

Living Transplant S1 E1 – Kadeem Morgan

[00:00:00] **Kadeem:** [00:00:00] I thought I died. I was like, this must be heaven, cause I, I was able to breathe, like it's hard, it's hard for you, to understand how I felt because breathing for you has always been second nature, first nature But for me it was never, it was always something I had to remember to do or remember to concentrate on is breathing right. Oh, but after my transplant, it was like, I honestly thought I went to heaven. Cause I couldn't believe that I was able to breathe without coughing without having a cough or anything like that.

[00:00:39] **Brittany:** [00:00:39] Welcome to Living Transplant.

[00:00:43] **Courtney:** [00:00:43] The podcast that takes you behind the scenes of the transplant program at Toronto General Hospital

[00:00:48] **Brittany:** [00:00:48] and brings you open and honest conversations about the transplant experience.

[00:00:52] **Courtney:** [00:00:52] My name is Courtney and I'm the communication specialist for the Centre for Living Organ Donation.

[00:00:57] **Brittany:** [00:00:57] And my name is Brittany. I'm a bedside nurse in the [00:01:00] Ajmera Transplant Centre.

[00:01:01] **Courtney:** [00:01:01] Full disclosure: we are not physicians.

[00:01:03] **Brittany:** [00:01:03] No. And we are not here to give you medical advice.

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[00:01:18] like you've never seen it before.

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[00:01:20] **Britt:** [00:01:20] Our guest today is Kadeem Morgan. Kadeem was diagnosed with CF when he was about one years old. And now he's 23 years old. So Kadeem welcome. Thank you for coming.

[00:01:32] **Kadeem:** [00:01:32] Hello, Hello.

[00:01:33] **Britt:** [00:01:33] So what is your connection to transplant?

[00:01:35] **Kadeem:** [00:01:35] Well, my connection to transplant is having cystic fibrosis. I received my transplant,

[00:01:42] back in 2017, ironically Easter weekend. Right before my transplant, right before I got the call, I was already an inpatient at St. Michael's Hospital battling a really bad, bad infection [00:02:00] or virus or a concoction of the two. And I was hospitalized for two months prior to getting the phone call. I got the phone call on good Friday,

[00:02:12] and by Easter Sunday, I was on the operating table.

[00:02:16] **Court:** [00:02:16] Wow.

[00:02:16] **Kadeem:** [00:02:16] Yeah. Luckily I was fortunate that I didn't have to wait too long to receive the phone call because I, I can't put it. I was on life support pretty much, before for my transplant and my doctors didn't think I was going to make it to see a transplant.

[00:02:35] So from the period between signing the papers and the consent forms to actually get the surgery, I probably waited like three weeks max. And that's pretty much almost record time because the average is what, six months, to a couple years, in fact, cause obviously they have to find the perfect set of lungs for you.

[00:02:59] Right. They [00:03:00] can't just get anybody's lungs and then just toss them into you, right?

[00:03:06] **Court:** [00:03:06] Yeah, for sure. So

[00:03:07] **Kadeem:** [00:03:07] yeah, my connection to the transplant program is having cystic fibrosis and receiving a double lung transplant.

[00:03:14] **Court:** [00:03:14] Nice. so as I mentioned to you at the beginning, before we started recording, I have no idea about, I have very basic knowledge of cystic fibrosis.

[00:03:24] Do you mind explaining what it is?

[00:03:26] **Kadeem:** [00:03:26] Okay. So , for sake of time, cystic fibrosis is, genetic disease. And so it is considered a rare disease, that primarily impacts the respiratory system, in order for someone to be diagnosed with cystic fibrosis, both the mother and father have to carry the CF gene.

[00:03:49] And even then if both parents carry the CF Gene, and I think the percentage is like the chances of the kid getting cystic fibrosis is probably like [00:04:00] 25%.

[00:04:00] **Britt:** [00:04:00] You're right.

[00:04:01] **Kadeem:** [00:04:01] The chances of people of color having cystic fibrosis is even lower. So like me personally, and my younger brother we're in a niche demographic already and then throw in cystic fibrosis.

[00:04:17] That's even more of a niche demographic. Yeah. Yeah. And I should note that cystic fibrosis also affects your pancreas. The lack of ability to produce enzymes, to break down your food and whatnot. It's also CF related diabetes. Some people, cancer related to cystic fibrosis - cystic fibrosis is just like a huge concoction of things.

[00:04:45] **Britt:** [00:04:45] It's like an umbrella term.

[00:04:46] **Kadeem:** [00:04:46] Yeah. I'm pretty much,

[00:04:48] **Britt:** [00:04:48] But essentially what it is like, pathophysiologically your lungs produce mucus normally. CF - [00:05:00] there's when you're, when you have CF you're missing a gene or that gene is mutated and it, so that the mucus that your lungs normally produce is thicker so essentially your lungs fill up with mucus, like thick mucus.

[00:05:14] **Kadeem:** [00:05:14] Basically you're drowning.

[00:05:15] **Britt:** [00:05:15] Yes.

[00:05:15] **Kadeem:** [00:05:15] In your own bodily fluids.

[00:05:17] **Court:** [00:05:17] Okay. Okay. Yeah. I see.

[00:05:19] **Kadeem:** [00:05:19] Okay. Too thick to get out - mucus equals bad.

[00:05:22] **Britt:** [00:05:22] Okay. Which that it creates more problems for infection.

[00:05:26] **Kadeem:** [00:05:26] Exactly.

[00:05:27] **Court:** [00:05:27] Right. Okay. So you mentioned it being really, I don't know if this is we're getting here already, but, you mentioned CF being really rare in people of color.

[00:05:37] **Kadeem:** [00:05:37] Oh, yes.

[00:05:37] **Court:** [00:05:37] Yeah. I, I did some preliminary research. I think what was it for? Because I looked up Asian patients and Black patients for the first two that came up.

[00:05:46] **Britt:** [00:05:46] So according to the CF foundation, in the States, the disease occurs in one in 2,500 to 3,500 white newborns.

