FF S3 Ep. 2.mp3

Caraline [00:00:00] Hello, everybody, and welcome back to another episode of the Fibro Friends podcast, as always, I'm one of your hosts, Caraline, and I also have my friend Mesha here.

Mesha [00:00:11] Hello.

Caraline [00:00:12] But just to start off the episode, I did want to remind everybody that the FCSA's Mariposa Gala is coming up on October twenty-second and it's going to be at a loft life venue in Newark, New Jersey. So if you're in the area or hey, if you want to make a trip to New Jersey, go for it. The tickets are on sale. We have general admission and VIP tickets. You can also just straight up donate to the FCSA. And all those funds are going straight to the Centers of Excellence Fund, which is the main thing that the FCSA has been trying to create and make happen, because it will be a place where care can all come together and we can truly get the help that most people with Fibromyalgia have been looking for, if not all people with Fibromyalgia. But we will make sure to put the link in the show notes. If we tell you that Mesha and me and Skye and some of our other really awesome friends will be there, maybe that helps boost your want to come. But if not, we'll definitely be taking some fun pictures that night because it'll be the first time all three of us will be in the same room together. So.

Mesha [00:01:22] Oh my god!

Caraline [00:01:25] Magic! But with that being said, I just want us to get right into today's episode. We have a new Fibro Friends with us who I'm very excited to introduce she's a fellow Fibro warrior. She has a blog named Fabulous and Fatigued, and she's also a Fibro advocate. Meet our new friend, Sara. Welcome, Sara.

Sara [00:01:46] Hi. Thanks so much for having me.

Caraline [00:01:49] Yes, we are very excited because you are our first friend, not from America.

Sara [00:01:54] Ooh, that is pretty cool.

Caraline [00:01:58] And that's why I'm honestly, like, really excited to talk about some of the differences, if there is any. I mean, I have to assume there's some.

Sara [00:02:05] Yeah, there are lots of differences, trust me.

Caraline [00:02:08] Yeah, I'm really excited to talk to you. So the first question we ask all our guests is, what is the weirdest piece of advice you've been given either by a health care professional or weird random lady on the street?

Sara [00:02:24] OK, I have the answer to that right away.

Caraline [00:02:28] Perfect!

Sara [00:02:28] I don't even need to think about it. I actually had my family practitioner once tell me that I should just get married and that would solve all my problems.

Caraline [00:02:38] What?!

Mesha [00:02:39] Why do they think men are the solution.

Caraline [00:02:40] They're the problem!

Mesha [00:02:42] Everything!

Sara [00:02:48] I just like in that moment was so shocked and, you know, to this date, it's been a few years since she said that to me. But I think it's just it's it's it's very cultural.

Caraline [00:03:02] Yeah.

Sara [00:03:03] It's something that's really embedded, especially in South Asian culture, that. You know, getting married is the end all, and it's your goal in life.

Caraline [00:03:17] Yeah.

Sara [00:03:17] You hit the jackpot, everything's going to be OK. So, you know, I still haven't hit the jackpot.

Caraline [00:03:25] Maybe they're like maybe to, like, boost the serotonin, some dopamine. I'd rather just go shopping or eat a cupcake. Seems like less work.

Sara [00:03:39] Well, yeah. Come to think of it, I'm sure like medically like it would help with the hormones, the oxytocin, a bunch of things are in there. But still that does not solve anything.

Caraline [00:03:51] Yes. That's very similar to the one that I had, which is I got told to get pregnant and I wasn't with anybody at the time.

Sara [00:04:02] OK, getting pregnant is actually one of my fears.

Caraline [00:04:05] Yeah!

Sara [00:04:06] Because I feel like on a daily basis we go through so much pain and pregnancy is so much pain on its own for a healthy person. So for us to go through it, I can't even imagine. So I don't know who gave you that advice and I don't know what they were thinking.

Caraline [00:04:25] Her rationale was that the pain of childbirth. So let's just forget that I would have to go through nine months of being pregnant. First of all, she thought that the pain of childbirth, because it's above Fibromyalgia on the pain scale, that it would just like cancel each other out.

Mesha [00:04:43] A reset. I don't think it works this way.

Caraline [00:04:44] Body reset.

Sara [00:04:44] Well then be like, yeah, only if I felt the pain of childbirth every single second of my life.

Caraline [00:04:53] And it's like, oh, I wouldn't possibly have to deal with postpartum depression or prenatal depression.

Sara [00:04:58] That's another thing that also scares me.

Mesha [00:05:01] Yeah, me too.

Sara [00:05:02] We're more likely to get all of that.

Caraline [00:05:04] Absolutely.

Mesha [00:05:04] All of it.

Caraline [00:05:04] Yeah.

Mesha [00:05:06] Great.

Caraline [00:05:06] Where do you get your research? Google.

Mesha [00:05:11] Right?!

Caraline [00:05:11] Oh, my gosh. That's a good one, though. That's one of the better ones I've heard better in a funny way, because we can laugh about it.

Mesha [00:05:18] Yep.

Caraline [00:05:19] Oh, my gosh. So I want to talk about your story with Fibromyalgia. We like to talk about people's journeys to where they are now. So when were you originally diagnosed?

Sara [00:05:31] It's been about 14 years now. And initially the diagnosis also took a couple of months or not a couple of months or a couple of years. I wish it took a couple of months.

Mesha [00:05:44] I was about to say, wow!

