

FF S4 Ep. 7.mp3

Caraline [00:00:00] Hello, everybody, and welcome back to season four, episode seven of your favorite Fibromyalgia podcast. It's Fibro Friends, woo woo.

Mesha [00:00:11] Ooh, yeah!

Caraline [00:00:11] I'm one of your hosts Caraline, and today I also have with me Skye.

Skye [00:00:16] Hello, I am Skye.

Caraline [00:00:18] And Mesha.

Mesha [00:00:19] Hello.

Caraline [00:00:21] And we're just ready to talk about stuff. I feel like we've been so we go every other week with recording, and I feel like it just amps us up even more.

Skye [00:00:31] It does.

[00:00:31] You know, we're tired as heck. We got a lot of stuff to talk about today because we've had three interviews in a row and we love talking to our guests. But we're ready to let it fly. So buckle up. But before we do that, hee-hee remember, if you listened to the last episode, I was like, Oh the Caterpillar Walk is coming up. Links in description. Sorry, they weren't there, but they will be now. So by the time you're listening to this episode, make sure you check the description for all the links to register for all the Caterpillar Walks. OK, there's three technically four events for the Caterpillar one this year, so there is the Caterpillar Walk that is in New York City. There is a Caterpillar Run that is in New Jersey. There is a Caterpillar Walk happening in Puerto Rico, but there's also a virtual Caterpillar Walk, which you can do for the entire month of May. They can do it in your own hometown. Grab your friends, family, go on a walk, pick a beautiful day and do it for Fibromyalgia. All that info for real this time will be in the description. I'm not kidding. You have to go, Look, this time I promise it's there. But anyways, we are kind of. Let's just let this be like a stream of consciousness podcast today because we do have like a semi topic that we want to talk about. But like I said, we just want to speak our minds because we've all been having some rough times. But basically, the overview of what we want to talk about today is labels and identity in Fibromyalgia, but also like adding a smidgen in of how to deal with disappointment because it happens a lot when you have chronic illness, unfortunately. So let's get into it. How is life? Because it's poeey on this end.

Mesha [00:02:44] True, true.

Skye [00:02:45] Yeah, man. I think like this whole episode is just our Tender Points lately.

Caraline [00:02:51] True.

Skye [00:02:53] We're all in three different states, and we're all just separately going through it.

Caraline [00:02:58] Uh huh.

Skye [00:02:59] But going through it together, we know we're going through it together, and I'm glad that I don't have to explain it just because I feel like I've been. I just also feel like I've been so absent from my friends lives lately, and I hate that feeling.

Caraline [00:03:12] Yeah.

Skye [00:03:13] Because I've just been so consumed with my own life and I don't want to be that person that is just absolutely consumed with work. But when you haven't been able to work and for years because of your chronic illness and then you finally can work again.

Caraline [00:03:31] Mm hmm.

Skye [00:03:32] I am having trouble figuring out a life work balance and like setting healthy boundaries for myself and my body. And that's been like my biggest struggle lately because I come home and I'm exhausted. Like I got home at 4:30 and I just woke up at like six twenty eight to jump on this podcast like I. It's just a different level of exhaustion, mainly mental exhaustion, and my brain just feels like mush. And I've noticed recently at work I've been making mistakes that I usually wouldn't make. And I can fix them. But you know, it's a good feeling when I show up to work at 7:15 in the morning and I've already been able to piss my boss off.

Caraline [00:04:25] Yeah, that's tough.

Skye [00:04:25] I fixed it. I bought him an apology coffee, but then it's just like a crappy feeling.

Mesha [00:04:33] Feeling, yeah.

Caraline [00:04:33] Yeah.

Mesha [00:04:34] Doesn't go away, yeah.

Skye [00:04:36] Yeah, right.

Caraline [00:04:38] Like under-performing. I feel that so much right now, even though I bet if you asked people that I work with, they would tell you the opposite. But like, I feel like. So it's spring break right now. So we have a bunch of kids and I plan the entire spring break curriculum, which I think I thought was good at the time. But then it's just like so dependent on like the kids you have and like what kind of day they're having. And they the plans I made weren't really like that flexible for those like variables. And so like we've done projects that have been like a complete failure and like, I had a kid tell me that like I ruined his whole day. Like, it does not help me to have brutally honest six, seven eight year olds telling me that, like my lesson, plans are crap. So that's been hard. And I texted Skye yesterday and we were having like a moment where we were like, my brain is literally like mashed potatoes, as we said. And I was like, yeah, at work I had someone asked me about something that I do know what they're talking about, but at the moment I was like, I literally can't comprehend what you're saying right now. Like, you need, maybe need a back up because brain is going to come out of my ears. And then I went through the McDonald's drive thru twice because I forgot the one thing I went for.

Mesha [00:06:05] Oh, the pain I feel.

Skye [00:06:08] That's never good.

Mesha [00:06:09] Oh.

Skye [00:06:10] And it's it's a feeling of under poor underperforming because of your illness.

Caraline [00:06:16] Yeah.

Skye [00:06:16] You know, deep down inside that if you didn't have this illness or if if you could sleep more, if you were able to sleep more, if you're able to eat better because you're just having a crappy day and all you want to do like you don't even have energy to cook, you just want to go to the drive McDonald's and.

Caraline [00:06:34] Yep.

Skye [00:06:35] There's nothing wrong with that. But at the same time, like I'll be the first person to admit that maybe I shouldn't be eating McDonald's at all. I eat it anyway. Like, I had a friend last night and I had it for lunch today. And is it good for me, no, but at least it's something in my body. I'd rather eat that than starve.

Mesha [00:06:56] Exactly.

Caraline [00:06:56] And when your life is so complicated, you look for small conveniences like that, like something that is just easy.

Mesha [00:07:04] Right, something that won't take more energy out of you.

Caraline [00:07:06] Yeah.

Skye [00:07:07] Right. Because cooking sometimes is just it's impossible. I just do.

Mesha [00:07:13] Yeah.

Skye [00:07:13] And I cannot do it. And. Hunter and recently was like Skye. We had to stop ordering their DoorDash because we spend \$2000 a month on DoorDash.

Mesha [00:07:26] Oh.

Caraline [00:07:27] Wow.

Skye [00:07:28] One. OK? Granted, he does order it at work almost every single day because he does mortgages. So it just was the time of year where it was so busy he couldn't even leave the office for lunch. But he needs to eat something. So he was just ordering it and then he'd come home from work.

