebook. But that initial want to do that was not there.

And I really didn't want to have to expose myself on social media like that about my health, when I was a private person when it came to [00:10:00] that subject. I didn't like telling people, I didn't like the judgment that came along with liver disease. And I also didn't like people who were my age thinking that it was too hard to be friends with me or too much to be around me and not know how to act.

But really, I was the same person. I was just with another badge.

Candice Coghlan: Yeah, that, that's got to be something all on its own, right? That you just want to be known as Afsana, like you don't want to be known as my sick friend. Right. How did you stay positive through, you know, your social media campaign and the wait and wondering?

I know for most people the wait is sometimes even harder than the act of the surgery.

Afsana Lallani: Yeah, it was really hard to wait and I tried to keep busy while that campaign was up and running that I finally had the [00:11:00] will to press post on. And it took nine months after the launch of that campaign to find an anonymous donor for me.

And during that time, I would say I kept very positive for the first half. Then the second half, I started to lose a little bit of hope. And then I lost my faith in the medical system, which regained when I got a donor call. But I did lose it. And I tried so hard to keep my positivity in my grasp. It didn't work for me after a while of waiting because I saw people around me in my community that were getting transplants and who were listed after me.

But they got theirs first, and I always questioned why not me? When is it my turn? How many more people get a liver and me not? [00:12:00] So, I had a lot of questions in my head as I got sicker waiting, but that positive first half went really well for me. I focused on friends, and I kept doing things in my daily life that made me still feel like a person separate from my disease.

Thank you. Even though I felt pretty restricted in what I could do in a day. I couldn't even wash my hair. But just something simple as petting my cat that day or cutting an apple was the biggest deal for me. That I was happy with just that. I could still be a cat mom person. That's, that's someone I want to be because I love my cat.

So when I was so sick and waiting, feeling like I had other Responsibilities kept me going and I also had a huge support system behind me. I can't echo that enough how important they are. [00:13:00] But they helped keep me positive. My friends, especially my family and everyone really behind me. I go to a prayer hall.

And there was a huge community there that supported me. And so I had lots of people who were helping me and keeping me positive. So I really appreciated that as well.

Candice Coghlan: So you said, you know, you waited those nine months and then you got a call that a donor had been found. What did it feel like when you picked up the phone and that was the call that you'd received?

Afsana Lallani: My immediate feeling was that it felt like Christmas morning, but in the form of a phone call. And I was really excited to hang up the phone and call my mom immediately. And that's exactly what I did. But as soon as I hung up the phone on my mom and got into my apartment, because I was

actually walking home from an appointment, um, I [00:14:00] came back up to my apartment, and I realized the reality of going through a transplant and I was so nervous and scared, but That fear went away because my faith in the medical system was restored.

Candice Coghlan: Yeah, getting that call must, uh, you must have all of the emotions, right? All sides of the coin all crashing into each other in one moment and not a lot of, Um, prep that you can have, you know, eventually the call is going to happen, but you just don't know when, right? So all happening at once. And so you, you went in, um, you know, your incredible donor donated a portion of their liver to you and, and, uh, you woke up the surgery was a success.

How was that recovery for you?

Afsana Lallani: Recovery was hard. I spent one month in the hospital recovering because I did have hiccups. [00:15:00] But I did come out of the hospital after that one month and learned that sometimes it's not as great to be out of the hospital during recovery because there's a whole other kind of recovery at home.

Because you don't have like your healthcare team to support you and get your meds for you. It's your turn to get up and go do it. So it was a lot of adjustments and a lot of learning that had to happen, including learning how to sit in a chair after a surgery, how to go walk down the hall in your unit.

That was all very hard to do while in pain right after a surgery with such a big incision on your tummy. But I was very motivated because I wanted to walk, eat. Go to the bathroom and go home. Those are my three goals. I'm focused on hyper focus. I would say [00:16:00] I'm going to agree with that. I think I, um, once I did get those checkpoints done with my three goals, I ended up getting acute liver rejection and so that kept me in the hospital for an extra two weeks.

