

FF S4 Ep. 4.mp3

Caraline [00:00:00] Hello, everybody, and welcome back to another episode of your Friendly Neighborhood Spider-Man. Just kidding. It's Fibro Friends.

Skye [00:00:10] Yay!

Caraline [00:00:10] Two out of three today because I'm one of your hosts Caraline. I almost said Miss Caraline and the amount of times I really do that is awful. But preschool teacher life hashtag. And I have my friend Skye with me, say Hello Skye.

Skye [00:00:27] Hello, I'm Skye.

Caraline [00:00:29] You could be Miss Skye, too, if you want.

Skye [00:00:31] I could be Miss Skye it's very true.

Caraline [00:00:34] So today we have a guest with us and going to jump right to it because don't we always unless we have groundhog things to talk about, like last episode, we just get right to the good stuff. She is a writer and a creator and one of our favorite people on Instagram that Skye and I share all the time.

Skye [00:00:53] Yes.

Caraline [00:00:53] It's our new friend Kay. What's up Kay?

Kay [00:00:57] Thanks. That was high praise. I really appreciate that.

Caraline [00:01:00] We are.

Skye [00:01:00] So true.

Caraline [00:01:00] Very happy to have you on. I am happy to be here. I was telling Kay before we got on, when we sat down Mesha, Skye and I to talk about this season and who we wanted to have on, I was like, Do you guys follow this Instagram Chronically Candid Memes and Skye was like, Yes, I love it, and I was like, I'm going to see if she wants to come on. And here we are. I'm so happy.

Skye [00:01:25] I love it.

Kay [00:01:27] I'm again, super happy. You asked me to be here. I'm happy that you guys enjoy my. My weird little memes that I make.

Caraline [00:01:36] It's so good and we'll get into how how great it is and why it's so great. But usually we start by asking our guests, I almost forgot this. We ask our guests the same question, and it is what is the weirdest piece of advice that you've gotten about your chronic illness slash illnesses from a either medical professional or random lady on the bus?

Kay [00:02:05] God, I have so many.

Caraline [00:02:07] I think I changed, I changed the lady's location every time I think.

Kay [00:02:11] I mean.

Skye [00:02:12] It's perfect.

Kay [00:02:12] Random ladies everywhere.

Caraline [00:02:15] Yeah.

Kay [00:02:17] Oh, God, I mean, there's so many, I think my favorite it wasn't necessarily Well, no, I was going to say it wasn't necessarily advice, but it was. This was a neurologist. He teaches at a med school, which is concerning, but he told me that I was too young and pretty to be sick.

Caraline [00:02:43] Eww.

Skye [00:02:43] Uh-huh.

Kay [00:02:43] Yeah, which to begin with was gross. He said that I would continue to improve after I spent 15 minutes detailing how much I had declined within the last six months or whatever. And then he told me to go home and stop seeing doctors, I was wasting everybody's time, including my own.

Caraline [00:03:07] Eww.

Kay [00:03:07] And I was like.

Skye [00:03:11] No!

Kay [00:03:11] And my mom goes, my mom turns to me and goes, we'll find someone else, and he says no, and he starts like, interjects like, no, you really shouldn't. And she's like, No, we're going to find somebody else. We left. And yeah, I was I was floored. I mean, it was still I just I love that the the advice was like, I don't see anybody else. Because it feels like it was like I'm trying to protect himself because he's like this going on here. I'm not able to.

Caraline [00:03:41] Yeah.

Kay [00:03:42] You know, I'm not able to put it, you know, I can't figure out what it is, so I'm just going to tell her. Oh, and he he threw in there that this is the exact advice that he would give to his daughter if she were in my situation.

Caraline [00:03:54] Ah, I hate when people do that.

Kay [00:03:56] I was like, God, I would hate to be your kid, like.

Skye [00:03:59] Wow, he sounds like a terrible father to you.

Kay [00:04:02] Yeah.

Skye [00:04:04] Not only are you a bad doctor, you just admitted, you're a terrible father.

Kay [00:04:06] Yeah I was like, OK, so we've established that you're a misogynist because I'm too young and pretty to be sick. And you don't wanna do.

Caraline [00:04:16] Chronic illness don't care how pretty you are.

Kay [00:04:18] He didn't do, he didn't do a single test, he didn't. This was like a consultation with him. He comes in, I tell him my story and he's just like, OK, got it. I'm just going to like, completely cut this child down. Here we go. You're too young. You too pretty. We're going to continue to get better, which is such gaslighting, because.

Caraline [00:04:38] Right.

Kay [00:04:40] He's like, I'm sorry, what part of our conversation made you believe that I was on an upward trajectory? Don't see anybody else because they'll probably contradict what I'm telling you. And yeah, don't don't see anybody. Just. Go home.

Caraline [00:04:57] Live your life.

Kay [00:04:58] Live your life, and I'm like, no.

Skye [00:05:02] Well, I hope he stubs its toe.

Kay [00:05:05] I hope so too. I hope he deals with constipation every day.

Skye [00:05:09] And like when people use the whole like, Oh, you're too pretty to be sick, it's like they think you should be happy about that.

Caraline [00:05:16] Yeah.

Kay [00:05:16] Like, it's a compliment. And I'm like, I'm sorry. Like I. What does that have to do with anything? What is that?

Caraline [00:05:28] It's like outer beauty, inner beauty thing oh my insides are ugly.

Kay [00:05:33] Yes! Like do you tell all your other patients that their ugly, like. What gives you the right to decide who is pretty enough? Is this something that you learned in med school? Is this something that you're teaching your med students.

Caraline [00:05:45] What rating scale are you using?

Kay [00:05:48] Yes! Exactly.

Skye [00:05:50] If they're pretty they're less likely to be sick.

Caraline [00:05:50] Yes.

Kay [00:05:50] Upon entering the room, we rate the patient on a scale of one to 10 hotness. And then based on that, we make our diagnosis and we create a treatment plan. If you're above a nine.

Caraline [00:06:00] It's like those little smiley.

Kay [00:06:00] You're out of luck!

Caraline [00:06:00] Face rating things, but it's like hot it's like flames.

Kay [00:06:00] Exactly, they circle on a little, on a little scale on their paperwork, put it in the chart.

Skye [00:06:00] Damn. I guess if you're ugly you really are screwed.

Kay [00:06:00] Like oh this lady's a two so she must be the real deal.

Caraline [00:06:00] She's a wreck, oh no!

Kay [00:06:00] She must be real sick.

Caraline [00:06:00] Yeah like a sort of similar thing happened to me when I was in high school. I don't know if I've told this story on the podcast before but um this was probably like my first instance of like medical gaslighting too now that I can think of it. But, I was a junior in high school and I was getting laryngitis like constantly. Like, I'd lose my voice all the time. And I was in like drama club so I did shows, I was in choir so like singing and talking was like, my life still is. And so we went to my pediatrician at the time, and I mean, I was under 18. So like you still, you could still go to the pediatrician. And I got one of the doctors that was in the practice, and I can still see her nasty, nasty face in my like vision. Like, she just honestly look like a witch like in real life. Like what a Halloween witch would look like that was her aesthetic.

Kay [00:07:25] Which is like an omen.

Caraline [00:07:26] And so like, the way she acted towards me was like, perfect on brand. But my dad took me, and my dad never took me to medical appointments. But my mom was working, so he took me in and I was telling her I was like, I get laryngitis and I feel like I might have acid reflux. That's causing it because I got heartburn and I feel like acid come up in my throat. And you know, when you come in thinking you have something they like to.

Kay [00:07:55] Yeah, they're like, Oh. Red flag.

Caraline [00:07:58] Yeah, yeah, you googled something. And so I was like, I just need to get this taken care of because I do this and that like drama choir. All this stuff and. I was telling her and the next year, my senior year, I was going to be looking into like when I go to college doing the Disney College Program, and I wanted to be a character performer, so I would obviously need to take care of my voice and I want to do like musical theater and stuff like that in college. And she, like straight up, looks me in my little 17 year old face and goes, Well, don't you think you should get a real job? So she basically told me that you

can't be a real job is not being a Disney princess. Tell that to like the like hundreds of people who work in entertainment for Disney.

Kay [00:08:50] Right, tell that to the people.

Caraline [00:08:51] Not hundreds like thousands.

Kay [00:08:52] That are being paid a salary.

Skye [00:08:55] Thousands.

Kay [00:08:56] Yeah.

Caraline [00:08:58] So we just like me and my dad liked locked eyes and we were like, what in the? No.

Skye [00:09:04] It just blows my mind how they think that they should give you their opinion.