Caraline [00:07:45] Yeah.

Skye [00:07:45] I'm a I'm a sack of potatoes on the couch I'm like, let's just order something.

Caraline [00:07:51] Yeah.

Mesha [00:07:51] Yeah.

Caraline [00:07:52] It's the same thing with like packing lunch for work. That takes just as much energy. I have to put a whole meal together for the next day. I don't want to do that.

Skye [00:08:00] And it's like I'd rather pay money for the convenience of not having to do that. But then when you look at your bank statement, you're like, Wow, is it worth it?

Caraline [00:08:11] What have I done?

Skye [00:08:13] Like, Oh yeah, like it's kinda worth it, but.

Mesha [00:08:16] Right.

Skye [00:08:18] It's. And this is this is an issue that only people with chronic illness will understand, like, I need to eat good food, but I don't have the energy to make it. So then I eat crap food, but then I don't have energy to do anything else because I just ate crap food. But I'm too tired. Do I starve? Do I feed myself crap? Like, what?

Caraline [00:08:35] A vicious cycle.

Mesha [00:08:37] You understand it? Yes.

Skye [00:08:39] But this is this is absolutely in my top three struggles.

Caraline [00:08:46] Food.

Skye [00:08:46] Is food.

Caraline [00:08:47] Yeah.

Skye [00:08:48] One hundred percent. And like, I'm only feeding myself. I can't imagine if I had a freaking kid right now and had to feed a kid, because if you don't feed that kid, obviously it dies, like.

Caraline [00:08:57] Yes. Is that your dinner Mesha?

Skye [00:08:58] Right.

Mesha [00:09:00] Yeah, I'm sorry, this box of doughnuts is my dinner tonight because.

Caraline [00:09:04] I was gonna say, Meesh, you have three jobs. When do you find time to eat?

Mesha [00:09:07] Hoo!

Skye [00:09:08] Right! And I'm over here compaining and Mesha is like working a million jobs, and you deserve those box of donuts like I am so.

Caraline [00:09:16] Amen!

Skye [00:09:17] I totally support you eating a box of donuts for dinner.

Mesha [00:09:20] Thank you.

Skye [00:09:20] As your as your friend, should I be like, Oh, is that a good idea? Maybe?

Caraline [00:09:25] A friend and chronic illness, go for it.

Mesha [00:09:28] Go for it.

Skye [00:09:28] Like, I'm also not going to snitch on you to Michelle Obama that you're not eating like your sectioned plate off.

Caraline [00:09:35] Yep.

Mesha [00:09:36] God, thank you. Listen. Oh yeah, it's been. What's the word I'm looking for? It's kind of more intense than a whirlpool, but not as.

Caraline [00:09:50] A tsunami?

Mesha [00:09:51] Not as intense as a tsunami either.

Skye [00:09:53] It's somewhere in the middle.

Caraline [00:09:55] Someone hitting you in the face with a kick board.

Mesha [00:09:58] Sure, let's go with that.

Skye [00:09:58] At the water park.

Mesha [00:10:00] Yeah, let's go with that. But while also getting sunburned.

Caraline [00:10:04] Yeah.

Mesha [00:10:05] And then dropping your ice cream on the ground?

Caraline [00:10:07] No, actually. I just said to someone the other day, I think that's funny when kids do that.

Mesha [00:10:14] Yeah, you ever seen.

Caraline [00:10:15] Yeah I'm that kind of person I think it's funny.

Mesha [00:10:17] In Lilo and Stich, you remember the guy he always like his ice cream that would always fall off. As soon as he gets it, he's like.

Caraline [00:10:25] Wahh.

Mesha [00:10:27] That's funny.

Skye [00:10:27] That's when you know you're cursed.

Mesha [00:10:27] Right? Yeah. Like it's been it's been so chaotic lately. I don't even know how I'm functioning. Like the same thing. Like you said Skye about mental exhaustion. I had a mental Fibro flare a couple of years ago, last for like a solid two weeks, and I didn't realize it at the time because my cognition is generally baseline four on the general end. And four is on the low end.

Mesha [00:11:00] Right.

Mesha [00:11:01] What I'm saying, it's generally a four, but last couple weeks it was like a one point eight. And that's not good.

Caraline [00:11:10] No comprende.

Mesha [00:11:10] No comprende, so and what made it worse, is that I had so many different types of trainings that I had to, you know, understand how to listen, have to sit and concentrate, sit in front of a computer for hours at a time. And the whole time I would just be like shifting because my back is hurting like, I don't know how to. I'm going to put my legs up, but I can't, because then my hip will start hurting, so I put them back down. It's like switching back and forth and thinking like, OK, concentrate, focus, focus, focus, focus and like, I'm hungry. I need food I don't have time to cook. I need to lay down right now. Should I eat first or sleep first, like stuff like that, like I've had to. I've spent so many hours staring at a calendar is a couple of weeks.

Caraline [00:11:59] I bet, yeah.

Mesha [00:12:01] Like, yeah, like looking at, OK, this is the time I have this first meeting. This is the next one. If I heat something up, I'll be able to eat much faster and then let my stomach settle for a half hour so I can go lay down at least a half hour.

Caraline [00:12:18] And you have to plan for a possible diarrhea.

Mesha [00:12:21] Exactly, I don't.

Caraline [00:12:22] Like, who else has to do that?

Mesha [00:12:25] It's like we, we we have to think about, OK, knowing.

Caraline [00:12:30] Or like nausea or anything, yeah.

Mesha [00:12:32] It's I want to sleep. I don't want to like bleh, you know? And then like and I've talked to a couple of people about this. I've been dealing with the worst, worst bout of imposter syndrome. Because like the one job that I got hard for which I want to stick with, I'm happy about. It's it's a whole different type of thing and it's just a lot. And even though my supervisor is amazing, though, she's like, I'm here for you every step of the way. I still get nervous about everything that seems like I have to do.

Caraline [00:13:11] Yeah.

Mesha [00:13:12] And then another job, it's like kind of conflicting with my already in place schedule for my first job that I've had since September.

Caraline [00:13:22] Yeah.

Mesha [00:13:22] And then the fourth job hasn't started yet. So I'm like in the back of my head worrying about what's happening with that. Should I just say, Hey, no thanks, guys.

Caraline [00:13:34] Nevermind.

