

A Successful Solution To Leg Spasticity - Sarah Curlee

Sarah Curlee had constant leg spasticity in her leg as a result of an ischemic stroke at age 27 and by age 29 she made the dramatic decision to have her leg amputated to solve the problem.

Social:

www.instagram.com/sarah__nickel/

Highlights:

00:48 Introduction

03:06 What happened to Sarah Curlee?

10:49 Dealing with spasticity

17:02 Leg Spasticity lead to amputation

21:10 Sara Curlee's life after amputation

28:19 The birth control factor

33:56 Overcoming difficult times

43:43 Sharing your story

54:25 Helping other people

57:42 What's in store for Sarah Curlee

1:04:51 There are better things to come

Transcription:

Bill 0:00

You made a decision to have the amputation though, like how do you make that decision? How do you make such a serious decision to have part of your body removed? How do you get to that? I imagine, was it a quick decision?

Sarah 0:18

It was a really quick decision. It was like instantaneous, like, I mean, like I woke up my foot start spasming in this hard cast and had to deal with it for so long. I was like I'm gonna cut it off. I didn't do it quickly.

Intro 0:34

This is the recovery after stroke podcast, with Bill Gasiamis, helping you navigate recovery after stroke.

Introduction - Leg Spasticity



Bill 0:48

Bill from recoveryafterstroke.com this is Episode 136 and my guest today is Sarah Curlee. Sarah experienced a stroke at age 27. That might have been caused by birth control, or a hole in the heart, also known as a PFO. And a few years after the stroke, Sarah decided to have her foot amputated.

Bill 1:11

This is a fascinating interview. So make sure you listen to the entire interview and get to the very end. Now, if you enjoy this episode, and you think others should hear Sarah's story, please share it on your favorite social media platform. And also leave the recovery after stroke podcast, a five-star review on iTunes, or your favorite podcast app.

Bill 1:37

And if you're watching on YouTube, click the thumbs up button and subscribe to get notified of new episodes. By doing this, you will make it easier for other stroke survivors to find The Recovery After Stroke Podcast and it may just be making huge difference for them, especially if they're in that early phase of stroke recovery where they're feeling alone, and like nobody understands them, and like they don't know anybody else who's been through what they've been through.

Bill 2:10

So it would be very much appreciated. If you did leave us a five-star review so that the show can get ranked higher. And also so that other people can find it. Now, thanks so much for listening to the podcast. And for encouraging me to get to Episode 136. It's a lot of work, but when I meet amazing people like Sarah, it makes it all worthwhile.

Bill 2:37

While the more while and when people reach out and tell me how much they enjoyed a particular podcast or a particular episode, it really makes the whole thing even more worth it. So thank you for being here and listening. Thank you for the amazing feedback. And now it's on with the show. Sarah Curlee, welcome to the podcast. Thank you so much for being here. Tell me a little bit about what happened to you?

What happened to Sarah Curlee?

Sarah 3:07

So I had a right hemisphere stroke in August of 2013. And I kind of wanted to know if you've ever heard anyone else have this backstory just because that's kind of why I want to do this because it's weird. So no one else has ever heard of this happening before. So please let me know if you know someone who's got this.

Sarah 3:27

So the stroke was on Monday, I was at work. I was caught very quickly. Luckily, I had a friend come up and talk to me. And I thought I was answering him but apparently, it wasn't. And then he walks off and I'm like, dude, like where you going? We're talking and then comes back with like a small army of people and like they sit down with me and they get me to stop working.

Sarah 3:46

And like, apparently my face is like really droopy? I don't know, no one took a picture. So I don't know what I was saying. I don't know what prompted and all just like, everyone just go full like, get her to the hospital mode. But I was lucky, and I got to the hospital within about 30 minutes of the stroke onset.

Sarah 3:49

I got TPA. So in the doctor's words, they took the blood clot size from a 9 out of 10 to 6 out of 10 when I had the TPA, and then the neurosurgeon removed the

blood clot later that day, and I remember waking up on the operating table fine I was totally okay.

Sarah 4:31

Like I remember asking the doctor questions. We're like, hey, like what's going on? Like, if you clued me into why I've been here all day, that would be really great. And the doctors just like kind of stared at me and didn't really know what to do with that because apparently it's not common first stroke survivor to wake up, like fully cognizant.

Sarah 4:49

And so I was on a Monday like I said, and then for the Tuesday and Wednesday, we did all the tests. We did the push-pull tests, we did all the cognitive tests which speech was fine, everything was fine. Like I passed every test with flying colors. And I remember like EMT would pop their heads in and they'd be like, are you really a stroke survivor, a young stroke survivor who's fine? Like no one could believe it.

Sarah 5:17

So I was out of the ICU by that Wednesday into the general ward. And then I left the hospital on Thursday. There's like nothing. There's no rehab you ever heard of that before?

Bill 5:31

Never heard of that before. So anyone who is listening to this episode, whoever is on Instagram, however, is anywhere in social media will do us a favor. Get in touch with Sarah, at Instagram, and let her know if you're one of those people that had a stroke and then woke up and went home and everything was back to normal.

Sarah 5:57

Well, not back to normal, but we thought it was gonna be I was supposed to be okay.

Bill 6:05

They missed, your diagnosis wasn't complete, and then they sent you home. And you missed out on all of the opportunities to go through rehab and all those types of things?

Sarah 6:15

Yeah, I never got any of that. Um, my brother's actually his wedding was like a week later, I went to that I was in it and everything. And then, so everything was fine. And then I got doctor permission to start working out again two weeks after my stroke, and he had no reason to say no.

Sarah 6:34

So I started kickboxing again two weeks after my stroke. And then it took about two or three sessions before I started, actually, I am saving my foot and that's why we're talking because I am TMF. I will get to it at some point in this but my arm was actually the first one to start to, like feel residuals, like, I'll hit the bag, and my left arm was dragging, I described as like having a bunch of tiny little rubber bands just like holding it back.

Sarah 7:00

And so I started working again, about a month after my stroke, again, no clue what was going on. I met analytical chemists. So like, I reviewed that all day. So I'm at a computer a lot. My hand was not working for the typing or anything like that. So I just stopped typing with it. Like I just stuck to my right hand.

Sarah 7:22

I went and I saw, I had tons of follow up appointments to like figure out what caused the stroke. Birth control and a hole in my heart are the two main contributing factors is a PFO, PFO got fixed and can't be on birth control anymore. So theoretically, we should be fine in that aspect.

