

Jennen Johnson

[00:00:00] [00:00:00] **Brittany:** Welcome to Living Transplant.

[00:00:02] **Courtney:** The podcast that takes you behind the scenes of the transplant program at Toronto General Hospital,

[00:00:07] **Brittany:** and brings you open and honest conversations about the transplant experience.

[00:00:11] **Courtney:** My name is Courtney and I'm the communication specialist for the Centre for Living Organ Donation.

[00:00:16] **Brittany:** And my name is Brittany. I'm a bedside nurse in the Ajmera Transplant Centre.

[00:00:20] **Courtney:** Full disclosure: we are not physicians.

[00:00:22] **Brittany:** No. And we are not here to give you medical advice.

[00:00:26] **Courtney:** Think of us like your guides through the world of transplant, as we know it,

[00:00:29] **Brittany:** Whether transplant is your past present or future your passion, or your curiosity,

[00:00:34] **Courtney:** Living Transplant will show you the world of transplant like you've never seen it before. Welcome back to Living Transplant. Our guest today is Jennen Johnson. It's nice to see you again

[00:00:45] **Jennen:** Nice to see you too.

[00:00:46] **Brittany:** It's very nice to see you.

[00:00:48] **Jennen:** Yes..

[00:00:49] **Courtney:** So, Jennen, what is your connection to transplant?

[00:00:52] **Jennen:** Well, I was diagnosed with kidney failure several years back. Actually I should go back a little bit., I was originally diagnosed [00:01:00] with lupus in my early twenties. And when I was diagnosed with this, I was told that at that time eventually I'll need to get a kidney transplant. So that's when it was just introduced to me at that point. So I, to be honest, prior to that, I knew of kidney transplants, but, it was nothing that I really looked into. It wasn't anything that I researched. It was just something that I heard of, you know, and that was pretty much it. I was told at that time.

[00:01:23] **Courtney:** I was just going to say, I feel like that's that's most, people's kind of, you know, experience with transplant where you know it, you know of it, you know, it's a

thing that can happen, but you don't really think of it until it you're in organ failure. So when you were first, I know nothing about lupus. I will confess the most I know about lupus is it's just like mentioned on House as like the disease that everyone thinks,, but House's always like "it's not lupus," so yeah. That's the go-to disease. Yeah. And I know like that's why Selena Gomez had her, her her kidney transplant as well. But yeah. Can you tell us a little bit about what lupus is?

[00:01:57] **Jennen:** Yes. So lupus is an autoimmune disease. So [00:02:00] basically your system turns against itself. So it'll go ahead and fight the bad guys. You know, the bad germs, bad bacteria is what have you, but then it can differentiate between good and bad. So essentially it turns against yourself, your kidneys, your, your organs are different, liver your liver, et cetera. So at that point you have to do something to fend it off. And in my case, since I was on the lower end of the spectrum, they gave me prednisone. And prednisone help fend it off for a bit. And also prednisone and it helps you gain a lot of weight in the process, but then it also helps, you know, fend off, you know, the, the joint issues and the stiffness in the muscles, et cetera. So that's what lupus is.

[00:02:38] **Brittany:** How did you know you had lupus? Like what brought you there?

[00:02:44] **Jennen:** Funny thing. I would, this is like I said, it's back in my twenties, so my early twenties, so you're, you're in college and you're going out and you're partying and you're doing that right, all that good stuff. Right. And so I'd come home late, sleep in later, wake up in the middle of the morning or in the middle [00:03:00] of the afternoon after like eight, nine hours of sleep. But I still look tired. Under my eyes was still baggy. So I'm like, okay, maybe we should just,, slow down a bit, you know, stop the whole late night partying and what have you. And I did slowed it down, slept normal hours, you know, at night, like everybody else. But I still looked tired, still had, puffy eyes and dark circles under my eyes. It was bothering me because I know normally naturally I don't look that way. So I went to my doctor and he asked me a whole bunch of questions, did a whole bunch of blood work. And then he said, he's going to refer me to a rheumatologist. I'm like, Oh, Okay. I thought it was just something simple as,, increase your vitamin C or vitamin D or something of the sort. So he referred me to a rheumatologist and the rhu- rheumatologists asked me a whole bunch of questions and did a whole bunch of tests.

[00:03:42] And it came back that I had lupus. And at that time, I had no idea what lupus was. Like you said, it was just something that, shows or, from time to time, I see a commercial about it saying, you know, one end, X amount of people in Canada has lupus, but I never really listened. I never really paid attention because honestly it wasn't affecting me. Right. But yeah, [00:04:00] that's how I was originally diagnosed the puffy dark eyes.

[00:04:05] **Brittany:** That sounds kind of frightening to be. Like at your doctor's office. And you're like, eh, it's just my vitamins and yeah. Then they're like, Oh, you have to go to rheumatologists. You're like, what, why? And then it kind of raises an eyebrow yeah. So when you, when that happened, like what went through your head?

[00:04:22] **Jennen:** Well, he explained to me what the rheumatologist was for, but I've always been that type of person that, well, not me. it's, it's a misdiagnosis, even when it's

cold, but you know, eventually down the road I'll need a kidney transplant. Nope. Not me, not me. That's not going to happen to me. I'll just eat healthier. I'll just exercise more. I'll do my cleanse or what have you. That's not me. That's that's the other person, you know what I mean? So when he told me that it was lupus, that's the mentality I had, not me. I just, I listened to what the doctor said. And I'm like, okay. Yes. Okay. I understand. And I understand what you're saying in the back of my mind, I'm like, Hmm, Nope.

[00:04:57] **Brittany:** So it's like, almost like some form of denial.

[00:05:00] [00:05:00] **Jennen:** Yeah. It definitely was not even, it wasn't, it was denial. Complete denial. Oh, listen to what he has to say. Right. But, and I'll do what he suggested. But it's not any type of long-term, it's nothing that's going to happen to me. Cause he told me it's a lifelong thing. Nope. Not me. I'll do what I gotta do. I'll exercise more. I'll lose weight. I'll eat healthier, my broccoli, whatever I need to do, but this is not going to be stuck in my body for the rest of my life.

[00:05:24] **Brittany:** No. Right. Yeah, for sure.

[00:05:26] **Courtney:** What a hard thing to hear when you're in your twenties, when like, I mean, it's not that all 20-year-olds think that they're invincible, but they're really, you know, you've only ever been young. There's no concept of mortality. Like really? There's Nothing about your body kind of like breaking down or anything like that. So how do you wrap your wrap your head around that?

[00:05:46] **Jennen:** At first it was just a lot of venting, like a, whether it was my girlfriend's, whether it's to my mom, just a lot of venting and they're very, they're always there. They always encouraged me very encouraging. And although I was talking to everybody, I was still doing my [00:06:00] own thing. Like I said, I'll exercise more, I'll eat better. I mean, I never drank a lot to begin with, but a little bit of alcohol. I did drink. Cut that out. And just do what I need to do. But if it wasn't for the support, I think it would've been a lot more difficult for me if it wasn't for the support.

[00:06:13] **Courtney:** Yeah, yeah, absolutely. At its at its worst. Cause I do remember you and I have obviously spoken before and you explained to me that lupus there are like flare ups and stuff. So yes. So at its worst during like a particularly bad flare up where I don't know if they're all the same, what does it lupus feel like in your body?

[00:06:32] **Jennen:** They're not the same. Sometimes the simple flare will just be, you know what, my knee, my knuckles are just, you know, tight. I won't be able to put my ring on. That's like, you know, a slight flare up, but at, at its worst, it'll be like, I'll be sleeping in the middle of the night. And all of a sudden my joints just like seize up in the middle of the night while I'm sleeping.

[00:06:49] So I have to like get on my bed and just try to walk. And I'm walking literally like Frankenstein because I can't move. My joints are stiff. My knees it's just. Everything's just stiff. And the whole [00:07:00] key is you have to, you can't just lie there. You know, like my mom will try to massage my leg. It didn't always work.