Mesha [00:13:35] But I kinda don't want to do that because I want to. I want to try it out and see how it goes, because it could really help me with. With my future, you know?

Caraline [00:13:47] Yeah.

Mesha [00:13:48] And just like I have a lot to deal with and on top of that, somehow, somehow I convinced myself that I should I should register for class for May for the summer semester, not the fall, the summer.

Caraline [00:14:08] Yeah.

Mesha [00:14:09] Because when I took this entire semester off from grad school, because last year I was just. A cesspool of poop. It was so bad, so I took this semester off with the intention to try to go back in the fall. But I don't know, I just kept thinking about like, I'm going to look at the schedule for the summer, like what's going to happen? And then I looked at it and I convinced myself enough to register for like. Seven classes.

Caraline [00:14:44] Oh, my goodness. Seven classes, four jobs, Mesha, you are going to explode.

Mesha [00:14:50] I will. The best part is.

Caraline [00:14:51] Of all your limbs are going to be ripped off. We're not going to have anything left of you.

Mesha [00:14:56] Except for glasses, except for the glasses.

Skye [00:14:59] The glasses, for real.

Skye [00:15:02] I don't know if there's enough time in the day.

Caraline [00:15:05] Yeah.

Mesha [00:15:06] I know.

Skye [00:15:07] I just do not think that any human ever, even if they didn't have Fibro, I do not think that they would have enough time in the day.

Caraline [00:15:18] Mm-hmm.

Skye [00:15:19] I am saying that because I care about you.

Mesha [00:15:21] I know.

Skye [00:15:22] And I don't want you to implode.

Mesha [00:15:25] I don't either because.

Skye [00:15:27] Seven classes?

Caraline [00:15:29] Now I'm trying to, like, go back in my brain and be like, how many credits the semester did I used to take when I was in college? I don't remember.

Skye [00:15:38] I took 12.

Caraline [00:15:38] So, yeah, I think I did, too, yeah.

Skye [00:15:40] And that was hard. That was rough.

Caraline [00:15:41] And maybe I pushed it to like 14 because I took like a weird, like two?

Skye [00:15:46] Yeah, or it was like a lab or something.

Caraline [00:15:49] Yeah, yeah. Yeah.

Mesha [00:15:51] Got it.

Skye [00:15:52] Well.

Caraline [00:15:53] We were overwhelmed for a second. I feel a little more confident in the process now.

Mesha [00:15:58] Yeah.

Skye [00:16:00] If your classes are like that and you only had to show up on a weekend.

Mesha [00:16:04] Yeah.

Skye [00:16:04] I might try and get my master's so that I can.

Mesha [00:16:08] Hey!

Caraline [00:16:08] Yeah, what, let's all do this!

Skye [00:16:09] I can defer my student loan payments if I take one class a semester. So I'm like.

Mesha [00:16:14] Let's go, let's go. Let's do it.

Skye [00:16:18] So that's like another bought of stress that's coming up, and it's like.

Caraline [00:16:21] Let me go scream into a pillow.

Skye [00:16:22] Right? Society told me I had to go to school in order to get a job, and now I have a job that I didn't need to go to school for and now you want me to pay for it, and.

Caraline [00:16:31] Oh, no.

Skye [00:16:33] In hopes that like one day, maybe I will use my degree.

Caraline [00:16:37] Mm hmm.

Mesha [00:16:37] Yeah.

Skye [00:16:39] But what's the point?

Caraline [00:16:41] What was your what was your major? Because I know your minor what to do major in?

Skye [00:16:44] Integrated studies, which is sociology. And in my mind, it was race and ethnic studies, so I can really do like H.R. or know a lot of places now care about having diversity boards. So that's a good thing.

Mesha [00:17:01] Yeah. Awesome, how did I not know that?

Skye [00:17:02] Yeah, I mean, for the minor, my minor recent ethnic studies, my professor and he was a professor that like if he said he wanted to meet with you.

Mesha [00:17:14] Yeah.

Skye [00:17:15] You like, you know, wanted to poop your pants because he's kind of scary, but it's also kind of an honor that you wanted to talk to you. And I met with him. He was like, Hey. So I noticed that you're two classes away from being able to get this minor anyway, he was like, you already took the coursework. So why don't you just add these two classes or change to these two classes and then you get to put a minor on your degree? And I was like, All right.

Caraline [00:17:41] I'm down.

Skye [00:17:42] I mean I already did all the work. So yeah, why not?

Mesha [00:17:46] Right.

Caraline [00:17:47] That's so good of him to like, bring that up because like most advisors would just be like, missed the mark on that, like.

Skye [00:17:53] Because it was a brand new minor. And so he was looking through people who had already taken most of the classes or the sociology degree, and he was like, Well, you can just add this because your two classes away from it.

Caraline [00:18:05] Yeah.

Skye [00:18:06] So I had to take like I took Women in the Holocaust and Genocide Studies, and that was like the ethnic part of my. And obviously, I mean, is race, race and ethnic. But that was the other part of my, um, my minor.

Mesha [00:18:23] Right.

Skye [00:18:24] So.

Mesha [00:18:25] Feel that.

Skye [00:18:25] I liked it. I wish I was using my degree.

Mesha [00:18:29] Yeah.

Skye [00:18:30] But I know it made me more well-rounded. A more well-rounded and.

Mesha [00:18:35] Right.

Caraline [00:18:35] Yeah. And sometimes you use your degrees in like secret ways you don't know and you're like, Oh, I remember I learned this like in this, right, so and so class, and I'm like, because I have two different associate's degrees, very different from each other in communications and media, arts and hospitality and event management. And now I have a bachelors in early childhood education because sometimes you don't figure out what you wanna do 'till later in life.

Mesha [00:19:03] I know right? I just had a conversation about that with somebody.

Caraline [00:19:06] Yeah, but I use different stuff. I use my communications and media arts to edit this flippin podcast, like.

Skye [00:19:13] Right.

Caraline [00:19:14] Brought to you by SUNY Broome Community College.

Mesha [00:19:19] Exactly.

Caraline [00:19:20] But I mean, just even bringing up the fact that I have three different degrees and very different things is like 100 percent identity problems because that entire time.

Skye [00:19:30] I was gonna say that.

