Episode 6\_Lets Talk About Pain\_v3

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Welcome. I'm Dr. Rachel Coakley, a pediatric pain psychologist at Boston Children's Hospital and the founder and director of the comfortability program. And this is chronic pain as you've never heard it talked about before. A podcast series developed and produced by the comfortability program peer advisory board. The amazing teens and young adults you're going to meet in this podcast episode, aren't here to offer up some of their best learn tips and tricks for coping with pain spread from great science back knowledge. And importantly, to let people who are struggling with chronic pain know you are not alone. So let's dive in. We're really glad you're here.

Hi, I'm Sophia, and this is today's episode, let's talk about pain.

Hi, I'm Brigitte and I'm also here joining Sophia.

I'm Brooke and I am here joining Sophia and Bridget on this episode.

Okay, so just starting off really simple. Do you still get asked about your pain?

Um, personally, like, Yes, I think because a lot of my pain for me happened like in that, basically that like six to eight month period right before COVID started. So I saw a ton of people like while I was on crutches while I was in the midst of like dealing with everything. And then it was quarantined. And that's where I really like for me learn to manage my pain. But then now it's like the whole world is opening up again. And you're seeing people I like I'm seeing people I haven't seen in like, two years. And you're like, Oh, how's that thing with your foot? Like, how's your pain and stuff like that? So I definitely, like still get asked about it. But it's just such a weird situation. Because it's like, because of COVID too, I think I get asked about it like even more by like random people.

I get asked about it. Um, I would say it really varies i It's been almost six years since I've been through pain rehabilitation. So because it's been so long, I've gone through college, I've gone through abroad, I'm now currently in grad school. So people that know me now such as my grad school classmates, they don't know me when I was at, they didn't know me when I was at my worst in high school. So they don't necessarily ask me about my pain. However, I would say if I do reveal that, to them that I do have chronic pain, I would say most people are surprised, I would say almost everybody is surprised by kind of how well I can function and manage despite the chronic pain. However, if I run into people from high school, if I'm back home or family members will sometimes ask me about my pain. And that's really where I have to focus my energy into making the conversation. productive one.

Yeah, so I would say for me, I like very rarely get asked about my pain, really. But it's kind of weird for me, because sometimes I feel like people very close to me need to know, except they didn't know me when I was going through the worst of my pain. So it's kind of like an awkward dialogue that I do have. However, like most people kind of just forgot about it. I remember it used to be kind of like the topic of discussion a lot. And they used to get asked about it daily. Now it really, really bothered me, but now I don't really, I don't mind it at all. And I feel like I've learned how to turn the pain discussion into something productive. And even like, educational in a sense about spreading awareness and also kind of trying to fight the boundaries that like, are the stereotype that pain chronic pain is like, debilitating, paralyzing, and like everyone can see it and you can't do anything normal. So I feel like for me, I get asked about it a lot less now, but still like those conversations come up.

The interesting thing about it is that if people knew me when I was in high school, they would just say like, oh, like, if I were to talk to you, I would know about your pain and the first four seconds of a conversation like it would be Hey, I'm Brooke. I'm, blah, blah, blah, like, I don't know, 15 years old, like oh, by the way, like I have chronic pain. And now I mean, sometimes I bring it up just because it's so integral to the work that I'm doing now as a clinical psychology graduate student, but also it's something I've become extremely passionate about. So I feel that I use it to the My advantage that I can spread awareness about chronic pain, but also, I'm always shocked about what people's misconceptions are about chronic pain, especially in adolescents and young adults.

Um, so for me, like those are like two stories I can totally relate to because Sophia, especially one where you said like that, like awkward dialogue you have with like people who you're like friends with now, we weren't friends with, like, while you were like in the midst of like the hardest part of your pain journey. And for me, that's something I really struggled with it first, like my best friends now, like, like my five, like really close best friends. Like little group of us. I didn't tell them anything for like three months, I was like, they don't need to know anything. Because it was like my new group of friends. You know what I mean? Just like freshman year high school. And I didn't tell them anything to like, maybe the beginning of the summer of like, last year. And I just remember because it was like this moment where I was like, on the stairs, I had like a little pain flare. And I was like, oh my god, I gotta sit down. And I was like, are you okay? And I finally like, Okay, here's the deal. And it was just really awkward, like conversation at first because it was totally something I like, kept in and didn't say anything about on purpose. Because I was like, these are my new friends. I don't want to be known as the one who like, has like a medical condition and stuff like that. But now we're totally go with it. It's not something we talk about unless I feel like I need to. But it's like at first I totally like understood what you're saying about that conversation with new people.

