

Shit We Don't Talk About

Episode 76 - How to be a living organ donor

Colleen Hjort-Frederiksen

SPEAKERS

Mia Voss, Colleen Hjort-Frederiksen

Mia Voss 00:04

Hey, welcome to the latest episode of shit. We don't talk about the podcast that takes on topics that need more open and honest discussion, which means some of these topics are triggering. So please take care when listening. And I'll always give you a trigger warning. For instance, here's one. Every episode contains swear words, you've been warned. Make sure to check out the show notes which include an accessibility transcript of the podcast and all of the links for our guests at Shitwedonttalkaboutpodcast.com. Boss it's episode 76. And my guest is Colleen Hjort-Frederiksen of the National Kidney Foundation. In this episode, we'll be discussing living organ donation and all the details on how to be an organ donor. And also how surprisingly easy it can be to donate. Strap in. It gets good. Here we go. Hi, Colleen, how are you? I am great. Yeah, how are you? I'm doing well. And I'm excited to speak with you today. Because this is definitely shit we don't talk about is kidney donations.

Colleen Hjort-Frederiksen 01:23

Yeah, it's definitely not something that is that is talked about a whole lot. There aren't a whole lot of people that have experience with it. So I like that I get to be able to come on and talk about my experience what I've been through, I have to be sure to let everybody know that I am not a doctor. I'm not a medical expert. But I definitely want to talk about my experiences with with living donation, which I love.

Mia Voss 01:47

You don't even need to play one on TV, which is fabulous as well, too. So, hey, we're gonna start off with my favorite thing to do which is talk about identifiers. So you have an idea of who the people that are talking what we look like. So I'm Mia Voss. I'm the host, I'm a woman in my 50s right now my hair is pulled back because I didn't wash it. Sorry about that little TMI blonde hair. I usually wear glasses. And my guests tell us about you tell us what you look like and then we'll dive into your story. Yeah, so I am a female in my 40s I have an asymmetrical haircut. With a little blonde a little silver, I've gotten to my natural hair color. And I did shower today just to let everybody know, your eyebrows look amazing. So let's start with that too. Thank you. I appreciate that. Tell, tell me your full name because you have a couple things going on with your name and I'm digging it.

Colleen Hjort-Frederiksen 02:36

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Colleen Hjort-Frederiksen

Yes, I do. My name is Colleen Hjort-Frederiksen .Excellent. So you are with the Kidney Foundation is it kidney.org It is I work for the National Kidney Foundation. I manage a living donor support program. And I am a living donor. I see.

Mia Voss 02:53

And I love that. So just to give you a little bit of backstory, I have someone in my family who recently has discovered that she's going to need a kidney donation. So being the Curious George that I am I started digging around. And then also finding out you know, I wanted to find out what that looks like for her for Living Donor Program. So I reached out to kind of just through the website and then he reached out to me and said, Hey, I'm on the, I guess the liaison advocate, and you have your own story. So tell me all about that. Tell me about your family background and how you got into this whole space.

Colleen Hjort-Frederiksen 03:27

Yeah, I will. I so polycystic kidney disease runs on my mom's side of the family. If you have polycystic kidney disease, it means that your kidneys grossest in and around them. They tend to grow bigger and bigger and start to cause all sorts of issues as well as diminished kidney function. So if you have polycystic kidney disease, the chances of giving it to your offspring are roughly 5050. My grandparents had four kids. Two had it too did not luckily my mom did not. So our direct family in line did not. And you know, it's one of those things that doesn't skip a generation. So we found out that my grandfather had it didn't know at the time that he passed, but he passed very early. And, you know, my uncle and my aunt had it as well. So my uncle needed a kidney transplant. I remember this, like in the 80s I was a little kid. My mom went and got blood type. She wasn't the right blood type. And that was that there weren't kidney donation chain swaps, you know, vouchers, any of those things that existed at that point in time. So I remember asking my parents if I could be tested to donate and they said no, and I thought that they were being mean to me, but they weren't. You can't do that as a very small child.

Mia Voss 04:41

So not done growing yet, ma'am. No, not yet. No giving away kidneys when you're a little kid.