Sarah 7:43

But I remember showing everyone my hand, like, I would play piano like I do like piano. And I like, it doesn't do it anymore. It did it better back then. But I'd be like, do a little piano was like slowed down quite a bit. And like my neurosurgeon like literally shrugs his shoulders.

Sarah 8:03

He's just like, Oh, okay. And then I had another follow up appointment with my GP that I was assigned. And by then my foot did start to take over, my foot started to, I don't know how to describe this in words without having a visual. So for the podcast sake, supposed to be flat, it started to turn on its outside, and then turn it inward, and then my toe is a hammer, so like becoming a clubfoot.

Sarah 8:31

And my ankle would start to give and it would start to give. So whenever I saw my GP, we focus mainly on that because I couldn't really not walk, like I needed to be able to walk, I could function without pain coming into walk. So she actually referred me to an orthopedic surgeon.

Sarah 8:50

And I've met with him. And he wanted to do surgery on me. I mean, that was the solution to fixing the foot and we did some rehab molded the section over him, but it's in physical therapy in the meantime. Because it spasming like it was like a foot spasm like all day every day, like constantly and so it took about a year before I finally walked myself in stress fractures.

Sarah 9:14

And I've been a walking cast. I was like, alright, let's do surgery. Let's do it. It's gonna fix everything right because Google even said that I was gonna fix everything every other orthopedic surgeons that it was gonna fix everything I was alright, well, let's do it. That's fine. And then I'll be okay. And I wasn't at all actually made like 10 times worse.

Bill 9:32

So the surgery made it more painful and more?

Sarah 9:39

Yeah. It made it way worse. I've never really found a good way to describe the pain but it hurt. And then so what he did was to help control the spasticity and this one I don't know that's what it was yet. I hadn't had a diagnosis yet so I haven't even seen a neurologist yet.

Sarah 10:00

To control the specificity, what he did was he cut the tendon that goes down the outside of my left leg and cut it into reattach half of it where it was on the outside of my foot, and then took the other half and attached it to the inside of my foot to help like straighten it back out.

Sarah 10:20

And then he did that same thing with the tendon going down the front of my leg, cut it in half, put half of it backwards, where it started and the other half on the inside. And so I woke up from the surgery and hard cast and as I looked down,

okay, okay, this is okay. And then a spasm really badly for like, four or five months.

Dealing with leg spasticity

Bill 10:50

What's that like? Because people go through this and there's not a lot spoken about what it's like to feel spasms and to feel spasticity. How do you cope with it for four or five months after you thought you fixed it? What does it do to you emotionally and mentally?

Sarah 11:07

It's demoralizing. I mean, it was I don't think I coped with it at all. I mean, physically, I would take my toes to the hard cast to try to get to stop spasming mentally, and emotionally. I don't think I ever I still, to this day I've really processed how much pain it caused.

Sarah 11:29

But I do know, I woke up in spasm and I was like, I'm gonna cut it off. Like, it's just gonna have to go. It was like, I mean, everyone at this point has had a muscle spasm in their life. Imagine that like all day, every day, 24/7, 365 like, you can't get it to stop. You don't know why.

Sarah 11:50

And so finally, the hard cast came off, and the orthopedic surgeon saw my foot and saw that was actually like back to being crooked. And then I got my neurologist referral. So that's when I found out that it was spasticity and dystonia, those are my post stroke diagnosis.

Bill 12:09

I'll give you a little bit of a, I did get misdiagnosed or not treated properly, I felt after the second time my brain bled, so it bled in 2012 in February, and then it bled in March. And in March, I went home, and I didn't know who had visited me, I couldn't type an email, I couldn't finish the sentence.

Bill 12:37

You know, I was getting stuck with words, I couldn't drive, I couldn't do anything. I was extremely fatigued. And the only thing I knew to do, because I had been seeing a counselor before that was to go and see my counselor and continue those

appointments.

Bill 12:53

And when I got to the counselor, I think it was about a month after I'd been discharged the second time. My counselor, my psychologist said, have you seen a neuropsychologist? And I said, What's that? Like I don't know what that is. And she said, well, it's somebody that's going to assess you to see where you're at cognitively and what you can and can't do.

Bill 13:17

And I said, oh no I didn't know that they existed. All right, I'll go and we tried to make an appointment and the appointment. It took about six months to get an appointment with a neuropsychologist because, again, I didn't realize that I could pay upfront to go and see somebody instead of waiting through our public hospital system to get a referral and go see somebody, but didn't realize that I could just go and pay.

Bill 13:43

So we waited, so in that time, I was zoned out, I was zonked out, I didn't know what was happening to me most of the time, had a lot of fatigue. I had a lot of spaced-out moments where I didn't know where I was in the world and what was happening. I was kind of in this kind of like a drugged phase of my life, like it was really bizarre.

Bill 14:07

So that's the most that I can relate to what you're saying that you went home and everyone thought, you're perfectly fine. Whereas when you went back to kickboxing, and all that kind of stuff, I went home and they thought I was perfectly fine. They didn't refer me to anybody.

Bill 14:23

But I struggled a lot with just being normal and being able to be in the world. So I think that's part of why I do this podcast. It's so that other people whose loved ones have had a stroke and when you've had the stroke you're not the one that can make the decision the rational decision or the correct decision about your health and well being.

Bill 14:48

So that loved ones or caregivers can perhaps stumble across one of these

episodes and go well I need to ring this person or I need to follow up on this. I need to do that for my loved one. So is that similar to how it happened to you? Do you feel like they just, you kind of slipped through the cracks and missed an important conversation somewhere?

Sarah 15:12

Yeah, that's probably the best way to describe it. I mean, once you're out of the system, at least where I was living, once I was on a system I was never able to get in. Like, I never. I mean, I told doctors constantly what was happening, and I was constantly looking for questions.

Sarah 15:31

And I was actively seeking out answers from the people that I thought had the answers, and no one could ever tell me what was wrong. Like, no one could ever tell me what to do. I mean, they were all more than willing to open my foot back up, and keep doing surgeries on it. But every single one, I gave them the same questions like, Can you take the pain away? None of them said, yes. So I was like, I'm not doing that again. I'm not putting myself to that kind of pain again.