It's so interesting that you say that because my therapist a few months ago, just I'm a senior in high school, I'm starting college in the fall. And my therapist asked me about talking about my pain in college and how I plan to do that. And for some reason, like my first immediate reaction was, Oh, I'm not going to tell anyone, this is a brand new start, like no one needs to know like, this is like a secret. And then I immediately like checked myself about like, Why does it need to be a secret? And actually, the people that know about my pain, have proven to be well, now that like, We're close, and like we've grown up and the people that I'm actually like, genuinely close to, they're incredibly supportive. And they'll notice things that maybe I don't notice, or will advocate for me, maybe when I can't advocate for myself, or don't think to advocate for myself, like we're in a larger group. And we're doing a ton of walking, what am I good friends will be like, why don't we just like, Stop, get some coffee or something like sit down for a second. Because walking for really, really long periods of time, still is something that like aggravates my pain. And even if I don't feel it in the moment, like pretty much all the time, if I walk a very long period of time, that night, I'll have a very bad pain flare. So it's just like interesting how it's something that like, even more recently, I was so guarded towards and like have kind of shifted my perspective in the sense where like, pain is not a bad word like, doesn't need to be something you're embarrassed about. It doesn't need to be something that you shy away from talking about. And it's crazy that I've gotten to the place now where I don't think of like having a pain conversation as something that's terrifying, but rather something that can be helpful or productive. Yeah, so I guess that brings me to my next question. How did you guys get to a place where talking about pain was no longer incredibly triggering or bothersome or anxiety inducing?

Um, so that's a really great question. And honestly, sometimes it can be extremely anxiety inducing, depending on who I talk to. And depending on what the situation is, but, for example, kind of what Sophia was just saying a minute ago, I really wanted to go to college and have a fresh start. I went to college a year after I finished my pain rehab program. And for a very long time, I was like, I'm not going to tell anybody nobody's going to know. And then I realized that I wanted to use my story of resilience to really kind of educate people and talk to them like, yes, this was where I've been, this is not where I currently am, however, you kind of have that humility that you know how bad things can get. And you know, that things can get really difficult, but you also have that really powerful inner strength. So, for me, I really did not talk about pain for I would say the first 12 months after my pain rehabilitation program, I was actually given a letter by the program to give to family and friends. Because it was majority of the time it was my family who would like not my immediate family, but extended family who would not necessarily respect my boundaries, and would pry questions and would keep asking questions that I wasn't necessarily comfortable answering. And I gave them a letter that the program typed out, they gave everybody the letter, and I pretty much said if you asked me how I am I'm just going like to say that I'm fine. And while I didn't really like that, in the beginning, it really kind of took the focus away from my pain, and really kind of gave the message to family that this is not necessarily the appropriate time to ask about it. I mean, I didn't want to be sitting at Thanksgiving and being asked questions about my pain, especially because chronic pain does run in my family some. So now, I'm at a point where I'll pretty much talk about it to anyone about anything at any time, like I'm very open about it. But it did take me I would say, a few years after leaving my pain program to really kind of change the way that I discussed pain.