[00:07:05] Like I have to move. So we had a stationary bike at my mom's house and I just get on the bike and I'll just kept pedaling and kept pedaling at two, three o'clock in the morning. I'm pedaling and pedaling painful. And you know, it's just throughout the legs, the knees, the joints, and then my hands everything's just, it's like seizes up all at once.

[00:07:23] And you, you can't, there's nothing, you can't take a pill, you can't lie down. For me personally. I had to literally ride it through, ride it through, and then eventually it starts relaxing. The muscles starts, you know, becoming a little bit more free. And then at that point you're afraid to go back and lie down and sleep at that point.

[00:07:38] So I would just literally just sit up on the sofa and just kinda like sit, you know, and kind of sleep sitting awkward because I don't want to get that again. You know what I mean? So I try. Try to hedge it off type of thing and just kind of sleep upright. And then a couple hours later when I feel okay, you know what?

[00:07:53] I think it's a bit better now then I'll go ahead and lay back down. But it's very painful. It's just everything seizes up all at once. There [00:08:00] is no, it starts with the fingers and it works its way to the elbows and that, no, it's just all at once and usually happened when I'm sleeping too, usually. Yeah.

[00:08:10] **Courtney:** I also remember saying to Brittany when we were, we were talking about interviewing you. And I was so excited to be like, she has lupus. Cause I thought, which like, sorry, but not in that way, but yeah. Cause I thought it was like really rare and Brittany was like lupus isn't rare. She's shaking her head at me now.

[00:08:28] **Brittany:** And I was like, no, like most of our kidney patients are because are lupus patients.

[00:08:31] **Courtney:** Yes. Right. Okay. So is there, is there like a big, big community that you're no of or that have you met lots of other people with lupus?

[00:08:41] **Jennen:** Honestly, just like Brittany said, the only time I actually met somebody that had lupus was while I was sitting in dialysis. I don't nobody in my family has lupus. I've never spoken to anybody that had lupus. Like I said, the only thing I knew about lupus was just a brief commercial that I would see on television. Nobody I'm the first in my family to have this. And the only time I would [00:09:00] actually know about lupus, like to meet someone that had it was while I'm sitting in dialysis, sitting there in the hospital. And there's someone right beside me. And, you know, he started talking at three, four hours to kill. So, you know, you get a lot of friendships in Laban's bonds that you make there. And. You can just start talking and saying, Oh, you got to think that I've looked as to how long have you had it. It was just like, you know wow me too? How does your use affect you? You just, you know, you just, and over that.

[00:09:23] **Brittany:** I don't know if this is an actual statistic. I'm sure it probably is out there somewhere, but I personally find that most of my patients that have lupus are A. Of African Canadian descent and B. Are typically Jamaican.

[00:09:40] **Jennen:** You know, I usually find that yes, it is African Canadian descent, but I just find it's women. It's just women, whether it's Jamaican, Trinidadian, what have you right. It's just usually just women, women, yes and I have read that it is predominantly in African Canadian or African-American and in Asians. So [00:10:00] yeah. Yeah, it's mainly. African Canadians and just women that I've experienced. Yeah.

[00:10:06] **Brittany:** So when did kidney failure start to really become a reality for you? When was that turning point?

[00:10:13] **Jennen:** 2016, I was realizing that certain things like tomatoes, for some reason, I'm not eating tomatoes anymore. It's it's not staying down or cucumbers. Love my tomatoes. Love make you coming into my salad, but for every time I ate it, it felt nauseous. And then I have to vomit afterwards. Okay. That's strange. So then I brought it back to my doctor. And he's basically said,, let's just keep an eye on. See, I don't want to assume anything. Let's just keep an eye on. See, and that is a sign that, things are progressing,, and the other direction, but let's just keep an eye on C and you know, kept going certain things like, fettuccine, Alfredo pasta, which I love can't eat it anymore.

[00:10:49] Every time I ate it, it comes back out. I'm like apples. Why am I like feeling nauseous after eating an Apple? Why am I feeling nauseous after eating, you know [00:11:00] festivals, you know, civils, right. And love my festivals can't eat anymore. Then I'm losing weight, but I'm not exercising, but I'm losing a lot of weight.

[00:11:09] What's going on. Brought it back to my doctor. Doctor ran some tests and there was, it was saying, you know what? You're, you're not clearing out the protein as you should and your urine. And so this is. The reaction, this is what, what happens. And that's when I realized, yeah, you know what? This is it. Because I said before I was in denial, I'm going to do the cleanse.

[00:11:30] I'm going to do detox. I'm going to fast. I'm going to eat healthier. What have you, but from, when I'm at work and I'm eating lunch and I run to the bathroom and puke in the bathroom, like at one point you have to realize, you know what, this is, this is real. This is real. I have to take this seriously and I need to fix this.

[00:11:48] I actually need a transplant. As they told me back in my twenties, when I denied it, this is it. I'm here. I need a transplant. Wow.

[00:11:58] So that's it, [00:12:00] it wasn't anything, it wasn't necessarily diet, but it's just whatever I was eating. And at that point, my system's like, Nope, we don't want that. Nope. Don't want this. Okay. You drink water. That's my orange juice. That's great. You don't have your cereal, but no, We don't want the chicken and rice today. We don't it's it was always -

[00:12:16] **Brittany:** - for me. It'd be the festival. I'd throw hands up and be like, no, I'm going to the doctor, like, give me the, give me the kidney, give me the kidney. That's where I would turn the point -I need that organ right now

[00:12:29] **Jennen:** It was hard. It was hard. I was on a trip to Las Vegas with a couple of my friends, but I've never been to Vegas and a couple of my girlfriends, like, let's go down, you

know, let's go for your birthday. Let's have fun. I'm like, yeah, I could totally do this right after I've already started dialysis. I was doing the peritoneal dialysis. Sorry, just got a little off topic, ladies. But I was doing peritoneal dialysis, So I just carried the bags with me. You know, how it works, right. Brittany is with me and just do the exchanges down there. No big deal. So I know I have to watch what I'm eating. Cause I'm still going [00:13:00] through that. You know, if I eat something I'm going to puke. Fight this am I puke? What I puke. If I eat this, I still don't know. Like I'm still sorting all of this out. Right? So I'm down there with my friends, having a great time, woke up the next morning, went out for breakfast. I'm sitting at the, now we're in the restaurant and I'm like, Oh, okay. I'll have,, scrambled eggs. I'll have, you know, slice of toast, blah, blah, blah. Everything's great. Starting the eggs. Do my usual stop. Wait. It seems okay. Cause I had no problem eating eggs at home. Right. Stop. Wait. No problem seems good. It's a more. And uh, I'll be back and just took off. And at this point they didn't know I was going through this. They didn't know. I mean, they knew that the kidney disease. Right. But they didn't know that certain things that I ate, I might, have a reaction and it comes back out. So I just jumped up from the table and took off to the washroom and they didn't know what was going on. They were just like, what is happening with Jennen? So then they came running after me and I was in the stall and I'm just doing my stuff and I felt so embarrassed. I'm like, Oh my goodness. Like something as simple as eggs. Love egg, [00:14:00] well loved eggs. I can't even eat with my girls. And I was like, what is going on? Like, how am I, I need to get this fixed. This has to, this is enough. Like it's too much.

[00:14:11] **Courtney:** So yeah, I actually, I don't think that story is off topic at all. I feel like it's actually a really good example of just kind of needing to accept where you're at, because like you said, you struggled with a lot of denial when you were younger, but even, when you're older and you're, faced with organ failure and all its realities, like it's still not, easy to accept because the next step is, telling people I can't keep food down. Like I need to change something dramatically, in kind of accepting that you needed to, that the big change was coming. Was there any kind of mourning for like did you feel like you were losing something or giving up something? what did it feel like knowing that there was something huge on the horizon?