Intro 15:59

If you've had a stroke, and you're in recovery, you'll know what a scary and confusing time it can be, you're likely to have a lot of questions going through your mind. Like, how long will it take to recover? Will I actually recover? What things should I avoid? In case I make matters worse, or doctors will explain things that obviously, you've never had a stroke before, you probably don't know what questions to ask.

Intro 16:23

If this is you, you may be missing out on doing things that could help speed up your recovery. If you're finding yourself in that situation, stop worrying, and head to recoveryafterstroke.com where you can download a guide that will help you it's called the seven questions to ask your doctor about your stroke.

Intro 16:43

These seven questions are the ones Bill wished he'd asked when he was recovering from a stroke, they'll not only help you better understand your condition, they'll help you take a more active role in your recovery. head to the website. Now, recoveryafterstroke.com and download the guide. It's free.

Leg Spasticity lead to amputation



Bill 17:02

And you made the decision to have the amputation though, like how do you make that decision? How do you make such a serious decision to have part of your body removed? How do you get to that? I imagine was it a quick decision what was that like?

Sarah 17:19

Oh yeah it was a really quick decision. It was like instantaneous, like, I mean, like I woke up my foot started spasming in this hard cast and had to deal with it for so long. I was like I want to cut it off. I didn't do it quickly, so my stroke was in August of 2013. And my mom was diagnosed with cancer in October of 2013. So she had to fight for her life and all that.

Sarah 17:47

And I wasn't gonna put myself in a position where I could possibly ruin my life and not be able to get to her whenever I needed to because we lived two states away. So like I wasn't gonna venture down that road until I was ready until she was ready. And ultimately, what made her ready was she did pass away in December of 2015.

Sarah 18:10

So she passed away in December 2015. So in between September ish of 2014 and December of 2015. I did all the research I did the botox that is apparently very common, it didn't work. I talked to all the orthopedic surgeons, they all gave me

the exact same answers.

Sarah 18:32

I did a lot of research on amputation. And what was out there, and what all, I really want to know if anyone else had ever amputated because of something like that, and I couldn't find anything. So I didn't really have any knowledge base for if it would work. And it was a huge risk. And I knew the huge risk. But once she passed away, I went ahead and just blindsided my whole family and all my friends with the decision to amputate the foot.

Sarah 18:58

Because I didn't talk to anyone about it. Like I didn't tell anyone like I was supposed to be okay. Like I wasn't supposed to have to be dealing with that kind of stuff. And like, I don't share. Well, you're actually the first person I've ever talked to about this seven years later. So yeah, yeah, so like, it's just like seven years later just now and like actually, like sharing any of this.

Sarah 19:22

So I blindsided everyone, like, my whole family was just like, what, like, you're gonna do what? And I mean, they were all supportive. They're totally okay with it. And when she passed once my mom passed, and I got through all that. I got back into Nashville and actually met, I met someone at the gym and we bonded through our crutches.

Sarah 19:47

Because I was on crutches at that point in time just because like I was on and out of crutches I was on and out of air cast I was in and out of AFO I was doing all that. And he was like he told me his story and I told him my story and he said he's like, but I'm gonna cut mine off. I'm like, who, what, when, where, why and how I want one.

Sarah 20:05

I was like, I've been wanting this for like over a year now. And he gave me his doctor's name and number. And this was like two seconds after I got back in Nashville life going again. I met the doctor, and he was a great guy. He's a vascular surgeon. He gave me my options.

Sarah 20:21

And it just everything he was saying made so much sense. And everything was

just so aligned with what I was wanting out of my life, I wanted my life back. And, it is unfortunate that my mom had to pass away to be able to start the journey. But once she did pass away, I was able to start looking for ways to get normal again, to get happy, again, to get out of my depression, funk and just the hate of life.

Sarah 20:50

But I met with the prosthesis. He actually runs a charity out in Nashville. I got very lucky with that as well, I talked to him, I was like, can I wear heels again? And I was like, can I run? Not again? But can I really don't because you always want we can't have you know, I was like, I can't run now I want to he unfortunately remember that, that I asked that question and made me run.

Sarah 21:15

I amputated in May 9th of 2016. And, in hindsight, there was a lot of morphine involved in my happiness at the very beginning, but I had no pain, like I was pain-free. Like I was just like, so happy and so relieved. And like, once the morphine were off, it took a little while to get back to that point.

Sarah 21:36

But like I was just so relieved that I didn't have anything spasming like the pain was gone. Like that you have to do inpatient rehab for two weeks, whenever you amputate. That's the first time we ever even focused on my hand. Like, I was so ready for the amputation. Like they didn't have anything they had to do with me for the foot. Like I was already like, Pelican, like Flamingoing whatever.

Sarah 22:00

More often not anyways, like I already took myself off on my left side as it was so I was so prepared for it just naturally, that we spent the whole time focused on the hand and working with it and trying to figure out how to, like get it stretched out and how to figure out how to like, get it functional again, if we even could. But yeah, it was the most insane I think I've ever experienced in my life.

Sara Curlee's life after amputation



Bill 22:23

Wow. It's absolutely fascinating that the thing that has made a difference to your life more than anything, after all these experiences that you've had is the amputation. And that improved your quality of life, I've got a friend who is double amputee.

Bill 22:39

And he was about 19 and experienced a condition that was called I can't remember right now, but I will remember it in a little bit. And as a result of meningococcal, and as a result of that, the bacteria attacks, the extremities of the limbs, he's lost a couple of fingers, and it impacted one of his legs severely and he had to have amputation.

Bill 23:09

And then it impacted his other leg as well, but not severely enough to need an amputation, but severely enough to cause a lot of pain and a lot of problems. So you had one leg, which was amputated, and had a prosthetic and the other one was just really painful and not really supporting him and able to allow him to get back to his life.

Bill 23:37

So he decided that he would also have that one amputated. And now he's a double amputee at the legs. And as he arranged it so that he was amputated, his leg was amputated in the same spot, so that he has really good balance. And now he's able to use amazing prosthetic limbs and walk properly and have no difficulties getting around and being active, and playing golf and doing all the things that he

loved to do.

Bill 24:12

I interviewed him for the podcast a few years ago. And what I'll do is I'll put a link in the show notes of the podcast episode with Mike Rolls. And if anyone's interested and curious about Mike, they can check him out at mikerolls.com.au. But all those links will be in the show notes.