Broke like that, like whole, like fresh jar idea. Something I'm still like, super like getting used to, because like my fresh start, I was like freshman year, you know, like high school like Mike because my pain, like for the most part of it, like that specific part of my journey happened in eighth grade. So I was like, Okay, I had quarantine, I learned how to manage it the best of my abilities, like I can do everything I want to do. So freshman year was like, my, it was my fresh start, I wasn't going to tell anybody. And I really carried that into like my sophomore year, I think, um, people who weren't like my close friends. And once I kind of joined the board, like with you guys, it's become a little bit more easier to have this conversation, like about pain, because it's something I'm still like working on. Like, like now, like when I'm out of the perspective, or like when I'm out of the middle of it, like now like reflecting back. Like, that's where I'm having these conversations. And it's a little bit different, I think. And I'm, like, it's so easy to talk about it with people, like who have experienced chronic pain, because like, everyone's just so understanding, but like sometimes even talking like just at school, like if it comes up and like that, I'm like, am I being like a Debbie Downer, like am I like making everyone else uncomfortable by talking about this. And I've really had to like use, like, thinking strategies of like, this is a conversation, like if you feel like it needs to be had like it can happen. And it's like super important to you. So I really had to remind myself like a lot. And that's strategy I've been continuing to use, and it's been working for me for the past few months. So really, really changed.

Something that has really helped me is kind of putting, getting into the mindset that everybody has something, everybody. Regardless if it's physical, emotional situation, almost everybody has their story. And this is my story, this is my story. And it's really not something that I should be ashamed of. And it's not something that I want to be ashamed of, because the pain I feel like and kind of going through this whole transformative process has really made me into the person that I am today. And I think that's really critical. I mean, I have some friends from the pain program who you can't even mention it around them. And that's fine. That's their choice. But it's also really transformed me into a way that I have to get very used to talking about pain with many people. Because that that's how it kind of I want to for my career and to being the pain psychologist, but also recognizing that this is an important part of my story and my life.

Yeah, and I think it's like, incredibly important that people have these conversations with those around them, because like you just said certain people don't want to talk about it. And that's okay. Also as long as it works for them, and it's healthy for them. But other people like for me now, like you both like we're talking about this in such a productive way. And that's what I think like is the really critical switch. Especially because Bridgette, I used to be the same way in the sense where I was like, I you literally don't want to talk about my pain because I feel like I'm being such a Debbie Downer. And I'm just like bringing down the mood and everything like that. And I also kind of went through a period where I just kind of like mouth, throw up like word vomit everywhere. Because I'd be like, Oh my god, like I need to justify myself. I need to justify why I'm limping. I need to justify why I'm on crutches one day, I'm not on crutches the next I need to justify, I need to talk to that teacher who made a weird comment, I need to do this, I need to do that. And then I've kind of gotten to the place now, where I really do see pain, like the discussion of pain as a choice and not a requirement. And this is As my story broke, like you were saying, like, everyone has their own story. And because it's mine, I am in charge of who I get to tell. And I can then mitigate what I tell to who and how much people should know. And if someone's consistently saying, like, behind my back, like, oh, I don't believe that that's real. Like, I've never seen pain like that. And I've done the best my ability to educate and like, actually try and explain what's going on. It shouldn't be something that's causing so much turmoil in my brain, because I can't control what other people think. I know, my pain is real. My doctors know My pain is real. And I've come to a place where, like, that's enough for myself. And so now, I see pain, like this discussion, as completely a choice. And like, I want to be here, I want to be talking about this. I want to be spreading awareness. And I'm, this isn't like an incredibly anxiety inducing conversation, because I think it's so important that just like realizing, you kind of it's your story. So you get to dictate who you tell it to and how much you tell. And that can change with different people.

Yeah, like, and like, even today, like I had a conversation, I was talking to like one of my best friends and biology and I was like, we were just talking about what we're doing. Like later. And he was like, aren't you recording your podcast tonight? And I was like, Oh my gosh, yeah. And my biology teacher who like I love, he's a great teacher. He was like, Oh, my gosh, you have a podcast. And he's like, what's it about? And I was telling him about it. And like, he responded in such to like, good manner, like, because I was like, informing him about, like, my chronic pain and how I've, like, now turned it into, like, a way to help people. And it's something I'm, like, super passionate about. And like, it also, like helped me realize that like, I'm, like, judging myself with this conversation, like more than people are judging me. Like, like people, like people can actually be really understanding probably more than I give them credit for. And it's a lot of like, my own anxiety. And I was like, after I was like, Oh, my God, like, look at that. I just had that conversation, and I felt so good about it afterwards. Um, so like, I think it's something that I've like, definitely, like, improved upon a lot. But I also it was a lot of like, my own, like, inner feelings about the situation rather than other people. And like you said, Sophia, if somebody like doesn't respond in like a way you want them to like, like in like number of times, like you've given them a few chances to really understand your perspective. Like, you don't owe them anything.