Caraline [00:19:31] Dealing with Fibromyalgia. So I changed from my initial major because I was I was hoping to work in like film and television as production assistant or something. I don't really know what I want to do, but I changed that because, no, this body can't handle that kind of work like I P.A on a show one time and I worked a 12 hour day and I didn't think I was coming back to life after that. So then I went to hospitality and event management. Same thing. If you're an event manager or you're up on your feet for like God knows how long every day.

Mesha [00:20:09] Eighty years.

Caraline [00:20:10] And there's obviously certain roles and positions and jobs that you can find that are more like geared towards people with chronic illness. Oh, I'm going to shout out this Instagram and this company again, Chronically Capable, right? That is their.

Mesha [00:20:25] Love them .

Caraline [00:20:27] They specifically have job listings for people with chronic illness. I will link them in the description for real I'll put it there and write myself a note right now.

Mesha [00:20:35] But actually, I went on there. I kind of forgot about them. I'm sorry. But then I was like Googling. I was like stress googling jobs for people with chronic illness like panicking.

Skye [00:20:46] I was stress googling.

Mesha [00:20:46] About finding more work I was stressing so hard. This is when my January, February and I was looking for work for money and I came across Chronically Capable and I was like ooh. But I think I did. I applied to a job from there, but did not.

Caraline [00:21:02] Right.

Mesha [00:21:02] Accept it.

Skye [00:21:04] Boo.

Caraline [00:21:04] But it was still available.

Mesha [00:21:05] It's still available.

Caraline [00:21:07] It was still an opportunity for someone who had a chronic illness. It's like a lot of work from home jobs and obviously things that like they know they're working with companies who are willing to work with people who have chronic illnesses. I think that's really good to have someone who is taken out a lot of the groundwork for being able to get a job and have a career that you like and want to do. So shout out to them Chronically Capable. Thank you for doing the Lord's work.

Mesha [00:21:37] Yes!

Skye [00:21:38] Yeah, and it's great because, you know. Then you have a job where. You have to convince your boss. You like you don't have to convince them about the accommodations.

Caraline [00:21:50] Yeah.

Skye [00:21:50] Because they're already like, they're already aware of the accommodations.

Caraline [00:21:52] We got this.

Skye [00:21:54] Whereas like now I have to convince my boss why I need brain breaks, you know?

Skye [00:22:00] Right.

Caraline [00:22:01] Yeah, for sure.

Skye [00:22:01] And then I'm like, I told him the other day I said, I have. I have to sit here and stare at a wall for five minutes.

Caraline [00:22:10] Yeah, you have to like reset.

Skye [00:22:12] Yeah, if I. If I consume.

Mesha [00:22:15] Refresh brain.

Skye [00:22:15] Any more knowledge about anything, if I consume more words in my brain or read one more thing, I think I'm going to have a mental breakdown. And that's the point I'm getting and I just.

Caraline [00:22:29] Yeah.

Skye [00:22:31] I'm glad I'm not alone. But it just bothers me because I'm trying so hard.

Mesha [00:22:36] Yeah.

Skye [00:22:37] But.

Caraline [00:22:37] Yeah.

Skye [00:22:37] Like because I'm trying so hard, I'm stressing myself out because.

Mesha [00:22:42] Right.

Skye [00:22:43] Because I'm stressing myself out I'm making myself worse and it's just.

Mesha [00:22:45] Right.

Skye [00:22:45] All it's a cycle of poo.

Mesha [00:22:48] It is a cycle. Like, listen, she was I about to say, Oh, two things one, I'm gonna send y'all, I don't know if we should link it at all here, OK, but I'm going to send you both a video. I literally just watched today because I recently got an iPad like two weeks ago, because since I had all these jobs coming up in school, I remember sitting through one of the trainings I had and I was like.

Mesha [00:23:22] I wish I had like a digital notebook, so I can just have everything in one place because my note taking is so, basura, I have pages of pieces of paper scattered everywhere, like random notes, and I don't know what anything is because. Oh yeah, and then I take notes.

Caraline [00:23:41] What does pickle toes mean? What? Why did I write this?

Mesha [00:23:44] Exactly?

Skye [00:23:45] Pickle toes?

Mesha [00:23:48] And it's just been I don't have a system, so I said to myself I need something that I can record all this in. And I was like. iPad? Money? I don't have money, but I want an iPad, so I'll finance it, make myself more poor. So. So I got I got an iPad mini to do that. But I'm just, you know, I'm not used to writing on the screen, right? So I've been the last week or so I've been looking on YouTube, watching how people use that and how they're being productive. So I came across a video today, not iPad related, but it's really

like beautifully shot mini movie of this man explaining how he should be. He trained himself to just work a little bit better. And I was just watching it and awe like, Wow, first of all, you need to be getting paid a lot of money for production. And secondly, I just want to I just want to thank him because I got so inspired by him that I was watching. I was in bed watching, is trying to get myself to go to sleep. But I still need to hear something but I thought it was gonna be boring. Soon as that video was done, I got up and went to the room and rearranged like half of the living room. So I could have like an actual workspace because I normally I just sit on the couch or sit at the island, the kitchen table island, but we had a table in the corner. But yeah, so all that said, I think there's in that video he mentions something saying that leisure is fuel for us. Well, leisure is fuel for anyone, but I think for us, especially having scheduled time to kind of. Set everything aside and literally stare at a wall will help help in in the slightest of ways like setting. Actually having timers go off for us to like just stop what we're doing. Walking around, drink water, lay on the floor, face down, scream and do some cartwheels.

Caraline [00:26:02] You gotta tea kettle.

Mesha [00:26:03] Tea kettle. Run the shower and just stick your head on it or something.

Caraline [00:26:10] Oh, that's my favorite thing to do.

Mesha [00:26:12] Oh, of course, comfortable.

Skye [00:26:14] Showers, showers in my safe space.

Mesha [00:26:17] Oh yes.

Skye [00:26:18] I'm like, I'm in physical pain. Hot water. My brain hurts the sound of the shower.

Caraline [00:26:24] Hot water.

Mesha [00:26:25] Burn it out. Burn it not burn it out.

Skye [00:26:26] Burn my skin.

Caraline [00:26:29] I always make it way too hot.

Skye [00:26:31] Yeah.

Caraline [00:26:31] I want new skin.

Skye [00:26:34] And in your body can't control heat. So then you're going to pass out.

Caraline [00:26:39] Yep.

Mesha [00:26:39] Yeah.