[00:14:50] **Jennen:** Honestly it wasn't really mourning something. I was just expectant of what's to come. Like I'm ready to leave that behind. I've had enough. Yeah. I'm [00:15:00] expected of, wants to what's to come so I could get back to the Jennen that I used to be.

[00:15:03] **Courtney:** Okay. So it was more like you were fed up with how things were.

[00:15:06] **Jennen:** Yes. That is the perfect word. Got it.

[00:15:08] **Courtney:** did you ever consider? I mean, I guess not, but like staying just on dialysis or was that kind of, not an option for you?

[00:15:15] **Jennen:** That wasn't an option. Like not, not even if I wanted to, my doctors wouldn't even let me, like they're saying, you know, you're young. This is just a setback. We can do this. The only problem is the transplant list or the donor list is like at that point 6 to 8 years. And I'm like, what? Yeah, it means so, but they never said,, this is something that's an

option for you. We can just keep you on dialysis for the rest of your life. So even if I wanted to, which I didn't, but if I wanted to that, wasn't an option for my doctors.

[00:15:43] **Courtney:** Yeah. The deceased donor list for kidney, unfortunately, the wait. Yeah. Is I think the average is seven to 12 years.

[00:15:49] **Jennen:** Oh now it's 7 to 12. Geez. Wow.

[00:15:52] **Brittany:** Who has that time?

[00:15:53] **Jennen:** Exactly. I was only given four years. I was only given four years to live. Like I was told, Oh, [00:16:00] well you will have, actually, I wasn't even told, I overheard from your doctor talking to a doctor that was in training, like a Sudan. And I overheard that I had, well, she has about four years to live. And so within that timeframe, and I don't even know what they said after that. Like I have no idea what they said after that. All I heard was four years. So my wet, how come she's finding out before me? Yeah.

[00:16:26] **Courtney:** I remember you telling me that that's unfortunate, that that happened. I'm really, really sorry.

[00:16:31] **Brittany:** So did they eventually tell you

[00:16:33] **Jennen:** or you just, yeah. When I confronted the actual doctor that came in, I thought I overheard you speaking to the other doctor and you told them that I had four years to live and he's like, yeah. And he went to his charts and I think he realized, Oh, shoot.

[00:16:52] So he pulled out his file, his chart, and he's looking at it and he's like, yes. You know, and this is just a proximate Ms. Johnson. This is just,, looking at the numbers and the blood and [00:17:00] how things are progressing with you right now. You, of course, it's, you know, we can be five years, six years, but this is just approximate and almost just like, wow.

[00:17:08] **Courtney:** So it's my life

[00:17:09] **Jennen:** like? Right. You know what I mean? Like, And he found it before me, this you're found out before me. So that was

[00:17:17] **Courtney:** even with dialysis. Cause I remember talking with you earlier you said that dialysis was not the smoothest.

[00:17:23] **Jennen:** No, it wasn't in that. Yeah, that was four years. I was given four years with dialysis. So I knew that something had ended to hear that the list at that time was eight years long. That's obviously not an option for me. So,, living donor was the route that I had to go, but dialysis was not at all a smooth route. So I went in and they had placed the catheter, placed the line in my neck. And I was doing dialysis no problem. One day I was just picking up, mash my daughter, just bent over to pick up, something from the floor there came the line and that same day I actually had to go in for dialysis. [00:18:00] Right. And so I'm standing here and I'm holding my neck thinking blood's probably going to be spewing out or something. I don't know what to expect. Right. So the line came out, it's on the ground.

I'm holding my neck. I told her I was in the bedroom. I don't want her to see what's going on. Cause he's going to freak out. She sees the line and I'm bleeding.

[00:18:15] And so I picked up the line and I ran to the bathroom, like what the, you know, shocked. And then I called up,, the unit and I told them, listen, I'm, I'm supposed to be coming in today for dialysis, but my line just kind of fell out of my neck. I wasn't even told that was a possibility, like what's happening. And she's like, Oh my goodness. Well, still come down and we still want to assess you. Obviously won't be able to have, dialysis today because of the line, but please come down. We need to see you right away. And I'm like, okay, sure. Um, So I ended up getting surgery a couple of days later and that's how I ended up getting peritoneal dialysis, right, right through the stomach. And what have you. And that's how that happened. So I've tried both, I've had both options given to me. Yeah.

[00:18:59] **Courtney:** We [00:19:00] did another interview last week with a gentleman who he was on dialysis, I think for seven years. And it was just such a smooth road for him. And it's just interesting how different it is, person to person. Totally. And also in that, in that story, you're just telling too, like it's also crazy to me how resilient transplant recipients are or anyone living with chronic disease. Cause not only is all this stuff going on inside your body, but then also to hear that, you're taking care of your daughter and like, you're like, you know, you're going to work.

[00:19:29] **Jennen:** You're here to dance class. Yeah.

[00:19:31] **Courtney:** You're in a partnership with someone like, how do you navigate all of your like home and family life? When you're dealing with issues like you were dealing with, like what was it like explaining to your daughter what's going on in your body?

[00:19:45] **Jennen:** Well, first I tried to keep it as natural as possible. Like I want my daughter to walk around thinking, Oh, this is my sick mommy or anybody really, because I don't need the sympathy. You know what I mean? So I wanted everybody to treat me as normal, So I tried to keep it as normal as [00:20:00] possible. I continued taking my daughter to her dance classes. I continued going to work. I'd find the furthest washroom possible at work if I needed to, vomit or anything. So no one would hear me. Right. And it just tried to keep it as normal as possible to go out to lunch with my friends at work. But I'd just be specific as to what I ate. Or I'd bring my own lunch and like, if you're going to a restaurant or whatever, I'd bring my own lunch and just kind of like pick at it, you know what I mean? So I tried to keep it as normal as possible, but in regards to Tatiana, I just explained to her that, you know, mommy's sick right now.

[00:20:29] And we always called her big girl. She's a big girl. I don't want her to feel,, she's just a little kid. So we always, my mom, my mom, my husband, those addressed her as a big, Oh my gosh, she's such a big girl. You actually did the dishes and try to, empower her that way. Right. So when I was telling her about my situation, I said, you know what?

[00:20:45] Mommy really needs her big girl because mommy needs help mommy sick right now. And I explained to her that,, it's something that you're going to see mommy sit there

on the bed, the side of the bed, and I'll be, doing this where I'm draining out this liquid, it's going to come from my stomach.

[00:20:59] And I showed her, [00:21:00] I engaged her. I had her take part in it, so she could actually feel she's part of the process. I didn't want to hide her from it. Okay. Stay out of the room. I'll be, I'll be in here for 20 minutes. Don't come in. Like, you know what I mean? I didn't want to. Keep brought out of the process and it came to the point, like she started taking things in, she started now she can tell you all the medications that I could, that I take, she knows the names she could like, if I need, if need be, she could call it the pharmacist and reorder them for me.

[00:21:22] If she needs to, she she's been involved from the beginning. She's 15 now. And I had her involved from the beginning. She would sit there. She knows she can't touch while I was draining out. But she could tell me, you know, Oh, are you gonna, put the five bag or the, this bag? Or which one are you doing today?

[00:21:37] Like she was always involved. She was always involved. It was sad at moments as well because her mom's sick. Right. So it was sad at moments, but I told her, this is just the process I have to go through to get better. This is not a permanent, this is not going to be mommy for the rest of her life. This is just the process that I have to go through, just to get better, just like when you're sick.

[00:21:59] When you have a [00:22:00] cold, you feel down, but after, you know, drinking orange juice, eating healthy, you know, beating your soup and stuff. You're fine. So this is for me, this is the same process as a little bit longer, as opposed to a cold, but I'm going to be better and we get to go out and have ice cream again.

[00:22:15] Cause I couldn't eat ice cream either. We'll be able to get up and go have ice cream again. And we'll be able to, sit there and have McDonald's fries again, because I couldn't do that either. So that was something she was looking forward to just to try to. Just to try and make it easier for her.