[00:05:55] Cystic fibrosis is less common in other ethnic groups affecting [00:06:00] one in about 17,000 African Americans and one in 31,000. Asian-Americans. Wow. Yeah. Just to get the picture of

[00:06:09] **Kadeem:** [00:06:09] how,

[00:06:10] **Britt:** [00:06:10] how rare it is for it is for this to have happen.

[00:06:13] **Court:** [00:06:13] Absolutely. So Kadeem, other than you, you mentioned your brother has CF as well.

[00:06:18] **Kadeem:** [00:06:18] Yes, he does. Okay.

[00:06:19] **Court:** [00:06:19] So other than your brother, have you met another black CF patient?

[00:06:23] **Kadeem:** [00:06:23] Throughout my years of being part of, CF programs and whatnot, I probably met two people with cystic fibrosis who are black. I also have a friend who is, she was born in Guatemala. She had cystic fibrosis as well, but besides those three people, mainly white people, I know that have cystic fibrosis.

[00:06:50] Yeah. It's yeah. It's it's it's interesting.

[00:06:54] **Britt:** [00:06:54] So how does it affect someone's life? That's a broad question. How [00:07:00] does it affects, how has it affected your life?

[00:07:02] **Kadeem:** [00:07:02] Cystic fibrosis?

[00:07:04] **Britt:** [00:07:04] Yeah.

[00:07:04] **Kadeem:** [00:07:04] See, the thing is before my transplant, I never really, I was never the one to plan around my cystic fibrosis. And what I mean by that is that

[00:07:17] I would never say no to going to an event or hanging out or doing anything, possible because of CF, I wouldn't let CF, discourage me towards doing things, right? Like for example, I know a lot of my CF friends, they can never, ever go on a rollercoaster at Wonderland. Hmm. Because like, because of the air pressure from all the, the rides and stuff.

[00:07:44] Me, on the other hand, I probably, the first time I went to Wonderland, went on Behemoth, like five times in a row, call me crazy. I was like, at, at the end of each run, I was just like gasping for air when I was like, no, I can't because [00:08:00] all my friends want it, didn't do it right? So I'm like, you know what?

[00:08:02] Yeah. Toughing it out. Let's go do it again. Front cart? Behemoth? Let's go. Yeah. So like, I never really let CF run my life. Obviously there's some things that I had to do in order to sustain my health. I used to have like a five hour routine regimen every morning. And every night before bed that consisted of taking.

[00:08:28] A lot of drugs, like pills and stuff, steroids. A lot of like inhaled antibiotics, stuff like, inhaled Ventolin or Pulmozyme or hypertonic saline through a nebulizer. Yeah, if it took five hours every night. Sorry, I didn't mean to say five. I meant like, I met like four, three, four hours max, four

[00:08:51] **Britt:** [00:08:51] Hours. Four hour to get ready for bed! My skincare routine's, like 40.

[00:08:57] And I'm like [00:09:00] --

[00:09:00] **Kadeem:** [00:09:00] I wish cause like, and I had to do it before school as well, which unfortunately I lived far from my school. Right. I made things harder on myself because I originally lived in Scarborough, but then I moved to Pickering, but I still attended

my Scarborough school. So that means I had to wake up even earlier to do all my treatments and stuff before I even leave the house.

[00:09:24] Right. But as far- as for that, like that's the only, that's probably right. The only thing about CF that made me, that made me, that made me plan around what I needed to do. Obviously, if I had to be hospitalized for IV antibiotics, there's nothing I can really do then. Right. But even when I was hospitalized, I was still like, trying to get all my homework done.

[00:09:51] Trying to do all these projects and stuff like that. I was just I was a workhorse. And if I wasn't working, I felt [00:10:00] like I was wasting time per se. So as much as I try to near to, like closer to getting a transplant, I never let CF dictate what I was going to do that day. I was dictating what I was going to do that day.

[00:10:17] And CF was like left on the back burner

[00:10:20] **Britt:** [00:10:20] Pretty incredible.

[00:10:21] **Court:** [00:10:21] Yeah, for sure.

[00:10:22] **Kadeem:** [00:10:22] Yeah.

[00:10:23] **Court:** [00:10:23] I mean, so obviously I'm fully starting to wrap my head around it, but obviously CF affects your respiratory system. So the air pressure thing, and then riding rollercoasters. That makes perfect sense when you say it, but I never would have thought of that

[00:10:37] **Britt:** [00:10:37] Nope.

[00:10:37] **Kadeem:** [00:10:37] Yeah cause like breathing for like the average person, just it's whatever. Right? For people with cystic fibrosis like you have to fully be conscious of your breathing. you can't like miss a breath. You can't like accidentally hold your breath. Cause that would just turn into a coughing fit right?

[00:10:55] **Court:** [00:10:55] Right.

[00:10:56] **Kadeem:** [00:10:56] So someone with cystic fibrosis is always [00:11:00] consciously thinking about their next breath, as opposed to someone else, someone that doesn't have any respiratory issues breathing just seems like whatever.

[00:11:10] Right. So, yeah.

[00:11:12] **Court:** [00:11:12] So, I guess just for the listeners and for myself, what are some kind of, I guess general rules or restrictions that they would tell you when you have CF, things that you should avoid or that you can't do.

[00:11:25] **Britt:** [00:11:25] The list is long, long. Okay.

[00:11:28] **Kadeem:** [00:11:28] It's a long list. And if I were to be completely honest, a lot of CF patients are rebels.

[00:11:36] So they don't always follow healthcare guidelines. It's hard though. It's hard because like, for example, say, say you have cancer, right? And then you go in a support group with people who have cancer, you could meet someone you could, go to lunch with them, like physically interact with them. But with cystic fibrosis, you [00:12:00] can't interact with other cystic fibrosis patients, fears of passing any like dangerous virus or bug to your fellow CF'r - like, for example, say Brittany, say you had CF. Right. And I had CF. One of my viruses may be like a regular routine thing that my body's used to, but if said virus got transferred to you, high possibility, it will kill you because your body doesn't know, recognize that virus, your body never had that virus.