Caraline [00:26:40] But that's why there's a floor in the shower.

Skye [00:26:41] Exactly.

Caraline [00:26:41] Lay down!

Mesha [00:26:44] Lay down.

Caraline [00:26:44] Don't drown.

Mesha [00:26:46] In the fetal position and rock yourself.

Caraline [00:26:50] That feels good, though, too.

Mesha [00:26:52] It does. It's good for the back actually, I was told.

Skye [00:26:54] Oh, so good.

Caraline [00:26:56] But also, I did want to bring up something like the biggest thing that I've been struggling with and I would have talked about in a Tender Point anyways. The past, like, it's been really bad this past month, but like the last couple of months, I've been really struggling with like self-esteem and like self-love and like just not liking myself at all, whether that be like outer beauty, inner beauty or whatever. That's all caca del Toro to me right now. So basically, I've struggled with like being backed up and like all that, the most I ever have in my life.

Mesha [00:27:38] Yeah.

Caraline [00:27:39] And the most with bloating, like, I've never struggled with bloating so much of my life. So to have a new thing be piled on, what I already have to deal with is like awful. So basically, the part of that I struggle with is that like, I'll be bloated all day and I'll have this like huge old like poo baby bump. And then I go to sleep and it all disappears and I wake up and I'm thinner again. And I'm chunky looking during the day and I'm like, I cannot deal with the back and forth. Like, I'm one way during the day and then the next day I'm like, it's like a whole different. I have to start over again, like, it's so hard on my mental health. And so because of that, I was like, You know what? I'm going to tone my hair because I as a blonde hate. When my hair is yellow, it's just like a pet peeve I have. And so I have toned my hair before. And but my roots had grown out, which were darker. And so I was like asking the people at Sally's who? I'm sorry. But if you work at a beauty supply store, you should really know what you're talking about and not just be talking out your butt.

Skye [00:28:52] They have to have their cosmetology. From my understanding to work at Sally's, you have to have your cosmetology license.

Caraline [00:28:57] Well, these ladies slipped around the red tape because.

Skye [00:29:01] Oh.

Caraline [00:29:01] I don't like them. They're not my friends. So they were like, Yeah, just do the whole thing, and then it'll tone it all up. No, it turned my roots orange. So then I panicked and box dyed it like a champagne brown or champagne blonde?

Mesha [00:29:16] Oh.

Caraline [00:29:17] Still orange roots.

Caraline [00:29:19] So then I was like, OK, I need to make a hair appointment and someone's going to fix it. So my people at my salon where like, booked up until, like next year was gone. So I was like, OK, I'll go to this other place I've been to before, where it's like individual like hair stylists in their own thing, but like in the big building. So I picked this girl. I look at her pictures of what she's done. It looks great. I see the girl that she took before me. Her hair looks amazing. So when I go in, I booked it for like a full, like a all over hair color because I don't even know what I. I had to ask her what she thinks I should do to my hair.

Mesha [00:29:56] Right.

Caraline [00:29:57] And so she's like, coming up with this game plan, whatever but she's like, it's going to like, cut into another appointment that I have. She's like do you mind if like while yours is like? Not curing whatever.

Skye [00:30:09] Processing?

Caraline [00:30:10] Processing. Yeah, like I'm a sausage. Or cheese. Do you mind if while you're processing I work on this other lady because she just had like a simple like root touch up to do. I was like, Sure, I've done that before, whatever. So then she does all the lady the lady leaves. She's pulling out mine. She's like, Oh my gosh, your roots are too dark. They were like chocolate brown and the bottom was like ash blond. So she like takes like dye remover and light lightens it a little bit, but there's still way too dark. And I told her that I wanted like my roots to blend in to the bottom because I know it's just going to grow out again. And she said she's going to do a root melt. No, I know the difference between that and a highlight like she did highlights. So it was like. Six hours in. I'm at this salon. I want to die because my body hurts so bad sitting in this chair all day. And so by the second time she's done, I don't even care what my hair looks like.

Skye [00:31:11] Yeah.

Caraline [00:31:12] I do care but I don't. I was like it looks great. Bye have a great day. I go home and cry in my car. The haircut was fine. I got it. I like cut a bunch of dead ends off whatever. That's easy to do, but she definitely was feeling rushed. She said she hadn't eaten all day. I was like, OK, so that doesn't really put me in a great position. And so by the time she was done, she was exhausted, too. So I was like, Well, I'm not going to make you do it a third time. I don't want to tell you the amount of money I paid to have my hair look the way it does right now, which is not great. It's higher than 100. You might look at it and go. It looks fine which a lot of people, didn't. I was like, Please stop talking. I know you're trying to make me feel better, but stop. And so I just like I had a meltdown the first time when I messed up and I was like, I'm so mad at myself because all I wanted to do was tone my hair, so I felt better about something on my body. And so I had a meltdown about this because I was like, This is awful, and I paid a lot of money for it now. So now I'm like in the hole and I still don't feel good about myself.

Skye [00:32:20] You're like not only does this suck, but I also already hated the way I look. And now.

Caraline [00:32:27] Yeah.

Skye [00:32:27] I don't have money!

Caraline [00:32:29] Right!

Skye [00:32:30] Now. I can't put gas in my car because I was sacrificing gas to feel better about myself. And now I don't have either.

Caraline [00:32:37] Right?

Mesha [00:32:38] The worst combination.

Caraline [00:32:38] So now I'm like, I was like, OK, I'll just try to use purple shampoo and like, tone the yellow out and it's still not working. So I'm contemplating going back to my original salon and again, the anxiety I have going back to my original salon being now. And being like, I did my hair. I went somewhere else, please help me and I'm just like, Please, I just wanted. I want to write a note and be like, don't say anything.

Mesha [00:33:02] Yeah.

Caraline [00:33:03] Just help me.

Mesha [00:33:03] Right? Right. Help. Please, somebody.

Caraline [00:33:05] But it's been so hard because it's like, like, Skye said. Like, I already didn't feel confident in myself and now I'm like, OK, the thing is like, I am a woman who tends to be attached to her hair and like what it looks like and it's attached to my head, so I can't change it like an outfit.

Mesha [00:33:24] Hmm.