Kay [00:09:08] Nobody asked. Like I don't remember asking your opinion.

Skye [00:09:12] Like I didn't that's not what I'm here asking you about. I'm asking about my laryngitis, not my like.

Kay [00:09:18] Career goal.

Caraline [00:09:19] Here's the kicker, so I don't. I think we may have waited to go to a different doctor and then just ended up not doing it because what I remember is that so many years later, I was actually diagnosed with acid reflux and GERD. So thank you. Medical malpractice.

Kay [00:09:37] Yeah, thanks for just pushing that diagnosis and the treatment down down the line for you.

Skye [00:09:49] All because you said you wanted to be a performer.

Kay [00:09:49] I feel like doctors are under the impression that like. If they don't diagnose you. Then you don't you're not affected by the symptoms. It's like the illness doesn't affect you. And so if I don't diagnose it's no skin off my back, it's no problem. But the reality is that they when they do that, they set the timeline back and they make it. So much longer until you can get a diagnosis and then when you do, sometimes irreparable damage has been done. So you've lived years now with this condition. They I don't think they see into the future that far into the future. They're just like, Oh, I don't want to diagnose her with GERD she's 17.

Caraline [00:10:32] And that is exactly what happened. Because when I got diagnosed with GERD and acid reflux, they also said I had the beginnings of Barrett's esophagus is when you're like stomach lining starts growing in your esophagus, which is a pre-cancerous condition, and I'm like.

Kay [00:10:49] Right, which wouldn't have progressed that far.

Caraline [00:10:50] I hate this lady forever. Again, her face, just like, showed up in my mind. The second they said that, I was like, grrr.

Kay [00:10:57] Yeah, I mean, again, they are doctors just think that they're like, Well, if? I don't know if they think that if they diagnose you, then they're responsible for you having the condition.

Caraline [00:11:08] Right.

Kay [00:11:08] And so they're like, like, I'm going to not diagnose because I don't want to deal with it.

Caraline [00:11:12] Yeah.

Kay [00:11:12] Or because I don't want them to have this condition. So I'm just not going to diagnose. But that's the opposite of do no harm when your patient is coming to you. Hey, I have these symptoms. I think I have GERD and you know, and then they're like, Nope, can't be you're. And then, you know, years down the line, you have to pay the price for that and they get to keep living their lives. No problem.

Caraline [00:11:37] Yeah.

Kay [00:11:38] Super fun is when it finally gets a common experience that we all share a lot with so many other people.

Caraline [00:11:43] I was gonna say.

Kay [00:11:47] That's the norm.

Caraline [00:11:47] A good segway. So speaking of shared experience, so obviously your fellow spoonie chronic illness warrior. So if you don't mind sharing a little bit about your story? And how it all began. Go back to the beginning.

Kay [00:12:04] We all love medical malpractice. And as we've dealt with, so I started out with Endometriosis. Had it ever since, I, you know, it runs in my family had it ever since I started getting a period, eventually when I was seven. No I think I was 18, 17 or 18. I went. I was referred to a gynecologist by my family doctor who had tried me on a couple of forms of birth control. We talked to the gynecologist and he which I feel like a gynecologist being a male is a red flag to begin with, bu.

Caraline [00:12:47] Absolutely, I think the same thing. And I know.

Kay [00:12:51] He was like, OK, he fully believe me, it ran in my family. It was, you know, it was. Once I was at the gynecologist, like my family doctor had brushed me off for years because I was too young. And so.

Caraline [00:13:07] Yeah.

Kay [00:13:08] Once I got to see him pretty quickly, he was like, OK, you've tried birth control, it didn't work. You have a family. History we'll get you in for a laparoscopy. So it's a

surgery that they have to do to diagnose Endometriosis we do the surgery, find Endometriosis. I'm not surprised, but I'm like, OK, great. Now we can start treating it and I can get better. He prescribes Lupron injections, which is a. Chemo type drug, it's used to treat males, prostate cancer, that's what it was.

Caraline [00:13:42] Wow.

Kay [00:13:42] Developed for, that's what it was created for. And then somebody tried it on a woman and was like, Oh, this puts women into a false menopause, and we can use that to treat Endometriosis. And. He was like, OK, we'll do six injections over six months, one injection a month, you'll go into a false menopause. The only side effects that you'll have are you know the effects of menopause, but it'll be totally fine and after six months, you should be good. And we won't have to do surgery again for a while because there's no cure for Endometriosis there's no real treatment apart from going in and surgically removing it, which he had done. I'm not sure if he didn't excision or ablation. There's a difference between like burning it or like cutting it out at the root.

Caraline [00:14:35] Yeah.

Kay [00:14:36] I'm pretty sure he did an ablation and. But I know he at least had some ablation.

Caraline [00:14:42] Yeah.

Kay [00:14:43] So I started out on Lupron and we weren't too concerned about, we didn't do any research on it because my aunt had been on it. And as far as we knew, she was fine, so we didn't give it a second thought and we thought he again didn't give us any pamphlets with side effects. No. I was like when I got my first shot, my only health issue was there was the endometriosis. By the third, fourth shot, I was in a wheelchair. I couldn't, couldn't function. I was I was actually a birthday party princess at the time, so.

Caraline [00:15:29] Nice!

Kay [00:15:30] Linking that into yours. I was dressing up as Rapunzel while I was Belle a lot, Anna from Frozen and I'm having to call out of birthday parties to go to the E.R. because I'm experiencing mid back pain, going all the way down through my legs. I'm starting to get weakness because I'm in so much pain. I can't use my legs again. I'm now. I'm like flaking out of work because I'm so he's like, I've never in my 25 years of giving this drug to people seeing this sort of effect, he's like, I think in 25 years I've only had like three people, stop taking it before the amount of time is up.

Caraline [00:16:16] Yeah.

Kay [00:16:16] And so. Basically, he starts, you know, making referrals, I go to a kidney doctor because it started in my mid back, it's not my kidneys. I go to a rheumatologist who I kid you not within three seconds of walking in the room, says Fibromyalgia, which is so odd considering how long it usually.

Caraline [00:16:38] What a throw-away diagnosis.

Kay [00:16:39] Right? And also, a lot of times that's a diagnosis of exclusion, right? Where you kind of have to.

Caraline [00:16:45] Uh-huh.

Kay [00:16:45] Be tested for everything. You have to be tested for other things.

Caraline [00:16:49] Yes.

Kay [00:16:50] And literally, he walks in the room, says Fibromyalgia walks out like it was. It was so fast.

Skye [00:16:56] Nope.

Caraline [00:16:57] Okay bye!

Kay [00:16:59] Right. And I'm like, What just happened? Because I knew I knew what Fibromyalgia was, and I knew that it was like a last kind of a, you know, a last step diagnosis where you have to And I was like, he didn't test me for anything. And then.

Caraline [00:17:16] That's why they don't treat it anymore.

Kay [00:17:18] It was so it was so bizarre to me because I was like, That doesn't make sense. Does that mean that like like, I definitely have it because he diagnosed me so quickly? Or does that mean that he doesn't want to put in the work?

Caraline [00:17:29] Right.

Kay [00:17:29] So I went back to see him. Whenever my follow up appointment was one two months later and my strength had deteriorated quite a bit, so I was getting weakness, which with Fibromyalgia, I mean, you guys know, it can have some weakness. But in terms of telltale signs, it's more. And so I had significant weakness in my legs where I couldn't do you know you have to do like pushing up on the on his hand and stuff like that. And so then he retracts the Fibromyalgia diagnosis and was like, No, just kidding. Maybe jumped on that one a little too fast. That's not Fibromyalgia. I'm like, OK, you just wasted the last two months but cool. And so, yeah, that just kind of started. I mean, so many tests so many doctors who just. Didn't care, didn't want to do the work, just saw so many doctors again to see a complicated patient like, I want no part in that. I don't I don't want any part in that. And during that time, I was getting significantly worse and I finally was eventually. Diagnosed with neuropathy first kind of autonomic neuropathy and then small Fibro neuropathy started getting some treatments for that started. Finally, I mean, this is over years. I'm finally getting referred to the correct doctors and get the correct tests. Then I'm getting the correct tests done again and done correctly, this time because other doctors had messed it up. And during that time, I'm diagnosed with so I have the autonomic small fiber neuropathy, I've got POTS, gastroparesis, MCAS, EDS so I'm getting like all of these diagnoses and it's not. And it felt overwhelming to be getting so many diagnoses. But after so long of being told that I didn't have anything wrong with me, it was I was kind of weighing it with like, I have these things wrong with me, regardless of whether I have a name for them or not.