Bill 24:39

He's a fascinating guy and he does some public speaking and it goes around Australia teaching helping other amputees survivors and it just a great guys. It's an amazing guy. Absolutely amazing. He was the first person I met who said that he was, you know, made the decision to have one of his own limbs amputated.

Bill 24:59

You're the second person, so it seems like it's probably rare. And it's not many people doing that. But it's great that both of you have had an amazing, positive outcome after doing something so drastic and what other people would say is really dramatic. And how could you possibly cut your own leg off?

Sarah 25:22

Yeah, it's kind of interesting because I don't have a percentage or anything, but a lot of empties are elective, like, a lot of us had something happen in life that we obviously didn't want to have happen. And we had the choice of keeping the limb and keeping the lower quality of life or removing the limb and having a higher quality of life. It's not as uncommon as I think most people realize.

Sarah 25:47

And I really realized that until I started meeting other amputees and they say, like, they could have kept their limb and they chose not to, it's actually quite common, I actually know a double amputee as well. And he was born to a genetic defect. I can't remember but he ended up amputated both of his legs as well.

Sarah 26:07

And his quality of life went through the roof as well. I mean, it's kind of, it's all about the mindset. You know, I mean, it's, no one ever wants to have a stroke. No one ever chooses to have a stroke. So it's a very depressing mindset. Like, it's really hard to come back from it's really hard to, to move on with life knowing what life was before. And it's just not something that you would ever wish upon

anyone. You'd never wished the invitation upon anyone.

Sarah 26:36

But if you choose to amputate, it's just completely different set of rules on the whole. That's in the power. Yeah, it is. It's very empowering. It is. Yeah. It's just like, when it works. It's a huge muscle release. I mean, huge, huge commercial, and then you can move on with life and prosthetics are great nowadays.

Sarah 26:57

We've come a long ways from the wooden legs. So I mean, it's just it's so impressive. I have three feet now. Actually, I have one for heels because Aaron. And then I have one for like everyday usage, it's got good ankle flexing. It's so I do get like a bit of an ankle. So I have that kind of.

Bill 27:24

Movement.

Sarah 27:25

Yes, thank you words. And then I have a running blade. He did remember I asked about running. But actually after I amputated I started walking a month after my amputation and I started running two months after my amputation, I ran two half marathons in a Ragnar all within a year and a half of amputating I have confirmed I'm not the biggest fan of running.

Sarah 27:49

And I actually did a lot of damage to my upper limb. Like my arm, I lost a lot of more mobility that I was already losing. And it's just so it's not worth it for me to keep running. I still use it at the gym a lot to like do like sled poles and stuff like that. And anything that requires like a little faster movement. But I don't run much at all anymore. But I mean, it's I couldn't have ever done any of that with my real foot. I could barely walk without a cane and with my real foot.

The birth control factor

Bill 28:19

I get it, it makes sense. I totally get a well done for doing it and going down that path. Have you ever stopped for a moment to consider the birth control issue, I know that you're about the fourth a woman or fifth woman I've interviewed who has seemingly been completely normal and healthy.

Bill 28:43

And at a very young age below 30 or even somewhere near 30 had a stroke. And the only thing that they could put it down to was that they were taking birth control. Is that something that plays on your mind? Is it a conversation that you've had with more people to get to the bottom of that?

Sarah 29:05

I think it is an incredibly important piece of information for everyone who's ever going to because birth control I've got found I was like 12 all for the same thing that most people that age get brought on. I mean, I'm a I'm a preteen with hormones I get it's just periods are incredibly painful.

Sarah 29:22

So they put you on birth control at such a young age. I was 27 I had the stroke. So do the math how many years it is I can't remember. But like, and it's just it comes with the warning labels, but we don't know to read them. Like we're kids. Our parents don't know that read them because they just want us to not be in pain once a month like and they're happy at the results that they see.

Sarah 29:43

And obviously, we're not trying to get pregnant if we're on birth control. So like it has so many benefits, but you never realize that the risks are high. And as actually, there's actually an episode of Oprah Winfrey Show I've never seen it but, she has like a ton of stroke survivors on her show all had strokes and their main reason was birth control.

Sarah 30:10

So I don't, I used to know the percentage, I can't remember percentage of birth control cause strokes, but it's higher than it should be. And then having that hole in my heart as well, the, the general theory is that the clot started in my legs, and instead of going down as my lungs, like I should have it pushed through the hole and went up into my brain.

Sarah 30:34

And I mean, that could have easily been solved with a bubble test, so a bubble test is whenever they shoot sailing into your heart, and then as the sailing stays where it's supposed to, you don't have a whole of the sailing moves into another chamber, you have a hole, but I'm just like, at least like, do some, like, check a

poor little girl who's about to start on birth control and make sure that she doesn't have any kind of pre-existing condition that could cause further problems down the road.

Sarah 31:06

It's just, really unfortunate how much it's not talked about. I've never really talked to him about it. But I don't really know how to talk to I don't know who to talk to, I don't know how to talk to people in general.

Bill 31:19

You're doing all right for somebody who doesn't know how to talk to people.

Sarah 31:23

Yeah, I wrote up a rubric. So I have my talking point.

Bill 31:29

That's all good. Look, I thought I'd ask just, I'm just so stunned about it, I keep meeting more and more women who have said the same thing. And I just, I can't believe it, I just cannot believe it. And I figured that somebody needs to do something about it or say something about it.

Bill 31:44

And I'm very surprised, I didn't know that there was an Oprah special on it or something like that. And that was done, though. Just Google that here. It was done in October of 2011. That was when she made a point of it, and did this particular show about it. So it's been a while.

Bill 32:07

And I dare say that there wouldn't be too many people moving to make any kind of change, because the perceived benefit of birth control, I'm assuming in society is far greater than the perceived risk of stroke. And even though people who have a stroke and were on birth control, it's still not definitive that they had the stroke because of the birth control.

Bill 32:34

And that's how they get out of saying, well, lots of things cause strokes, we don't know, and not necessarily the birth control. Although there is a warning label on birth control that does say it does increase the possibility of stroke.

Sarah 32:49

Yeah, and I mean, every environmental factor can be thrown into what can cause a stroke, a lot of strokes are perfect storms, I mean, you have everything fall into the right spot to have a stroke. Like if we go down farther down, like dehydration was a concern of the for the stroke.