[00:22:27] You know what I mean? Like this is, yeah. It's just a moment. That's time. That's all. So

[00:22:32] **Brittany:** when you got your transplant or better yet, when you had to explain to her that you were getting a transplant, how did she take that?

[00:22:42] **Jennen:** Um, She was happy, but it was a mix of emotions. She was happy, but then she was sad as well, because she doesn't like being away from me.

[00:22:49] So she knows the hospital and she won't be able to stay with me. So that part really bothered her. So they go, let me, who's going to help you. I'm the one who always helps you. You know what I mean? Like if, when we're at home, she would get the bag for me. You [00:23:00] should put it in the warmer. What have you, so now who's going to help you.

[00:23:03] Who's going to, so I tried to explain to her, there's lots of nurses and lots of doctors there, but you know, if they're not doing a good job, I'll call you and daddy will bring you to the hospital and you can help me out.

[00:23:11] Okay. It's amazing. She's 12. Right? So those are the things that help encourage her. Right? So she, she felt better with that. But the thing that really bothers the fact that we were away from each other. Yeah. She understood that, you know, I'm getting a kidney will help me live longer and feel healthy. I could eat anything I want now well not anything, but I still can't eat eggs. But I could eat the way I would before. And she was happy about that. We could go have ice cream again, but she just didn't like the fact that the distance that bothered her. So, right.

[00:23:41] **Brittany:** Why can't you eat eggs?

[00:23:43] **Jenn:** I don't know. Honestly, to this day I still can't eat eggs. Now, if I eat it, I just feel nauseous, trigger effect. Like if I feel nauseous, I'm like, Oh gosh, she's going to come back up again. So probably since like I've had the, I had the transplant back in 2018 and I've tried since then, it won't [00:24:00] work eggs and tomatoes are still the two things that I can't eat and cucumbers, but everything else I'm back to my festivals. I could still, you know, of all. Right. That's important. So I'm back to eating everything else normally, but eggs, the cucumbers and tomatoes. No, it still doesn't work. but I give up the eggs over the festivals.

[00:24:20] **Brittany:** Yeah. A hundred percent. Yeah.

[00:24:23] **Courtney:** So coming to the acceptance that you need a kidney transplant like it sounds like it was a bit of like a hard road, but you eventually got there cause, you were fed up, what is it like to realize that, you need a living donor and you're gonna have to. Like did, did your family know that you were sick? Like where did you have a lot of people to tell that you needed this transplant and that you needed a living donor, that you had kidney failure?

[00:24:49] **Jenn:** Um, it was, yeah, it was a lot of people that I had to tell because a lot of nobody in my family, other than my mother, my husband and my daughter knew that I even had lupus.

[00:24:58] So [00:25:00] nobody, nobody knew of anything. So now for me to come out and tell them, I'm going through kidney failure and I would, hopefully I would like you to get tested, to see if you can help save my life. Oh. And by the way, on top of that, I have lupus because the first question is, well, how did you get kidney failure?

[00:25:13] What happened? Where did that come from? Yes. I just tell him about the lupus and, Oh, well, back in my twenties, I was diagnosed with lupus. So it was a lot of information to put out there all at once and share that with my family and friends, because like I said, literally nobody knew about the lupus, just my mom, my, my husband and my daughter.

[00:25:31] **Brittany:** I mean, do you feel like if you were to go back into your twenties, do you wish you told more people that you had lupus or like obviously health is a very personal

thing. And because I had, we had another interview with a different patient who I can't remember exactly if she had lupus or not. Claudia. Courtney-

[00:25:50] **Courtney:** -she, she had PKD. So polycystic kidney

[00:25:53] **Brittany:** -right? Right. Okay. So she didn't same thing. She didn't also tell anybody. Especially when she was going to [00:26:00] dialysis, she said that she made a reference that she said she was going to the spa. Wow. Like three times a week. So they were like, wow, Claudia, like,

[00:26:08] **Jennen:** wow,

[00:26:09] **Brittany:** wow. This girl over here. But she didn't tell anyone either. So do you feel like. If I don't know how many people came forward to try and help or whatever, but do you feel like you should have been more open or is that something that you would have remained the same?

[00:26:27] **Jennen:** I think from the way I was raised in the Caribbean background, it's always been - keep your business to yourself, right? I mean, keep it within the household and just keep your business to yourself. Not even my aunts, like, you know, when I was, I was close with my aunt or I am close with my aunt, even, she didn't know anything.

[00:26:44] So it's always, it's just like a culture for me. I dunno if I, cause if you just do the same thing, Brittany, but it was a cultural thing that you keep your business to yourself. Right show the happy stuff. Oh, I'm getting married, you know, I'm you know about to have a baby or, Oh, I bought a house or, but you don't share, you know what?

[00:27:00] [00:26:59] I'm in financial distress, you don't care. I have health issues. You don't share me and my man we're, you know, we're arguing or going through a divorce or just certain things you just don't share. Raise that way. If I could do it differently. Definitely. I would say something that I brought onto myself and I'm not ashamed of it.

[00:27:19] It's not like I did something wrong. Right. So I would definitely share if I could do it all over again.

[00:27:26] **Courtney:** Right. Was knowing that like, you know, everyone kind of has the same ideas. Like you keep your business to yourself. Is it the same hearing then about someone's business, where they are in distress and they do need some help, like needing a living donor? Like, is that a weird thing to hear? Like how was it received by your family by

[00:27:44] **Jennen:** well it's, it's okay to receive that information. Yeah. They were accepting of it, right? It was, first of all, it wasn't as bad as I thought it would be, telling them so they're accepting and they're more than willing to help.

[00:27:54] So I, I think it was just a stigma. Like, you know, you just feel that you can't tell them [00:28:00] for whatever reason and when you're younger, you don't question. You don't question your mom, you don't question your dad when they tell you don't say anything, just keep it to yourself. You don't question it. Okay.

[00:28:07] Well, they know what they're talking about. Right. But when I finally did come out and say something, they were there, they were supportive. They were accepting. They were willing to help. Lots of prayers, lots of prayer sent my way. my aunts would call up and pray with me on the phone because we're very religious, big religious family.

[00:28:22] Right. We'll call up and pray with me on the phone. My uncle, my real relatives from New York, like it was, it was okay. We're there for you, so It definitely would've said something earlier.

[00:28:33] **Courtney:** Yeah. So in a way you had this whole like, support network that was just like untapped because yeah. Oh, that's well, it's nice that like, even if you, if it was, late to get there, like it's nice that it

[00:28:45] **Jennen:** was there.

[00:28:45] **Courtney:** Yeah, absolutely. Definitely. Definitely. How did you find your living donor?

[00:28:50] **Jennen:** Well it's an interesting story. So my mom was in the shower. My mom, we always say that my mom thinks best in water. Like I swear, she's a [00:29:00] fish. Wow. Oh, cool. What's what's the when's - get,

[00:29:05] **Brittany:** yeah. What, what's your sign? Because I was going to, I was actually going to ask your sign, but I didn't want to,

[00:29:11] **Jennen:** well, I'm a cancer. Oh, I was going to say like, I'm a water sign. Yeah, my mom she's November 16th. So Scorpio Scorpio. So she's also water is water, right? So she thinks the best in the water, whether her hands are in the kitchen and the dishes and your hands in the water is in the shower. Things always come to her while she's in water. So she calls me up one day and she's like, Jennen I have an idea and I'm like, okay, what's going on? Then she goes, I just came out of the shower, just out my towel wrapped around me and just hit me. You need to put an ad in the newspaper and ask for a donor. I don't like. Okay. Let's do it. Let's do it. She's okay. I'm going to go get dressed and I'll call you back and we'll figure this out. I'm like, all right. Sounds good. That's amazing. So I started reaching out to different newspapers, the sun, the star, [00:30:00] the globe, and I'm saying, you know, I asked them, can I put an ad in the newspaper? How much would cost to put an ad in the newspaper advertising that I'm looking for a kidney donor or particular O-type kidney, donor. And I'm not, it's not like any type of transaction. I'm not trying to buy it or anything. And everybody turned me down the star, the sun, the globe, everybody said, no, we can't put this in the newspaper. It could be perceived that you're trying to buy it and sell it on the black market. And once it goes through, we won't be there to kind of verify the transactions. I mean, we hear you saying that you don't want to buy it. But we don't really know.