Caraline [00:19:47] Yeah.

Kay [00:19:48] So I think I need the name. I need to be able to label it so that I can then create a way to treat it like I need to.

Caraline [00:19:59] Yeah.

Kay [00:20:00] Have all of the information because I know how it feels. I know how my body feels. I don't know how to explain it to other people. I don't know how to describe it. And I don't know. I don't have anything solid like written down that I. So as I'm getting these diagnoses, I'm like, OK, like now I have something now we can start treating something instead of treating the symptoms. I was treating the pain for such a long time. I was treating different the weakness, trying to treat the weakness, trying to treat my stomach, hurting, trying to treat. You know, my lightheadedness, and so finally, we're getting. Names and we're starting treatments and we're digging deeper into what's causing, so we found out that the basically the Lupron triggered a bunch of genetic stuff that would have maybe remained dormant, stuff that I was predisposed to, but probably wouldn't have.

Caraline [00:20:57] Yeah.

Kay [00:20:59] So. And also, the Lupron triggered my body to start attacking my small fiber and autonomic nerves. It was autoimmune in nature where my body just decided. Or we think because Lupron, this problem is Lupron. It has a long list of side effects. That.

Caraline [00:21:21] Yeah.

Kay [00:21:21] I mean, people are told not to worry about and one of the big ones is neuropathy and nobody. Nobody mentions it, nobody, but so many people end up starting with Lupron and end up with neuropathy and bone density loss, which I don't have, but a bunch of scary things and painful things, and it triggers POTS and EDS and stuff like that. And it's just, yeah, the fact that, of course, by the time that I started looking into malpractice because every other thing I decided after that gynecologist as I'm still in a wheelchair like super sick looking for help. He looked me in the eyes and said I would love to deliver your baby one day. And I'm like.

Caraline [00:22:16] *Vomit sound* No!

Kay [00:22:16] I'm like.

Caraline [00:22:19] I would love to punch you in your teeth.

Kay [00:22:21] I was like, OK, I don't want kids. And I made that pretty clear. I feel I like another. I'm 20 at this time. Like, I'm like, That's not appropriate. And also like, I'm really, really sick and I don't know why. And so I'm not even. Thinking about it, like.

Caraline [00:22:44] That's a whole other conversation.

Skye [00:22:45] Right.

Kay [00:22:45] How did he miss the plot so drastically? I'm like why? Why on earth would you say that to me right now? And so I start seeing other gynos and I was like, I'm done that was that was it because I'm like.

Caraline [00:23:01] Yeah.

Kay [00:23:02] He was like on the board at my insurance. So I like hung out with him while I was trying to figure like other stuff, get referrals and stuff because he he did feel responsible.

Skye [00:23:14] Good.

Kay [00:23:14] So.

Skye [00:23:15] He is!

Kay [00:23:16] Channeled. Oh, yeah. But so by the time that I started looking into like malpractise and stuff like suing him, the statute of limitations was up. And I mean, that was the time that it took for me to start seeing the specialists to start seeing gynecologist who looked me in the eyes and said I would never give that drug to an 18 year old, that's reckless. Like. And that was like a common thing, like people, anyone who I talked to about the drug and knew what the drug was was like, they should never have given it to you, especially not as like a first like that would have been like a last resort. There are other tamer treatments that should have been. And so. Yeah, it just completely changed the trajectory of my life. I'm still getting. Like, diagnosed with stuff, I'm like, no, I really prefer to just deal with the ones that I have for now thank you.

Caraline [00:24:12] I'm good. I feel like that all the time.

Kay [00:24:15] I'm done.

Caraline [00:24:17] No more please.

Kay [00:24:19] I've got enough answers for now. I think I think I need to focus on. But I mean, I finally, it's been almost six years since I got the Lupron to begin with. And like I finally just within the last year and a half. Started improving. And getting on treatments that are actually consistently helping and. It's just. Like, I think a lot about like how much time in that six years I like deteriorated and how what spot in my life I would be in a if he had never given me the Lupron which I'm kind of a little bit past that now because it's been such a long time that I need to regroup and work with the cards that I've been dealt. But. Yeah, just a lot of you know, maybe I could have been at this point in my health a couple of years ago if I had been, you know, I shouldn't just now be able to walk down my street or around the block like I I was. Bed bound for a good year and a half, and that was at the beginning where I was deteriorating and I was so sick. And doctors were just. Brushing me off as being a dramatic 18 year old who couldn't hack it in the real world or whatever.

Caraline [00:25:47] Yeah.

Kay [00:25:49] So, yeah.

Caraline [00:25:50] That's like around the edges too that, like Skye and I got our like Fibro diagnosis, and it's totally like they they think you're you have Munchausen, they think you have hypochondria. They're like, What are you talking about? I'm like, No, I'm just a young person who's sick.

Kay [00:26:08] Yeah. And for the amount of us, like I, you know, went into the online community, I found this. Huge, huge group of people in my age demographic who were going through the same experiences that I was and being treated the same way, and when you sit and you think about. How many of us there are there is no excuse for doctors to still look at us and be like, I've never seen this before. That's impossible. There's no way that someone your age and your. Like, there are I don't know why we're made to believe that, I don't know why that's such a I mean, I do know why it's because we're women and.

Caraline [00:26:51] Right.

Kay [00:26:52] You know, then the medical profession is so steeped in, you know, anti-women bias of like it's hysteria. I mean, we're we're, you know, diagnosed with the modern equivalent of hysteria.

Caraline [00:27:04] Yes!

Kay [00:27:06] You know, we're just emotional we're unfulfilled. We're overwhelmed by the world and the way that it is. And we need attention.

Caraline [00:27:14] So give us all diagnoses.

Kay [00:27:16] Yeah. And we need attention when when what we need is medical attention because we fall into a very common demographic of young women who for one reason or another, are acquiring chronic illnesses young. It's not uncommon if you look up, if you Google doctor Google, if you Google so many illnesses, especially a lot of the ones that like I see online, which is POTS, MCAS.

Caraline [00:27:44] Yeah.

Kay [00:27:47] EDS, gastroparesis stuff like that you look at or in like autoimmune stuff, lupus, the stuff like that, and you look it up. We. We're listed in the demographic, it's young women who are getting diagnosed, and so it's so odd to me the the dissonance between this, this information is readily available on the internet. Not only that, but there's such a huge amount of us who fit the bill. And just because, you know, not all of us are going to present exactly the same, not all of us are going to have the same origin story, but it doesn't mean that we don't share a lot of qualities that should make it relatively easy for us to be believed.

Caraline [00:28:32] Yes.

Kay [00:28:35] And it's just so interesting to see how there are so many of us out there when the doctors that are supposed to be helping us make us feel like an anomaly and like, we're alone. And it's just us.

Caraline [00:28:47] I was going to say, like most of the stuff that like Skye has that I have that you have like are not rare disorders like I always see, like the community I follow on

Instagram. A lot of chronic illness, people that do have like what are qualified as rare disorders. And I'm like, I don't fit into that bracket like.

Kay [00:29:06] No.

Caraline [00:29:06] I'm not rare and you are absolutely right. You were made to feel like it's we're in this rare bracket and we're not like so many people have this and a lot of people just don't talk about it because they're they're squashed down.

Kay [00:29:20] Yeah.

Caraline [00:29:21] And made to feel like it's not real.

Kay [00:29:23] That experience in and of itself is gaslighting. You don't have to be necessarily manipulated and gaslit by a specific doctor, but just the fact that young women are made to feel like we. Cannot go into the doctor and be believed.

Caraline [00:29:40] Yeah.

Kay [00:29:40] Because. Our peers aren't believed in because I mean, you're starting to see more articles and stuff now, or at least I am where it's like, Oh, a young woman goes into the doctor, he says she's just hormonal and then they pull out of volleyball sized tumor.

Caraline [00:29:58] Yeah!

Kay [00:29:59] It's like. Or like in the yeah was like she goes into the doctor. He says that she needs to lose weight. She says that she keeps the she can't eat anything, so she is losing weight he's like, congratulations, then she's got colon cancer. And it's like.

Caraline [00:30:13] Yeah.

Kay [00:30:14] What is it going to take?

Caraline [00:30:16] Right. And when we go in and we we advocate and then they're like, offended.

Kay [00:30:23] Right?

Caraline [00:30:24] Sorry.

Kay [00:30:25] I would. I just I have a really, really supportive mom, and she's been taking me.

Skye [00:30:32] Shout out, Mom.