[00:12:33] Therefore it would be life threatening to you. So that's like one of the biggest restrictions CF patients have, there's also like constant, like hygiene checks. Make sure you wash your hands with hand sanitizer everywhere you go.

[00:12:49] Every time you touch something in public, for the, for like the more severe patients, they always wear a mask. Even before this whole COVID thing. So [00:13:00] basically basically all the precautions you take for like COVID or just general diseases and whatnot that's basically the life of a cystic fibrosis patient.

[00:13:12] That's like a normal thing.

[00:13:14] **Britt:** [00:13:14] Yeah.

[00:13:14] **Kadeem:** [00:13:14] Yeah. Yeah. They say, and the various cystic fibrosis groups, they say cystic fibrosis patients are like taught to be doctors and nurses from a very young age.

[00:13:29] **Court:** [00:13:29] Yeah, that's an interesting way of putting it. I've never thought of that.

[00:13:33] Yeah. Yeah. It is. It is funny talking to transplant recipients and or candidates and immunocompromised people are already, you know, you ask them, "are you scared about COVID?" and "they're like, not really. I just keep doing what I've been doing for a while." Yeah.

[00:13:47] **Kadeem:** [00:13:47] Exactly. Yeah. Social distancing and stuff is nothing new.

[00:13:53] Really. It's just. Okay. I've been doing this my whole life. The only differences is like the whole world has [00:14:00] shut down. Before I, if anything it's easier now for us than before COVID because before COVID the whole world was still going around and we had to like, carefully place ourselves and carefully figure out what we have to do without getting sick.

[00:14:17] But now that the world is closed, it's like, whatever, we've been doing this all our lives.

[00:14:23] **Court:** [00:14:23] Yeah. I mean, I don't know if this is typical of CF patients, but like, in a lot of ways right now, anyway, your disease seems like invisible. So how would someone know that they have to keep a distance from you to keep you safe?

[00:14:35] **Kadeem:** [00:14:35] Honestly. I'll use my brother as an example. If you saw him, you wouldn't even know he had cystic fibrosis. He, he doesn't get admitted, he doesn't really get sick. He doesn't take pancreatic enzymes, which is usually one of the main forms of treatment. Cystic fibrosis patients take.

[00:14:59] He doesn't have to do [00:15:00] nebulizers. He he looks like a normal 19 year old kid or young man right, opposed to me when I was his age, I was coughing nonstop. Like I probably like, I, I would cough so much. I probably wouldn't even be able to do this. Talking with you guys. Cause like I couldn't go five words without coughing.

[00:15:22] And it was like, I had to go through that for like a good 20 years of my life. It just became normal. But yeah, sometimes it can be invisible if you're not fully aware of the person. Yeah. If I didn't cough, a lot of people wouldn't have known I had cystic fibrosis.

[00:15:40] **Court:** [00:15:40] Yeah. I would have, I would have no idea.

[00:15:43] **Kadeem:** [00:15:43] Yeah.

[00:15:44] **Britt:** [00:15:44] Was your diagnosis prolonged due to the likelihood of you even having CF?

[00:15:50] **Court:** [00:15:50] Or like the, the statistics of it being a... like you being a statistical rarity, like, do you think that prolonged your [00:16:00] diagnosis?

[00:16:00] **Kadeem:** [00:16:00] Yeah. Oh yeah, of course. Until I was born, obviously, well, obviously, cause I'm a, I'm of Caribbean descent, Jamaica and Barbados respectively. And obviously because of the history, there were white people in my ancestry, right. Because of slavery plantations all that.

[00:16:19] That's a fact. So on my dad's side, my great, great, great grandfather was Irish. And on my grandmother's side or my mom's side, my great, great grandfather was half Scottish. Until then my whole family didn't realize how many white Europeans we had in the family until we actually looked at our family tree.

[00:16:43] And unfortunately -those white family members are far down in my ancestry line - my brother and I were the lucky ones to catch cystic fibrosis. Like my parents were the lucky one to both be carriers. Right. but back [00:17:00] in, dating back to 96 when I was born, forget now being rare and people of color. Think about 96, and the nineties.

[00:17:07] Right, right. Doctors thought I had sickle cell anemia. They thought I had glorified asthma. They thought all my symptoms, I would just grow out of it and whatnot and, nothing.

[00:17:19] **Court:** [00:17:19] Wow. Yeah. And it makes you wonder how many people are out there. Undiagnosed.

[00:17:24] **Kadeem:** [00:17:24] Yeah,

[00:17:24] **Britt:** [00:17:24] well, cause a lot of people are carriers, but a lot don't know.

[00:17:28] **Kadeem:** [00:17:28] I know this is more common, of course, with white European CF patients. I know some people that weren't even diagnosed until they were like 30. They never had flareups or whatever. Right? Not even, no respiratory problems, no pancreas problems, no GI problems, nothing. So like cystic fibrosis is weird. Cause it's like there's no way of putting an umbrella over it.

[00:17:55] Cystic fibrosis, because it's almost like a case by case [00:18:00] situation. Like my CF it's different from another person's. Yeah. Right. So what might help another person, may not help me because of the different genetic makeup.

[00:18:12] **Court:** [00:18:12] Yeah. Sorry. I feel like I'm asking, I just have so many questions, but, how common is it for two siblings to, to both have CF? Is that.

[00:18:23] **Britt:** [00:18:23] It's 25% chance because it's a 25% chance that both parents will have that. Yeah. Yeah. So I'd say it's still very, it's just rare. It's like -

[00:18:35] **Kadeem:** [00:18:35] Yeah. Cause I know a couple of people, couple of friends with cystic fibrosis, they have the same mothers and fathers. And they're older or the younger sibling didn't have cystic fibrosis.

[00:18:46] **Court:** [00:18:46] Hmm, but

[00:18:47] **Britt:** [00:18:47] I have heard of, I've actually had a couple of patients that have had brothers or twins that have, that are CF twins or CF siblings. I've heard of it only a couple of times though.