Sara [00:05:45] No no, it took a couple of years. It was a lot of so initially it was a hit and run accident. So a car hit me on my back and the guy just left obviously just ran away. I was actually on school premises. I was in grade eleven.

Caraline [00:06:02] Wow.

Sara [00:06:02] So I was pretty young. I was like sixteen, I think. And I walked back to like I walked up to class and I told my teacher I was a nerd. It was a full-on nerd. And so I go to my math teacher because it was math class and I loved my math teacher and he loved me back because I was getting one hundred. I loved him because he was giving me one hundred. He loved me because I wasn't giving him any trouble. It was all mutual. So yeah, I was laughing and I was telling him, guess what happened? A car hit me on my back and I

just thought it was really funny that I got up and I'm fine. And I was like, See, no bruises, no fractures, no nothing from head to toe. I'm absolutely OK. And he looked petrified and I just didn't understand why I was just in grade 11. And naturally that was because my idea of pain was it's anything that's visible.

Caraline [00:07:01] Yeah.

Sara [00:07:01] And so he forced me to go to the principal's office and let them know. And I had an entire back and forth going with him saying, no, I'm not going to go because I was skipping class for the first time in my whole entire life. And for a nerd, that's a huge deal. I was like, so we're going to ask me why I was skipping class. No, I'm not doing that. He's like, when you tell them you got into an accident, that's the last thing they're going to think about.

Caraline [00:07:29] Yeah.

Sara [00:07:30] So anyway, that happened. The cops came, an ambulance came, I went, I got rushed to the E.R. E.R. doctors just sent me home with painkillers. And you know.

Mesha [00:07:44] No exam? .

Sara [00:07:46] I think they did x rays.

Mesha [00:07:48] Oh, I was about to say.

Caraline [00:07:48] Good.

Sara [00:07:48] Yeah, I think they did x rays, but yeah, everything looked fine. So they sent me back home. And then a couple of days later, I was still in excruciating pain. So they took me to the E.R. again, same thing, head to toe. I look fine. And then that entire summer I spent in bed and I think for about two years I was just on really strong painkillers, the kind that I'd actually have to take medicine before it to sort of protect the stomach the lining of my stomach.

Mesha [00:08:21] Yeah.

Sara [00:08:22] And and that's that's all I could do. And I was doing physiotherapy and I was bedridden and I couldn't walk for a long period of time. I couldn't sit for a long period of time. I barely went to half my classes in grade 12, didn't think I'd make it to university. You know, every few months we go to my family practitioner and my parents and I would be like, what's going on? Why am I not better? I look fine. What's going on? So, yeah, eventually she referred me to a specialist and I got diagnosed with some disease that I could not pronounce or spell at the time.

Caraline [00:09:08] Yeah.

Sara [00:09:08] Thankfully now I can.

Mesha [00:09:12] How it goes, yeah.

Sara [00:09:12] So, yeah, that was the start of my journey.

Caraline [00:09:15] Oh wow.

Mesha [00:09:16] Oh man.

Caraline [00:09:17] That's crazy. And it just shows that like traumatic injury and illness, like one hundred percent are the triggers like if that doesn't if doesn't make it black and white. I don't know what does.

Sara [00:09:31] Yeah, one hundred percent. A hundred percent.

Caraline [00:09:34] So when did you get into like sharing your story.

Sara [00:09:39] That happened only recently about, I would say two years ago.

Caraline [00:09:43] Oh, wow awesome.

Mesha [00:09:45] Wow.

Sara [00:09:45] Yeah, so for a good 12 years, it was a big hush hush secret that nobody knew except for my immediate family. And my best friends knew my cousins. My cousins didn't know. My grandma didn't know. My aunts, my uncles, nobody knew. And the reason was that I come from a South Asian background and. For you to have an illness or for you, it's very stigmatized.

Caraline [00:10:18] Yeah.

Mesha [00:10:18] Yeah. Yep.

Sara [00:10:19] And, you know, it's the kind where people right away don't think about your health and how your life is right away. The very first thought they're going to have is, oh, my God, who's going to get married to her? Nobody is going to want to get married to her. She has an illness.

Mesha [00:10:35] Oh, my goodness.

Sara [00:10:36] And so and that was something that worried my parents for the longest time. We would get into arguments all the time where my parents would tell me not to tell anybody and. Especially if I was talking to someone that would be like, don't tell any boys you talk to that you have this illness because then they're not going to want to be with you. So, you know, I got told that for a good 12 years.

Caraline [00:11:04] Yeah.

Sara [00:11:05] So it was it's literally embedded in me at this point in time. And I always fought back and I said, no, I'm not going to start a relationship that's supposed to be based on trust and honesty. By lying to someone.

Mesha [00:11:22] Of course.

[00:11:23] I've also had a very tough time initially at home with my immediate family recognizing my illness because again, because it was invisible, they thought I was being dramatic and nothing was taken seriously. And a part of it also had to do with the fact that it was easier for them to pretend like I was OK than stuff that I have an illness. So they did that for a long time. So for that reason, I sort of had this huge thing about my life from everyone. And it's not because I believed what they would say to me. I genuinely knew that it was something I wasn't going to lie to someone about. I always knew that. But at the same time, I also thought that if I went around telling people, it would hurt them. And and so I kind of decided that I was going to not say anything until maybe I was in a relationship or I got engaged or married and that way once because that was like a huge worry for the right.

Caraline [00:12:32] And make them feel secure.