And it was a tough treatment to go through, but I made it through after a while and. Here today, my liver is very happy, and we get along now just fine, so I don't have the texting anymore. And I got to go home to my cat right before Christmas, so all the timing worked out there. But then at home, getting out of bed was a whole new challenge that I had to learn how to do.

Baking, choosing crackers, cleaning. That was all hard to do with the new scar, so I had my mom there to help me. She stayed with me for two months, I would say, [00:17:00] after surgery, when I was discharged. And she helped me. She

made my cheese and crackers for me, and she made my tea for me, and she helped with the cleaning a lot, and it was nice to have someone around to just talk to.

Especially when you're on all those medications for the first time and learning to adjust them. It was nice to have someone to talk to.

Candice Coghlan: And yeah, that that roller coaster. I remember my, my nephrologist after my transplant said, um, don't be afraid of the word rejection because most patients go through rejection.

It's just making sure that we catch it and we can treat it and then you can continue on. And I remember hearing that and thinking, oh my goodness, but it kind of took that, um, That edge off of it to know that it's, you know, a lot of us are in this and that there's others that have been through this before and reaching out to those [00:18:00] people who, um, have been through that.

But, you know, thinking about your recovery, you. We're also going through school at this point. And so did you put, did you, um, pause your, your degree while you were, um, in hospital or did you just pause it, um, for the actual surgery?

Afsana Lallani: So I did end up taking a semester off school for my transplant and recovery time period.

I, I lucked out because my transplant happened during my university's exams and winter break. So it led into a brand new semester so I could complete the semester I had already been in and then take a leave for a semester, which I really didn't want to take. I tried, I went to the first class in January, but my brain was not ready to go back, I think, and my recovery wasn't there yet.

Oh, I [00:19:00] took the semester off and focused on building up strength and working my mind again. And then once the summer hit, I did summer school to kind of catch up a little bit and then go back fully in September.

Candice Coghlan: That's incredible. And so you recently graduated with a nursing degree, like you said, congratulations.

How did that feel to walk across that stage and, you know, get your diploma and shake that hand with that green ribbon around your neck, knowing that you've been through all of this and yet still you, you persevered and now you're going

to be able to. You go back into that system that just, you know, it saved your life and help other people yourself.

Afsana Lallani: Yeah. Um, I do want to say the green ribbon was so important to me to wear. I know it wasn't typical for a student to wear [00:20:00] something that wasn't part of the graduation gown that they provide. And I had to go through some channels to get them to agree. I, it was important because I wanted to represent what I've been through, through this degree, and to bring awareness to what it is, and to say thank you to everyone who was a part of my journey to get me to cross that stage.

And it was extremely rewarding and accomplishing to get to walk across the stage finally. And I've been through so much with my health during that degree that when I took each step walking across the stage, it felt like I was being rewarded for my perseverance, my determination, being brave in the degree and in my health.

But also, I just felt so complete and whole and that my dreams finally came [00:21:00] true, and I was going to be a nurse, finally. And that was the mindset I had when I was sick, just to focus on reaching my goals. And that's what I finally did. And I was really happy about that. I'm proud of myself.

Candice Coghlan: Yeah, you should be very proud of yourself.

That's such an incredible accomplishment. And like you said, such bravery and perseverance to, to get there. So congratulations. And the people who are going to have you as your, their nurse are incredibly, uh, lucky that, that they get to have you. That's, that's amazing. So I'm wondering, um, if you can tell me a little bit about too, um, you were part of our great actions, leave a mark campaign recently, and you know, there's been a lot of press around that and discussion about living organ donation and the and what it all means to you.

Why did you decide to join the campaign? [00:22:00]

Afsana Lallani: I believe that my scar is really a beautiful mark, which is a big part of the campaign and what the meaning is behind that. And for me specifically, that mark represented my strength and perseverance through the adversity. And it reminded me of all the love and hope in the world that I was awakened to, I think, after my surgery.

I was reminded through my SCAR that there are really rare people out there and really kind hearted, loving people out there, selfless people, and I happened to

have caught one of those people and gotten the rarest gift ever from them, which is the gift of life. So participating in the campaign meant I got to show people my SCAR, which, N turned into, I get to [00:23:00] show people.

Who I am and my star is me and it is my supportive community around me. Which I was really proud to share with the world.