Sarah 33:08

But they tried to say kickboxing was part of the reason I had a stroke. Like there was a laundry list of reasons why I possibly had the stroke. It's just those were the top two. But you're right. I mean, with so many other different factors that can be put that can play into having a stroke, you could never pin it on just birth control.

Bill 33:25

No, you can't.

Sarah 33:26

But it really should come as a red warning label instead of like a tiny like in the middle of a word. warning label.

Bill 33:34

Yeah, I agree with you. So your mum passed away at the same time when you're recovering from stroke when you're suffering and struggling through all these other issues as well, that I'm gonna make a bloody obvious statement. But obviously, it was hard. I know it was hard.

Overcoming difficult times



Bill 33:56

How do you get through it though? Like how do you overcome all the shit that you've got to deal with at the same time in your life and you're fairly young and like most people who are below 30 don't have a lot of experience in overcoming such emotionally difficult times as well throw a stroke into the mix. But how did you get through what did you need to do to overcome and get through?

Sarah 34:24

I kept busy, I cried a lot. I have a dog. I know it's not the same but my dog is like, literally the definition of an emotional support animal. Like she was like the sole reason that I ever even remotely wanted to continue trying. Because I mean my mom was failing daily.

Sarah 34:51

And she was actually the only one I ever really talked to about anything. So like it was really great to have her support. So just sit there and talk about our failing bodies and like so I at least had her to talk to about it. I'm gonna talk to you what else about it, especially my family, I don't want them to know what I was going through whenever we get hurt or worry about, I just a lot of crying.

Sarah 35:14

And I'd be that threw myself back into work, I was working like 70 hour day, that not days, what, like 70 hour weeks, whenever I was needed, I would just work a lot, I would try to get out there and be normal, I stayed active in the gym for sure. To this day, the gym is easily like my happy place.

Sarah 35:36

If I'm on the top bowed mountain, or headed to the top of a mountain with with Caya. I just I tried not to think about it failed more often than not, but try not to think about it. And pre amputation, I didn't have any other option, but to just ignore it as much as I could, because I had no solution to the problem.

Sarah 36:03

And then once I amputated, or once well once my mom had passed once I amputated i was able, that's whenever I was finally able to figure out how to be happy again. But I definitely spent the two-ish years just in a funk, like depressed, anxious, like I didn't know anyone to talk to had no one to like, tell what's going on didn't even have an answer to what was going on.

Bill 36:39

You seem like a pretty outgoing person I can't believe you didn't have anyone to talk to Is it because you chose not to? Or because you're not that kind of person. How is it that you didn't have anyone to talk to I find that amazing that people say that I get that they say it, and I understand how they say it and how they might get to that point.

Bill 37:01

But I find it fascinating that of, you know, you're one person, and you're surrounded with people wherever you live, unless you're in a remote location. And you felt like you had no one to talk to about it? Was it just something that you imagined that you didn't have anyone to talk about?

Sarah 37:22

I isolated I'm not gonna say willingly, but it is probably more subconscious than anything. my significant other time was a rock, he was great at the whole thing. The stroke ended up causing a lot of arguments, because he wanted life to go back to normal.

Sarah 37:40

And again, I was supposed to be fine. So life was supposed to go back to normal. So a lot of arguments about that, because I couldn't go back to normal. I couldn't go back to like being a social butterfly while I was overseas, like going out, like going out places with him and like doing all these things that we were doing pre stroke.

Sarah 37:56

So I followed up on that end, and then the stroke ultimately ended up ending us because I kind of talked to him about it and then work again, I was supposed to be fine. So no one knew what was going on. And once I there was actually one time that I had a cane, I love my cane, I think she's awesome.

Sarah 38:19

And I would break her out whenever I needed to back when I had my real foot because it would hurt. And so there's one day I needed my cane back. And so I broke it back out and I was at work with it. And like one of my co-workers like literally pointed at it and laughed.

Sarah 38:35

Like, actually that day, I just found out that my mom got diagnosed with stage four cancer like so it was a really bad day. Like I didn't leave the bathroom for like two hours, like I was in there crying for like two hours. But like I would hone in on things like that. And I would hone in on my behavior and my attitude and how like I was just so unhappy. And I would get snippy because of it.

Sarah 38:59

And like so I just opted to not talk to anyone like it was easier that way. It was easier to not share than it was to share, especially since I still didn't know what was wrong. I still didn't know how to fix it. And I wish I had sought out answers on how to make it better before knowing how to make it better. That makes sense?

Bill 39:23

Makes sense, complete sence. And that's why I question you on, how do you feel alone and I kind of knew what you were gonna say but people listening and watching this are gonna definitely feel alone and they might recognize something in you that they haven't recognized in themselves.

Bill 39:42

And they might be able to say, okay, I've got to do something about this situation that I mean, and maybe the feeling of being alone is just a creation in your own mind and I get how rude could somebody possibly be by pointing at your cane and laughing.

Sarah 40:03

The rudeness was not intended, I know that.

Bill 40:06

It's still rude. And, that makes sense that you would retract from interactions with people because you're trying to protect yourself and you're trying to keep yourself from being further emotionally impacted. Not only you're going through a stroke, your mum's unwell, and there's people laughing at your cane like ridiculous how stupid?

Sarah 40:34

Yeah, in hindsight, actually, if I had known it was gonna be like a social study amputating my foot, I really would have documented this better. But back when I was in my air cast, strangers would walk up to me like all the time, like, Oh, my

gosh, what happened? What did you do? How did you hurt yourself? And I never had an answer to that.

Sarah 40:51

I was always like, I had surgery. But no one ever cared about my answer to is they always wanted to tell me their story on how they ended up in air castle how they ended up with two air casts how they like, fell off a mountain skiing and how they ended up breaking both their feet.

Sarah 41:03

Like everyone just wanted to tell me their story because it was so relatable, right? And I amputated the foot, very rarely do I get asked what happened? Like, more often than not, I get people who stare at me for sure. And it's kind of funny, because now I want to talk about it.

Sarah 41:17

I'm like, Oh, ask me I want to tell you, I'm ready to tell you. But I wish I had used that time and that air cast as a chance to talk about it. Like I wish I had been honest and been like a stroke. Like, I had a stroke. And I'm not like, I can't walk without this or I can't walk out the AFO and I could have at least practiced on strangers.