Kay [00:30:32] To all of, my yeah, shout out to my mom. She's a bad ass and she's amazing. And she's believed me from the beginning. She's advocated for me from the beginning. And I mean, she would dress up in her business attire to take me to doctor's appointments so that even though I was looking, I mean, I look so schleppepy because I just felt gross and I was like, I can't focus on. I mean, I know people who do put on makeup to

go to the doctor, and I remember getting doctors back from the pain doctor who is like, she's in her pajamas, and I'm like, These are my nice lounge clothes.

Skye [00:31:11] These are my nice pajamas, okay?

Caraline [00:31:11] Haven't you heard of athleisure? Come on!

Kay [00:31:14] I was like, this is a new sweater. This is, these are new sweatpants.

Caraline [00:31:21] But I also think too like stretchy, like you wear stretchy, comfortable stuff like because you don't know what they're going to have to do. Like, I make sure my sleeve can go like up.

Kay [00:31:31] Getting there. We know we're going be there for hours.

Skye [00:31:34] I'm gonna have to take my pants off anyway what does it matter?

Caraline [00:31:36] Yep.

Kay [00:31:37] Yeah. So but my mom would dress up in like her business clothes and go, and she would still we had a cardiologist tell her to shut up. She tried it. He is. She tried to end it, he told me. So I was in a wheelchair. I told him I'm unable to stand for more than a few seconds and he goes very clearly, not believing that anything's wrong with me. He said, Oh, he took my heart rate. I was tachycardic. He told me that I was making myself tachycardia on purpose.

Caraline [00:32:06] No!

Kay [00:32:08] I made a meme about it because it's not just me, that it's happened. He said you're just you're just making that happen.

Caraline [00:32:18] You'd literally have to stand there and be like *quick breathing sounds*.

Kay [00:32:21] I was sitting! I don't.

Skye [00:32:24] You're like, I'm in a wheelchair how can I do that?

Kay [00:32:27] Then he goes, So he goes, Well, he's like, I don't want to run any tests. You're fine, you're just making your heart go fast. And I could put you on a treadmill and my mom goes, she's in a wheelchair, and he goes, I don't want to hear from you. And.

Caraline [00:32:45] Oh no.

Skye [00:32:47] What did your mom do?

Kay [00:32:49] No, OK. The thing is usually it's doctors saying something like that to me and my mom jumping in, I got like, This is probably the first time that I just I was like, No.

Caraline [00:33:01] Not putting up with it.

Kay [00:33:01] That's not OK. She's advocating for me, you said something ridiculous because I am in a wheelchair and I can't walk on a treadmill. I was like, She's here. She knows all of my medical stuff better than you do. So.

Skye [00:33:13] Yeah.

Kay [00:33:14] Like we, I was like, I, we laughed and we just looked at each other like, what just happened?

Caraline [00:33:21] Mm hmm.

Kay [00:33:22] It was so. I was like, no, no, she's allowed to say whatever she wants.

Caraline [00:33:27] Yeah.

Kay [00:33:28] If she says something that's wrong, I will correct her, but she doesn't. And.

Skye [00:33:35] Right.

Caraline [00:33:35] Mom knows what's up.

Kay [00:33:35] She was pointing out obvious, she was pointing out like an obvious thing when I was too stunned to be like this. Did this guy tell me to get on a treadmill? I mean.

Caraline [00:33:47] Do you want me to put the whole wheelchair on the treadmill?

Kay [00:33:49] I'm like.

Skye [00:33:49] Yeah, like?

Kay [00:33:50] I'm like processing how weird that request is, and my mom jumps in and he tells her to shut up and we're like. Oh, my God. And so now we tell that story to other doctors. Just so that they know that them telling her to shut up, it's not.

Caraline [00:34:10] Let me set the bar.

Kay [00:34:11] But we're we'll. A lot of times we'll like. Tell stories now in my appointments of things that have happened in past appointments, just being like, you know, kind of slyly just being like, and this is the kind of behavior that we find unacceptable. I'm spoon feeding them like, Hey, how about we don't try this today?

Caraline [00:34:36] Tee hee, get it?

Kay [00:34:39] Like, Oh God, can you imagine a doctor saying that they're so stupid? And you know, if you say anything like this, we will tell other doctors about you.

Caraline [00:34:52] Yes!

Kay [00:34:52] And how ridiculous you are.

Caraline [00:34:54] We're gonna talk smack about you.

Kay [00:34:54] To make it uncomfortable.

Skye [00:34:57] Yeah, make it uncomfortable to the point where they just like, we don't want this.

Kay [00:35:00] Oh my God, we don't want to mess with that. And I think there's a fine line between like being the patient that nobody wants to mess with and then being the patient that is called noncompliant because like, I'm perfectly I'm I'm perfectly compliant. If you know what you're saying is.

Caraline [00:35:17] If you're nut job.

Kay [00:35:18] Has merit and right, and if you're giving a giving a treatment plan that actually works and I'm comfortable with something that like I haven't tried before, God, I hate when doctors are like. I know you've tried this med four times, but.

Caraline [00:35:35] One more times not gonna hurt.

Kay [00:35:37] I'm like would you like to maybe try it again just to see if it'll work when I prescribe it. Since it hasn't worked to when other doctors have prescribed it as if that makes a difference.

Caraline [00:35:52] I have Dr. Evil going "How 'bout no!"

Kay [00:35:55] Right? I seriously. I mean, I've made memes about all this stuff I've got when the doctors telling you the time that they've already tried. And you're like. Because so much of us, we want to be compliant, they want to try everything, we want to try everything twice unless we've had like a terrible reaction I have some meds, that I'm like, Absolutely not.

Caraline [00:36:22] Yeah.

Kay [00:36:22] Never again. Not in this lifetime. It's a hard pass. But I feel like we struggle so much with this internal kind of like doctor pleasing where we just want to pad their ego, and we want to do what they want us to do so that they'll keep us on as a patient because we don't have other options or we don't want to go through having to find God, it takes so much time to find a doctor.

Caraline [00:36:50] Right.

Kay [00:36:51] That works of your insurance and then you get an appointment scheduled and then you get in for a consultation and then they suck. And then you have to go back to your referring doctor and be like, I need another referral because the person you referred me to told my mom to shut up and then it's like. It's so we're constantly on our tiptoes, walking around these egos and this system that's not built for chronic patients.

Caraline [00:37:23] Yeah.

Kay [00:37:24] Like so much of medicine, was structured to fix and release and.

Caraline [00:37:30] One and done, yeah.

Kay [00:37:32] That's not conducive with. I mean. Especially nobody wants to be on the hook for a patient for 40 years, which I feel like is part of the reason why young women are coming in being like, Hey, something's wrong with me, and they're like. That sucks.

Caraline [00:37:53] Yes. No thank you.

Kay [00:37:55] Sorry. Because you you say that she's got all of these incurable conditions and then what? She's got another decade to five left? What? They just don't want to think that they want people they can fix.

Caraline [00:38:16] Yeah.

Skye [00:38:16] Mm-Hmm

Kay [00:38:17] So. And then we're then shouldering the brunt of that, we're we're like, OK, but.

Caraline [00:38:24] Yeah.

Kay [00:38:26] And that's the thing, too, is like maybe some of the things that are wrong with me are fixable, but no one wants to touch me with a 10 foot pole.

Caraline [00:38:34] Yeah.

Skye [00:38:34] Sure.

Kay [00:38:35] And so then they kind of, you know, degenerate into something that's now not fixable. And it's like.

Skye [00:38:42] Right.

Caraline [00:38:43] Yeah.

Skye [00:38:45] So in in 2018. So I've seen eight gynecologist. I was finally diagnosed Endometriosis a couple of months ago after 11 years of fighting.

Kay [00:38:56] Congratulations.

Skye [00:38:59] Thanks.

Kay [00:38:59] I mean, that's a, I mean.

Skye [00:39:01] Yeah.

Kay [00:39:01] You had it the whole time. That's the thing is like you had at the right time, you had it for 11 years and it took. Pain and sweat and tears and.

Skye [00:39:11] Right.

Kay [00:39:13] Gaslighting to.

Skye [00:39:15] And same thing, it runs in my family, but I think it was twenty eighteen after I had my first laparoscopy, my doctor wanted to put me on Lupron. And so when you're talking about I was like, That is absolutely the medication he wanted me to go on it.

Kay [00:39:30] It's it's the standard of care, which is.

Skye [00:39:33] Yeah.

Kay [00:39:34] Freaking scary because you do any research and there are women being like, from what I can tell, it's great for treating prostate cancer.

Caraline [00:39:44] Great!