Caraline [00:33:25] So that's been a real big struggle. But I'm wearing a lot of headbands, a lot of hats, and it's tough because. I know that, like I try to be strong. A lot of the time, but I was just like, This is awful and I'm like, is this also maybe because I started taking Lyrica? Like, Is this a side effect of that? Because if it is, I don't like this because I've not been this close to dipping into a bad depression since, like the like time that I went through a horrible breakup in like twenty fourteen. So it's scary to like, dip back into it again, and I don't even want to get near that. So then I'm like, OK, I really need to go to therapy because like, I need someone to help me. That's not a family or friends.

Mesha [00:34:17] Yeah.

Caraline [00:34:18] God, it's so frickin hard to find a therapist.

Skye [00:34:21] It's so hard.

Mesha [00:34:23] It's a journey.

Caraline [00:34:24] Works after hours.

Mesha [00:34:26] A whole job.

Caraline [00:34:27] For telehealth is a person that I want to talk to and feel comfortable talking to. And so there's a silver lining here. Don't worry. So yesterday I was on hold my

entire break with this company, who is covered under my insurance to try to find someone who works after six p.m. because I'm I'm a full time teacher. I don't. I can't, I can't. And I will not take a break in the middle of the day to do therapy, because how do you think that's going to work for me or anyone else I have to be around?

Skye [00:34:58] Yeah.

Caraline [00:34:58] Because I will probably cry.

Mesha [00:35:00] Right? Of course.

Caraline [00:35:01] So I was like, so peeved about that. So then I'm driving home and I get this call from a number I don't know it to look like a local number, but I was like, I don't really answer calls that I don't know. But for some reason I was like, I'm going to answer this call, and it happens to be someone who works for Aetna, my insurance company. And it was this wonderful woman named Thai shout out to Thai.

Mesha [00:35:23] Hey!

Skye [00:35:23] What's up Thai?!

Caraline [00:35:25] And she's like, Hi, I'm I'm from Aetna. I just want to tell you about this program we have with Aetna called Able To where it's an eight week program, where we hook you up with a therapist and a health coach who can help you manage your health care and help you with life. And I was like, I'm about to crash my car because I'm gonna cry.

Mesha [00:35:46] Awe.

Caraline [00:35:47] Like, the universe is so weird is like, I almost didn't answer the call and like, she was exactly what I needed. And for that to happen, I was just like, Thank you like that was wonderful. And I told her I was like, You don't know what I've been through. And I was telling her about all this stuff with Fibro because she's like, Tell me about your health and stuff, and she was just like.

Skye [00:36:13] And you're like, do you really know?

Caraline [00:36:14] That's what I'm saying. So like, she was so genuinely like, interested in what I had to say about Fibromyalgia and like how I manage it. And I was like, You deserve a raise. All the awards, you're just like a good, genuine, kind person. And I'm glad I'm not talking to like a robot right now.

Mesha [00:36:32] Yeah.

Caraline [00:36:32] That's absolutely not what I needed. And so I signed up for the program and have my first appointment with my therapist next Thursday at seven p.m.

Mesha [00:36:41] YAY!

Caraline [00:36:41] How hard was that?

Skye [00:36:43] Yes!

Mesha [00:36:43] I'm so happy for you.

Caraline [00:36:44] So, yeah, that was going to be my Visible Victory because. Yeah, the world works in mysterious ways.

Mesha [00:36:51] It sure does.

Caraline [00:36:51] And it was absolutely what I needed. Still hate my hair, but hopefully we'll fix that soon. Not me, someone else is gonna fix it.

Mesha [00:36:55] Yes, let's do it. Able To is amazing. I had that before.

Caraline [00:37:00] Really? Good. OK.

Mesha [00:37:02] I did. It was wonderful.

Skye [00:37:03] So I guess after an episode of hearing us complain, I'm like, I'm glad that you have a good, a good outlook or something.

Caraline [00:37:13] Yeah, yeah. And I'm like, I'm not going to be so naive to think that they just like randomly called me and they didn't just see that I was like searching for a psychiatrist on their website.

Mesha [00:37:24] Right, right.

Caraline [00:37:27] But it came at the perfect time, and I couldn't have asked for like a nicer person to talk to and like, get me situated. And I googled the person that is supposed to my therapist, and I think she's like a professor. And like, she looks really nice, and I'm pretty sure it's this person. So I'm very excited. But I did want to quickly talk about the labels part of having Fibromyalgia because I was talking to the girls and I was like, I saw something on Instagram. I'm so sorry to the person whose Instagram. This was because I cannot remember who it was. Sorry Fibro fog. But they were talking about the different labels for people with chronic illness. So. Some examples would be like a warrior or spooning or a zebra with a zebra is more specific to rare diseases. But they all. They all have their own like reasoning why people with chronic illness are called this, and they were arguing that they didn't really love those labels and not to get too much into like what they said because I I want to really talk about it and hear it, you guys have to say. But I mean, just a general blanket statement about all of them. I have no problem with any of them because I mean, I always call someone by their first name, but.

Mesha [00:38:46] Exactly!

Caraline [00:38:47] What they want to be called, but.

Mesha [00:38:49] End of story.

Caraline [00:38:50] When we were and really, I feel like in the community, it's how we refer to each other.

Mesha [00:38:55] Yeah.

Caraline [00:38:55] Like, I've never had some random person come to me and be like, Oh, you're a spoonie and they have no idea what they're talking about, like,.

Mesha [00:39:02] Right.

Skye [00:39:02] Right.

Caraline [00:39:03] You can have someone come up into the street and call you in a hole and they just do it because they want to.

Mesha [00:39:07] That's just an insult.

Caraline [00:39:08] No one's just like throwing things around, not knowing, what spoonie or a warrior or a zebra, because I think it's a more chronic illness community thing.

Mesha [00:39:17] Yeah. Only people who know, know.

Caraline [00:39:17] Yeah, yeah. So I have no issue calling someone a Fibro warrior. Because when I think of a warrior, a 100 percent people with Fibro are warriors. We have to put up with so much crap every day from our mind or body, from outer like things coming into play like we are strong. He's right, but I will call you a warrior. Unless you don't want me to.

Mesha [00:39:44] Right.

Caraline [00:39:44] But I'll feel it inside and keep the secret to you.

Skye [00:39:51] Whatever people want to be called, I totally, you know, like if someone doesn't like being called spoonie, I'm not going to call them that, but I do. The reason I like it is because like, I see someone mention it somewhere, or if I go on someone's Instagram profile and I see that they have that in their bio, I know I can follow them and I know there somebody that understands. So I think it's a good term to be able to understand, to be able to identify somebody else that understands you. The only labels I don't do are the ones that are just generally rooted in able-isms, like if someone tries differently abled. That.