Sarah 41:42

What to say to people that I knew and people that I cared about. And then instead of I was pushing them away. Instead I was actually like avoiding them because I couldn't talk about it. Like I really wish I had practiced on strangers I guess.

Bill 41:58

But now it's a great thing to reflect on and to share now because people listening right now might go Okay, let me test out my sob story on somebody I don't know and I'm never gonna see again.

Sarah 42:12

Exactly so random person in a grocery store and tell him your whole life. I mean, it's good practice.

Bill 42:18

If they're keen enough to ask, they're gonna have to listen to the answer.

Sarah 42:24

That is true. I had to listen to their stories. They have to listen to yours. It's true. Very true.

Bill 42:29

And isn't it amazing that questioning is a way to open up an opportunity for them to tell you what happened to them so that they can get it off their chest. And they don't really give a shit about you.

Sarah 42:40

Yeah. I would always say um, I would always say I'm just gonna like say like something funny. Like I saved a calf from a burning building or something like that, like some so I've never actually did it because I don't know. I just I couldn't ever get the words out because not that eloquent with words.

Sarah 42:58

But, but now that I actually tell the truth on the rare occasion, someone will ask me what happened to my foot more people ask me my hand in general, but like, I'll always answer with I had a stroke. And that's weird enough. Apparently. Everyone's just like, Oh, I don't know what that means.

Sarah 43:14

I was like, Oh, you were so young. I'm like, yeah, I was 27 when I had it, and then it's just awkward silence. And then I walk away from the stranger. And but I practiced. So yeah, so I mean, it's just such a strange answer as it is. So it never it very rarely leads to follow-up questions I love it when it leads to follow-up questions. And those are some of my favorite conversations. But it just doesn't happen that often. So apparently, I had the weird story all along. I just never knew it.

Sharing your story



Bill 43:44

You should do just before my surgery, I was really eating really well. No sugar, no gluten, no dairy, no alcohol. And of course, when you go to a party and you're not having any of that stuff, and people are offering you cake and alcohol and all that, they ask you unknowingly Oh, how come you're not drinking? or How come you're not eating cake or whatever.

Bill 44:10

And then I got to that point where at some stage I started telling them and they you could tell they regret asking me about 45 minutes later and their trying to be polite and not get out of the conversation. And they asked you had a stroke. Yeah, and I bled and and this happened and that happened and they cut my head open and they did all that stuff.

Bill 44:31

And people are just sitting there going geez I wish I'd never asked that question. They're not gonna tell that their thinking that but they're too polite to walk away and they're people that I kind of know through other people. So it was you know, not the right time for them to walk away and get out of it but I didn't do it to annoy them or upset them or anything like that.

Bill 44:55

I did them because I felt I think like you I felt like it was time to start sharing. I think I felt like they were old enough to have a stroke that people that were asking me, so maybe I was kind of raising awareness about it. And I wanted to tell them that I stopped smoking. And I wanted to tell them that I stopped drinking,

because, like you, I did have the perfect storm, but I think I created the perfect storm myself.

Bill 44:55

So I did all these little things that did lead to that weak blood vessel in my head finally going, we can't cope anymore, I'm gonna bleed out, you know. And then I started to take control back of my health and well being, and I was proud of that. So I wanted to tell people that that's what I was doing.

Sarah 45:43

You should be proud of that. You have such a positive mindset as well, that's so great. It's hard to have a positive mindset after having something like that happen. It's so much easier to just fall in a black hole.

Bill 45:57

Yeah, well, I did. I shared that story as well, on episode 100, I interviewed my wife, you know, and, at the time, a week or two before my surgery, her mom passed away. So we were going through her mom's passing, and then we were preparing for the funeral. And at the same time, we were preparing for potentially life altering brain surgery.

Bill 46:23

And it was just a real shit time, in every way, shape, and form. And if you didn't have a positive mindset, even, even in the midst of all the distress and the depression, and the anxiety and the you know, bad feelings and the bad emotions. If you didn't have a positive mindset, I don't know how we would have got through it.

Bill 46:44

We had two kids, you know, you can't just collapsed in a heap. And it doesn't work, there's too much going on to do that. So what's the solution? The solution for me was just to find ways to have a positive impact on my own life. And for me, it wasn't an amputation, but I can so relate to what you said about how you chose amputation, it seemed like the harder path, but it was the path that gave you back your life.

Bill 47:13

And that's kind of what I did, I chose what appeared to be like the harder path. And for some people, some people would appreciate this stopping alcohol is a

hard path for some people. But for me, that was easy. Because now that that's done, I can just go back to not having to worry about am I again, creating the perfect storm to have another stroke? And if I have another stroke, how much worse is it going to be than what it is now? Because it's not gonna be better?

Sarah 47:45

How old were you when you had your stroke, or your bleed?

Bill 47:50

I was 37. You know, and working 16 hours a day and two kids and wife and mortgage and cars and all that shit, right? And then it was like, everyone I know, around me is doing exactly what I'm doing. Like they are a candidate for having the same experience that I'm having.

Bill 48:12

And maybe by me sharing my story, they'll just pay attention a little bit and reconsider a couple of things on it. I don't know what but maybe they won't, but maybe they will. I don't know. It's kind of where I was coming from. And also, I was getting used to being public about it and getting used to my next phase.

Bill 48:36

Getting prepared for my next phase, which was to do the podcast and to do you know, recovery, stroke recovery coaching and to do YouTube videos and to do Instagram lives, you know, so it was kind of my proving ground. It was I got those suckers involved and practice my message or story or whatever.

Sarah 48:57

Yeah. And how long ago did you start this podcast? I'm trying to find out, I can't really get an answer.

Bill 49:03

I started it in 2015. And I didn't do a lot of episodes back then I was only doing probably, you know, maybe three or four episodes every few months. And it really ramped up in the last three years or so where I've been doing about an episode a week. So we're on close to about doing 50 or so episodes a year. And at the beginning it was called the transit lounge podcast and I was just interviewing random people about different things that they ever come.

Bill 49:35

And then there was some cancer survivors and then there was a lady who overcome multiple sclerosis. And there was Mike Rolls who I mentioned earlier who had the double amputation.

Bill 49:49

So I was just interviewing people about having overcome things but then I realized that actually my real passion and my real community and the people that are related to who related to to me the most was stroke survivors. So I changed it about a year and a half ago, two years ago, and I called it The Recovery After Stroke Podcast. And, it took off from there.