Colleen Hjort-Frederiksen 04:49

So, my uncle ended up receiving a deceased donor kidney that he had for the rest of his life, which was I think 15 issues. I'm not exactly sure exactly how long he had that deceased donor kidney. But you know, he, he lived a good life after that. And then his only biological child, my, my cousin Debbie was diagnosed with polycystic kidney disease. And she ended up having her kidneys removed in 2013. And my mom, is that because they were growing? Is that what I think they was heard that too, because if they're just going to keep growing, you don't have room for it. Right? Right. They start to wreak havoc on your other internal organs, they start to do a whole lot of of pushing things around, and just, it's just not good. So she ended up having her kidneys removed. And, you know, was on dialysis four days a week. So she was dilating, had multiple people who tested to donate to her. Everybody else was ruled out. And I was her Lucky number seven, so I was able to donate to her in March of 2014.

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Mia Voss 06:00

So wow, so six years, no, eight years in as well, too. So you are in your 30s Talk about that journey for you. Obviously, you're have a bit of an unusual circumstance of knowing about this since you were a kid and then having it come up. What a beautiful way, by the way to have a tribute to your family if you'd wanted it for her father, and now you're able to help her as well, too. But I don't think a lot of people know about that. So talk about your journey of discovery of obviously one you You're number seven, Lucky number seven. But But talk about that how it got started and what some of the obviously I mean, you've been living with one kidney for we said eight years, talking about how that affects you and how it affects people who want to be a donor. Yeah.

Colleen Hjort-Frederiksen 06:44

So I, you know, I went I went through the testing, I found out that I have extra renal arteries, that was the whole thing. But I ended up being approved, I donated at the University of Utah, and really like long term wise, as far as what you know what I have to be careful about or how I've, I'm affected afterwards, there really isn't a whole lot. I am not supposed to take any NSAIDs. So no, you know, Motrin, Advil, Aleve, that kind of stuff. And also no high protein diets. And then no contact sports, which I donated in my late 30s. I wasn't going to take up rugby, so I was totally fine with that. And just

Mia Voss 07:25

ingesting now. Yeah, rule me out. I'm all good on the context.

Colleen Hjort-Frederiksen 07:31

And then, you know, moving forward, after that, I decided to have a pretty big life change. After I donated, I decided that a career that I was in wasn't for me. And I went and started working in the nonprofit world and ended up working for the National Kidney Foundation, serving Iowa, Nebraska for two and a half years and was looking for a new challenge and ended up taking on this job with the National Kidney Foundation headquarters office. So I get to talk to living donors or potential living donors every single day. And it's pretty darn awesome.

Mia Voss 08:03

Like me, I mean, and what I loved the phone call that we had the discovery chat, is I really got to ask a lot of questions as well. And then I'm on the journey of looking into that too, to see if I'm a match for my family member. But probably one of the biggest things that I learned too, was the difference between living donor or non directed or Altruistic donors, and someone who donates their organs upon their death. Talk about that.

Colleen Hjort-Frederiksen 08:30

So, you know, all there's the, there's directed donation, and there's non directed donation. So directed donation is what I did, I had an intended recipient, my cousin, Debbie, everything worked out well. There's also non directed, which means that people are being tested to donate to a stranger. And I get to talk to people fairly often who want to test to donate to a stranger, they, you know, with everything

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going on in the world, they want to do some good and they want to have a positive impact. And it's pretty, pretty darn amazing to talk about talk to people about that. But you know, obviously, you can also sign up to be a deceased donor, and you can put that on your driver's license, and you can share that with your family that that's your desire. And it's also extremely important. You know, to go ahead and make that decision if that's what you want for yourself after you pass. There are a lot of people in this world who need those, those organs or tissues or skin or eyes or whatever, you know, so

Mia Voss 09:34

I've had a, I've had a couple episodes about death planning, death, doulas in and then planning to plan so that when you are and I have an episode coming up on the podcast to have a friend of mine, it's called Get your shit together. And it does talk about that of letting everybody know these directives so that it's not just in a random piece of paper, or maybe you thought about it and we're talking about it over cocktails or something that you you make the very, very clear what your wishes are. And this this conversation is another important reason for that, too. Yeah, definitely. Yeah, we, you know, I've talked to my family members about, you know, I want to be able to give as much life as possible. And when I'm gone, I don't need this body anymore. So go ahead and you know, take a crack on it, whatever can be donated, totally. So that to them, the biggest difference again, between the living and the deceased donation is how much longer a kidney that is directed, or not our non directed that you can give that while you're still living, how much longer that lasts for someone. That's incredible. Yeah, so it's pretty crazy how much how much longer it lasts, you know, a deceased donor, the average, hold on, I want to make sure that I'm, I'm saying the right numbers.