Caraline [00:40:28] Yes, I was gonna talk about that.

Mesha [00:40:28] I hate it so much.

Skye [00:40:30] That one triggers me that one pisses me off because I'm like, You don't know what you're saying.

Mesha [00:40:37] Exactly.

Skye [00:40:39] For me, it's just a term that was made by able bodied people to feel better about themselves, like oh I'm doing a good deed I'm like, I'm also telling them that they're able, but like they're still not like they're different.

Caraline [00:40:52] In their own special way.

Skye [00:40:53] Right.

Mesha [00:40:54] Someone I know said distinctions before and I was like, eww.

Skye [00:40:59] Excuse me, what?

Mesha [00:41:00] Distinction. It's like people that people with different distinctions like sir?

Skye [00:41:06] That is so weird. What?! I don't like that.

Caraline [00:41:12] You're trying to make us sound fancy, but also we can't do ish like.

Skye [00:41:17] My own distinctions like, I don't have an honorary PHD bro, okay?

Caraline [00:41:20] I'm not a sir or lady.

Skye [00:41:23] I just have a back shaped like an s, and I can't frickin walk like this isn't There's nothing distinguished about it. Distinctive, but that's annoying. Eww.

Mesha [00:41:33] So annoying.

Skye [00:41:36] I hope that guy stubs his toe.

Caraline [00:41:37] Again, it's like people making up their own crap, too like feel comfy.

Mesha [00:41:41] Exactly.

Caraline [00:41:42] It's like, you know, spoonies, zebra, warrior that came from us. We're calling ourselves. And we will call our fellow like chronic illness community members. If they would choose to be called that. That's what we call them.

Mesha [00:41:53] Right?

Caraline [00:41:53] And the outsiders didn't need not apply.

Mesha [00:41:56] Exactly. And I don't really like I don't really mind the labels, either. I would say, like, I really don't care, but I would say, I, I same thing like if I see somebody you spoonie or x y z warrior or what have you like any label associated with the community? I'm like, OK.

Caraline [00:42:16] Yeah.

Mesha [00:42:18] I can like the same thing I can reach out I can I confide in you. I just don't I don't like to be called or referred to as a spoonie because I personally never like. I like the description, but I don't like the fact that it's spoons. That's the only thing like.

Caraline [00:42:36] Yeah, it was like a weird situation like that the whole family story came from.

Mesha [00:42:42] Yeah, exactly. And I totally get it because the person had that's what they had at their disposal, I think, and it was a good visual for the time. So that's why I'm like, I'm totally for it. But like, that's I just I just kind of if I have to explain it, I just say, like like batteries. I think about it in terms of a battery, like your battery, you have this much

percentage of a battery every day. The same thing is, OK, you have 12 spoons in a day, but you may have eight when you wake up the next day, things like that. So it's like it's interchangeable. But and it's not like, I shouldn't say, like, I don't like it. It's just I'm indifferent. Like, it doesn't. It's not a big deal. And this is the first and only time we'll ever talk about it, too so.

Caraline [00:43:25] Yeah.

Skye [00:43:25] Yeah.

Caraline [00:43:26] Yeah, like I have a shirt from Spoonie Sister Shop.

Mesha [00:43:30] Yeah.

Caraline [00:43:30] It's a rainbow. It has a little spoon underneath and I'll wear it somewhere and they'll be like what's with the spoon? And I was like, Yeah, it's.

Skye [00:43:36] We like get it.

Mesha [00:43:39] It's my favorite utensil.

Caraline [00:43:39] Yeah, that's what's tricky because it's like, Do I want to take the opportunity? Like if it's someone I don't know, but like, do I have the energy or the time or want to, like, explain the spoon theory to you? I'd be like, That's my favorite utensil, because then, you know, on the inside that you're like, I know what I'm talking about.

Skye [00:44:00] Team spoon not for team. Fork. I will say I have a shirt. My friend got me for my birthday and she is a type one diabetes warrior, so she which she knows I call her warrior and she calls me it, you know, like, we just get it. She is an amazing human and she got me a shirt and it's chronic bad ass on it.

Mesha [00:44:25] Awe.

Caraline [00:44:25] Yeah!

Skye [00:44:25] And if you know me, you know, that's my favorite shirt, and I'm like, That's a label I will take to my grave.

Mesha [00:44:34] Right.

Caraline [00:44:35] Mm-Hmm.

Skye [00:44:35] Because that's what we are. We are.

Caraline [00:44:37] Chronically bad ass chronically cool.

Mesha [00:44:39] Chronically cool.

Skye [00:44:41] Yeah.

Caraline [00:44:41] All the things.

Mesha [00:44:42] Chronically chill. We're chronically ill we're also, you know.

Caraline [00:44:46] I mean, my still my favorite shirt of yours is the back and body hurts.

Mesha [00:44:49] That one is so good.

Caraline [00:44:51] Can't top that one.

Skye [00:44:52] Yeah, I love wearing that to doctor's appointments. All the nurses love it.

Mesha [00:44:56] Listen.

Skye [00:44:56] I need to get a new one because you can tell it's like not. I mean, you can tell it's a shirt off Amazon.

Caraline [00:45:02] They fade so fast.

Skye [00:45:03] So it's fading a little bit.

Mesha [00:45:04] Right.

Skye [00:45:05] But I also wear so much because why wouldn't I wear that?

Caraline [00:45:08] Yeah, it's awesome.

Mesha [00:45:09] It's I like the shirt I wore today, like everyone loved it. I went to the chiropractor it says wildly under what does it say?

Caraline [00:45:17] Wildly unprepared for the day.

Mesha [00:45:20] Wildly unprepared for the day. And it was like me.

Skye [00:45:21] I love those little guys. I follow them on Instagram.

Mesha [00:45:25] Nathan Plye, I think Strange Planet.

Skye [00:45:28] Yeah.

Caraline [00:45:28] He looks like a big spoon was a person like.

Mesha [00:45:31] Oh.

Skye [00:45:33] He does.

Mesha [00:45:34] There we go talk about labels.

Caraline [00:45:36] Unprepared for the day. Doesn't know what's going on.

Mesha [00:45:39] Not at all.