[00:18:59] **Kadeem:** [00:18:59] Yeah. [00:19:00] It's, it's rare. It's rare. Very rare.

[00:19:02] But like luckily if one child has CF, if the mother plants to have another kid, generally speaking, the doctors are gonna suspect that the next kid will have CF just for precaution, right? Especially now, like, since they have like CF as part of the newborn screening as well, because as a precaution, like they did with my brother, because they knew I had CF, they planned for my brother to have CF in which helped him in the long run. I was pretty much the guinea pig. Not that I'm not, not that I'm not about that or anything. Yeah. It's, it is what it is. Right. As long as I know my brother's good. He's healthy and I'm part of that, the reason why, I'm happy, you know? Cause I, I know what I've been through. I've been through a lot and I don't know how I would react if my [00:20:00] brother went through the same things I've gone through.

[00:20:03] Right, right.

[00:20:04] **Britt:** [00:20:04] Where did you grow up?

[00:20:06] **Kadeem:** [00:20:06] I grew up in Scarborough.

[00:20:07] **Britt:** [00:20:07] A Scarborough ting. Yeah.

[00:20:13] **Court:** [00:20:13] And what was it like growing up in Scarborough with CF and also being Afro Canadian.

[00:20:24] **Kadeem:** [00:20:24] I mean, it's growing up in Scarborough. What? Like - I think that's like enough explanation, but like, well, the thing is

[00:20:35] **Court:** [00:20:35] like -

[00:20:35] I'm from I'm from Victoria BC and I think our listeners are kind of spread out across the country. So give us like a Scarbrough vibe. What Scarborough in a nutshell?

[00:20:44] **Kadeem:** [00:20:44] Scarbrough is the most, it's the most ghetto, but upbeat place in Toronto is ghetto, but it's like, it sets itself at like such high standards. It's [00:21:00] like, it's, it's hard to, it's hard to explain. For the most part you meet a good amount of different individuals from different classes, different social standards and what not.

[00:21:15] It's a huge melting pot. Pretty much. You never have one race or group stick to their own. Every clique you see you, you have like your fair amount of Asians, Blacks, white. There's a lot of diversity. No one really discriminates. It's nice. Like, but for me though, when I grew up in Scarborough, I grew up in the one pocket of Scarborough that was predominantly white.

[00:21:40] Okay. in elementary school, I kid you not K to eight I was the only black kid or straight black. There was like one girl that was like mixed white, black. Bi-racial. But, from K to eight, for the most part, I was the only black kid. I was the token black [00:22:00] kid. Pretty much so

[00:22:01] **Britt:** [00:22:01] I was the token black girl,

[00:22:03] **Kadeem:** [00:22:03] It's tough because like, I'm already so different.

[00:22:06] I have to, like, I felt like I had to uphold certain standards, because - in order to not to be stereotyped as a black individual. Right. So I already have that social standard to uphold. And on top of that, I had cystic fibrosis. And the one thing that I did not want and I tried my hardest and I think I succeeded, but I did not want to be looked at or viewed as, the sick child, right?

[00:22:36] I wanted to be normal. I wanted to be like my healthy counterparts. Right. But. Yeah, life didn't grant me that.

[00:22:45] **Court:** [00:22:45] Yeah. So did, did your friends know that you had CF or you kept that pretty close to the vest?

[00:22:51] **Kadeem:** [00:22:51] I had one friend, God rest her soul. Her name's, Christiana. She had cancer she was like the first friend I [00:23:00] considered family.

[00:23:01] She knew I had CF ironically, we met before. kindergarten, we met in the atrium of Sick Kids Hospital I don't know how or why we talked then, but we did. And then two weeks later, I go to kindergarten, first class, I see her. They're like, "oh, here, go your here?" Yeah. So like she became my first like sister friend and she knew I had CF.

[00:23:28] I usually kept the people who knew I had CF to a minimum to like only my closest and best friends knew. Cause again, I didn't want to be stereotyped. I didn't want people to worry or like, I didn't want to deal with people's ignorance, both intentional and non-intentional, you know?

[00:23:48] **Court:** [00:23:48] Yeah. And like pitty too, who want to

[00:23:50] do you don't want these pitty?

[00:23:51] **Kadeem:** [00:23:51] Yeah, to be honest, I was hospitalized a lot. Sometimes it got as bad as like three times a year [00:24:00] and each hospitalization, it was like at least three weeks. Right. So I didn't want people to talk amongst themselves saying, "oh, I think Kadeem's dying blah, blah, blah", whatever. Right. Because honestly, being hospitalized the way I, and the CF community views it is like a car getting a tune up.

[00:24:21] Pretty much, that's it really other people won't understand that because

[00:24:26] **Court:** [00:24:26] I love that.

[00:24:27] **Britt:** [00:24:27] I love that too.

[00:24:29] **Kadeem:** [00:24:29] Like, I'm not sick, I'm just getting a tune up, you know? Yeah.

[00:24:34] **Court:** [00:24:34] So what, what did you tell people when you were hospitalized or you just didn't say anything?

[00:24:38] **Kadeem:** [00:24:38] I lied. Yeah. I just told them, then I got, went, tell them I'm going on vacation, stuff like that.

[00:24:46] **Court:** [00:24:46] They probably thought you were the luckiest kid in the world.

[00:24:48] **Kadeem:** [00:24:48] Probably. If I sold the lie, a lot of them probably thought that.

[00:24:56] **Britt:** [00:24:56] Did you ever experience any bullying because of it?

[00:24:59][00:25:00] **Kadeem:** [00:24:59] Not bullying just ignorance. I coughed a lot. Right. So people would be like, "oh, Kadeem can't do this. He coughs a lot, blah, blah, blah," whatever. Funny story actually, on that note. In elementary school we had like these little soccer leagues that me and my friends participated in and one person was like, "oh, he has CF. I don't think he should play. I don't think he should play forward, putting him as defense."