Colleen Hjort-Frederiksen 10:57

So a deceased donor average, I believe, is like seven to 10 years. And then a living living donor kidney can last up to 15, maybe even 20 years, and some have lasted much longer. I have met recipients who have had their kidneys for 3035 40 years, from a living donor and also from a deceased donor. So just because it comes from a deceased donor, that doesn't necessarily mean it's going to last less time. On average. That's kind of what they're finding is that living donor kidneys last longer.

Mia Voss 11:33

And interesting that that really is the one thing that you can donate from an organ standpoint, right?

Colleen Hjort-Frederiksen 11:44

You can donate a kidney, they can donate a lobe of your liver.

Mia Voss 11:47

That's right, because those little crafty buggers they just grow right back. Do they're like starfish. They totally are. I love that talk about a bone marrow. I know that's something as well to that people.

Colleen Hjort-Frederiksen 11:59

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Colleen Hjort-Frederiksen

Yeah, you can also donate bone marrow. I have been on the bone marrow registry for 15 years, and I've never gotten a call. I think I believe I read not too long ago, I kind of looked into it again. You know, on average, there are roughly I think 7000 ish people on the bone marrow transplant list at any given time. And there are generally speaking 90,000 Plus on the kidney transplant list at any given time. So the need for kidneys is larger. And I don't know much about bone marrow, but I believe it's it's a little more complicated. The the matching is a little more complicated.

Mia Voss 12:40

Gotcha. But I love that there's processes in place such as your organization to that's matching people up, talk about that process once you've been kind of from the start what what happens and I'm sort of in the middle of it too. But what happens once you say, Yes, I want to look into this either as a directed means I'm going to donate to someone specifically or non directed the altruistic, which is amazing. You said there's a lot of people that do that to just like, hey, I because I can do this, I'm going to

Colleen Hjort-Frederiksen 13:09

Yeah, definitely. If you're interested in donating, if you know someone that is in need of a kidney, you know, the easiest way is to contact their transplant center directly, you'll want to have their full name and their date of birth before you reach out to their transplant center. And then work you can work directly with their transplant center. If you don't know someone, you can go to our website kidney.org forward slash transplantation. And you can read more about living donation and learn more about it and then you know, there are some further steps that you can take there you can also just reach out to your local Transplant Center if you want to, if you want to donate non directed as well or there are different organizations that that help people to find living donors and we have some information about that on our

Mia Voss 13:57

website. So once you do make that decision, though, talk about like you know, the the hoops you have to go through because the matching piece which you and I have giggled offline about this. They were like Oh, I'm gonna wake up you know, in a tub of ice with a kidney Miss,

14:15

I promise that is not the case.

Mia Voss 14:17

It's just due to doesn't work that way. They just you just can't randomly throw them in people because there is there such that matching hoops to jump through right?

Colleen Hjort-Frederiksen 14:27

Yeah. So, blood type is your first your first indicator. If you are Type O You are a universal donor, but you can only receive from other type O. So I am typo. So as my cousin Debbie, so she could only receive from another typo but I could have donated to anyone with any blood type as long as all of the

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other markers matched. And then you know, they can do quite a bit with anti rejection medications and all of the different Have you know it, the doctors kind of, you know, to they, they figure out that end of everything with the recipient. But as a donor, you know, you're going to do a lot of blood blood draws, you're going to do a few different urinalysis tests more than a few different, you are going to do a 24 hour urine collection, which is one of the most interesting things I've ever done in my life. And I always just recommend to people, I'm like, just stay home for 24 hours, like, just stay home. Like,

Mia Voss 15:35

I'm not gonna ask why. But I had a feeling that's what it was, too. Yeah, yeah, I'm consuming. Yeah.