Candice Coghlan: And I'm wondering before I ask mom to join us, do you have any advice for other people who are waiting for an organ right now? Yes,

Afsana Lallani: I would say be patient, and to stay positive and hopeful, because those are very important.

But also to continue to live your life for you, and not for your health. It doesn't really define who you are as a person, so it's important to keep up the things you love. Keep that positivity and hopefulness going. It almost fuels the other. So, I would remind people of that fact, reading.

Candice Coghlan: Thank you so much off sauna.

We're so grateful to have you here today, but also to have you part of our campaign and part of [00:24:00] our volunteer committee and everything that you do for the community. It's incredibly brave and, and your strength shows through and in all ways. And we're very, um, proud and grateful to have you as part of our team.

So thank you so much. And now mom, I'm wondering if you can, can join in. Okay. Thank you so much for having me. So I'm wondering if you can tell us a little bit about yourself, if you can introduce yourself to our listeners.

Dilshad Lallani: Sure. Um, well, I am a mom to three lovely daughters, ages 26, 24 and 18, a son of being the middle child, and also a wife to a very kind and loving husband who everyone loves.

Professionally, I'm a nurse practitioner, started out my career in pediatric cardiology as a staff nurse. And in the last eight years, I've been practicing at Holland Bloorview Kids Rehab Hospital with the spinal cord and spinal, um, spinal bifida, [00:25:00] uh, injury clinic. And, um, I, um, care for teenagers and young adults from ages 18, sorry, from ages 14 to 25.

Wow.

Candice Coghlan: And so were you in that role supporting youth at the same time that your daughter's health started to deteriorate?

Dilshad Lallani: That's right. In fact, I had just started that particular job at Holland Bloorview. I started August 10th, I believe. And she was diagnosed Labor Day weekend. But before that, I also worked in primary care where I managed pediatrics and women's health.

So, yes. Wow.

Candice Coghlan: So, you know, as a nurse and then as a mother on top of that, when she, her health started to decline and you received that diagnosis, how did that feel and how did you, I guess, kind of [00:26:00] balance those two parts of yourself in this journey?

Dilshad Lallani: Yeah, that's an interesting question and it was definitely a balancing act.

And I think that my first emotional response was really informed, honestly, both. My nursing knowledge and maternal instinct, if you will, um, although I think from recalling what I said immediately after, um, it was more the nurse in me than the mother. So intertwined, and, um, I recall being really concerned about the impact her diagnosis would have on her, um, adolescent health and vice versa, her development, um, and I didn't focus so much on the mortality rate that was program prognosticated or relate to us.

Whereas her dad, you know, asked very specific questions about the prognosis and exactly what PSE was and all the details of [00:27:00] the anatomy and physiology.

Candice Coghlan: Yeah, that's a, an interesting place to, to come from the, the two sides of the coin of, you know, where, where parents are, and out of curiosity, what does he do as a career.

Dilshad Lallani: Well, he was in finance, so it was no surprise that it was, you know, focused on the numbers. Right. Yes.

Candice Coghlan: And that, those must have been some scary stats for, for him as well.

Dilshad Lallani: Yes, definitely. And I do recall, you know, once we got home and we were all quiet, I was sitting on the couch and Afsana was making her way to the kitchen.

I said to her, hey, Afsana, you know, this is, Such a rare disease as I was doing more reading about it, um, and you have to get it. And then, you know, I used the word sucks, and I said, that really sucks for you, right? And she made a U turn and said, and came face to face with me, and she said, Mom, it's [00:28:00] okay.

Because it's such a rare disease, like it was 0. 001 or something like that. And, uh, I've been diagnosed and which means no other child will be diagnosed this year. Yeah. And it was at that point at that time that, you know, it dawned on me that I was going to support this kid with PSC. She was handling it so well and she had allowed it to be what it was and that she was going to live with it, manage it, respond to it, but at the same time it was not going to define her at all.

Candice Coghlan: That must have been a really proud moment for you as a mom.

Dilshad Lallani: Um, it was it was very telling of her personality from day one. I've always said that she's an old soul, a very kindred spirit. And so it was quite a profound comment that she made and very much telling of who she is. [00:29:00] And we can see that today as well.