Sara [00:12:33] Yeah. So I was like, once that happens, if I talk about it, it doesn't matter. However, I realized that I was doing something that I hated the most. I was waiting for a certain moment to happen for me to do something that I've always wanted to do. I always wanted to share my journey with people. I always wanted to help people, because when I got diagnosed, this was 14 years ago. At the time, there were no online communities. It was such a huge stigma. Nobody was talking about it. I didn't know anybody to confide in. I didn't know a single other young person who was sick.

Caraline [00:13:15] Absolutely.

Sara [00:13:16] That could relate to me. So. I always knew that I wanted to talk about it so I could help others that were in similar situations. I guess I was just holding off on doing that until I was with someone.

Caraline [00:13:32] Yeah.

Sara [00:13:33] Well, once I had the realization that I was doing the one thing that I hated the most waiting.

Caraline [00:13:39] Yeah.

Sara [00:13:39] Why wait when it's something I really want to do. Who knows what is going to happen tomorrow.

Caraline [00:13:46] Yeah.

Sara [00:13:47] So yeah. Like I, it was a random conversation with my sister and she said start a blog and if you don't feel comfortable about telling the world that it's you just start an anonymous blog. And I was like, oh, that way my parents are going to be looking at and I'm not going to hurt them. Or so I started working on it. I designed my website I made my.

Caraline [00:14:12] Which is gorgeous, by the way.

Mesha [00:14:13] I love it.

Sara [00:14:13] Thank you so much.

Caraline [00:14:15] I'm a font snob. And I was like, ooh that's a good font on this blog.

Sara [00:14:16] And I you know, I was working on it day in and day out and my mom realized that there's something that I'm working on because she saw that I was always busy in my room for 10, 12 hours a day just working on the computer. When she started asking my siblings and she came to me and I told her what I was doing, but I was like, you know, don't worry, it's anonymous. Nobody's going to know. And I think that's what made her feel comfortable. And she was actually very supportive. And in fact, when I was starting my blog, she even got me like she she I was getting myself a celebration cupcake and she wanted to pay for it.

Caraline [00:15:07] Awe.

Mesha [00:15:07] Awe.

Sara [00:15:08] So, yeah. So she has come a long way. And at this point, obviously, it's not a it's not an anonymous blog. And she knows that as well. She's comfortable with it as well. But yeah. So so it took a long time and it was a lot that happened in between for me to actually start speaking up about it. And I remember even when I was hitting like, you know, for my hitting the button for my website to go, like I was so scared because I knew that it was the first time in my entire life that, you know, my cousins would know.

Caraline [00:15:42] Yeah.

Sara [00:15:43] Or my immediate not my immediate family. Sorry, but like the rest of my family, my aunts, my uncles, everyone, the entire world had access to it.

Caraline [00:15:53] Yeah.

Sara [00:15:54] So, yeah, it was pretty scary.

Caraline [00:15:56] That's awesome though that it was kind of a way to create acceptance within your family.

Sara [00:16:03] Yeah for sure.

Mesha [00:16:05] And you did it in such a beautiful way and I really commend you on your work, it's really gorgeous and you're such a great writer, too.

Sara [00:16:14] Thank you so much. You know, hearing that I'm such a great writer is so weird to hear because I've never written before.

Caraline [00:16:25] That's crazy.

Sara [00:16:26] Yeah. So this is the first time I'm writing and I've heard that complement from a few other people and I'm just like, what? Are you sure. No, no, no, no. You're just you're saying that.

Mesha [00:16:38] Are you sure? Been there.

Sara [00:16:39] I'm like you're just you're just making me feel good, right? Because there is no way like I've never written. So this can't be that. No.

Caraline [00:16:46] Yeah.

Mesha [00:16:49] Awe.

Sara [00:16:49] I'm starting to accept it now.

Mesha [00:16:52] Yeah.

Caraline [00:16:52] I feel like it's so much easier though, when it's something you're passionate about and that you feel comfortable writing about that it just comes out more naturally.

Sara [00:17:00] One hundred percent. Yeah. Because it's it's more feeling.

Mesha [00:17:03] Exactly.

Sara [00:17:05] That's going into it than just you writing about something that you read about or know about from someone else. It's it's literally your life story.

Mesha [00:17:16] Exactly.

Caraline [00:17:17] I was going to ask you, how do you come up with ideas about things to write about? Because here's a weird parallel that I found when I was doing a blog also, which I quickly gave up on. But like so when we talk about, like early on in our journey is that there is nothing really to pull from, like as far as like a young person living the Fibromyalgia. Now, I feel like if I go to post something, I'm like, oh, I swear, I just saw someone post the same thing. And I think it might be tricky because we do all at one point feel like similar about a specific topic. But is it hard for you to come up with things to write about?

Sara [00:17:56] I think that so. So at one point in time, my blogs kind of turn into work where it was. It was one of those where it's like, I have to post this many times a week and I have to have a blog post go up at least once a month.

Caraline [00:18:13] Yeah.

Sara [00:18:13] When it was that way, it was kind of hard. But over the last couple of years, like, you know, I've been I've been like that, but I've also been in situations where I'm like, you know what? I'm only going to write when I feel like it, when it's coming from the heart.

Mesha [00:18:33] Exactly, yeah.

Caraline [00:18:33] Yeah.

Sara [00:18:33] And and, you know, there are times where I'll focus on one thing, times where I'll focus on another thing. So I think the first two years I was actually writing a lot of blog posts. I actually haven't written a single blog post this year.

Caraline [00:18:46] Oh, wow. But that's good, though, that, you know, to pace yourself like that.