Colleen Hjort-Frederiksen 15:40

And, and you have to keep the jug that you put the urine and you have to keep it refrigerated, generally speaking. So that's also another thing, like people don't obviously want to be taking that to work and whatever. But so you go through

Mia Voss 15:54

this whole thing. Just give you a note No, 30 years or

Colleen Hjort-Frederiksen 16:01

so yeah. So you go through those tests. And then, generally speaking, there's a big day of testing at the transplant center. And that is, sometimes it's a it's a two day extravaganza, sometimes it's a full day. And you have you know, a chest X ray and a kidney CT. And you talk to everybody on the team about you know, what's going to happen and how you need to if there are things you need to change after you donate, you know, like I said, the no NSAIDs, the no high protein diet, that type of thing. You can meet with a nutritionist, you can meet with a you know, you have to meet with a social worker or a psychologist to talk about, you know, your, your mental state, and, you know, any concerns that you might have there. So there's it is the workup of a lifetime, I have always I have told a lot of people that I don't know that any insurance company would just allow anybody to do all of this because it is it's pretty intense, the entire workup. So you know, that way that the team is very concerned, obviously, about how you do post donation. So if there are any red flags, if there's anything that they see that they don't, that they're, you know, unsure of, or they're uncomfortable with, they're going to ask you to step back and you know, take care of your health first.

Mia Voss 17:20

Wow, that makes a lot of sense of how extensive it is. I mean, if you're curious about your health, go, go get curious about donating kidney because you'll find out all your all the mysteries of yourself too. And that leads me to we'll just briefly touch on this too, because that all of that is covered by the, the person you're going to donate to is that right? Like their insurance?

Colleen Hjort-Frederiksen 17:43

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Colleen Hjort-Frederiksen

Yeah, the recipients insurance covers everything. So you know, people I've had people ask me, Hey, I want to donate non directed, but I don't know how that works. Because I know typically, it's the recipients insurance, and it still gets built the recipients insurance. So there should be no out of pocket cost, you're never going to share your insurance information or any of that for any of the testing that's directly related to the kidney donation. And there are organizations out there that offer last wage reimbursement and travel cost reimbursement if you need to travel. So there are definitely a lot of options out there. So that, you know, I had to travel to Utah, and I did not have any trouble cost reimbursement. I owned a business, a small business and I was a server. So I did not have FMLA I did not have paid vacation, I didn't have paid sick time, you know, so my my friends held the giant fundraiser for me. And luckily, I have an amazing community. And, you know, a lot of people came out and and raised money so that I didn't have to worry about that while I was recovering. But, you know, now there's all these organizations that will help you out with that, which is pretty amazing.

Mia Voss 18:55

Right? I mean, since you've done that, again, eight years ago, there's been a lot more and even just the brief time that I looked into it, the bit of brief research that I did, I noticed that as well, too. So that's really great to know, what are some of the things you think that people don't? Or misunderstand the most I know, we touched on some of them about about organ donation or kidney donations.

Colleen Hjort-Frederiksen 19:18

Um, I think a lot of people have, you know, some some misconceptions about how it affects their lives moving forward. You know, and I have made very few change changes. I've always drink a lot of water and you know, that's important, but I have my kidney health monitored at least once a year when I do my annual physical and sometimes more if I have to go in and have tests drawn by my doctor. Oh, so she's like, let's just throw in a renal panel and just see how everything's go in there. And, you know, so far it's been great. You know, I think that people are concerned about you know, if they have a loved one who they want to be tested on behalf of like, what if their loved one is putting undue pressure on them, and that is not okay. And the great thing about it is that any point in time, you can go ahead and walk away from your testing. And if it's for a loved one, the hospital will tell them that it was for another reason, they will not say, your family member has decided they don't want to do this anymore. They will say, you know, there was XYZ reason that that their your family member is going to be unable to donate to you. Up until the point, literally, they asked you right before they put you under for surgery, and more time.