[00:30:36] **Courtney:** Also, even if you did want to buy a kidney and sell it on the black market, this is the sloppiest way of going about it.

[00:30:42] **Jennen:** Right.

[00:30:44] **Courtney:** There's surely a better way to go about it instead of putting it in the paper.

[00:30:50] **Jennen:** Right. So they all turned me down. They all turned me down and then I reached out to my mom was like, Nope, that's, we're not, we're not just stopping there. If we have to reach out to, you know, Caribbean [00:31:00] newspapers, if you have to reach out to it, doesn't matter where this is not it. So I reached out to now magazine and I told him he was a situation I'd like to put an ad in there.

[00:31:08] And it was so hot. I was so nervous no nervous cause I don't know a lot of newspapers in the city. Right. So I'm like, know, this is my situation. And I like to put an ad in the newspaper. It's like, yeah, sure. It's going to cost at a duh. When did you want to have a run? Did you want to put it in this week? And she was just so easy about it. I'm like, Oh, okay. So I drafted up a little, little blurb as to what I'd like to have in the newspaper. Sent it to her and she put it in the newspaper the following week. And I'm like, why was everybody else freaking out? Yeah. Why? You know what I mean? Like now magazine never once said, Oh, we can't because you might take it and sell it. Like they were so good about it right

[00:31:46] **Courtney:** And now it's so common for them to tell stories of people that need, need kidneys, or need, need liver transplants. Or are looking for liver donors. Like it's a lot. Yeah. It's a lot more living donors, rather. It's a lot more common now. But I, I [00:32:00] feel like probably just because it hadn't been done because everyone knows that buying and selling organs is illegal. That they're just like, I don't want anything to do with that.

[00:32:08] **Jennen:** And that's what now was saying now, actually, cause I asked her and I remember her name was Debra, such a nice woman. And she said, you know, we've never done this before. It'll be a first time putting an ad, but yeah, let's do it. And at that time I needed help financially. My mom wasn't able to help me out. And so I said, you know what? I don't want to try and like reach out to every family member and they could only do so much, you know what I mean? So I put up a GoFundMe page, just explaining my situation, just what I'm trying to live. And then, I'm going through kidney failure. And if you think that you can possibly help save my life. So I can be there for my family and my daughter looking for an old owner. And that was it. And so I put the go-fund me out there. I raised the money needed for the ad and I posted it on Facebook. It was in the newspaper, the now newspaper as well.

[00:32:55] And at that point, it just, it started blowing up. It just kept trending and trending.

[00:33:00] Wow. It's so people are seeing it. That's great now, so excited. My cousin Maggie, she took it and we posted it on her Facebook page. And so one of her friends that she used to go to church with until she moved away from the church she went to church with a wonderful young lady named Christine Olin and Christie saw the ad on her Facebook page. And Chris is like, Hey, I'm a no. What do I need to do? And my cousin freaked out. She's like, okay, just reach out to my cousin and her Facebook page. And then unless she called me, my friend Christie she's, she says, she's an old when she wants to help you out. And I'm like, great. You know, so, and not even five minutes later, Christie messaged me and she said,, I saw your ad and it kind of touched me when you said about your daughter.

[00:33:39] So I'd like to get tested. So I said, Oh my goodness. Not at this point. It's just a little backstory. I had other people before Christy reached out. I had other people reach out to me saying that they saw my ad and they wanted to, go ahead and get tested. So I sent them the link to get tested. But I didn't think everybody was going to do it because, you know, everybody has good intentions.

[00:33:59] Some people [00:34:00] might say, yeah, I'll do it tomorrow. And the tomorrow, it's another day and another day doesn't happen, which is fine. Everybody has their life to live. You know what I mean? Christie did it, literally, when she said she was going to do it, she sent in the application, she messaged me back. She took a screenshot showing me that she sent it and I'm like, Oh wow, she's she's serious. You know what I mean? Not saying that the others weren't, but she did it like right away. Right. And so she saw the ad, she submitted application she's or her forms. And that was it. That's how she found out about it through my cousin. And I was just very excited

[00:34:35] **Brittany:** hearing that gives me faith in humanity. Seriously. It really does. Like, your sort of story sounds similar to Claudia's and how she found a donor as well. And same thing, like just Act of God and

[00:34:48] **Jennen:** like, just like,

[00:34:51] **Brittany:** yeah. And it's like, it really it's like you hear all these negative stories in this, in the news all the time, literally, but you never get to hear the good ones and [00:35:00] yes. So was this we might be jumping the gun with this question, but was this story ever published in NOW magazine?

[00:35:06] **Jennen:** Oh, yeah.

[00:35:07] **Brittany:** Okay. Like Toronto Sun seriously missed out on an opportunity for this amazing story.

[00:35:13] **Courtney:** So this is like the pretty woman moment where you should like walk back in and be like huge mistake. Huge.

[00:35:20] **Brittany:** Yeah. Seriously. Like I mean, you could've had an excellent story guys and it's true promoted organ donation in the best ways, but you missed it actually.

[00:35:30] **Jennen:** I don't know if you could. See, that's the actual ad that was in now magazine. Oh, wow. Amazing. Wow. Oh, fantastic. yeah, and I took that and it just posted it on Facebook and my cousin re posted it.

[00:35:45] And the funny part is The Toronto star owns the Hamilton spectator. Christie my donor she's from Hamilton. So the Hamilton spectator, AKA Toronto star then saw the ad [00:36:00] in now and saw this actually reached to global news as well. So then when they saw on global news that this wonderful woman from Hamilton reached out and she was trying to get my kidney donor, then the Hamilton spectator reached out to me and Christie.

[00:36:16] Saying, you know what I'm going to do an article on you and blah, blah, blah. And I'm like, wait a second, but

[00:36:21] **Brittany:** you didn't want to help her.

[00:36:24] **Jennen:** Right. I reached out to you first through the Toronto star, but now there's some traction on this story and it's in global news and Tom Hayes is interviewing us and he's there all of a sudden, you want to come and talk to us?

[00:36:37] Hmm. Interesting. Okay. Funny. But I made sure I told the, the editor, the person that was interviewing us well, by the way, you know, this came to you first through the star, right? I have to say something absolutely.

[00:36:50] **Brittany:** A hundred percent. Yeah.

[00:36:52] **Courtney:** You have to say something for sure. So, when you first met Christi cause I know you guys have met before the [00:37:00] transplants what was, what was that like meeting a stranger that had just, you know, read your ad and was like, I'm going to yeah.

[00:37:07] **Jennen:** Literally tears. It was just tears. We met at the hospital because she was going in to get tested. And it was just tears. I saw her, Oh my gosh. And I said it, wasn't gonna do this. So when you say something

[00:37:21] **Brittany:** Every single time, we tried to bring tissues. I'm at home and I should have a tissue box, but I don't,

[00:37:28] **Courtney:** my tissue box is over there, but I don't, I guess I can't help. I

[00:37:32] **Jennen:** It's okay. It's okay. It's all good. So anyhow, so I'll her in the hospital and, automatically started crying and I thanked her just a lot of thinking. And she said, no problem, cause this is what you're supposed to do. You're supposed to help. And she was just so nonchalant and was just like nothing. And I'm like, there's a lot of, a lot of stigma about giving an organ. You feel that if you donate. [00:38:00] You're reducing your life. if you donate the kidney and you're going to reduce your personal lifeline and you're not gonna live as long. she said, no, that never crossed her mind. Once she said she saw the ad and you know, I have a daughter and if she could do something to help me be there for my daughter, why not? So she just did it without even thinking twice.