Mesha [00:18:50] Yeah.

Sara [00:18:50] Yeah because there are other things that I'm concentrating on this year that I wasn't doing last year, so. Considering I have fatigue, I only have a limited amount of capacity, I cannot do everything that I have to do so great. I I wrote a lot of blog posts the first two years, but now I'm mainly trying to work on my Instagram and my following or have more conversations like these speaking engagements. So for for that obviously that a lot of time also goes into that. So I haven't been posting regularly on Instagram either. So I think that it really depends how you look at your blog. If you look at it like work, it'll turn into work and it'll become annoying and it'll become hard for you to come up with things all the time. But when you don't think of it like that, I have a I have an entire document on my phone where any time I get a random thought or even a random sentence that I really like inspires me, I'll quickly write it down. So then that way ideas sort of come together and then I can post about it whenever I feel like it.

Caraline [00:20:11] That's awesome.

Mesha [00:20:11] There you go. Work on your own time.

Caraline [00:20:14] Yeah.

Mesha [00:20:15] I love that.

Caraline [00:20:15] Yeah, for sure. All right. Now for the Question of the Day. How's Canada?

Sara [00:20:23] How's, Canada? Canada is awesome. We have to free health care. We have Trudeau.

Mesha [00:20:30] I'll see you soon!

Caraline [00:20:33] Here we come!

Sara [00:20:34] We have. We have the beautiful Horseshoe Falls because, you know, the Canadian Canadian Niagara Falls is way prettier than the American side.

Caraline [00:20:45] Yep.

Mesha [00:20:45] Of course it is.

Sara [00:20:46] Let's be real. We have maple syrup. We have Justin Bieber.

Caraline [00:20:51] Wowee. That's amazing.

Sara [00:21:00] Anyway.

Caraline [00:21:02] That's just like my go to phrase, though, is like every time something wrong with my health care system here, I'm just like, that's it. I'm going to Canada.

Mesha [00:21:10] Yep. Same.

Sara [00:21:12] No. But keeping all those things aside, there are definitely a lot of flaws within the Canadian health care system. One of the biggest things that I can point out is the fact that I think that our entire health care system is based on treating acute problems or illnesses.

Caraline [00:21:35] Not long-term stuff.

Sara [00:21:37] Anything and everything that is visible. Oh, there's a fracture. Let's take care of it. There's blood. Let's go take care of it.

Caraline [00:21:48] Yeah.

Sara [00:21:48] But when it comes to chronic or invisible illnesses, there isn't much help out there, because if you think about it, most chronic illnesses require there is no just you can't just take one medicine. There is no take one thing and I'll fix the entire condition. In order for you to treat your symptoms, you have to do 10 different things.

Caraline [00:22:14] Yeah.

Sara [00:22:15] And that includes includes things like physiotherapy, massage, chiropractor, acupuncture, going to a naturopath, maybe going to the gym. None of these things are obviously covered by OHIP.

Caraline [00:22:28] Yeah.

Sara [00:22:29] So which is the Ontario Health Insurance Plan in case you guys were wondering.

Mesha [00:22:34] OK.

Sara [00:22:36] And so in the grand scheme of things, if you have a chronic illness, it's very fucking expensive. I don't know if I can swear.

Caraline [00:22:48] Oh heck yeah.

Sara [00:22:49] Okay. But to have a chronic illness.

Caraline [00:22:52] Yeah.

Mesha [00:22:52] Yeah.

Sara [00:22:53] And we mostly rely on Eastern medicine not Western medicine and OHIP only covers Western medicine. So for someone like me, to be honest, it's not that helpful. Sure, I do go see my doctor more often, so that is definitely covered and that is a blessing. If I need blood tests done, if I need to get like a vitamin B12 shot, I go every month to get

my B12 shot. It helps with my fatigue. So I don't have to pay for that but to control my actual symptoms. I have to pay out of my pocket.

Caraline [00:23:36] Yeah.

Mesha [00:23:36] Oh, wow. Okay.

Sara [00:23:37] Well, you know, and so it it makes a difference for sure.

Caraline [00:23:44] Yeah.

Sara [00:23:44] I would say having free health care, but I, I also don't think it makes that huge of a difference if you have a chronic illness because. You're mostly relying on. Eastern medicine, and that's all coming out of your pocket.

Mesha [00:24:00] Got that, wow.

Caraline [00:24:01] That's very eye-opening and it's like same. Because, I was just researching I don't remember how it came up, but like functional medicine. And I was like, OK, what's the difference between functional medicine and regular medicine? And basically the difference being that like regular Western medicine face like focuses on pathology, like test results and functional medicine focuses on finding the root cause of disease. And I was like, oh, no wonder no one over here can help me because everything comes back normal, and I was like, no wonder they're not going to cover anything over here because they think we're Booboo Joujou. Like it's like it's like hippy dippy medicine. And I'm like, but I was like, why are they separate?

Mesha [00:24:44] Exactly.

Caraline [00:24:45] I said, why can there not be a doctor who knows both and treats the patient whether or not they're one or the other?

Sara [00:24:53] Yeah like.

Mesha [00:24:53] And is affordable.

Caraline [00:24:54] Yes.

Sara [00:24:56] Sorry. I've actually gone into the E.R. at times where I couldn't sit for a second. I'm in so much pain and I like wait nine hours only to hear, oh yeah, you should just take some painkillers and maybe go see a chiropractor, one physiotherapist. Someone should be able to help you. I'm not sure who can help you.