Skye [00:39:44] I'm sure!

Kay [00:39:47] It's also used to chemically castrate sex offenders.

Caraline [00:39:49] Oh.

Kay [00:39:51] In some, some states.

Skye [00:39:53] Okay.

Kay [00:39:53] And stuff like that.

Skye [00:39:54] So it works great if you have a prostate, but if you don't have a prostate.

Caraline [00:39:59] Maybe don't do that.

Skye [00:40:00] For some reason.

Kay [00:40:01] That' so much of medicine.

Skye [00:40:03] Wow, who would have thought of that?

Kay [00:40:05] Medicine was like created by white men for white men anyway.

Caraline [00:40:12] Amen.

Kay [00:40:13] Anyway, Lupron.

Skye [00:40:14] Yeah, I I for some reason said, no, I think it's because he said, you know, this will put you in menopause and you know, my mom because she had already had a hysterectomy at that point, she was like, Skye, like, I don't know, you're really young.

Kay [00:40:30] Yeah.

Skye [00:40:30] And the thing that bothered me about this doctor specifically, he was like, well, everything we're trying to do is to try and protect your fertility.

Kay [00:40:36] Oh God, I hate that so much.

Skye [00:40:39] I hate it.

Kay [00:40:40] I am not a baby making factory just because I have a baby maker, like.

Caraline [00:40:45] Yes.

Skye [00:40:45] Right. And my doctor that I see now, right? There's other things and the doctor I see now. I straight up asked her. I said, look like what would happen to me medically if I were to have a hysterectomy? Like, I get it. You know, I'm young and I change my mind and barf barf barf. But like, what would happen medically? And she is the first doctor out of eight, and I think it's because she's she's a young woman. She's fresh out of med school like she's super cool, super nice.

Kay [00:41:15] That's pretty unique my.

Skye [00:41:17] Right, like, she is fresh, she is fresh out of med school. She was like, well, what would happen, you know, if we were to take out your uterus Endometriosis is still controlled by your ovaries. So even if we take out your uterus, you could still have issues because if say you have Endometriosis on your bowels. Well, your ovaries are controlling them and you're hormones.

Kay [00:41:38] It's about the estrogen.

Caraline [00:41:40] Yeah.

Skye [00:41:40] And right, and she's like, and being twenty four, getting your ovaries out. Not a good idea. And I said I told her, I said, you were the first doctor to give me an actual medical explanation to my medical question.

Kay [00:41:55] Yeah.

Skye [00:41:55] I was like, Thank you. I said, That's all I've ever wanted, because that is how I'm gonna make a decision.

Kay [00:41:59] Because no other doctors will entertain the question.

Caraline [00:42:01] Yeah.

Skye [00:42:02] Right, because all they want to say is, well, you might wanna have kids.

Kay [00:42:04] What if your husband wants kids one day?

Caraline [00:42:08] Who frickin cares? He's not in pain!

Skye [00:42:11] Who cares what he wants.

Kay [00:42:11] Why is it up to my partner?

Skye [00:42:12] Because at this rate.

Caraline [00:42:13] Yeah.

Kay [00:42:14] Yeah.

Skye [00:42:15] Right! At this rate, who knows if I'm going to be able to have kids?

Kay [00:42:18] Yeah.

Skye [00:42:18] So like, give me a medical answer, and I've sure had no doctor before, I said, and this was a it was a cardiologist or no, no, sorry, it was a blood doctor, was a hematologist who said to me, Well, if you do like, chemo, you might want to have kids. And I said, there are so many, I shut it down. I was like, There are so many ways for me to have kids.

Kay [00:42:36] Yeah.

Skye [00:42:36] I said, I can adopt, I can foster kids. I can have a surrogate. You know, my one of my friends will carry a kid for me. Like, there's so many ways.

Caraline [00:42:46] Yeah.

Skye [00:42:47] There's so many ways for me to be a mom.

Caraline [00:42:49] Mm-hmm.

Skye [00:42:50] Like.

Kay [00:42:50] Some people just like weren't cut out to be parents and or.

Caraline [00:42:55] Yeah.

Kay [00:42:55] Or can afford to be parents. That's just assumed that everybody with a uterus a has a functional uterus.

Caraline [00:43:03] Right.

Skye [00:43:03] Right.

Kay [00:43:03] Like that could be a devastating comment for someone. If you know if you're infertile. I mean, I just assume I'm infertile. I don't know, because you assume.

Caraline [00:43:16] Right.

Skye [00:43:23] That's like the dark humor I used to cope I'm like, well probably.

Kay [00:43:29] Well, I'm just like, well, the thing is, I find comfort in that because I have never wanted children. I don't want children.

Skye [00:43:36] Right.

Kay [00:43:37] I.

Skye [00:43:37] Right.

Kay [00:43:38] I can barely keep myself alive I don't have the patience to deal with other people's issues. I don't have the.

Skye [00:43:44] Right.

Kay [00:43:45] Patience for, like tiny humans who I don't have any desire to be responsible for another person.

Skye [00:43:50] And their bodily fluids.

Kay [00:43:52] Ahh the bodily fluids like I have, I have my worst nightmare. Is like having to coordinate driving a kid to soccer practice and stuff like God could you imagine being a soccer mom like that is.

Caraline [00:44:11] Yeah.

Kay [00:44:13] That is like my worst nightmare. And I completely understand that people love it and that is good on them all power to you. My mom is a soccer mom.

Skye [00:44:23] Yeah.

Kay [00:44:23] She's not a big fan of soccer, but she.

Skye [00:44:26] Right.

Kay [00:44:27] But she loves all of that.

Skye [00:44:27] She's a soccer mom anyway. Right.

Kay [00:44:29] Right. I, that is seriously like, someone's like, Do you want kids? And I immediately picture having to pack a lunch and put a child in the car and drive them to a sports practice and sit and watch.

Skye [00:44:45] And sit there.

Kay [00:44:46] Enagage with other moms and other children. And it is like it makes me feel like I want to vomit. I.

Skye [00:44:55] Right.

Kay [00:44:55] Like, so I just I'm like, you know, God.

Skye [00:45:01] And it's totally okay, normalize women not wanting kids it is totally okay.

Kay [00:45:04] Right. So it's not like hurtful. It was not hurtful for me to be diagnosed with something that could. Sure, that could impact my fertility.

Caraline [00:45:16] Mmm-Hmm.

Kay [00:45:17] It was wild to me when the doctor who diagnosed me with that told me he wanted to deliver my babies.

Skye [00:45:24] Yeah.

Kay [00:45:25] It was. I mean. It's just it's so concerning to me that. Especially gynecology. Is so. Obstetrics focused, where it's very much. The end goal is successful pregnancies, plural. It's always, well, you have one and then they're like, When's the next one?

Caraline [00:45:52] Yeah.

Kay [00:45:53] It.

Skye [00:45:55] It's weird.

Kay [00:45:56] That so. That's such a personal decision, and it's something that carries a lot of hurt for a lot of women and people and other people with uteruses, it's just. It's such a personal question, and for people to blatantly be like, so when are you having kids or, oh, I wouldn't do a hysterectomy because you're twenty four and you don't have kids yet. Like that's so. Narrow-Minded, it's such tunnel vision, and it's so ridiculous, and it gets in the way of our care where.

Caraline [00:46:30] Yes.

Kay [00:46:31] We are looking for what's best for us and our body and our wants and needs, and we're kind of tunneled into the stereotype of where you're eventually going to want to make a baby one day and it's not even a question.

Skye [00:46:46] Right.

Caraline [00:46:46] Yes.

Kay [00:46:46] It's you're going to want to make a baby. So we're going to do what we need to do to get you a baby, and that's fine. If someone wants a baby, but don't you think you should ask the person who is going to be making a baby theoretically?

Skye [00:47:01] Well, for me, I'm like, well, in order for me to have a baby, well, I want to be healthy first.

Kay [00:47:06] Right! I need my other health problems. And that is not that. It's so not even in the realm of my body.

Skye [00:47:13] Right!

Kay [00:47:13] Right now, regardless.

Skye [00:47:15] Right.

Caraline [00:47:15] Yeah.

Kay [00:47:16] It's like, I'm not in the place to have a baby. I don't we have a baby is medical advice that a lot of gynecologists will give someone who has just been diagnosed with Endometriosis and I have talked to people who have Endometriosis and who have had babies and still shocker still have Endometriosis.

Caraline [00:47:37] Yeah, that was my weird medical advice story was I got told to get pregnant as a single 20 year old woman.

Kay [00:47:45] Right!