[00:38:21] **Brittany:** It's almost like a maternal instinct. Yes. It's definitely exactly what mothers do is they just, it's just like, this is what we have to do and let's

[00:38:30] **Jennen:** She didn't even think it twice. So I would go with her, but with her to some of the. It could be the tests and stuff that she had to do. And after a while she said, no, no, no, don't worry about it. I don't want you to come anymore. It's okay. They're long and they're tedious and you wanna sit here for hours and whatever, I'll just call you afterwards and let you know what happened, So that's what you kept in contact. And she would just let me know whatever, you know, I'm going to the hospital today and I'll let you know scheme all the way from Hamilton and no, of course it was like super grateful.

[00:38:56] Every time she came down, you know, she's like, Oh my gosh, she's here again because you never [00:39:00] knew. We never knew my mama and myself. We never knew

that it would be so like so many tests, like so long, you know what I mean? We didn't expect, but it's like, she, she didn't think twice. It never discouraged her.

[00:39:12] She never, Oh, I gotta do another test again. Like sometimes it's twice a week. Sometimes he was doing testing. And she didn't even think twice about it. She came down. No problem.

[00:39:21] **Brittany:** Angel, literally.

[00:39:23] **Courtney:** And so what's, what's Christie sign?

[00:39:30] **Jennen:** Her birthday is like a few days before mine. So she's a Cancer.

[00:39:35] **Courtney:** Water signs man.

[00:39:36] **Jennen:** Exactly.

[00:39:37] **Brittany:** Okay. I think Courtney is trying to prove a point here because she's a water sign. Sorry. The context of the story is Courtney's a water sign-- she's trying to prove something amazing.

[00:39:52] **Courtney:** We're very feeling, very sensitive. Yeah.

[00:39:54] **Brittany:** Astrology has come up a lot in this show. Like too often?

[00:39:58] **Courtney:** I have a feeling it's going to come [00:40:00] up a lot ongoing.

[00:40:03] **Jennen:** So yeah, this was born. This whole concept of the ad was born from the water, right. And so yeah, here we are.

[00:40:11] **Courtney:** And yeah. Wow. So I know you and Christie still talk. Did you feel. Was there like kind of an instant connection. I feel like oftentimes donor and recipients there's just something it's odd when people are a match, they also are a match in like they're compatible personality. It seems to be, yes.

[00:40:30] **Jennen:** Yeah. There was like instant connection. And the more we spoke, we just sat there in the cafeteria. This is, you know, obviously pre COVID, so you can sit and talk at that time.

[00:40:38] So we sat in the cafeteria of the hospital and we would talk and her best friend was a Trinidadian and I'm Trinidadian. So I'm like, Oh my gosh, that's interesting. And then she could like dish out the names of different Caribbean dishes, just like. Like nothing. Like she, she makes it and I'm like, okay, hold on. I don't even make it. What do you mean? So she's like literally a sister from another mother. Like, she's just forget what the skin [00:41:00] complexion looks like. We are literally intertwined one. You know what I mean? There's a lot of connections. It was crazy. Literally was a story in the making way before we even knew, like, this is how we've, summarized it. all those time, like back in my twenties when I was in denial and when I was thinking like a fix it myself, God had his plan. Like he was working things behind the scenes.

[00:41:23] He was planning, okay, you're going to do this. You don't know it yet, but you're going to do this. It's good to reach this person because your cousin met someone at church and they're a good friend and it all connected, no matter how much I was in denial, Christy was going about her business, living her life.

[00:41:38] My cousin's doing her thing. And behind the scenes, all this stuff was being worked out and it all came to a head and I was like, wow. Look at that, it just seamlessly, like, you know, you hear stories of people on dialysis, like you said, five, six, seven years for ages. I was on dialysis for about a year.

[00:41:54] It didn't feel like it with all the mishaps and things, falling out of my neck and it didn't feel like it, it felt like [00:42:00] longer, but the whole process dialysis was a year. And then I got the transplant 2018 and now I'm here. Like it, it was just. Like I said at that time it's felt like forever, but looking back on it now, it's like, geez, it wasn't that long.

[00:42:16] Like everything goes so quickly. But looking back on it now, it's like, I'm really blessed because I didn't have to, get to the point where I was in the hospital, in a bed with tubes and all that other stuff, just all just waiting.

[00:42:30] I was actually still living my life, doing what I had to do, and it just happened so quickly. That's all. And it could have been much longer.

[00:42:40] **Brittany:** So do you remember anything from surgery?

[00:42:42] **Jenn:** I remember coming out of surgery. Waking up in the hospital room and there's like a whole bunch of people around me, like nurses. I see my mom, my husband, my daughter. And I remember first saying, where's Tatiana, we're assessing Hannah. And then she comes over like here, mommy. And I'm like, [00:43:00] which one are you? I see like four of you all drugged up. Right. She goes, I'm here. And she came closer as you hug them, like, Oh, there's my baby. Okay. And then I woke up, I don't know how much longer after, but I woke up and everybody was still there. So I'm assuming it's the same day. And then I was just like, Oh, I have to get my phone. I need to, I need to tell everybody on Facebook that I'm okay. And looking back on it now, and I'm like, girl, you supposed to sit there and arrest, what do you mean?

[00:43:29] But I'm like, I have to steam in my phone when I need to, you know, put a message out, let everybody know that the transplant went well and I'm fine. So I grabbed my phone, sorry. My husband gave me the phone and I was literally just like calling friendly. And just like falling asleep with the phone in my hand.

[00:43:45] And he tried to take it from me and I'm like, no, what are you doing? I'm not done yet. It's just like, well, I have to put the message out. And they took a picture of me on the bed with the phone and I'm just like sleeping the message. I was just [00:44:00] out. And then they're laughing at me. Yeah. How's that message going?

[00:44:05] Yeah, that's all I remember.

[00:44:07] **Courtney:** Do, do you remember the first time you saw Christie after surgery?

[00:44:10] **Jennen:** Yes. It was the day after surgery.

[00:44:14] **Courtney:** Did you go to her? Did she come to you?

[00:44:15] **Jennen:** I guess she came to me. Oh yeah. She came to me. Yeah. She was wheeled in her best friends. Ann Marie she wheeled her and the Trinidadian I was talking about she wheeled her in and that was just like, Oh my gosh, hi, how are you? And it's just like, how are you doing? And did they do this? How does your stomach look and how do you feel? And just like, kind of compare it. And you know what I mean? And it's a goal. I still have my stuff on. I can't see it, but I can't sit up.

[00:44:38] Right. It hurts. And she goes, yeah, me too. But she bounced back, like nothing. I was just like, is it the yoga that you're because she's a yoga, like you said, the yoga that you're doing, like, like nothing, meanwhile, I'm, still healing. And then I left the hospital when I had to go back in again, because I was having a reaction to this and that.

[00:44:56] And I'm like, and Christie's open about doing her thing. And I'm like, damn.,
[00:45:00]

[00:45:00] **Brittany:** one of our doctors told me that in, I can't remember what country it is kidney donor surgeries are day surgeries.

[00:45:08] **Jennen:** What. Day surgeries, drug, what kind of medication are they using?

[00:45:16] **Brittany:** Well, the donor's kidney donors can typically perk right back up and they should, because they came in, walked in healthy and if they should walk out healthy as well. Right. Whereas with the recipient. it's so different. Like it's like your life, you feel so much different afterwards. And you're like, wow, I didn't even realize like, Just how badly I needed that kidney.