Caraline [00:25:20] Neither are we.

Mesha [00:25:23] That is why I'm here.

Sara [00:25:25] Yeah. And so also.

Mesha [00:25:27] That's horrible.

Sara [00:25:28] OK. And also it also really depends on the doctor that you end up seeing because you could go see a doctor that is very knowledgeable about Fibro. So they'll actually go do those extra tests and go take that those extra steps that are required for you. However, for other most other doctors, they're not going to do that. Like, for example, my previous family practitioner didn't give me any medicine for my Fibromyalgia at all. She just gave me painkillers.

Caraline [00:26:05] Wow.

Sara [00:26:05] I had to go to a specialist that I got sent to because we actually sued our insurance company. We had to sue our insurance company because the guy that hit me on my back didn't even have a license.

Caraline [00:26:25] Oh, my gosh.

Sara [00:26:26] So we couldn't see anyone else. So we ended up suing them. And so in order for them to prove that there's nothing wrong with me and I look absolutely fine visibly and I'm just making stuff up. Yeah, they sent me to a specialist and. That specialist wrote like 30 page review, and he is the one who initially said, oh, yeah, there are a lot of things out there for Fibromyalgia you can take these injections. There are these few medications that you can take. And so it was maybe like. Three or four years after my diagnosis that I went back to my family practitioner and I was like, oh, that specialist that I went to, he said there's something else that I could take for a better quality of life. Right now, I have no quality of life.

Caraline [00:27:17] Yeah.

Mesha [00:27:17] Right.

Sara [00:27:18] And so she had no idea. She kept me on painkillers. And so had I not gone to that doctor, I would have I probably still would have been taking painkillers, you know. So, yeah, it also it also really depends on your family doctor, I would say.

Caraline [00:27:37] Yeah. So do you know of any like pain management centers are like pain clinics in Canada because those are like far and few between here. Like, that's why we are talking about the Centers of Excellence. We're trying to create collaborative care for Fibromyalgia patients because instead of having to hop, hop, hop around to all these doctors, it's it's a center where you can literally one stop, shop it and figure out what you need and then they'll connect you with who you need in your hometown, which is hallelujah. Is that not what everybody is looking for?

Sara [00:28:15] That actually sounds pretty fucking awesome. And I haven't been to anything of that sort, to be honest.

Caraline [00:28:21] Yeah.

Sara [00:28:22] I have had to do that on my own.

Caraline [00:28:24] Right.

Sara [00:28:25] About three years ago, I was I had a back injury and I was bedridden for about eight months. And it was just a regular inflammation that was supposed to be fixed in a couple of weeks. But it didn't take a couple of weeks that I'm sitting here going, what the hell is going on? And so I ended up seeing ten different doctors at a time, seeing a specialist, a pain specialist, a sleep specialist, you name it. I literally seeing ten different doctors familiar. But I felt like I felt like that was my full time job.

Caraline [00:29:04] Yeah.

Sara [00:29:05] What's going on with me right now? But I was doing it all on my own. So there is nothing of the sort that you're mentioning, mentioning unless it's something that exists out there. But I'm just unaware of it, which I could very well be the case.

Caraline [00:29:21] Yeah.

Sara [00:29:22] But yeah, not that I know of.

Caraline [00:29:24] Because I can think of like if for example, if you have like cystic fibrosis, you usually have a team of doctors because there's a lot of things that go into having cystic fibrosis. It's not just purely the lungs. It affects a lot of other parts of your body and you have comorbidities as well. And so usually they have a care team. And I was like, why is that not conditions like syndrome disease wide? Like why is that it's not possible. Why do doctors not want to communicate with each other like it's not that hard, just be like, hey, I did this. What do you think you can do this for this person? And it's bananas. I mean, recently I mentioned this in the last episode. I've been trying to just focus on the autonomic nervous system portion of Fibromyalgia because, I mean, Skye and I have both been diagnosed with POTS, which is an autonomic nervous system disorder. And it's all having to do with the brain not making the right decisions, which that to Fibromyalgia is. It doesn't know how to properly function because it thinks it's not safe. And so, to my knowledge, doing research, really the only people who are treating Dysautonomia are cardiologist's because a lot of the times the stuff that goes with Dysautonomia happens to be cardi, cardiological? A word? Sure, I just made it up, but I'm like, OK, but that's not where the root of the problem is. I said, this is what's causing the the cardiology the heart problem.

Mesha [00:31:03] Cardiac.

Sara [00:31:05] Cardiac! That's right!

Caraline [00:31:06] Yes!. So I'm like.

Mesha [00:31:08] It's okay, it took us all a second.

Caraline [00:31:10] Why is no one looking at the brain? And so that's why when Skye told us she was going to a Dysautonomia clinic, I'm like, I so hope they're going to look into the full body and not just your heart, because every time I look for a Dysautonomia doctor, it's always a cardiologist. And I was like, I got heart problems, but those are under control. I take medicine that actually works for that. It's like everything else that needs to get it together. So it's it's like I was like at a crossroads where I'm like, I don't even know where to go anymore because it's like you start at a rheumatologist or your primary care doctor, and they suggest you to go to some other person, whether it be like a physical therapist or

whatever it may be, but along the way, if that's just not working, it's like, what are my other options? And it's like like you said, we're doing all the work I've done all the research I've ever done myself, because no one else is going to do it for me. And so, you know what? If there was someone to pay to do it for me, what I consider it. Sure, because there is so much work, we're already fatigued enough. And I'd hardly have the brain fog and like lack of mental capacity to focus most of the time. So it's like, where do you think I have the extra spoons for this? Because I don't.