Caraline [00:47:45] To fix my Fibromyalgia. Okay I will be maybe not have Fibromyalgia, but I'll also have a human who is contributing to the climate problem and has to be on this garbage planet.

Kay [00:47:58] I'm sorry but you're telling me that the cure for the illness I have is to create a life.

Caraline [00:48:04] No thank you.

Kay [00:48:06] Doesn't that seem a bit extreme. I can't take that back.

Caraline [00:48:09] Yeah.

Skye [00:48:10] People think it's so casual.

Kay [00:48:14] That's one done that can't be undid. You can't.

Skye [00:48:16] That is one thing like you cannot hit the undo button.

Kay [00:48:20] It's the biggest commitment a person can make. And they're saying.

Skye [00:48:24] For your entire life.

Kay [00:48:25] They're saying it like it's the same thing as taking an antibiotic that's not.

Skye [00:48:30] Just have a kid!

Kay [00:48:31] That's not condusive like that does not compute. That's not the same thing. That's not medical advice.

Caraline [00:48:37] Uh-uh.

Kay [00:48:37] And let's say even I can't. Yeah, I mean, my my aunt was, I think, diagnosed that like 19, her doctors have a baby and my grandma is like, Hell no!

Skye [00:48:47] No.

Caraline [00:48:47] Stop it!

Kay [00:48:49] Absolutely not. But I mean, also, you'd imagine Endometriosis causes fertility problems and imagine doctors like just have a baby.

Caraline [00:48:57] Right, why are you putting two and two together.

Kay [00:48:58] And then you can't have a baby.

Caraline [00:49:02] Yeah.

Kay [00:49:02] But you know, it's just it's such a slippery slope that doesn't even need to be a thing because you just all you have to do to avoid it is just not assume that everybody wants the same thing, which I feel like.

Skye [00:49:16] Right.

Kay [00:49:17] Isn't that much of an ask.

Skye [00:49:18] I mean, in twenty twenty two.

Caraline [00:49:20] Yeah.

Kay [00:49:20] Right?

Skye [00:49:20] They should know that I mean, at this point, having a baby just for our generation specifically like Caraline said.

Kay [00:49:26] We can't afford to have a baby.

Caraline [00:49:27] Yeah.

Kay [00:49:28] Like everyone's living with their parents or with like seven roommates. And it's like, why would I want to bring in a person to this?

Skye [00:49:35] Cancel student loan debt and maybe we'll have kids, people.

Kay [00:49:37] Right? With inflation. We're being paid seven dollars an hour.

Caraline [00:49:42] Mm hmm.

Kay [00:49:44] Like I don't understand how this doesn't compute and how that's affecting our medical care like God.

Skye [00:49:52] Because they're doctors with doctor salaries.

Kay [00:49:53] Yeah.

Caraline [00:49:54] When all of this stresses you out though, a great places to go is Kay's Instagram.

Kay [00:50:01] Oh yes, that's a good segway.

Skye [00:50:02] 100 percent! Let's talk about the happy stuff now.

Kay [00:50:06] I am Kay and I endorse that message.

Caraline [00:50:09] So the best way I can describe it and describe to anyone I talk about it to which as many people I'm like, she makes these ingenious means about chronic illness and then beautifully paced them over like a renaissance painting of a lady with her boob out, like.

Skye [00:50:27] How did this? How did this idea happen?

Caraline [00:50:29] Yes, please share.

Kay [00:50:31] Okay, so basically I follow. I started following accounts that we're also doing that were also doing kind of like classical art memes and I became, you know drawn to this medium of I started realizing that, like my favorite memes were the ones of. Like on Renaissance paintings, and not only that, but my eyes are kind of open to how meme-able classical paintings are.

Caraline [00:51:01] Yeah!

Skye [00:51:01] Yeah.

Kay [00:51:02] Because you really I mean, you think like, you know, Mona Lisa.

Caraline [00:51:08] Mm hmm. No, I like the ones that flopped over chairs.

Kay [00:51:13] Right? One of my favorites is this painting. It's two nude women from the chest up, of course. And one of them is like, very daintily holding the other one's nipple.

Skye [00:51:26] I saw that one!

Kay [00:51:29] I didn't realize this until I memed it, but the painting is of sisters, so it's like extra, extra funny.

Caraline [00:51:40] Spicy!

Kay [00:51:40] And I put a caption on it that was like how it feels when people give weird strangers give completely unfounded really personal medical advice. So basically, I was following these accounts like this one called classical art shit. Depressed art memes, and I started going on to those. And then because I was following those accounts, I was having different classical memes or not. Classical paintings show up on my For You page. And so I started sharing those posts onto my story and putting a caption on them. And then I got a bunch of people messaging me like, I went to share this and I couldn't do it because it wasn't its own post. They would click on it and they would just see the picture. You need to do, you need to post these? And I was like, I do not want to bug. Everyone who's following me on my personal account.

Skye [00:52:40] Right.

Kay [00:52:41] I don't want to bug so I just was like, Okay, I'll just make another account. And then it kind of like took off and people really enjoyed it. And yeah, it was. I don't know. I have a lot of fun doing it. I have a lot of fun when people respond to it. I have. I mean, there are so many paintings that I find that just the painting makes me laugh out loud it's so ludicrous.

Skye [00:53:05] It's hilarious.

Caraline [00:53:05] Yeah.

Kay [00:53:06] It's so I mean, some of them, I some of them are beautiful and I will put some, but there are some that are just wacky there these painters who paint people's expressions as they actually were. And so they're awkward as all heck, and they just lend themselves so well to yeah just chronic illness. I mean, I've found ever since the beginning if I'm not laughing about it. Then it's not a good time, like.

Skye [00:53:39] You have to laugh about it.

Kay [00:53:39] I need to find some levity in it because.

Skye [00:53:40] Yeah.

Kay [00:53:41] And so I was like, if I can combine these like wacky ass photos or paintings and some of I actually like photography and like, you know, just anything old fashioned and kind of weird, and I can turn it into something that people can relate to. I also, I mean, I just feel like those paintings kind of in a weird way, lend themselves very well to chronic illness.

Skye [00:54:08] Yeah.

Caraline [00:54:09] And who knows, maybe they were going through it and we don't know.

Kay [00:54:13] Honestly, they probably were. They're like, God, I'm.

Caraline [00:54:15] They look like it.

Kay [00:54:15] Going to die at like twenty-seven. I'm 16 and unmarried, so I'm a spinster.

Caraline [00:54:21] Oh no.

Kay [00:54:22] So it's time to pose for a painting with my tits out.

Skye [00:54:25] Not a spinster! It's so funny that like when you think about it in some of these paintings that like these are actually real people that lived one day and now.

Kay [00:54:36] Yeah.

Skye [00:54:37] Hundreds of years later, we're just laughing at them. That was totally not their intention. It's what's happening.

Kay [00:54:45] These are very a lot of them are very wealthy people who paid for you to sit for a painter.

Caraline [00:54:51] A portrait.

Kay [00:54:52] And then the painter paints them with the weirdest face. And now, lo and behold, they're like a chronic illness meme and I think about that a lot right now.

Caraline [00:55:02] Sorry not sorry.

Kay [00:55:04] I'm like, well it's public domain.

Skye [00:55:06] I just like I have.

Kay [00:55:08] This is what happens when you pay a painter.

Skye [00:55:11] I have to know if those sisters, like, actually were holding each other's nipples.

Caraline [00:55:15] Yeah.

Kay [00:55:16] Nobody knows. I've tried looking into that painting, and it's just kind of like, we think they're sisters and we don't know why. I don't know why.

Caraline [00:55:25] Yeah.

Kay [00:55:26] This painting exists. It's such a bizarre. God, I love that painting so much.

Skye [00:55:31] Hold her nipple, yeah, that looks good.

Caraline [00:55:33] And you have to hold it.

Kay [00:55:35] It was so great, delicate, and I'm pretty sure they're both looking at the painter. And so she's just.

Caraline [00:55:44] Uhh direct eye contact.

Skye [00:55:44] Gotta find it.

Kay [00:55:46] I yeah, I think, too, that it helps, kind of. It counteracts people's ideas of these paintings where you think classical painting is boring.

Caraline [00:55:57] Yeah.

Kay [00:55:58] When really they're like.

Skye [00:56:00] It's not!

Caraline [00:56:00] No.

Kay [00:56:01] There's weird shit out there, man.

Caraline [00:56:03] Yeah.

Skye [00:56:03] Yeah.

Caraline [00:56:04] And then you slap your, you just like word like everything, like just so perfectly. And I know Skye and I have, like, shared them with each other. We both post them on our stories all the time. I'm pretty sure we both commented on a few like, we just can't help it, we're obsessed.