[00:45:41] **Jennen:** Exactly. It's true. Because every thing, literally after surgeon was lying in bed, they're like looking and he's like, her face looks so different. Your color. Oh yeah. Her color looks so different. She's shining. So when I did wake up and I. More awake. Right. And I was actually more coherent now. They're like, what [00:46:00] are you wearing makeup? My sister would say, are you wearing makeup? And I'm like, no, I don't think so. I'm just, my kidney. Okay. It's my new kidney girl. But anyhow.

[00:46:20] But yeah, that's, that's what you hear. Like, you know, you look so different. Christy did leave the hospital before me. Right. So she did,, like I said, she bounced back a lot faster, but I don't know how you can be a day surgery though.

[00:46:32] **Brittany:** Yeah, I know that spooked me too. I was like,

[00:46:35] **Jennen:** like, even as a donor, you're still drugged up your staff, you know? So.

[00:46:39] **Brittany:** I remember leslie telling me that. And I was like, what?

[00:46:43] **Jennen:** That's crazy. Yeah, no.

[00:46:46] **Courtney:** I remember this like post-surgery detail from the first time we spoke Jennen also. And as someone who drinks a lot of water. I feel like Brittany's always joking. At some point we'll be talking and we'll have been talking for hours and then she'd be like, do you need to pee? And I'm like, yeah. But I drink a ton of water and [00:47:00] I remember it stood out to me. So clearly that you saying after surgery, one of the best feelings was going pee. It's like, cause you actually were like peeing

[00:47:10] **Jennen:** and it was sitting there and. Peeing. And the crazy thing is you. Yeah. Look at me go. But the first thing Dr. Lee, who performed my surgery, the first thing he said after surgery, when he went to tell my mom and everybody was waiting in the waiting room, but the surgery, he said, she's peeing. She's not - oh, you know, the surgery went well or no, just keep, let you know that Jennen is doing well. No, she's peeing she peeing. And everybody's like, yes, it was just like won the lottery or something, you know? So that was the first thing he told them. And then he went into the surgery, but yeah, I'm peeing.

[00:47:55] **Brittany:** I had a patient. I'll never forget this. He was an awesome kidney, [00:48:00] trans post kidney transplant recipient. And I had him in step down and he was such a cool guy. And by the end of my shift around 1800, which is six o'clock, I told him his creatine. And he was with his family and everyone started crying. It was so cool. It was so cool. I was like, I got to deliver that news, but I was like, guess your creatine. And, and I think his creatine number. Was probably in the six hundreds before. And it was down in the one hundreds. I was like, guessing everyone gave it gas and I'm like, it's like one 30 and everyone started

[00:48:38] **Jennen:** See, that's some good news.

[00:48:39] **Brittany:** That was so cool.

[00:48:41] **Jennen:** that's big. That was big. Yeah. That's huge.

[00:48:45] **Brittany:** So who is your support person throughout this? Was it your husband? Was it your mom? Cause I know in the transplant process you have to have a support person or you don't get an Oregon. So who was that person for you and how did they [00:49:00] cope with it?

[00:49:00] **Jennen:** It was both my mom, actually, I had more than one, but my mom, my husband and my daughter, cause I can't leave my daughter out. Like it's not even an option. You know what I mean? Of course, but it wasn't three of them. And so they were there when I want to cry. When I want to vent, when I wanted to express how optimistic I am about everything. When I want to express how frustrated about. Whatever the process, you know, they were there when I went in to have surgery, get the catheter, put in, it, fell out, put it back in again. But the other catheter in the stomach, he got tied up. Take that out and put another one in like they were there. They were there for the whole process. The only thing I didn't want them, therefore wasn't as actually doing dialysis in the hospital. And that's because it's like four hours. Yeah. And my husband always offered, he came a couple of times and my daughter came a couple of times, but my family, my husband, my daughter, and my mom. They're my biggest support system.

[00:49:49] **Courtney:** I'm just wondering, do you have any advice you would offer to someone who's maybe at the, beginning of their lupus journey, the beginning of their kidney failure journey? [00:50:00] Like what is something you would tell someone who's maybe struggling with denial, similar to what you went through at the beginning of your journey?

[00:50:07] **Jennen:** I'd say don't do what I did. Don't sit there and say denial. Cause it's just delaying your process. You have to talk, you have to tell them, you have to share your story with your family. If you haven't told them about the lupus, let them know the sooner, the better. If you haven't told them about the kidney disease. And you're wondering how to tell them, be honest, just come out and express to them. This is my situation and I need your help. I would love it. If you could get tested and see if you can help save my life.

[00:50:33] Right. Just be honest, don't do the denial thing. Cause it's just a disservice to yourself in the end. Be honest and put it out there and you have to have faith regardless of who you believe in, whether it's God, whether it's Buddha, whomever, it is, you need to keep the faith because it's going to get to those times.

[00:50:49] You're going to have those times where you feel like this is not going to happen. This is not going to work out, but you have to have faith.

[00:50:56] And I always said, if there's anybody that needs to talk, if someone wants to speak to [00:51:00] someone that went through it, I'm your girl, give them my number. It's okay. I don't mind, telling my story, sharing with them, what I did, what have you, but don't get discouraged.

[00:51:09] Don't get discouraged. This is just a stepping stone.

[00:51:11] **Courtney:** You saying that, you left your name and your contact info behind at the hospital being like, if anyone wants to talk to me, like, I love that about you. And also Brittany, I don't know if you know, the way that Jennen and I met is Paula just sent me on a goose chase. She sent me a video of Jennen and Christie being interviewed on Jennen's cousin's show and was like, I love this woman. Find this woman .

[00:51:32] **Jennen:** I didn't know that I was a patient at the hospital, or she just wanted you to just look and try to find me.

[00:51:39] **Courtney:** I don't know how she found the video. I don't know what it was, but she was like, I liked this woman go find her. And I was like, all right. And then Jennen's is so water signs man. It was so like trusting that I just added her as a friend on Facebook and sent her a message and was like, Hey.

[00:51:55] **Jennen:** Okay. Yeah. [00:52:00] Nice. Okay.

[00:52:01] **Courtney:** Yeah. So that's how we started talking and I like didn't think that was gonna work. But it did. Why is bringing that up about like what how that's something that I like really like about you that you're so open and sharing with your experience. And so generous with your story for others is, is because you are going to be hosting this YouTube channel that the Centre is supporting through the ACTION project, which is a project that we

have to support equitable access to living donor kidney transplants specifically in the African Caribbean and Black communities- is the Ontario version of that project. So, I'm so excited that you're going to be hosting this channel because it's just perfect for you. Like this is, I think this interview is going to need, I think personally minimal editing because you're just so good at kind of like articulating this experience and Yeah. Like I feel like I. Yeah, I can picture your, your experience is so, so perfectly based on your description, what are, what are some of the things you're going to talk about, [00:53:00] on your channel?

[00:53:00] **Jennen:** Well, first I'm going to do is get like boxes of tissues and just have it there. Guaranteed, I'll be crying, several times throughout the show. Cause I I'm just a baby that way. I just, but yeah, I'm really excited about it too. It's gonna be, we're having worked at all the details just yet, but we're just gonna be covering. Different topics. It's all based around kidney, kidney disease and any type of kidney issue. And that doesn't mean that if you don't have kidney disease or kidney issues, you can't watch, you can definitely watch because it's done the lifestyle. It's going to be talking about health and fitness. We're talking about cooking. You get to see me cook. I'm not the best cook, but you can just, right. Let's just say good thing. It's not taste of vision. You don't have to try it or anything. So you'll see me do it. We'll be talking to, different. People who went through or who's going through or went through kidney failure, I'm talking about those, who's going through it.

[00:53:47] Now, those who went through it with their life is like now talking about, their family that supported them, we're talking about intimacy and and kidney failure. How does that work? Does it work, or are we talking about, having the child's point [00:54:00] of view, I'm going to have Tatiana on there as well.