Yeah, that is, like, so well said, because I was very worried about people believing that my pain was real. And that was something that I struggled with for a very long time in high school, that I was very worried that people would not believe that what I was going through was real, or they would see me in school, but leave early or they always see me at the nurse or like, but then I kind of realized that they're, they're not in any position to judge what I'm going through, or any person with a chronic illness is going through just as I wouldn't judge somebody else about what kind of situation they're dealing with, because I'm not living in their body, and I'm not living in their shoes. And I think that that's something that once I realized that nobody can really take that away from me is that sense of power, and that sense of, oh, I can share the story that I want to share. And I don't really care what they say, it doesn't really matter. It doesn't. It doesn't move my needle in any capacity, what they say, because that's their problem.

I feel like it's kind of taking ownership, like it's taking some back some power back from pain, because I think I can speak for all of us when I say that pain definitely had some control over our lives at some point, whether it be a long period of time, whether it'd be a lot of control or a little, but I feel like now that I've like come to the place where I'm like, This is my story. It's mine, I have ownership of it. And I get to decide what to do with it. And it's just so I don't I don't want to sound like cliche, but it's empowering. And it also makes me think of how like, there are different people you're going to encounter. And you're going to tell different people different things depending on levels of closeness or comfort, I guess. So I want to ask you guys like how do you guys talk to friends or peers about pain?

Um, so something I did originally, which is still really helped me one of my favorite methods is I made myself a little chart, like with my psychologist, boss childrens and I, we made like me a little chart of people who need to like what people need to know. So it's like this little bubble chart we'd fill in. So you have like, one circle, like the inner circle, like like super close people, like people you're genuinely friends with, like, you're super close, like the family that you want to know. Like that you want them to know what's happening. And then you had like, your middle circle who like, you know, your good school friends, like, like sports friends, maybe people who you're like, friends with, but they're not like, like people you're genuinely close with. And then like, you just had that outer bubble of like people you just see at school, like, even just people in public, like random people who will see you on crutches and be like, are you okay? And that like method of like categorizing people, which sounds awful, but like that method for me, like really helped? Because I'd come up with like, little things to say to like, each group of people. Like things I've rehearsed in my head, about, like, who needs to know what, and then like, what do I say to them. And that strategy really helped me and like, some people have, like, bounced back and forth, like in between this categories as time goes on. But there are people I've gone to school with for years, who I've just like, used the same strategy with them every time.

Yeah, I remember, I actually filled out that exact same chart when I did I my pain program, and that was something that was extremely beneficial. I mean, every time I kind of entered a new stage in my life, I always kind of go through this whole, okay, like, I'm not going to tell people, I'm gonna not even use accommodations, I'm going to really just try to like, pretend to be like everyone else. But then I also, like, a couple weeks into the year, I'm always just like, alright, this is not working out. So great. I probably should advocate for myself. I always kind of tell people, when, when it's a good friend, they'll kind of know. Like, some of my best friends, though, pretty much like they'll know if they don't hear from me for a little while. Or they'll they'll know like, if I'm just acting a little different, but most people won't know. And I definitely have learned that people don't pay as close attention as you think they are. But most of the time, I've really kind of talked to friends about it, like, oh, like, I literally will say like, I have chronic full body pain. I have had it for many years. I went to a pain rehabilitation program. That's why I need to do XY and Z. Or like, sometimes people make little comments like, oh, Brooke, you're always working out? Or why do you go to bed so early, or even just like little things that they don't bother me anymore, but they used to. And then I'll be like, oh, like, I just have to do it to manage my chronic pain. And it usually ends at that.