Skye [00:45:39] I mean, hey, labels. Labels also give us the opportunity to have cool shirts.

Mesha [00:45:45] Exactly.

Skye [00:45:45] Look at it that way.

Caraline [00:45:46] Yeah. Yeah.

Mesha [00:45:48] Oh yeah.

Caraline [00:45:49] Cool shirts, cool conversations, if you feel like it.

Mesha [00:45:52] Mm hmm.

Caraline [00:45:52] Sometimes we don't know, but.

Skye [00:45:54] Yeah, I I like wearing my shirt sometimes. Yeah, I like wearing my shirts out sometimes because it does give me the opportunity to talk to people about it. Or to explain to people about it when I'm in the mood, you know, like, sometimes I'm in the mood. I'm like, You know what? I have the energy today, but some days, you know, like, I don't I don't don't have the energy for people. But I think that comes back to you are totally allowed to identify yourself as whatever you want and you can call yourself whatever you want. You know, there are, you know, some disabled people who have chosen to take on terms that were typically very demeaning when they're trying to take the power around words and they use it for themselves. And you know, there was this video I actually watched in sociology class and it's it's very it's very good and I'm going to I'm going to say the word for the sake of it. You know, some guy said, Well, when my wife is with her girlfriends, they call each other bitch like, hey bitch what's up? Stuff like that. They had. They used those terms to each other because they're in the group. He's, like, dropped it and said that, OK, well, that means something different.

Mesha [00:47:08] Right.

Caraline [00:47:08] Yeah.

Mesha [00:47:09] He's going to get smacked.

Skye [00:47:10] Right? If you're in the club, you can say it. That's like a lot of disabled people. We call ourselves certain things or we call our friends certain things. It's OK because we're in the club are like, you can make fun of ourselves. Like, I'll make comments about like how I used to have my seizures now. I passed out. And it's funny because I know.

Caraline [00:47:27] Yes.

Skye [00:47:30] But if someone comes along. And they're making fun of me, convulsing OK, well, I'm throwing hands like, Why are you talking me like that? OK?

Caraline [00:47:35] Right right.

Skye [00:47:35] You can't talk about me like that. You can't talk about my illness like that, but I can. And I think this is something that can relate is like. Chris Rock's joke.

Mesha [00:47:45] I was literally just thinking that.

Skye [00:47:46] This is controversial. I don't agree with either of them. But if Jada, if Jada Smith wanted to call herself G.I. Jane, that's one thing.

Mesha [00:47:59] One thing.

Skye [00:48:00] It's one thing because she's made, you know, she's making light of her own disability and her own illness and her own.

Caraline [00:48:05] If you want to use humor to cope.

Skye [00:48:06] But if other people to make fun of it, it's like.

Mesha [00:48:10] Like chill out.

Caraline [00:48:11] Yeah.

Mesha [00:48:12] Like end that.

Caraline [00:48:12] Right? Right.

Mesha [00:48:15] Yeah.

Caraline [00:48:15] Yeah, that was.

Mesha [00:48:17] A situation.

Caraline [00:48:18] Bananas?

Skye [00:48:19] Yeah, yeah, we can leave it but that was bananas.

Mesha [00:48:22] But that's where we'll leave it there. Yeah.

Caraline [00:48:24] That's was bananas.

Skye [00:48:26] The best example. Like, we're allowed to make fun of ourselves because of our own illnesses.

Caraline [00:48:31] We're in it. We're living it.

Skye [00:48:33] We're in it, we're living in it, and we're trying to claim that power back from society, that society has made a joke out of us. And that's hard. You know? Life can just be more difficult for us. As you know, if you have listened for the past hour, life isn't so fine and dandy out here, and sometimes we have some hard days.

Mesha [00:48:57] It aint fine out in these streets.

Skye [00:48:59] Right? It is it tough.

Caraline [00:49:00] But that's why I think this podcast is so important because we are here, to be honest about it. Like.

Skye [00:49:06] Yeah.

Mesha [00:49:06] Yes.

Caraline [00:49:07] And I think we've held true to that in every episode. Like, we are very honest about how life is the Fibromyalgia and if there's one thing I would like people who do not have Fibromyalgia or chronic illness to get out of this podcast is to just hear what people go through and whether you're hearing it from us, hear it from the person you do know with Fibromyalgia, if they're not talking about it, let them vent. Like.

Skye [00:49:32] Ask them how they're doing.

Caraline [00:49:35] This is our chance to vent. Yeah, yeah, and it's just so important for people to hear these stories. And as much as this sounded like a like a bitch fest, like I feel better, like I feel a little bit better now.

Mesha [00:49:51] Good.

Skye [00:49:52] I do feel better.

Caraline [00:49:53] I hope that if you're having a tough time, like all of us are that you have someone to reach out to and if you do not. We always joke about how there's cobwebs in our emails, but please reach out to us because as much as we have our own stuff like I'm always willing to be there for a friend and you know, and it we'll be honest, you know, if it is too much, hey, maybe there's three of us. We're a team. Maybe it's not too much for someone else. We'll pass it on to another person on Team Fibro Friends.

Mesha [00:50:23] I will absolutely listen.

Caraline [00:50:23] We are here for you. So fibrofriendspod@fibro.org you can leave an email. You can also leave us a voicemail, which is private. If you just want to talk out loud, because sometimes that's how we are in our text messages. It's easier to talk out loud.

Mesha [00:50:40] Yeah.

Caraline [00:50:42] Yeah. Just reach out to us in any way possible if you're needing a friend, Fibro or not. We're here for you.

Mesha [00:50:49] Yes, we are here for you.

Caraline [00:50:51] We're your friends. Yeah. And I always forget to mention like we share Instagrams in the description as well. Give us a follow like send us like a direct message on there that sounded very old lady of me. Send us a DM.

Mesha [00:51:05] Direct message.

Skye [00:51:07] Slide into my DM's.

Mesha [00:51:08] Yes.

Caraline [00:51:10] Oh yeah. Just just reach out. Know that we're here.

Skye [00:51:14] I love when Fibro Friends slides into my DM's.

Caraline [00:51:16] Yeah. But anyways, as always, check the descriptions for anything we have may have mentioned in this episode. And you know it will be there because I promised you I would do what I will. I promise. OK. Anyways, we love you and we'll see you soon. Goodbye.

Mesha [00:51:36] Goodbye.

Skye [00:51:37] Bye.