Skye [00:56:20] Yeah, yeah.

Caraline [00:56:21] And it's just a good community that we like.

Kay [00:56:25] Yeah!

Caraline [00:56:25] Joined because of it.

Kay [00:56:26] And there's a lot of people.

Caraline [00:56:28] Yay, more people coping with dark humor. We love it.

Kay [00:56:32] I feel like a lot of times people.

Skye [00:56:33] And you have fifteen thousand followers.

Kay [00:56:35] I do, which kind of I don't know, that surprises me.

Skye [00:56:38] Is it weird?

Kay [00:56:39] It's so weird. And it's just weird that like that many people like, cared enough to follow me. I mean, I guess I don't care a whole lot when I follow somebody on Instagram, but still people were like into it, where it's just.

Caraline [00:56:57] Yeah, like I gotta see when a new one comes out.

Skye [00:56:57] They're the best that's ever been made.

Kay [00:56:58] Yeah, it is. Like, there's also.

Skye [00:57:00] You know.

Kay [00:57:00] Me sending these to my friends being like, you know, Oh, this looks like someone who is reading a pharmacy side effect sheet and like just freaking out like this, you know, like when.

Caraline [00:57:16] Yeah.

Kay [00:57:17] That was that was one of my first ones was the woman chucking like a little booklet off of a balcony and it was like throwing away every side effect warning packet that the pharmacy hands me like because like who reads those, but.

Caraline [00:57:36] I've only just started unraveling those things they're like a CVS receipt.

Skye [00:57:41] Same. I mean, I just Google it now to get like the too long don't read version.

Kay [00:57:46] I would like the WebMD abridged version where it just lists things really easily you don't have to fish through all the words, yeah.

Caraline [00:57:55] Yeah.

Skye [00:57:56] Yeah.

Kay [00:57:56] There's so many I mean, I get comments every day and it's like, I thought it was just me. And it's like a lot of those comments every day and I'm like, Hey, have you met so-and-so who just commented the same thing? It's not just you.

Caraline [00:58:09] Yeah.

Skye [00:58:09] Mm-hmm.

Kay [00:58:10] And like it. I don't know, like the reason why I make the memes is because I've kind of come to the point where I know it's not just me. I don't I don't dare to assume that anything is just me anymore, because for everything that I think is just happening to me and that I felt alone over, I realized that there was community and I'm not the only one who experienced it. And so for me to be able to take these like. I mean, it's all just. From my brain, like it's not. I don't know a lot of people think that it's like more than one person behind the account, so there's like multiple of us and we're all like little meme making machines and it's just like me.

Caraline [00:58:56] Oh no, it's a one women show.

Kay [00:58:58] Yeah, and I just I will think of a caption, and have I've saved a bunch of like paintings in my, you know?

Caraline [00:59:07] Yeah.

Kay [00:59:07] And I'll go and I'll have a caption of mine and I'll scroll until I find a painting that works and I'll slap it on there. Or I'll be scrolling in my for you page and see a painting and slap a caption on. But it's all stuff that like, know, just like, Oh yeah, that chronic illness life that's just, how things this is how things are and people, people get it.

Caraline [00:59:29] Yeah. And I mean, when you like, read something and it hits you like so perfectly it just makes you feel a hundred times better.

Kay [00:59:34] And it takes away the stigma where we're made to feel like it's just us like we're alone in it and like, it's you know.

Caraline [00:59:43] Yeah.

Kay [00:59:44] We're made to feel like we're the exception to the rule and we're somehow doing it wrong.

Caraline [00:59:49] Yeah like isolated.

Kay [00:59:50] And for, you know, for I know it helps for me to see memes that, you know, dealt with that and just. Had the people who had the. I don't know the wherewithal the post that everybody's thinking like everybody thinking.

Caraline [01:00:10] Yeah, that takes guts.

Kay [01:00:11] Or like you're thinking it but you've been suppressing it so much that you don't acknowledge that you're thinking it and then for someone to explain it and say it in a funny way and you're like, Wait a minute, it's not just me. It's somebody else. And it's actually.

Caraline [01:00:26] Yeah.

Kay [01:00:27] It's so common that it's funny or it's so wild that we all think it's just us.

Caraline [01:00:32] Anything that it can like make you out loud wherever you are. Just go. Yes, yes. Yes. I've done that many times while reading these like she gets it.

Kay [01:00:45] That's I mean, that's the that's the goal. I just want to make people because again, I'm very aware that my audience. Is straight up not having a good time in life.

Caraline [01:00:59] Yeah.

Kay [01:01:00] We're all miserable. I'm right there like I am very aware of that. And so if I can do something light hearted with that and you know, I just have a really dark sense of humor, and I feel like that has been kind of formed over the last six years of being stepped on by the medical community. And if I can do that for myself and like a couple other people, then I works for me, man. I don't know.

Caraline [01:01:35] Yeah.

Kay [01:01:36] It makes me mad that. People. Are made to feel like it's just them, I don't think that anybody should be made to feel like it's just you and like you're you're ostracized by yourself in your abnormal. And I think a good way that we combat that is by dark humor and by finding the weird, funny bits of all that trauma which sounds, sounds really fun.

Caraline [01:02:09] It'd be a sad existence otherwise, honestly.

Kay [01:02:10] God, imagine imagine like an infomercial for my meme page and I'm like, It's the funny bits of all the trauma.

Caraline [01:02:20] Call 1-800- blah blah blah.

Kay [01:02:24] Oh my God.

Caraline [01:02:26] Well Kay, to end all of our podcast, we do a section called Visible Victories and Tender Points. So they're kind of like highs and lows of the week. So Visible Victory is something good that happened to this week, and a Tender Point would be something not so good. So if you have any, you can share them first.

Kay [01:02:47] OK. Yesterday, in terms of a victory, ModCloth, the brand ModCloth, which is like a vintage clothing brand.

Caraline [01:02:55] Love them.

Kay [01:02:57] Posted one of my memes completely unprompted and they actually credited me.

Skye [01:03:02] What?!

Caraline [01:03:03] Yay!

Kay [01:03:03] And I was like.

Caraline [01:03:05] That's even better.

Skye [01:03:05] OK.

Kay [01:03:06] Posted it to their feed. I have some people who and some accounts that will share my stuff and not credit me. It was completely unprompted. I literally was just like. Sitting in my house and I get this notification that ModCloth tagged me in a post. And I was like, I'm sorry, ModCloth? Like the brand?

Caraline [01:03:31] Yeah.

Kay [01:03:32] And then I opened it and I was like, Oh my God. And it wasn't even like it was a meme that I posted a long time ago. It wasn't anything like recent.

Kay [01:03:40] Ooh, that means they were searching. I don't know how long that's been. Like, you know, that's been like simmering over there, but I'm like, I'll take it like that. It just felt like a win. It kind of came out of nowhere and just made me incredibly excited that made my day.

Caraline [01:03:57] Yay.

Kay [01:03:58] Oh, this seems like a kind of trivial, like, not happy thing, because right in the grand scheme of things, it's not illness related or anything. Amazon. Amazon lost my grandma's birthday present.

Caraline [01:04:10] Oh.

Skye [01:04:11] That's awesome.

Kay [01:04:12] OK. It was so I ordered it. This is her birthday this Valentine's Day, so we were celebrating on Sunday and on Friday or Saturday, I was like, We haven't really gotten or anything. So we waited and it was just kind of normal. And I'm like, Oh my God, or something. And my family is like yeah so I ordered it. It was supposed to come on Sunday. So I'm great. Perfect. Will come on Sunday. I think I ordered it Friday. I was going to come on Sunday. It might come while she's here, but it'll still be here by her birthday and then I

get a notification while she's at our house like, Oh, it's delayed. It'll come. It'll come Monday or Tuesday.

Caraline [01:04:59] No.

Kay [01:05:01] I was like bummer, like I had made her cupcakes, so it wasn't like we had nothing. We have a card, so I was like, OK, your gifts coming. It's delayed. I'm like, we'll get it to you next time we see you or we'll have folks drive by and get it to you and then. I kept checking like tracking and stuff, and it was still as of yesterday afternoon was like perfect, it'll still be here to be here today. And then like great, and then I realize this afternoon that it never showed up. I went into my Amazon like my orders, and it was gone like straight up.

Caraline [01:05:42] Oh my gosh.

Kay [01:05:43] Gone as if I had never ordered it. And I'm like, Well, that's not going to fly. So I went into my email and found the tracking number and clicked on that came up. And it's like your package may have been lost.