Yeah. And another thing like, for me, this is like kind of a different bubble. But like, teachers, I used to get so annoyed with repeating myself all the time, about what I'm going through what I need, blah, blah, blah. And now, I actually have no problem with it and have no problem advocating for myself and having these conversations however many times they need to be had, however, especially when I was at the beginning part of like managing my chronic pain and actually like, trying to set plans and things like that having a point person at school was so so beneficial, because then I didn't need to repeat myself over and over again. And I mean, I was in middle school, quite frankly, because nobody or at least not enough people know enough about chronic pain to understand what it looks like how it might affect your work ethic, how might affect the quality of work you produce, why you might need accommodations, like getting up to stretch in the middle of a test and things like that. Having a point person at school helped me do that and like kind of talked to my teachers for me was so so beneficial. So like I didn't always used to talk to my teachers, but now I do and I don't know. Yeah,

I I found it very difficult, quite frankly, in high school to talk to teachers just because I was really trying to figure out what was going on. And it took me so long to actually figure out what was going on that I it was like every four or five weeks it was like a new doctor a new plan. Kind of but then once I went to the pain rehabilitation program, I really kind of got like a two second script, figured it out in college actually. I'll go up to my professors at the end of it My first class with them, and I would just be like, yeah, hi, like, I just want to introduce myself. I'm still working on sending over to you my formal accommodation plan. I don't suspect it being an issue, but in case it does, this is what I will do such as, like, I'll email them, I will kind of files something with like the Office of Disability Services. And really kind of advocating for yourself before you need to advocate has been probably one of the most beneficial things I do. I've just found teachers and professors are way more accommodating. If you tell them before there is a problem, then when there's when you're in the thick of a problem

broke. That's like something I totally agree with. And like, one of the biggest lessons I've taken away from like, this entire situation is like learning to advocate for yourself. It's like one of the biggest things. It took me like, like my parents, like, they obviously didn't do everything for me, but like, they were my parents, you know what I mean? Like that, like, that was their job when I was like 1213 years old. And now I just like, it feels weird to have my parents. I'm like, oh, like to have them like email a teacher for me. Like, when it's not at that point yet. So I think advocating myself for myself and like all aspects of life has been like, huge, not just with like, pain, but with like school, and sports and all that stuff. And you kind of feel better if you do it yourself, too. It's like, like, I just did this like you like, it makes you feel like a little bit grown up a little bit more mature. And it also just establishes like a healthier relationship. I think if you like Brooke said, like, are the one to go to like your teacher first. And say, because like, they'll appreciate that, because so many teachers just get frustrated. I think when kids come with problems last minute. Um, so I think it just makes, it'll like end up bettering your own situation, if you like advocate for yourself.

That actually brings me to a question, do you guys talk about pain differently with your parents? Or family? Then you do like friends or other people? Like where do they fall and you're talking about pain? She because for me, now, we only talked about it when I bring it up, because they kind of know not to ask, but for a while, like pain consumed every single conversation in my house. So much so that we literally didn't like my doctors were like, no, no, this is not gonna work like, you know, talking about pain at all. So we just like didn't talk about pain.

Yes, so I had the same situation where pain was like, literally all we talked about for three, four years. And then once I went to the pain rehab program, I really, they were like, Yeah, you're not going to talk about it. And now, like, I remember being like, oh my god, what am I going to talk about? Like, I have nothing else to say. But then I the only time honestly, like, my family and I talk about pain is usually if we're talking about something that happened. And I was very fortunate that I had a very positive experience at the pain rehab program. So we'll talk about that. Or we'll talk about like, if we talked to some certain people that we were with and like sometimes, like, my mom will still keep in touch with a few of the parents and I still keep in touch with a few of the kids. So like, I'll be like, Oh, I heard from this person today. But yeah, my mom, dad, sister, like, nobody ever like unsolicited is like, oh, Brooke, by the way, how's your pain today? Like, that has not been even like a question. Almost six years?