So how did

Candice Coghlan: you as a family and, and you as a mom deal with her diagnosis and, you know, her journey from diagnosis and prior up until that potential transplant time?

Dilshad Lallani: When she first started to complain about her intrepid pain, like it would have been in 2015. And then it became very persistent and I'll never forget the night when she wanted to go to the ER.

I think it was 2 a. m. or something. And she came into my room and tap, tap, tap. And I was startled. Right? And she said, it's time to go to the ER. Take me to the ER. And I said, it's that bad. And she said, yes. And she's been through pain since she was 15 months old. You know, she has a chronic condition. She's got arthritis.

So she wasn't, you know, pain was not new to her at all. But I feel that when Oksana says it's time to go to the eMERGE, it's actually, it's Time to go to the emerge. Um, fast forward when she was [00:30:00] deteriorating a year before transplant, I would say, you know, she, you know, she became more noticeably more fatigued her skin color, uh, more pale and ash.

The white of her eyes were yellow. She couldn't climb the stairs anymore at home and her dad had to carry her up. And, you know, I was saddened that. Home wasn't a good place for her anymore. And in fact, her condo downtown Toronto was better because it was smaller, she could reach, she didn't have to climb the stairs, she could be more independent there.

And that's what was good for her. But it meant that we couldn't be together. So that was really difficult moment. But you know, the focus was off sauna. And so we had to do what we had to do. And we supported her staying downtown on her own. She did that. And I would visit her every weekend, if she was ill, then I would see her.

stay with her. Um, so that was a very difficult moment for us where she couldn't be at home as a parent. You want her at home. You want to nurture her. You want to take care of her. You want to be [00:31:00] there every minute. Yet I have to allow this independence. And so I knew that that independence was very important.

And I think my nursing background also helped to me because I'm. You know, I manage teenagers and I know, you know, the milestones, um, when they are adolescent, as they grow into young adults, and that this was a necessary step and that Afsana wanted to be Afsana and not Afsana who has a PSC, no matter how sick she was, right?

She can, for example, she continued on school. Right. So, um, the nursing background really did help my mothering role. There's no doubt about it. And, um, in terms of coping, I mean, there's no doubt it was a very difficult journey since we had to watch us on a deteriorate and come face to face. Uh, with the possibility of death, since she had such a difficult time, [00:32:00] uh, finding a match.

Um, we rode through that journey, I would say, with fortitude, uh, grace and faith, um, as a result of the incredible support we received, um, from a, from diverse communities. In terms of culture, religion, and race around the globe. I had people from Africa emailing me and messaging me about what is her name.

We're going to church today at Sunday. We have to submit her name to the pastor here in Canada, in our community as well. You know, we had people praying for her. So knowing and feeling that this type of love, um, existed. Right. Really, um, I think helped us feel on and understand that we were not alone. And so it was quite transformative of a journey, the kind that you truly realize that we are all but one humanity, right?

We're part of one [00:33:00] humanity that we are more than the sum of the parts. And that awareness, I think helped us to be formidable, right? Which is we were bigger than just ourselves.

Candice Coghlan: And that's so big for other people to hear as well, that there are all of these people who want to help. Maybe sometimes they just don't know how as well, but there are people from all over who are rooting for you and want you to be successful through this journey and however they can support.

Afsana Lallani: I would like to commend my mom though on how well she coped through it all. I was surprised. I thought there would be more tears involved and more clinginess. Um, as I would expect from any mother with a dying child, but she did a really good job and she did give me that space that I needed and I know I didn't always have the best brain because the [00:34:00] toxins went to my brain a lot and after a certain point it changed my personality and I had a very short fuse with my mom.

Candice Coghlan: Yeah, that's, that is something that unfortunately I feel like us as kids do to our parents often is you trust them and you know, you're, they're always going to be there and they're always going to support you. So they unfortunately get the wrath of all of our feelings and, you know, the emotional dumping gets on them.

And so I'm wondering, um, Dilshad, if you could tell me a little bit about how you felt. when that call came in for transplant and when you found out that that donor had been found?