[00:25:26] Right. I'm like, "no, I'm like, okay. You know what? Forget this. Let me just go play." I ended up scoring four goals for my team. We won. And like, that was a huge milestone moment for me, because I was like, yes, I have CF, but it doesn't mean I can't do what other people can do. Right. Yeah. It may take me little longer.

[00:25:49] It might be a little more difficult, but like in the famous words of Justin Bieber and never say never. Right? Yeah.

[00:26:00] [00:25:59] **Court:** [00:25:59] Okay. So leading up to you, your transplant, did you always know that you were going to need a lung transplant?

[00:26:07] **Kadeem:** [00:26:07] Well, my doctors at sick kids brought it up to me before I turned 18, before I transferred to the adult program.

[00:26:15] In the back of my head, I always knew something like that were to happen. But then again, I believe, I thought that I was invincible and I'm like, "nah, that's not going to happen to me. I'm not that bad."

[00:26:27] **Court:** [00:26:27] Yeah. You're the exception

[00:26:29] **Kadeem:** [00:26:29] I really like, and I think most of that was because of fear. Like I always like having control of my surroundings and what not. Having a transplant. I give other people control over my life. All I'm doing there is laying on a table getting sliced and diced. Right. And I think another fear was being put to sleep and not waking up again. Cause like no one wants to have a serious surgery, right? No one, no one's willing to sign papers for [00:27:00] surgeons to cut them up.

[00:27:02] But yeah, that was, at the back of my head, I knew it was going to be a reality, but I tried to like pass it off.

[00:27:11] **Court:** [00:27:11] Yeah. Was your double lung transplant your first major surgery?

[00:27:16] **Kadeem:** [00:27:16] Yeah. Yeah.

[00:27:18] **Court:** [00:27:18] That is scary. Yeah, that's terrifying.

[00:27:22] **Kadeem:** [00:27:22] It was. But honestly, when I had my transplant, I wasn't too worried because I was tired of being sick or having lung problems. Yeah.

[00:27:36] **Britt:** [00:27:36] So Kadeem, not a lot of your friends, like knew that you had CF and you only told like a couple of people.

[00:27:44] **Kadeem:** [00:27:44] Yeah.

[00:27:44] **Britt:** [00:27:44] Why is that? And when did you become so open about this?

[00:27:48] **Kadeem:** [00:27:48] Believe it or not right before my surgery. I was just tired of keeping up my lies. Cause I'm like, we're talking about 20 years of secrets, you know how much energy [00:28:00] that takes keeping up one lie for a week is a lot of energy keeping up a lie for 20 years? Jeeze! Like, now that I'm think - I'm rubbing my head, wondering how I did it, but like, the reason why I did it is mainly because I signed the papers to have a double lung transplant, at a time where I was really invested in my music career and school and whatnot.

[00:28:26] And , I was very, very social. Like I was talking to everyone and anyone. So like I thought about it, about the whole lung transplant process. I would have to go ghost for like three months. Right. And if I go ghost for three months, people are going to start questioning "where, where the hell is Kadeem and what's happening?"

[00:28:46] Yeah. Yeah. That's bad for business, pretty much. I was like, I can't just go ghost for three months and not have anything to show for it. [00:29:00] So I don't know how, I don't know, what made me, but my first- I call it "breakout" - was I made a post on Facebook saying, "oh, I had cystic fibrosis for 20 years. I'm getting a double lung transplant."

[00:29:14] And after that, the weight of the world just left my shoulders. It, it felt really, it, it felt like I never knew I had such an elephant on my back. It felt so good just to let everything out and like, nothing was a secret anymore. yeah, because of the transplant, that's why I'm so open about everything.

[00:29:42] Yeah, it's pretty amazing. And honestly, when I tell my story, if I'm not open, it just leaves plot holes and even more questions. And so why not just tell it like it is right

[00:29:55] **Court:** [00:29:55] For sure I mean, we really need to start bringing tissues, Britt - [00:30:00] this keeps happening to us. But, yeah, I mean like already it's. You know, it must be hard to navigate the world feeling a little bit different than everyone else. And then on top of that, trying to like cover it up with all these lies, like you said, expending so much energy, just to pretend that you're different than how you are. That must be really hard. I'm really glad you're, you're comfortable being open now. That's awesome.

[00:30:23] **Kadeem:** [00:30:23] Yeah. Being different was a huge factor throughout my whole childhood. Pretty much. I wanted to be quote unquote normal. Yeah. Whatever normal is. Right. I just want it to be like my friends. I wanted to do things like my friends did, but I couldn't. I had to find alternate ways to do what my friends did.

[00:30:44] Most of them worked. Most of them were to kind of, I guess my parents would say stupid and reckless, but at the time I was a kid, right. All I wanted to do was be a kid, but it's commonly said in the CF community that [00:31:00] patients with cystic fibrosis, we grow up 10 times faster than your average human being.

[00:31:07] We mature by the time we're like 10, right? By the time I was 10, not even, by the time I was eight, my parents felt comfortable with leaving me in the hospital, "tell him to go IV antibiotics," they trusted me to tell them everything the doctor says - this is 8 years old. And honestly by 10 years old, I already knew how to work the whole IV pump, machine, stuff like that, the G tube feeding, machine, whatever.

[00:31:39] **Britt:** [00:31:39] I've been teaching my patients that like every day, every single day .

[00:31:43] **Kadeem:** [00:31:43] Yeah. Yeah, no, I had that down pat.

[00:31:45] **Britt:** [00:31:45] Kadeem, Kadeem... how did we meet?

[00:31:50] **Kadeem:** [00:31:50] So since my whole life, I've been back and forth through hospitals, that means a lot of IV antibiotics, and all [00:32:00] those goodie drugs like, I have no veins whatsoever. We met because no one else could start an IV on me, no one else could get blood from me. And -

[00:32:13] **Court:** [00:32:13] I mean, I've heard of, I've heard of Britt's IV skills, so it's nice to have that confirmed.

[00:32:18] **Kadeem:** [00:32:18] Yeah. She, she came in, she came into my room. I'm like, you know what? Pick your poison. Good luck.