Sarah 50:12

I've tried my hardest after my stroke to find something like this, or find a support group or anything like that. So I never found one. So what you're doing is really very impressive. I mean, everyone has been through something like we've been through wants to find someone out there who they can talk to and relate to and know that they're not alone.

Sarah 50:35

And it's great that you have a platform that you're reminding us and letting us all know that we're not alone or telling us in the first place that we're not alone. Because it's a very, it's scary in of itself. But the idea that you think that you can't ever talk to anyone and have them understand what you're talking about makes it scarier, trying to get life back on track. So it's great that you're doing this.

Bill 51:00

I was seeking out anyone near me that had a stroke, or I could relate to but the people I was meeting were all older than me. And then I did meet a few locals that were younger than me. And we kind of did relate. But then I think the main reason I did the podcast was so I can meet other people that I related to.

Bill 51:18

So I wouldn't feel alone. And so I would feel like somebody understood me and knew what I was going through. Even though they were on the other side of the planet, it didn't really matter. So now I've met 130 stroke survivors who have shared their story on the podcast who are, like me, similar to me understand me, and I don't feel so alone. And when I reach out to them on Instagram and ask, you know, silly questions, I get a heap of answers, people respond.

Sarah 51:48

I love those answers. I love that you asked those questions. I've spent more time reading your comments than any other comments on Instagram.

Bill 51:56

It's fascinating to me that people A would want to respond, and I'm glad that they do because it then makes Instagram worth being on. You know, just today, I put another post there and I asked, What is something that stroke caused that you would pay anything to make better or go away?

Bill 52:16

I'm really looking forward to what people have to say about that.

Sarah 52:20

I'll answer it when we're done with this.

Bill 52:22

And they're already on there, you know, I only posted it 10 minutes before we got on to this episode. And they're already on the leaving, you know, comments like neuro-fatigue, it's hard to explain to somebody, and I guess to someone it sounds made up, but it's very real similar to a migraine, I often feel like, I need to lie down in a dark room with no external stimuli to feel better.

Bill 52:46

People are just posted, there's like, already 10 comments on there. And I just posted it 40 minutes ago, 50 minutes ago. So I love that I can do that. And I get a lot from it. But the people who comment get a lot from it. And I'm so glad that you're one of them.

Sarah 53:04

Yeah, mine's chronic pain, to answer that. I really wish the chronic pain will go away your questions. I mean, they're just they're such great conversation starters. And it's this there's a stroke survivor support group in Nashville now I actually found them because I ran a 5k for them after I amputated obviously.

Sarah 53:31

But it's called Seriously Awesome Stroke Survivors. But she was Trista is actually, she's never had a stroke. She's just, few last podcast with Peter, he was talking about something that I can't remember what it was. But it made me think of

Trista. Oh, on how she's never had a stroke. But she's sitting there trying to help everyone who has and how she's just like this most selfless person and like want to help someone which doesn't actually personally know what they're going through.

Sarah 54:01

But I met a lot of stroke survivors through them. But yeah, same thing. They were all older, I still never met many younger stroke survivors. But they were all such amazing people, though, it is great to be able to share the stories on a personal level. But that's actually why I started my Instagram was to find other stroke survivors as well. So I think I guess I probably found you about a year ago. I just started on tiny change sort of recovering from a stroke.

Helping other people

Bill 54:25

Yeah, something like that. It makes sense. That's when it kind of really took off. Peter G. Levine was Episode 135. So his the episode just before you, I just released that today. And it's gonna go live. It's live already. And he's a clinical researcher, and he and his family and his wife and I don't know how many people he knows are all involved in helping other people overcome brain injuries and recover from stroke and all that kind of stuff.

Bill 54:56

And I'm like, why would you do that? I think it's so fascinating. That's the path that they choose, and they go down. And when I met people like that in Melbourne in my hometown, I again didn't feel like I was alone. Because there was thousands of researchers doing work. At these institutes and at these hospitals to help people like us. It's such an amazing thing. I find it fascinating.

Sarah 55:25

I didn't realize that until that podcast that, I know Australia had the Stroke Foundation, I follow them on Instagram, but I didn't realize that Australia was so passionate about strokes and figuring out what causes them how many people better after them? And I don't know if that I don't know if the US has much like that honestly if they do I haven't ever heard about it. So I think the US is still stumbling through most of it.

Bill 55:49

Yeah, there are a lot of researchers that are working and doing amazing work in the US. And especially the I think it's the Heart and Stroke Foundation in the US that does really good work in that space. But there'll be a ton of bodies that really focusing on neurological interventions, or how to help people having neurological issues, you know, what's really bad about what they do, they don't do a real good job of advertising themselves.

Bill 56:17

And of letting people know that they exist. Because they're so focused on rehabilitation and learning new things. And, you know, discovering new discoveries, they're not really good at telling people about the things that they've discovered. And when they do discover them, their version of Instagram or whatever is some medical journal that only doctors read.

Sarah 56:41

Yeah, trying to get through those is impossible, like, like, I didn't even know what neuro plasticity was until, like, within the last few years. And that's something that they've apparently known about forever. And they didn't ever put it in an easily read Instagram post, like our attention spans are like, shorter and shorter, the more modern day becomes more overwhelming with all the information out there, our attention spans are too short to read that long post.

Bill 57:12

So that's pretty much why I would say we don't know about them. And, you know, I've never really been interested in neurological stuff until I had a stroke. And then I needed to know all about the neurological stuff. So I started to really focus and try and research but back then, when you and I had our stroke, it was early days, it was really early days, 2012 there was nothing around and I was looking everywhere for that stuff.

Sarah 57:39

I was too yeah, there was nothing.

What's in store for Sarah Curlee

Bill 57:42

So that's kind of what instigated me to get my act together and get the ball rolling

on my podcast now I'm curious, though. How's the future looking for you? What's, you know what's coming up, that's exciting that you'll be doing or going to continue to do how things evolving now.

Sarah 58:04

So I moved to Utah to do the things that I want to do. Nashville is great. And I loved it. It's just like, I had to drive three hours for a hike and ABR Amputee Blade Runners were phenomenal in getting me up and running. But Utah has this place out here called the National Ability Center.