Mesha [00:32:34] Nope.

Sara [00:32:34] Completely agree. See, the thing is something similar to what you're mentioning. Your for us. We go back and forth between like our family physician and the specialist that you go to, for example, let's see. Let's say I want to go see a psychiatrist and, you know, he'll send notes back to my family doctor. And then I sit down with my family doctor and I'll be like, well, that was useless. That didn't help in any way. So then she'll be like, OK, how about you go do something else? OK, how about you go to a tech specialist and then I'll go to a tech specialist and work with the tech specialists and then come back to my family doctor again.

Caraline [00:33:17] Yeah.

Sara [00:33:18] Once that case is closed, though, you know.

Caraline [00:33:21] Yeah.

Sara [00:33:23] But there is. What you're mentioning would be really freaking cool and amazing because it's like someone is actually like a team. I've actually worked out a long term care facility and I've noticed that a lot of times the team comes together and they'll talk about like a resident and he needs this. And then someone else, another nurse will say no, but he needs that. Like there are a bunch of people sitting together talking about that one resident, how they can help him or her the best way possible. That would be really fucking cool.

Caraline [00:34:04] Yeah!

Sara [00:34:04] If that was possible.

Caraline [00:34:05] Right.

Sara [00:34:07] Let's make it happen, girls. I don't know how.

Caraline [00:34:10] We're working out. We got a lot of money saved up. We saved our pretty little pennies to make that happen. I mean, that's why it's one of the the organization's biggest goals, because it's truly what this health care system is lacking is just putting the pieces together. And it's it's really too much work for the patient and not and I am very involved. Obviously, I have to be it's my like it's my Fibromyalgia, but I'm very involved. Like, I want to know all the details. I want to know I read the after notes that they put up on my MyChart and I'm like, I got to know everything. And I take notes and I do more research about it. And so it's like I want to be involved. I just don't want to be involved in like the you figuring out what is best for me. I don't know. I did not go to medical school. That's your job.

Sara [00:35:04] But see, I think med school in med school, they only literally will either read a paragraph about Fibromyalgia or a sentence.

Caraline [00:35:12] Yeah, we had a doctor confirm that. Thanks Dr. Lenz.

Sara [00:35:15] Yeah. Yeah. So so. So you can't really blame them for it either because they literally just read. There's so many things out there and so they're not getting into the details. So I guess I guess what it comes down to is the fact that the medical system does not think that these illnesses are important enough, debilitating enough to be looked into to that extent.

Caraline [00:35:43] Yeah.

Sara [00:35:44] That that all the research or all the knowledge out there that is provided to people usually is about things that are life-threatening. So, you know, let's say it's cancer or heart attack or things of that sort, there aren't a lot of people doing research or looking into illnesses that affect us on a daily basis, but also they're invisible. So people think that we're just living normal lives and we're just making excuses and we're just tired. And we love naps and.

Caraline [00:36:30] No, and I love that you used the word life threatening because it's definitely has two different meanings, like whether it's life threatening, because you have a virus or you have like a serious something going on, your bloods or whatever, like you think of it in another term, whether it's life threatening to me, because due to the fact that I can't figure out who cares about me in the medical system or how I can ever get better, it's life threatening to me because my mental health deteriorates every time a doctor tells me I don't know what to do for you and then think about how life-threatening that is.

Mesha [00:37:10] Speak it, oh.

Caraline [00:37:11] Yeah.

Mesha [00:37:11] That hit. Oh my god.

Sara [00:37:12] The way it screws with your mental health.

Caraline [00:37:17] Yes.

Sara [00:37:17] Oh boy.

Caraline [00:37:19] Right. You're like I care, don't you care?

Sara [00:37:23] I am literally living it right now. I, I haven't been doing well.

Caraline [00:37:28] Right.

Sara [00:37:28] Recently. And so I think yesterday. Yeah. I came with my parents to Niagara Falls yesterday and I'm someone who absolutely loves traveling. I cannot emphasize that enough.

Caraline [00:37:43] Yeah.

Sara [00:37:44] I love traveling. I love going out. I love checking out new places. I love going to cafes. You know, these are things that keep me happy and I kid you not. I was being forced to come here. I was crying because I didn't want to come here. And that's when I realized that this is not me and this is my illness at this point that has completely taken over my mind, my emotions, my body, because the real me would be excited to come to Niagara Falls. The real me would do anything to get away for a day. Are you sitting here crying about that? I'm going somewhere, you know, so. So, yeah, it really fucks with you mentally.

Caraline [00:38:31] Yeah, for sure. For sure. I mean, it sucks the life out of you or even like your personality changes, because recently I was saying that I'm kind of rediscovering my actual personality because I think for a long time I've multiplied my personality by ten to cope with the fact that the underlying Fibromyalgia and every other illness that I have is so shitty that I'm just like magnified my personality so that it's like you would never know I was sick, even though you would literally never know because I look fine. So I'm like, oh, now I'm like, I doing that and I'm like that. I'm annoying myself. Like, who is that? So now I'm just like rediscovering who I even am because it definitely hasn't been for a while.

Sara [00:39:28] I absolutely love that you said that because it that's exactly how I feel. It's basically bursts of bubbles, if you think about it.

Caraline [00:39:39] Yeah.