[00:54:02] She's going to share her story, how she felt. Watching me go through kidney failure and what was going through her mind. And,, she could give advice too, because she's not the first child to go through this. Right. So she can give her advice and opinion on that as well. So it's going to be talking about a various amount of various surveys of things, and I'm really excited.

[00:54:18] I'm really excited to share this story and because I could relate, you know, and I want it to be about them, the viewers, so they can share their story with me. I can share wise with them and just helping each other out.

[00:54:30] **Brittany:** So you mentioned something that I need to ask. So tell me about intimacy and transplant. . Did your relationship change with your husband at all during the transplant pre-transplant and post transplant, what was intimacy like for you?

[00:54:49] **Jennen:** Pre-transplant there was no intimacy and it wasn't because of, you know, lack of, or I wasn't attracted to him anymore. I love my husband to the moon and back [00:55:00] just did it feel it was there and he would try, he would try to get intimate with me. He would, you know, and start off with, you know, simple things as do and what have you, but I just did it feel it, I wasn't in the mood. I just didn't want to go there. Like it wasn't, it wasn't there. Like it literally just someone turned it off. Right. Any type of, sensation or arousal or anything, it was just gone all about. I was just focused. I need to make sure I

change my, fluids on time at home, on time to make dinner, make sure we're there to take Tatiana to our classes, make sure testing.

[00:55:34] And it goes to bed on time when she goes to bed, I'm out. I'm tired. I want to go, you know what I mean? And he was very understanding, like, can you, he knew what was going on because before this, you were wild. Rabbits were good. You know what I mean? Like there was issues, but then this started and it's just, just complete downturn. And it's partially because of, the medications and it was partially because of, like I said, I just didn't feel it. I [00:56:00] was not into it. I just. But, you know, I would still you know, we cuddle and you know what I mean? But actual physical intimacy, I just wasn't about it, but he knew, and he understood after transplant.

[00:56:12] Then to be honest, it didn't even start up right away after transplant. Yeah. Was, you know, that was still healing. And then I still had side effects, I had to go back into the hospital a couple of times after the transplant, because the medication was still, we were still adjusting medication was either too much or it wasn't enough. And I almost passed out a couple of times. And so the last thing you're thinking about is sex to be on. Right. So it took, I'd like to say maybe. At least five, six months after transplant were started feelings. They feelings started coming back up again, Hey, it's working, what's coming, you know, slowly but surely. And I started getting back into my own. Again, I started feeling. Well as a woman again, you know what I mean? Yeah. He was completely understanding throughout the whole process and around, I was like, Oh, well, how come? Like he, nothing, [00:57:00] nothing of this sort.

[00:57:00] **Courtney:** That's amazing.

[00:57:01] **Brittany:** That's a solid, man. Yeah.

[00:57:03] **Jennen:** You have to have someone that's there for you like that.

[00:57:05] Yes, absolutely. There's someone there for you like that.

[00:57:08] **Courtney:** It's so important to understand, like when you're going through health stuff that like it's ha- it's you can't have sex and enjoy sex if you don't feel so sexy.

[00:57:16] **Jennen:** Exactly. Oh my gosh. That's 100% true. That's the last thing on your mind is sex. Like you don't. Yeah. You don't feel sexy. You don't feel like you want to put on anything sexy. You don't feel let's put on some, romantic music. No, you don't feel that. I just want to go to sleep. You want to go to sleep or I just want to lay here and just watch television. Like, I don't feel that you understood.

[00:57:39] **Courtney:** Yeah. I think if you are, I imagine when you're struggling with kind of illness and stuff, you're taking it one day at a time already. Yeah. It's like, it's not even on your radar. Like, it sounds like for a lot of people that I've talked to, as they progress in their organ failure, their world kind of gets smaller and smaller, their daily activities get shorter and shorter and [00:58:00] polycystic, kidney disease, people that I've talked to, especially like you just get you're just so tired. You're like, sure. Yeah. One woman I know that I spoke to, she was like, I my day was a task to do list of three things. Cause that's all I can manage to

do in one day. And they could be things like go to the grocery store. That could be number one. And that's a full, full chunk of the day. That's one third of my day. Cause that's all you can manage.

[00:58:24] **Jennen:** Yeah. But I am happy to say we're back. It's good. There's no issues now. So amazing.

[00:58:34] **Courtney:** That's that's, that's great to hear. And I'm so excited. You're going to be addressing that topic on your YouTube channel. And also Brittany wants to do like an entire episode on that, which I totally agree with and would love to do so we might have to have you back.

[00:58:47] **Jennen:** I'll be there. Yeah, i'll be there.

[00:58:49] **Brittany:** It is incredibly important. And literally. Mind blowing to me that this is not a [00:59:00] topic that is discussed within transplant in the five years. Not a long time. Okay. I'm not like I've been here forever in the five years that I've worked with in the transplant program. I have never.

[00:59:13] Had a conversation with one of my patients. I've never heard of this coming up as a topic within, because it's very, it is very PR not saying it doesn't happen within maybe a doctor and a patient because it, most, it, it has to,

[00:59:28] **Jennen:** but with me

[00:59:30] **Brittany:** It is so true.

[00:59:31] I don't necessarily think it's like the transplant program. I just think society in general, that it's very taboo to talk about these things, which blows my mind, because these are things that are incredibly important, definitely to humans and how we act and everything like. So I it's my mind. So I think we have an awesome opportunity to.

[00:59:59] Open up [01:00:00] conversation and use this as a platform to discuss these things,

[01:00:03] **Jennen:** yeah, it's true. And it never came up with once with me, with any of my doctors and I had quite a few doctors.

[01:00:09] Never once with the doctors, with the nurses. Nobody. No. Well, I started feeling well, wait a second. Where's my drive. Where's my urge. Where is it? You know what, and this is before. Like I said all the tons of meds that they put me on after the transplant, this is like, this is just going through the beginning stages.

[01:00:26] You know what I mean? What's going on. And honestly didn't even cross my mind until I started feeling those things. Right. Never crossed my mind when I was told. Yeah, you're going to need a kidney when I was told. Yeah, you've got to go in and get a catheter put in that never crossed my mind.

[01:00:40] Only crossed my mind when we try to get into it and say, right. I don't really feel like it. And then I realized, wait a second, why am I not feeling like it? Why is it so many times I don't feel like it what's going on, Right. But yeah. Never gets addressed.

[01:00:53] And that's yeah, this is definitely, we need to talk about that because it's part of the process, just like the [01:01:00] transplant, just like the recovery, just like they talked to you about nutrition pre and post pap transplant. intimacy should be in there. It's something that gets you ahead.

[01:01:07] **Brittany:** In terms of your mental health, regardless, if anybody wants to address it's something that gets you.

[01:01:14] Ahead and put you in a better, a better positive head space to do things. So it doesn't even need to necessarily be physical sex, intimacy is like an umbrella term for many things. Right? So. if it's not happening at all, I mean, that's a pretty big part of your mental health it's not being

[01:01:34] talked about.

[01:01:35] **Jennen:** Absolutely. True. Very true. Very true.

[01:01:38] **Courtney:** Yeah. That's a future episode. I'm really looking forward to,

[01:01:40] And

[01:01:40] thank you so much for joining us Jennen It's been amazing talking to you again and. This whole conversation was just such a pleasure. Such a pleasure.

[01:01:49] **Jennen:** Loved talking to you ladies. I'm glad I was here. I'm glad you invited me. Thank you very much. Sorry for the tears, but you know, You guys are doing a great job, so thank you so much.

[01:01:59] [01:02:00] **Courtney:** Thanks for listening to this episode of Living Transplant. If you have questions or suggestions for future episodes, email us at livingorgandonation@uhn.ca

[01:02:09] **Brit:** Don't forget to subscribe, rate, and review living transplant on iTunes, Spotify, or wherever you listen to podcasts

[01:02:16] **Courtney:** and follow us @givelifeUHN on Facebook, Twitter, and Instagram.

[01:02:20] **Brit:** See you next time.

[01:02:21]