Dilshad Lallani: Well, uh, describing it in words, to be honest, is difficult, right? It's really difficult, but I would say that hands down, uh, we felt this overwhelming sense of relief [00:35:00] mixed with joy and gratitude.

We were so thrilled And, um, I felt like it was, I felt like it was, it was a bizarre feeling, but that, you know, uh, I was going to be a parent all over again, you know, because I was going to have another chance at life. Right, because we

were in fact preparing for her not to have a transplant, not to be able to get a match.

And so preparing for palliation. Right. And so when my call came, it was a second chance, it was going to be a rebirth. Right. All I could, yeah, just super relieved and a sense of peace for that moment, for that time. I knew that there was, of course, a transplant still to come, the surgery, the risks involved.

But at that moment, at that time, there was just that, you know, moment where you can grab that peaceful [00:36:00] moment and just experience it for what it was. It's

Candice Coghlan: that call, that surgery, all of that, that, like you said, gave Afsana a second chance at life. You are in a unique situation where you're a nurse and a mother and you, you deal with youth as well.

How do you feel, um, transplants and, and this second gift of life? impact people who are this age? Is it different from adults? Is it, um, unique for, for this age group? How, how would that be different for say somebody in their fifties or sixties? Have you seen? From,

Dilshad Lallani: um, a knowledge standpoint, it has to be different.

There's no doubt about it because, you know, I, a younger person is going to react or respond based on something. stages and ages, right? And so, you know, in that particular stage, [00:37:00] you know, they're often, Oh, it's not going to happen to me. But this was something that happened to Asana. And, you know, the journey took her to places where other adolescent her age would not have experienced, right?

So she, and her awareness just became at. Even higher and more deeper than I would say a 40 50 60 70 80 year old because it had an experience coming face to face with dad. And so the transplant itself, you know what it might mean to a, um, teen versus 50 year old at the end because death is death. Right.

And so when you come face to face, I don't really think that it matters whether you're a teenager versus a 50, 60 year old from a practical standpoint, you [00:38:00] know, for a teen, I would think that they would feel that they could actually be. You know, reach their goals that they haven't already, right? They haven't met those milestones yet.

And now there's an opportunity to do so.

Candice Coghlan: I'm wondering if, uh, Afsaneh has changed since this whole process and if your family has changed at all.

Dilshad Lallani: Um, I think so. She has to have for eight. Um, so I think, you know, of Sona was always very creative, independent, self determined from day one. She was very hard working towards our goals.

And I think that the journey has been very much transformative for her. Um, she was always an old soul, as I said earlier, um, similar to her [00:39:00] father. But, um, the level of maturity, the awareness about life and its potential, Purpose has been her greatest area of growth. I would say, um, this awareness I think is very much transcending too.

Um, and I really enjoy listening to her perspectives because they are very deep, but yet so simply put. Right. So, you know, I'm very much at all with her and sometimes I look at her and I think, is she really my kid? Right. And I have to shape myself.

Afsana Lallani: That's funny you say that, because I look at you accomplish things and I think, wow, that's really my mom.

Dilshad Lallani: Thanks, Osana.

Candice Coghlan: That's beautiful. Um, I'm wondering if you have any advice for parents with children in similar situations, either as mom or as a [00:40:00] nurse or both?

Dilshad Lallani: Yeah. Um, I think that, you know, I would say to families that in similar situations, um, to coach their children to self manage and to respect their wishes.

And support them in that and, you know, the parental role changes instead of parenting. It turns into a coaching role really. Right? So as to enable them to be as independent as possible in order for them to continue to thrive amidst this terrible journey. Would be, yeah, I think that that would probably be like, my number 1 thing to say and also, of course, the self care piece and not to take things personally when.

You know, um, there's a lot of pain and there are changes with [00:41:00] personality that go along with that and I constantly had to remind myself that's not really a sauna. That's not my kid. And sometimes I would say it out loud and

I would say a sauna. Where's my kid? Where's my kid? Right? That's not my kid, right?

So, um, all open communication, honest communication and humor, you know, played a huge role in our coping, right? We were, um, yeah, we use that quite a bit actually. And sometimes we made fun of the condition, right? And we, we, we made fun, like you made fun, uh, you know, of your eyes, for example. Right. I did. Yeah.