Sara [00:39:39] So when we're meeting people, we're at our highest and we're so lively and, you know, just so excited about life and things and updating people. And then when we come back home, just that interaction was so tiring then, you know, you're just in bed and it doesn't have to be from walking. It could literally just be from talking. You could get really tired.

Caraline [00:40:07] Yeah.

Sara [00:40:07] And so now when when I'm not like, excited all the time, whenever I see my friends and I'm just normal, they'll always ask what's wrong. Oh you know, and and so I think I'm starting to also. Except being more vulnerable around them, and if I feel a certain way, that's just how I feel.

Caraline [00:40:35] Yeah.

Sara [00:40:36] I'm starting to. Feel comfortable in being vulnerable, even like to my Instagram family in front of them last week, I think it was the first time I ever posted like a short clip of me crying or cares. And I had so many people message me. And the craziest part was. Then most of those people that messaged me. Appreciated the fact that I posted that they said it was raw, it was authentic, it was. But the most shocked were friends and family that know me because they've always just seen me, you know, when everything's all right.

Caraline [00:41:23] Yeah.

Mesha [00:41:23] Yeah.

Sara [00:41:23] And I'm putting on that face where my my illness does not phase me out. It doesn't change that part of my life. And and so it's the first time they're getting to see that and they're surprised. But my reply to that was that was just a normal day was the first time I reported it. And that's the only difference.

Caraline [00:41:46] Yeah.

Sara [00:41:47] That's literally the only difference. It's a regular day. I have days like this all the time, yet I just never felt comfortable. And I thought people would think I'm being dramatic and whatever. So I would never post something like that before. But I just did. And, you know, they were the most shocked and everyone was reaching out to my siblings asking them if I was OK. And everyone was like, yeah, she's fine. But yeah, you know, strangers were not phased out by it at all because these strangers are actually people that are on the same boat as me. That have similar experiences as me.

Caraline [00:42:29] We're like, we get it.

Sara [00:42:31] Exactly. Exactly.

Caraline [00:42:34] Yeah. Well, Sara, it has been so wonderful talking to you. I feel like we love adding to our Fibro Friends family. And.

Mesha [00:42:44] Sure do.

Caraline [00:42:44] I have mentioned before we end our episodes talking about a Tender Point and a Visible Victory. So your Tender Point would be something from this week that has not been super great and then a Visible Victory would be something during the week that was very great. So do you have one or both?

Sara [00:43:03] I love that first because, you know, right before signing off, you're making someone think of something really tough that they did, but then also something good that came out of it.

Caraline [00:43:20] Yes.

Sara [00:43:21] Not necessarily from the tough thing. Just something positive. Sort of like gratitude.

Caraline [00:43:26] Yes. Yes.

Mesha [00:43:26] Yeah.

Sara [00:43:27] So thank you I actually really appreciate that.

Caraline [00:43:29] Yes absolutely we love it, too.

Mesha [00:43:30] Yes.

Sara [00:43:31] And so I guess my tender moment would be. So this entire week or for the past two weeks, I've been having panic attacks every day, sometimes even four times a day.

Caraline [00:43:45] Yeah.

Sara [00:43:45] I've been getting nausea, so it's been really hard to eat. And I've been throwing up anything that I eat. I haven't been able to sleep because of the panic attacks and more pain because of the panic attacks. So there's just so much going on. And then on Sunday night, I'm literally just sitting and I turn around and I turned around in the wrong way or Lord knows what happened. And I pulled something in my shoulder blade and I had that piercing kind of pain.

Caraline [00:44:21] Yeah.

Sara [00:44:23] I literally was screaming from pain. And at that point, I was laying in bed and thinking to myself that I should just stay right here and not move because I feel like even the slightest influence is just causing one thing or another, because it just feels like anything and everything that could go wrong with my body is what's happening at the moment.

Caraline [00:44:50] Yeah.

Sara [00:44:50] It you know, so that was like that final like I guess Cherry. Well I wouldn't really say cherry on the cake because.

Caraline [00:45:00] I think cherries are gross so I would consider it a cherry.

Sara [00:45:01] OK, so it was the tipping point, I guess.

Caraline [00:45:06] The straw that broke the camel's back.

Sara [00:45:09] Yeah. And so yeah that was my tender moment for sure. And my victory moment I guess would be. Having this conversation with you guys.

Caraline [00:45:23] Awe, yay!

Mesha [00:45:23] Awe!

Sara [00:45:24] Yeah, because, you know, like we we had to reschedule once because of how I've been feeling. And I'm sitting here in my hotel room in Niagara Falls, and I had a good day.

Caraline [00:45:40] Yeah.

Sara [00:45:41] Even even though, you know, I think in the longest time today was the first day that so far I haven't had a panic attack and I've so far had a good day. Knock on wood.

Caraline [00:45:53] Yeah.

Sara [00:45:53] I was kind of scared that having this conversation might bring up certain memories that could trigger with me again.

Caraline [00:46:05] Yeah.

Sara [00:46:06] But I feel OK.

Mesha [00:46:07] Valid.

Caraline [00:46:08] Yay!

Sara [00:46:10] So, you know, thank you for having me.

Caraline [00:46:15] You're welcome!

Sara [00:46:15] And asking me all these lovely questions.

Caraline [00:46:16] Absolutely. We don't get too hard-hitting on this podcast.

Mesha [00:46:19] Nah.

Caraline [00:46:21] Mesha. What about you?

Mesha [00:46:23] Well, Tender Point yeah it's been an extended Tender Point as well.

Caraline [00:46:30] Darn it.