[00:32:26] **Britt:** [00:32:26] You literally said "good luck."

[00:32:29] **Kadeem:** [00:32:29] And she was like, "no, no, don't worry. I'm good." I'm like, "oh, that's what everyone says." Right. And then she spent time looking. Looking, whatever I'm like, "okay, whatever, hurry up." Yeah. And then she's like, "all right, I'm ready." I'm like, "go ahead." And I think she said something like, "how, why are you so calm?" I'm like, "just go do it. You're probably going to miss it." And she actually got it. And I'm like, holy. I was like, I need your number [00:33:00] just in case this ever happens again. Cause it's been a long, long time since someone got an IV to start on me in one poke. Yeah. It was like -

[00:33:13] **Court:** [00:33:13] Nice job Britt!

[00:33:14] **Britt:** [00:33:14] Right?

[00:33:15] **Kadeem:** [00:33:15] Yeah. Like, oh, I didn't even see that one.

[00:33:19] **Court:** [00:33:19] Okay. Are you ready for what might be a super dumb question, but as someone who doesn't have a medical background, since you had your transplant and CF is in your lungs, do you still have CF?

[00:33:30] **Kadeem:** [00:33:30] Yes, because its a genetiic disease its in my genes.

[00:33:34] **Court:** [00:33:34] Okay. Okay.

[00:33:35] **Britt:** [00:33:35] I don't think it was a dumb question Courtney No, yeah.

[00:33:40] I'm like, "is this a dumb question, but do you still have CF?" But yeah, it makes sense. Cause is genetic, right? So lung transplant, like this is a dumb question , but in terms of the lungs and the mucus buildup, does it get rid of that?

[00:33:56] **Kadeem:** [00:33:56] Yeah, it basically, for lack of better [00:34:00] wording, like just so you can understand it to the full extent the transplant cured, the lung aspect of cystic fibrosi. Cystic fibrosis still affects my GI system and pancreas thus needing pancreatic enzymes every time I have a meal and stuff like that, that CF is still there, but the lung CF is not.

[00:34:23] **Britt:** [00:34:23] So, what are some ways that you've ever needed to advocate for yourself, for your health, for yourself or your parents? Do you know what I mean?

[00:34:37] **Kadeem:** [00:34:37] I never really had to advocate for myself per se.

[00:34:40] I know people who don't really have faith in the healthcare system, given their history. I understand, but for me, I never had to advocate all my doctors. All my nurses were

like, amazing. from Sick Kids, from Sick Kids to St. Mike's to Toronto [00:35:00] Gen everyone just listened.

[00:35:03] Everyone was just attentive. I never had any problems with doctors or nurses, not understanding how I felt or what I needed to be, what I needed to get done in terms of my cystic fibrosis. Right. So, I'm extremely grateful for that. Cause I know people who weren't as lucky as me to have those kinds of doctors and nurses.

[00:35:25] **Court:** [00:35:25] Yeah. That's awesome to hear because yeah, there's definitely a lot of mistrust and rightfully so, given a lot of historical atrocities that have been committed. So that's, that's really good to hear that you've never had a bad experience like that. Yeah.

[00:35:38] **Kadeem:** [00:35:38] My healthcare team was pretty much my second family. Like honestly, and truthfully speaking.

[00:35:44] **Court:** [00:35:44] So your transplant in 2017, did you get transplanted on your first call or how many times were you called in?

[00:35:51] **Kadeem:** [00:35:51] First call, first try, everything. Yeah, well, like I said, I was extremely lucky.

[00:35:57] I only had to wait like three weeks [00:36:00] to be called.

[00:36:01] **Britt:** [00:36:01] What are some of the things that have changed for you after transplant? Like positive or negative? Big question again, but what are some like big things that have really impacted your life from having had a transplant?

[00:36:16] **Kadeem:** [00:36:16] To be honest, like first things first, I am extremely grateful that I have gotten a transplant because if I didn't, I am a hundred percent sure I wouldn't be here right now talking to you. Positive changes. I don't cough a lot. It's a huge change. Goals are just easier to attain.

[00:36:36] Like any type of goals, maybe physical mental, goals about work, school, is just easier to maintain or easier to achieve. Just cause I'm not in the hospital as much as I used to be. I'm not always sick and catching viruses and colds like that. So that's a positive, just the [00:37:00] biggest positive is being alive. Right? You don't have to struggle to live every day, living feels natural after a transplant. Right.

[00:37:08] **Britt:** [00:37:08] Did you have to learn how to breathe again?

[00:37:11] **Kadeem:** [00:37:11] No, funny story actually when I, when I first gained consciousness after my surgery, I was still all hooked up to IVs, chest tubes different monitors I even had a breathing tube down my throat, but when I woke up, I kid you not, I was trying to talk and I thought my parents and my nurses could understand what I was saying, but they couldn't. And it got to the point where one of my nurses told me I needed to shut up or she was going to put me to sleep because if I tried to talk over the tube, it could damage your throat and stuff like that. So I was like, "oh shoot, I better shut up." But like being able to talk without coughing or feeling the [00:38:00] sensation of coughing was like so foreign to me.

[00:38:03] **Britt:** [00:38:03] Those first, like we, at first, like week, was it like, was it like unbelievable?

[00:38:09] **Kadeem:** [00:38:09] Oh, I thought I died. Okay. Okay. I thought I died. I was like, this must be heaven. Cause I, I was able to breathe like it's hard. It's hard for you to understand how I felt because breathing for you has always been second nature, first nature - but for me it was never, it was always something I had to remember to do or remember to concentrate on is breathing right. Oh, but after my transplant, it was like, I honestly thought I went to heaven. Cause I couldn't believe that I was able to breathe without coughing, without having a cough or anything like that.

[00:38:51] **Britt:** [00:38:51] Yeah. Yeah. Wild.

[00:38:52] **Court:** [00:38:52] Have you ever, written to, or considered writing to you your donor's family?