Sarah 58:20

And what they do is they work with people with disabilities or PTSD and help them either get into outdoor rec or get back into outdoor rec and so pre-stroke. I dabbled in snowboarding sucked at it dabbled in mountain biking terrified me. But now that I know that I'm poststroke and post-amputation like I can start doing these things and I'm like I want to go out and do this.

Sarah 58:42

And so actually the double amputee that I saw earlier, posted has experienced that and I already want to move out to this coast anyways because humidity is like the worst thing ever like Nashville has. So actually targeted Utah so that I could work with them and I started snowboarding with them.

Sarah 59:01

I found out I can't do that because my upper limb but I got to try at a much cheaper rate than I would have if I had gone out and bought everything and tried on my own. So I also got to try mountain biking with them. Same issue with upper limb like it just since my left side so tight, everything that I do especially with an adrenaline rush like my left side like immediately like tenses up and then I just fall over.

Sarah 59:27

But I still get a trial this which is really fun. I went cross country skiing like week or two ago. That was really fun. I'm going to try that again because I actually I only fell because I really get excited and then I fall but like my strokes I was fine with that. So I'm excited to try that again.

Sarah 59:44

Hiking, I love to hike I love that I can hike again. My significant other and I we go

on hikes as often as we can, you know seasons out here so like it's not like just constant like rain or hot or like I just wanna go outside and play. That's all I want to do that's all I wanted to do, like I have two dogs now and I have my significant other, we just come out here we just go outside to play and we're in such a great area for it.

Sarah 1:00:15

And the NAC is just like such a good resource to like, let me try it like, I'm gonna try Archery with them. I've never done it, but I've always wanted to try it. And so I'll do that and like horseback riding and like all this stuff and like, my upper limb is definitely the constraints.

Sarah 1:00:30

But now that I have amputated my lower leg and remove that, I mean, there's so many new things that I can do, like so many things that I can do. And the amputation itself is called erl amputation, I guess I checked on this a little bit because I have had people reach out to me before about the amputation and stroke all that. So it's an erl amputation, it's not conventional.

Sarah 1:00:54

So conventional amputation, they amputate the foot and they leave the two bones, the tibia and the fibula. And they just leave them free floating. So they basically are just there to like tear up soft tissue. So the erl does is it takes one of the bones that amputated and it reconnects them. So they use tightline and reconnect them so I can like impact. Like I have a stump that I can just beat.

Sarah 1:01:25

And I actually literally had to beat it with like roll up magazines to desensitize it. But because of that, I can be more active than a lot of conventional amputees because I have that support in my stump. And with that, I'm able to go out and try all these things and not get like the like the skin breakdown as easily and not get the Phantom pains aren't nearly as bad as they can be.

Sarah 1:01:52

Phantom Pain is a really common thing for amputees. I always feel the foot I've my toes are always tingling, it hurts sometimes if most part it's just a phantom sensation. But the erl helps avoid the phantom pain as well. Going off on tangents now.

Bill 1:02:09

You were just talking about why you're so active and how that particular amputation is helping you because and you wanted to share that because people ask you about it.

Sarah 1:02:20

Yeah, I have had quite a few people ask me about amputating their foot because of their stroke. And I'm never like yes, do that. But I do share them my story because it's not the perfect solution for everyone. And it's not, I just got very lucky that my residuals were for the most part located in my arm and my foot.

Sarah 1:02:41

So like my left leg doesn't move as well as it did, like I do have limited mobility. And I do have limited mind muscle connection, but it's not as severe as my foot was. So I have had quite, so every time I talk to someone about it, I just make sure that they know that it's not necessarily going to fix everything didn't fix everything for me. But it did it would make life way better.

Sarah 1:03:01

And I strongly encourage thinking outside of the box for how to get your life back. A stroke survivor the other day reached out to me about amputating his arm because he saw how I was on amputating my foot and I was like, dude, I would have cut that thing off. I would have asked for Bogo if I could cut that thing off easily. But it's really hard to replace an arm unfortunately.

Bill 1:03:27

So you couldn't possibly have known how good a decision there was going to be to amputate a leg, I didn't think you knew how much it was gonna change your life for the better. You just wanted to get rid of the pain and if that was gone, and that would have been fine.

Sarah 1:03:43

Yeah, it was a huge risk. I mean, it was a huge risk. I owned a house in Nashville with the significant other at the time. And after we ended our everything, I sold the house, and I paid off all my debt, all my student loans, all my medical bills, everything just in case, I have made a really bad mistake and could not go back from it.

Sarah 1:04:03

So like I set myself up to possibly have to move back in with my dad and have him be my caretaker. I mean, I obviously didn't tell him all this because I wasn't gonna like scare him. But like I said, I set myself up to where like I was ready for the risk. And I was ready for it to go wrong if it did, but every finger and toe and everything was crossed, it would go right and it went right. So we're very lucky with that.

Bill 1:04:31

You sure that you got lucky after being unlucky a few times. So you know what, I think you deserve that and you earned a little bit of luck and a little bit of things going your way. I mean, it's a great message to people listening that are going through really hard time because stroke makes things a bit worse.

There are better things to come

Bill 1:04:51

Even if you know, the stuff you're going through is still there and then you got to deal with stroke and everything gets compounded. So it's a great message for people listening to that. You know, there's a bit of things to come there is a light at the end of the tunnel, you can focus on what you want to do and what you want to achieve and you can get there.

Bill 1:05:08

And yeah, I'm just stunned that what you've been able to go through and achieve, and I just hope that you continue to do well and play, you know, go outside and play and have fun with the dogs and enjoy a full a full life, you know, whatever that means for you. I really hope that that's how it goes for you.

Sarah 1:05:33

Well, thank you. I appreciate it. So far, it's been pretty good. If work would stop having to pay me to be better, go outside and play more, but I'm just happy that I can still work and do everything that I wanted to do.

Bill 1:05:49

Yeah. Sarah, thank you so much for being on the podcast. If anyone wanted to reach out to you, I've got a feeling that a few people might reach out to you. On Instagram, what's your handle? Where are they going to find you?

Sarah 1:06:01

It's Sara_Nickel. There's two underscores between Sara and Nickel and I don't have anything else besides Instagram.

Bill 1:06:09

Cool. I'll make sure that your Instagram link is there so people can find it as well.

Sarah 1:06:14

Just keep doing what you do you're already doing so much.

Intro 1:06:21

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Intro 1:06:48

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Intro 1:07:10

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Intro 1:07:25

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Intro 1:07:50

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