Afsana Lallani: I called them these glowing werewolf eyes because they were so yellow.

Dilshad Lallani: This

Candice Coghlan: is a big one. If you could speak to Afsana's donor, what would you say to them?

Dilshad Lallani: Oh, um, so much to say, um, yet, you know, there [00:42:00] aren't enough words really to express my gratitude and everything else that I feel is just impossible really.

But I would simply, um, say, thank you for saving my child's life, or Thank you for giving her a second chance at life.

Candice Coghlan: Now, for the both of you, is there anything else that I perhaps didn't ask you about today that either of you would want to share or ask each other as well?

Afsana Lallani: Um, I would definitely add that it's okay to ask for help, whether you're the patient or the caregiver.

You have your community around you, you have your health team, you have your friends, your family, everyone around you, that you can ask for little things like, Can you make me a meal today? I could really use a salad. Takes two seconds and if they're five minutes away down the road, they'll be more than happy and that's their way of helping you without them even knowing how to help [00:43:00] you, you're telling them in that way.

Dilshad Lallani: I think for myself, I would say in terms of asking for help. The ultimate help in this kind of a situation is also okay to ask for. I know Afsana had a tremendously difficult time to put herself on a transplant list, right, and start her campaign. She did not want a living donor at first and she waited a

whole year and we worried that and her transplant team worried that she was going to deteriorate to the point of then not being able to have a transplant period.

And so it took her a while to come to terms with, um, it's okay to ask for the ultimate gift because there's somebody out there that wants to do it. And our transplant team, I recall speaking to her and saying, don't take that choice away from somebody else, just because you think they're going to go through pain and you don't want them to go through pain because that's.

What was on how off sauna felt is that I will not put anybody else through pain. Cause when you look at us on a [00:44:00] today, you know, she's had her transplant and she's already made tremendous amount of impact in fact, she's contributed to others having transplants and saving their lives, right? So my question to have sauna is like, you know, when I asked you, you know, what changed your mind and I know you've had a lot of existential conversations with dad, um, you said to me, well, I'm choosing life.

And it was as simple as that. So having chosen life, having put yourself out there, given that you, you know, as difficult as it was because you were a very private person and you had to expose yourself. What are your thoughts on the fact that you chose life? You went ahead in comparison to no, I don't want this.

Afsana Lallani: I think it was worth it because I I remember thinking really late at night when insomnia was bad that I'm going to choose life, and I'm going to tell my mom tomorrow [00:45:00] that I'm choosing life. For a second, she's awake, she's getting that text. And that night when I was thinking about it, I thought about the other option of not choosing life.

And What I'd be missing out on, and the only thing I could even bear the thought of, and did not like it at all, was that I'd be leaving behind my loved ones, and I couldn't do that to them. It wasn't about me. Once you die, you're dead. And at that point, I didn't believe in an afterlife, so I thought it was just lights out.

But I remembered that, just because it's lights out, happily ever after, no more pain for me. I'm giving my pain to the people who love me then. And so why can't I accept that one person wants to do that for me? To go through [00:46:00] pain so that I can live instead of me dying and causing this whole tsunami of pain for a lot more people than just one person who wants to do this.

And it may not be as painful as I think it's gonna be because I haven't been through a transplant at that point. So What do I really know in the end?

Candice Coghlan: And look at all you've accomplished now, right? In such a short amount of time. Wow. Well, you've both and your family have been on such an incredible journey and, you know, it's, it's so amazing to get to sit here and see how well you're doing off sauna and get to, you know, be part of your life and in the way that I am now and get to see all of the, the ripple effect of what your anonymous donor did and what your family has done to, to keep you here.

And, and this is just the beginning of, of your, of your life and just the beginning of your journey. And there are so many more incredible things to [00:47:00] come and how lucky again, that all of those patients who are going to have you as their nurse are going to be so. Thank you to both of you for being on the podcast today.

We, we truly appreciate what you've done and what you continue to do.

Dilshad Lallani: Thank

Candice Coghlan: you for having us. We hope you enjoyed this episode of the Living Transplant podcast. If you did, please leave us a review and share with your friends. Don't forget to subscribe to Living Transplant wherever you are listening today.

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