[00:38:58] **Kadeem:** [00:38:58] I have written to them, [00:39:00] but I never sent them anything. Like it was more so a letter for me, but addressed to them and whatnot. Yeah. That's I guess as one of the negative things to come out of having a transplant, it's just survivor's guilt knowing someone died so you can live, right. That's, that's one of the negatives about having a transplant, the possible effects of depression and anxiety. Survivor's guilt. It's a huge thing. It, unfortunately, it's not as talked about, when you're recovering, but it's a huge, it plays a huge factor in your recovery and life after transplant.

[00:39:45] **Britt:** [00:39:45] Was that like immediate that you felt like that?

[00:39:48] **Kadeem:** [00:39:48] No, it was after all the hype died down. Yeah. That's when, like, after, for me, it happened after my birthday, my 21st birthday, [00:40:00] around that. And that's when I started feeling the lows after transplant. Cause yeah, because survivor's guilt and not believing I'm where I am at the moment because someone died. It's a thought that still runs through my head sometimes.

[00:40:17] **Court:** [00:40:17] Yeah, I was going to ask how do you cope with it now? Or is it still, when it creeps up on you, is it still just as heavy as it was then?

[00:40:25] **Kadeem:** [00:40:25] Yeah, it's still heavy, but the way I cope with it is that I put it this way - I treat my body like a temple and the best way for me to say "thank you" is to live every day. That's how I cope with it. Yeah, not putting these lungs to waste, you know?

[00:40:43] **Britt:** [00:40:43] Yeah. Oh man. I worked, I worked with a lot of patients and obviously worked in transplant for years, but we never get a moment to really think about those things.

[00:40:59] **Kadeem:** [00:40:59] [00:41:00] I had a friend, his name's Matt, God rest his soul. It's harder to see other CF patients go through the same things you go through, but they never get to see a transplant because they unfortunately pass away.

[00:41:17] And that's part of survivor's guilt. Right? Wondering why. If I survived, how come my friend couldn't, right. Yeah. That kind of stuff. And it's something that you think about,

you try not to think about it, but at the same time, it's like, it's your friend, right? I've never had problems with like depression or anxiety before my transplant, after my transplant that's when it started like kicking in.

[00:41:42] You just answered one of the questions I was going to ask. Your mental health when you were younger -

[00:41:47] It was great. I was egotistical, like always bigging myself up in every way, shape or form.

[00:41:56] **Britt:** [00:41:56] Did your parents have a part in that, that they always feed you with good positive - ?

[00:42:02] **Kadeem:** [00:42:02] No. I mean, no, no, that was over-exaggerated sorry, mom and dad love you guys lots.

[00:42:16] My parents, well, my dad when I was younger, he was like the stereotypical Jamaican and was like, always like tough love with him and stuff like that. He was a very, very tough love oriented dad. Like for a while, I almost like completely hated him because he was so tough.

[00:42:37] But now that I'm older thinking back, I needed him to show me that tough love in order to be the man I am today. My discipline and my willingness to see things through to the end, I owe to my dad. As much as I may have pissed him off or teased him [00:43:00] as a kid, he really... yeah. I, it was true, true tough love. Yeah. I don't know how else to explain it.

[00:43:10] **Britt:** [00:43:10] And your mom?

[00:43:11] **Kadeem:** [00:43:11] My mom, she was kind of the same in the sense, but obviously sometimes the mothers are more affectionate with their kids and since I was her first born, right, my mum wasn't as tough love, she did inherit some of those personality traits from my dad just naturally and whatnot. My mom was a lot kinder in that sense. Like for example, if I, had any problems, I'd probably go to my mom before my dad. But like, yeah, so like they're kind of polar opposites, but at the same time, my mom did inherit some of that tough love. and plus, if anything, I knew more about CF than they did, because I had it. Yeah. Right. They didn't really know. They only knew what they were told. Right. And when you're told something, you draw your own [00:44:00] conclusions. You don't actually feel it cause like they didn't, they didn't, they just didn't understand cystic fibrosis.

[00:44:07] And how could they right, they didn't understand the symptoms. So every time, they thought I was doing something wrong or I wasn't taking care of myself adequately, but in reality, it was just cystic fibrosis, but they didn't know that. Right. How could they, if they didn't know how to, how it felt.

[00:44:25] **Britt:** [00:44:25] And after the transplant, your mental health kind of changed?

[00:44:31] **Kadeem:** [00:44:31] Yeah. Yeah.

[00:44:33] **Britt:** [00:44:33] And were your, how were your parents after that? Or your support system, really? Whoever it might be.

[00:44:39] **Kadeem:** [00:44:39] My parents, they're still the tough love kind of parents, but at the same time, they're more open to listening and understanding as well. I, my support system is great. Even though I have like only like five or six friends that I really talk to, like people outside of my immediate family. I love them to death. They [00:45:00] look out for me. And I, I love them to death for that. Essentially they're my other family.

[00:45:05] **Court:** [00:45:05] So in the future, where do you see yourself?

[00:45:10] **Kadeem:** [00:45:10] I don't know. Like, I don't know. I always wanted it to be a professional musician, make millions, you know, the glamour and glitz of life. I never knew I'd be where I am today, like I'm advocating for cystic fibrosis and advocating for the treatments, supports for families, I never thought I'd be doing that. I still want to become a social worker, a music therapist, for youth and children with rare diseases, because I know how difficult it could be for someone with a rare disease or any child with mental problems or health problems, whatnot. I know how hard it is for them to advocate for themselves or explain how they feel. Because a lot of like, I'm not [00:46:00] discrediting like doctors or whatnot, obviously because I've had the best doctors in my life, but they only know the science right. You don't really understand something fully until you I've actually experienced it. Right. I feel like that's where I could use my expertise to help because I've experienced it. I experienced not being able to voice what's wrong with me and whatnot, that kind of stuff. Or having troubles, dictating how it felt and stuff like that. So I want to try to be a music therapist and a child and youth social worker. That's the plan for the future.