Mesha [00:46:33] I know right, not again! Very, very overwhelmed, again, dealing with a lot of. Anxiety about the future, because my health insurance is going to be gone at the end of September. Yeah, so freaking out about that, honestly, like literally freaking out got crying, all that, all that stuff.

Caraline [00:46:58] No one prepares you for that, so.

Sara [00:47:01] Can I just say, even though one thing that has really helped me or one thing that I've constantly been telling myself the past couple of days, I'm going through a shitty phase. I'm just going to accept it instead of trying to fight it or constantly thinking, oh, this is shitty, phase one is going to end. All this is when is this going to end? That kind of prolongs it.

Mesha [00:47:31] Oh yeah.

Sara [00:47:32] If you just accept it, OK, it's a shitty phase. I'm just going to let it go on. However long it takes. It came and soon it's here and soon it's going to leave. Sort of like, you know, thinking of the clouds in the sky. I guess.

Mesha [00:47:48] Clouds yeah, you know, they're going to pass.

Sara [00:47:51] Yeah. So like, if you close your eyes, you know, the thought comes, you think about it and then you just let it go.

Caraline [00:47:58] Right.

Mesha [00:47:58] Yeah.

Sara [00:47:59] I don't know if that was helpful.

Sara [00:48:02] Thank you, no, I got you. I got you. I'm gonna try it. It's yeah. It seems like like it feels like there is no end in sight.

Sara [00:48:12] Yeah.

Mesha [00:48:13] I want to have some hope.

Caraline [00:48:14] Yeah.

Mesha [00:48:15] But it's not coming.

Sara [00:48:16] Sending you all the positive vibes.

Mesha [00:48:23] Thank you. Yeah. So figuring that out hopefully I can get Medicaid until I can. Find a. Job that I, for one, like to get at, I mean, has benefits.

Caraline [00:48:37] Yeah.

Mesha [00:48:38] So.

Sara [00:48:39] We're all looking for that.

Mesha [00:48:41] Yeah, we're doing.

Sara [00:48:42] We're looking for that.

Mesha [00:48:43] Yeah, child. Oh my gosh. It's hard out here.

Sara [00:48:49] I feel you.

Mesha [00:48:50] Yeah. I think a positive. Oh, I'm blanking, but I guess, you know, today I got some rest, I went before we hopped on, I just decided to lay down for, like, I don't know if it was supposed to be a nap, but I probably didn't let me sleep because my body doesn't like me, sometimes.

Caraline [00:49:12] Yeah, rude. It's very rude.

Mesha [00:49:14] But yeah. But just just resting, though, just laying there for that time in the school's relaxing and all this stuff that definitely did did me so good.

Caraline [00:49:27] Yay, Awesome!

Sara [00:49:29] Yay!

Mesha [00:49:29] Caraline, what about you?

Caraline [00:49:30] Well, like I said, mine kind of intertwined. So I had been doing that research about functional medicine and had found a functional neurology clinic near me. And I was like, ooh, awesome. Looked into them. They do brain retraining because if anyone doesn't know, your brain is always pliable and building synapses every day.

Mesha [00:49:50] Yeah.

Caraline [00:49:50] So it is possible to make your brain think differently as Fibro likes to make it think wrong. And.

Sara [00:49:58] I did neuroscience in university actually.

Caraline [00:50:01] Yes. You know what I'm talking about.

Mesha [00:50:03] There you go.

Caraline [00:50:04] So I was like so excited. And so I was like, OK, I'm going to call. So I call. And of course my first question is what's covered by insurance? And she's like, well, nothing. And the first appointment costs six hundred and fifty dollars. And I said, Oh, thank you. Have a nice day. Goodbye.

Mesha [00:50:24] Oh, this is going nowhere.

Caraline [00:50:25] So just to get in the door before I would even know if they could help me was six hundred and fifty dollars. So I was like, no thank you. So it was like a it's like the two sides of a coin, like you find something and you're like, yay, I hope I maybe can get better. And then I was like, never mind. So back to the drawing board on that one. But I'm staying hopeful because I do still have the possibility of of going to a pain clinic that is around here that has a neurologist. They have a pain psychologist an acupuncturist is like lots of different things in one building. So that's a positive. So I'm a stay hopeful that that works out. And I know that mostly is covered by insurance, so might as well get my money's worth because wow are they robbing me blind. But, but yeah. So that's pretty much what I have. But again Sara, thank you so much for joining us.

Mesha [00:51:22] Yes, thank you.

Caraline [00:51:22] We will leave all of your links in the show notes for everybody. Please, please go check her blog and her Instagram out just give her a follow because she's an amazing person to be following.

Sara [00:51:33] Thank you so much. It was so lovely to e-meet you guys.

Caraline [00:51:38] I know I'm like someday we're going to have a Fibro Friends meetup where every person we've ever interviewed is going to meet in one place.

Sara [00:51:45] That would be awesome.

Mesha [00:51:48] That would be amazing.

Caraline [00:51:48] We'll make it happen. Yeah.

Caraline [00:51:51] As always, make sure you go on Apple Podcasts and rate review and subscribe over there, and you can also leave us a voicemail, following the link in our bio, not bio. Gosh, this is so Instagram. Through the link in our show notes. And you can tell us what's up. Say hey, you can say hi to Sara. We'll pass the note along if you say hi. But thank you so much for joining us for another episode. And we'll see you next time. Goodbye.

Mesha [00:52:17] Bye!

Sara [00:52:17] Sounds good, bye guys!