Caraline [01:05:58] Umm? May have?

Kay [01:05:59] Considering there's no.

Caraline [01:05:59] It's a yes or no thing!

Kay [01:06:04] Considering you have no idea where it is. Yeah, I think it may have been lost. So. I got a refund and then ordered her something different, because hopefully that will come from it was similar but different, so it'll come from a different place and maybe have a better chance. I mean, I've got the. The Postal Service right now, like I have an Etsy store, and I sent out an order last Friday and it was going, I'm in the L.A. area and it was going from the L.A. area to Texas. Mm-Hmm. And it made it to Texas like a sorting center in Texas. And then last I heard is back in L.A. at a sorting center in L.A. like it was supposed to be delivered by now. I had to email my customer and be like, Hey, I've been watching the tracking info, and it seems like your package is lost in the US postal system. If it never gets to you. Please let me know and I'll send you a replacement.

Caraline [01:07:08] Yeah, it went backwards.

Kay [01:07:11] And like the fact that that timing is coinciding with my.

Skye [01:07:15] Makes no sense.

Kay [01:07:16] Grandmother's stuff being lost. I feel like.

Caraline [01:07:18] Something's going on.

Kay [01:07:19] Is indicative that there's something up with the postal service.

Caraline [01:07:23] Oh man. Grandma's need birthday presents. Come on.

Kay [01:07:27] Yeah, I mean this woman is eighty one like we need to be showing her how much we appreciate her.

Caraline [01:07:34] Yes. Skye what about you?

Skye [01:07:39] Umm, do I have any Visible Victories?

Kay [01:07:41] Oh, no, I totally feel that.

Skye [01:07:44] It's not that like it's not that like everything bad.

Caraline [01:07:48] Right. It's hard to think of them.

Skye [01:07:50] OK, here's mine. I walked in my first runway show on Saturday.

Kay [01:07:54] How is that not?

Caraline [01:07:54] Oh yeah.

Kay [01:07:55] That's so cool.

Skye [01:07:57] Yeah, so I had to think bout it.

Caraline [01:08:03] You looked like a goddess.

Skye [01:08:03] Thank you. It was so amazing it looked like I should be in one of Kay's paintings.

Caraline [01:08:08] Okay, yeah.

Skye [01:08:09] The dress I wore was like it, just like a Queen Mary dress, it was.

Caraline [01:08:15] Amazing. You two should get together. You have to wear that outfit, and then we're going to take a picture of you and you have to have an awkward facial expression. And then we're going to slap a meme over you.

Skye [01:08:24] Perfect.

Kay [01:08:24] I mean, you could just send me a picture that you already have and I could put a caption on it.

Skye [01:08:28] You guys.

Caraline [01:08:29] It's happening.

Kay [01:08:29] I have done that for somebody before she sent me a picture of herself.

Caraline [01:08:32] Oh fun!

Kay [01:08:32] And I put it on. Yeah.

Caraline [01:08:34] Love it.

Skye [01:08:35] Hell yeah! And then I guess my what's the other one? Fibro fog, sorry.

Caraline [01:08:43] Tender Point.

Skye [01:08:45] Thank you, my whole body.

Caraline [01:08:48] Yeah.

Skye [01:08:48] I I think I'm in a flare right now. I don't know and I know work has a lot to do with it. I've been working a lot. And I just need a vacation, you know, like.

Kay [01:09:00] I would like a vacation away from my body.

Caraline [01:09:03] Yeah.

Skye [01:09:03] Right.

Kay [01:09:04] I would like to get out of this physical form for like just a bit. And then.

Caraline [01:09:11] Yeah, just a tad.

Skye [01:09:12] Right.

Kay [01:09:12] Like, not not permanently.

Caraline [01:09:15] Right, no thank you.

Kay [01:09:15] But I need a break.

Caraline [01:09:17] Yeah.

Kay [01:09:18] Yeah, just a little bit.

Skye [01:09:19] Yeah. Every day when I sit down like my neck just starts going numb, and like my shoulder, and I just don't like it. And like, even now, it's bothering me because the way I'm sitting al keep trying to move, but like, it's just not a good time. So I'm hurting, but I'm alive.

Caraline [01:09:36] Woo!

Kay [01:09:37] That's like the base level. Like.

Skye [01:09:40] Right.

Kay [01:09:41] Alive is the jumping off point.

Caraline [01:09:44] Yeah, my my Visible Victory for this week would be heatless hairstyles.

Skye [01:09:53] OK.

Caraline [01:09:54] Which kind of ties into my Tender Point, but basically, I.

Kay [01:09:58] Love that.

Caraline [01:09:59] I was getting bored I was getting bored of just having plain straight, flat, thin hair. So I was like, I'm gonna start doing braids at night and so I get a little something.

Kay [01:10:09] Add little body I do that.

Caraline [01:10:11] Jazzes it up a bit. Yeah. So, yay for heat hairstyles, my Tender Point would be, is that my body image is like not it's like down the tubes these days.

Kay [01:10:23] Yep, right there.

Caraline [01:10:25] Which I kind of attribute it to two things which is making it really bad right now, which is like all my stomach issues is making my stomach like so distended, like the worst bloating ever had in my life. So like, my body looks different. And then it's also like, not quite spring yet. And I talked about this last week, but I just dress like trash in the winter because you got to do what you got to do to stay warm.

Skye [01:10:51] Right.

Caraline [01:10:51] So I like, don't feel the most beautiful right now. I'm just tomorrow supposed to be 70. I think I'm just going to go balls to the wall. I'm gonna find the prettiest dress in my closet. I don't care if a kid's going to sneeze on it tomorrow because I teach preschool. I want to feel cute. So, yeah, that's been not fun because I don't usually like battle with that as hard as I have recently, but I'm working through it and I'm just trying to be nicer to myself about it.

Kay [01:11:19] Yeah.

Skye [01:11:19] All you can do.

Kay [01:11:20] I had to change out of leggings today because I was so bloated that the waistband was killing me, so.

Caraline [01:11:27] I know that I hate that.

Kay [01:11:29] It was.

Caraline [01:11:29] I'm like, I'll just wear a mumu.

Kay [01:11:30] And it's like, not normally an issue for me in terms of waistbands. I usually, since I have neuropathy, usually have an issue with like fabric and stuff in my legs.

Caraline [01:11:39] Yeah.

Kay [01:11:39] But lately it's been my stomach, so I like completely. Feel you on that it is not a good time.

Caraline [01:11:47] Yeah, well Kay thank you so much for joining us again. We loved having you and we may have set a record for the longest podcast episode.

Skye [01:11:55] We did.

Kay [01:11:56] Sorry.

Caraline [01:11:56] And you should feel so proud because we loved chatting with you.

Kay [01:12:00] Okay, it's an accomplishment. All right.

Skye [01:12:02] Yeah.

Caraline [01:12:04] And we will make sure to share all of Kay's information and social media and where you can find her funny, funny memes in our description for the podcast, so make sure you check that out. I always forget this is at the end of the podcast, but I've been checking out our like demographic not demographics. But like our analytics for the podcast and y'all are just listening to us on Apple Podcasts a lot. So I figured I would say to rate and review and subscribe. So rating, obviously, you can give us five out of five stars, just go ahead and just.

Skye [01:12:39] Obviously.

Caraline [01:12:42] No need to do any lower.

Kay [01:12:42] Make sure you rate it correctly. Nothing less than five.

Caraline [01:12:46] But for real like, be honest, share what you want to share.

Kay [01:12:49] Be honest but only if it's a five.

Caraline [01:12:51] We've said that before totally and definitely like give us reviews we'd love to know like what you actually think of the podcast. Please don't be like brutal but like constructive criticism would be nice. We'd love to know what we do. And then if you subscribe you, you're automatically getting our podcast going right to your little, your little iPhone. So we also still have our email that you can chat with us at, which is fibrofriendspod@fibro.org? Question mark, yes it is.

Kay [01:13:29] Probably, maybe.

Caraline [01:13:32] Just check the description I always tell you everything is there. Don't trust me. You could leave us a voicemail to. You can tell us how much you love Kay's memes as well, and we'll make sure we tell her.

Kay [01:13:43] Yeah do that.

Caraline [01:13:43] And we also have our Spotify playlist. Anyways. Ramble, ramble, ramble, blah blah, blah. Kay, thank you again. We're so happy.

Kay [01:13:52] Thanks for having me.

Caraline [01:13:52] We need to go. So see you later.

Skye [01:13:55] Bye.

Caraline [01:13:56] Bye.