[00:46:39] **Britt:** [00:46:39] That's really exciting. Yeah. So Kadeem

[00:46:47] **Kadeem:** [00:46:47] Yeah,

[00:46:50] **Britt:** [00:46:50] I have a question. What do you look for in a partner?

[00:46:56] [00:47:00] **Kadeem:** [00:47:02] Just so when he is not close minded to things, right? I wouldn't consider myself high maintenance. I'm really laid back. I go with the flow.

[00:47:13] **Britt:** [00:47:13] You seem like that

[00:47:14] **Kadeem:** [00:47:14] I don't get angry. Like it really takes. A lot for me to get angry so yeah, someone who is understanding, open-minded, yeah, that's really, I don't really have any specifications like that, obviously they can't smoke. Yeah. Yeah. Yeah.

[00:47:36] **Court:** [00:47:36] That's for lots of people, even if you don't have CF.

[00:47:38] **Kadeem:** [00:47:38] Yeah. Right. And yeah, just someone who is really open minded and just - cause like, I could also say I want someone who's as mature as me, but I understand that I'm a lot more mature than people expect because of everything I've been through. And I think that's like shooting for the stars pretty [00:48:00] much because not everyone has been through a lot in such a short span of their life, right?

[00:48:06] **Britt:** [00:48:06] I remember you said earlier that CF patients are reckless or rebellious. So is that something that you see often, or is that, is, is that like a natural connection between two CF people?

[00:48:23] **Kadeem:** [00:48:23] Well, you have to understand that humans are social creatures, right? Right. And not supposed to be confined. Like if I tell you not to do something, you're more than likely going to do that. So telling a CF patient, you can't hang out with another CF patient. But yeah, I know plenty of CF patients who are best friends and they like physically interacted and stuff like that. I did once too. I'm not gonna lie, it was probably the best time I had with a friend ever up to this day because like CF patients, we're one in one the same, pretty much. We all go through the same treatments, same [00:49:00] experiences. They're like the sibling God never gave you, pretty much, but yeah.

[00:49:09] **Britt:** [00:49:09] Yeah. Did the - that's the hardest part would you say with having CF is just naturally want to connect with somebody because you've been through all the same things and you want to be able to just leech onto something or someone that can say, yeah, like this is what happened to me and this is how I dealt with it. Thankfully we live in a social and a technological world.

[00:49:35] **Kadeem:** [00:49:35] Oh yeah.

[00:49:35] **Britt:** [00:49:35] But at the same time, like you just said, you just want to leech onto something or somebody that, you just naturally connect. So it's hard to just be like, nope.

[00:49:46] **Kadeem:** [00:49:46] Yeah. Pretty much like, yeah. Like everyone has their support group, different support groups. Right. But they, with the CF community, everybody's so close, but yet still, so far apart, like, so, so far. [00:50:00]

[00:50:00] **Court:** [00:50:00] One final question for you what's something you would tell someone who's struggling to accept the reality of their CF diagnosis or transplant, or transplant.

[00:50:13] **Kadeem:** [00:50:13] It's going to sound so cliché when I would say you're not alone. and I mean that to its fullest extent, I know how it feels to think that you're the special occasion. You're the only one that this is all happening too, which is not true at all. There's always someone who's been through the same thing or if not, worse. I wish I knew that before my transplant, while growing up with CF, I wish I knew that people out there besides my brother felt the same things I've felt, went through the same things I went through. If I had that, I probably would have been more open about my cystic fibrosis. [00:51:00] But the main point is, my situation, no one looked like me, no one acted like me, so I felt very alone, but thank God now, in the 21st century, we're able to put ourselves in different support groups. And stuff like that. When I was growing up, I then we only had in mind, My Space and that's not like the safest place for kids right. Yeah. You're not alone. There are support groups out there. there are people out there who are willing to talk and to share their experiences with you and whatnot.

[00:51:38] **Britt:** [00:51:38] So Kadeem, did it ever create some form of, tension between you and your brother.

[00:51:44] **Kadeem:** [00:51:44] No, not really. I knew that I went through everything I went through in order to like help him. Yeah. Very, very low key, I am jealous of his health situation because he's a lot healthier than I've ever [00:52:00] been. And especially at that age. But other than that, I'm just grateful, like, because of me he's able to live like that. The roles could have easily been reversed. It could have been me, the youngest sibling and him, being the sicker older sibling, you know? So I'm just glad that he didn't have to go through even nearly half the things I went through right. Yeah. So it just, it doesn't create any tension. It humbles me he's yeah. He's great.

[00:52:35] **Britt:** [00:52:35] Really, and truly by you speaking out so confidently and comfortably about your experience with CF and transplant, I know for a fact that it at least affects someone else's life. Just being able to hear that someone else went through a similar thing. So on that behalf, thank you for coming, for speaking out. [00:53:00] Just hearing somebody has gone through something similar to you, especially when it's so silent and so secretive and so scary, even hearing somebody go through the same thing, it doesn't make it better, but it just, it just helps a bit.

[00:53:17] **Kadeem:** [00:53:17] it's like a mental game, just knowing someone feels and been through the things you've been through. It feels good to relate to something, right? Yeah. Empathy, empathy. You're not alone. Right. And that in itself is very beneficial for healthcare.

[00:53:37] **Britt:** [00:53:37] Absolutely. Yeah. So thank you for coming.

[00:53:40] **Court:** [00:53:40] Thank you so much.

[00:53:41] **Kadeem:** [00:53:41] My pleasure.

[00:53:46] **Courtney:** [00:53:46] Thanks for listening to this episode of living transplant. If you have questions or suggestions for future episodes, email us at livingorgandonation@uhn.ca.

[00:53:55] **Britt:** [00:53:55] Don't forget to subscribe, rate, and review living transplant on iTunes, [00:54:00] Spotify, or wherever you listen to podcasts

[00:54:02] **Courtney:** [00:54:02] And follow us @GiveLifeUHN on Facebook, Twitter, and Instagram.

[00:54:06] **Brit:** [00:54:06] See you next time

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