Mia Voss 20:32

Yeah, you're sure you're sure? Yeah,

20:35

I was asked I think 789 times that to make sure that I was not being pressured that I was not, you know, that there was nothing illegal happening there. You know, it's it's illegal in the state in the in the US to pay for someone to give you a kidney. And so that was also asked many times, like, is anybody giving

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you money? Is there you know, any any incentive there that should not be there? You know, because that's, that's not allowed. So,

Mia Voss 21:06

yeah, that's definitely things we didn't know about. I mean, one that makes a lot of sense. And that's a great relief, as well to say that they will take care of that of letting whoever it was that you had made that agreement with and that mean that that's a huge piece, too. I mean, people have a hard time saying no to holiday dinner invites little. Yeah, saying Nope, I change my mind about this. And then also the fact of I loved again that, you know, the psychological workup as well, too. I mean, that is, that is a somewhat traumatic thing, right to have to go in and have this done to remove it. Here's a little question. I don't know, if you get asked, What does the scar look like?

Colleen Hjort-Frederiksen 21:46

So I had a laparoscopic surgery. So I have, I have three like little tiny incisions, kind of down the baseline down the center of my of my torso, like, there's one, I don't know, four or five inches, maybe above my belly button, there's one in the top of my belly button. And then there's another one, I think in between those two points, I can't remember. And then I have a C section basically scar, which is where they took the kidney out. But there are a variety of different ways that they do it. Not every not every hospital does it that way, you know, mine is a is a horizontal incision, you know, kind of on the pelvic bone, I have heard of, of, you know, vertical incisions from like the belly button down to kind of the pelvic bone. I've heard of a variety of different ways. And apparently it used to be, I think they did like a big incision, like kind of on your back was how they did it. But the way it was explained to me was my my anesthesiologist said, he said, You know how like fish nets work, like when you're getting a fish out of a fish tank. And I was like, Yeah, where are you going with this? And he's like, Well, it's sort of like that, but obviously much more sterile. And he's like, they put it up in there and they get the kidney and they like, there was like a, I don't know, something that they could pull to like tighten it to make sure that the kidney stayed in there. And then they take it out and transplant it into your cousin.

Mia Voss 23:12

Why am I shaking me giggle? Like scooping it up? I had in my mind, like this big straw. You know, like, stuck, right? And like it just kind of like, goes into there too. So? And yes. According to the urban legends, it was the big scar on the back of what I understand. Right with the kidney. So we got this we got that cleared

23:32

up. Yeah, so sometimes that definitely happens.

Mia Voss 23:34

Yeah, exactly. I love this conversation. I appreciate appreciate what you've done for your family personally, and like walking the talk and then working with this organization to I've really appreciated that time, that time that you spent on the phone with me. And then it sounds like that is something that's

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continuous as people go through this journey of deciding to be a viable or a non viable are directed or non directed, or altruistic donor I love. Alright, so tell us where to find you how to find out more information. Of course, I'll have this in the show notes as well. But why don't we say it out loud just for giggles. Yeah.

Colleen Hjort-Frederiksen 24:10

So if you want to learn more, so I, you know, our program. I didn't mention this earlier, but it is a peer mentoring program that I manage. We have trained volunteers who have donated kidneys, we also have trained volunteers on the patient side. So our program is called nkf peers. It's a one to one peer mentoring program. And it's it's really fantastic. It's a great support. You know, if you're looking to donate, you'll be matched with a peer supporter who has donated, they'll tell you their story. And then they'll kind of be an emotional support throughout the entire process of testing, donating and even after the fact if you would like So to learn more about that you can go to [community.org forward slash peers](http://community.org/forward/slash/peers). To learn more about living donation, you can go to [kidney.org forward slash transplantation](http://kidney.org/forward/slash/transplantation) and if you just go to kidney.org you Um, that's our main landing page for the nkf. We will see right at the top, there's some major headers and kidney, you know, kidney. I think living donor is one of them. And then other than that people can reach out to me directly. And I can share my email address. I'm not going to say it because it's way too long. Just put it in the show notes.

Mia Voss 25:21

We will put it in the show notes. Absolutely. Go to ShitWeDonttalkabout.com If you want more information on that, this has been very delightfully informative. Thank you so much. I appreciate you. You're very well. Thank you, Mia. Thanks everyone. Hey, thanks for tuning in. You can check out the show notes and guests links at [ship we don't talk about podcast.com](http://shipwe dont talk about podcast.com) If you liked this episode, please subscribe and give it a like or leave a review, especially if it's a good one. See you next time. Bye.