Yeah, I think that's like, one of the most like, like one of the biggest differences you see after you like, learn to manage your pain and like the healthiest way possible for you. It's like, it's not like that lingering conversation cloud, if that makes sense. It's not like that conversation topic that you just directly go to, like me, and my parents only talk about it really, when like, I feel like I am having like an issue and I need to bring it up. Or sometimes it'll just be like, weirdly, in a stall tactic about it. It'll be like, march 2022. And it's like, think of what we were doing like two years ago, like you couldn't walk. It's like, look at you now. Uh huh. And like look at how you've grown as a person like because of this whole situation. And it tends to be in a very, like positive manner now, I think whereas comparing it to like, just two years ago, it was just like, this dark, negative energy cloud, I guess like they just but there was nothing else to like, talk about like that was really like who you were. And it was like Did your parents obviously feel the need to care for you? So like asking, like, how are you doing? And like all that stuff just come so naturally to them. So it was just this big like shift. But now it's like we do look back on it and like a positive way. It's like think about like, like you said, Sophie, like how far you've come.

It's really interesting. Because if somebody was to ask me, seven, eight years ago, how are you? I would be like, okay, my pain is this level today, that would be how I would respond. Now, it's not even something that would cross my mind. And I vividly remember driving in the car with my mom, I must have been 14 or 15 years old. This was at the real the really early, beginning stages of my journey. And I had a doctor tell me, oh, like, just try to only talk about the pain, like twice a week. And I wasn't like a huge fan of how she put like a quantity on it. However, I was like, how am I supposed to do this? Like, how am I supposed to only like, how am I supposed to not talk about it all the time, if I'm in pain, 24/7. And now like, realizing how important it is to not necessarily dwell on it and ruminate about it. 24/7 is so psychologically beneficial.

It's also crazy to me, because I used to think if I didn't talk about my pain, it wasn't real enough. And that if I didn't talk about my pain, like people would forget about it, people would forget everything that I'm going through. And like I needed some external validation that like, this is hard, and people recognize it's hard. And it's such a hard cycle to break. Because while that's valid, like you want your feelings, no one wants to feel invalidated. But talking about it all the time, makes you think about it all the time, and gives pain, even more power. And I think like that's something that I struggled with a lot. And something that actually like really, really helped with that was like journaling about it. Because then you're still like, you're kind of validating yourself in a way, where like, you're putting it down on paper, you're making it tangible you're making, you're seeing that your feelings are real and concrete and tangible. I guess I just said tangible, but still. And instead, like, it's not consuming your brain in such a way and like consuming your household. And I don't know, that's something that was a really, really hard shift for me also

represent. That's something I like totally agree with. And honestly, I think my mom did more of it than I did with the journaling stuff, because she was always big on that. But she was like, Yes, I can get into it. Especially like after the comfortability, I think where my parents were, like, told, like, don't have this conversation with your kid, like 24/7, because all it's going to do is like remind them of their pain. And like what they're feeling. So like, I think like my mom really got into like journaling, it was her way of how it was your outlet for it, I think. And for me personally, like, I didn't realize, like, what the pain conversation was about and like, kind of like, tone it down. Until I went to therapy. That was what really helped me was psychology therapy. And it was, and now it's shifted from like, it used to be like the pain conversation. And like a negative way. And now it's the pain conversation in a positive way. And that's why I can have conversations more now. But in like the thick of it, that was like, what was really like, reminding me of my pain 24/7. And like you said, Sophia, that's what like make like can make your pain like hurt, like, can make you hurt even more. So it's like that shift from like the negative talking about it to like the positive talking about it now.

Yeah. And it's been really, I think also having a new relationship with myself. After the pain rehab program really has been beneficial. I started doing journaling and yoga and really just a lot of introspection and meditation and mindfulness. And that really helped me form a new relationship with myself and kind of realized, okay, like, you can have pain, the pain doesn't necessarily have to been, something's wrong. It's not always a bad thing. And like really kind of take things. Step 20 steps back whereas a few years earlier, if I was in pain for like, a week, I would end up at the emergency room. Yeah,

I think like the entire even like with the pain conversation, and like the way I've looked at it over the years, I think it's just such a telltale sign of growth, and how far we've all come and like the pain conversation for me was a very hard adjustment because I felt as though it kind of flooded all aspects of my life. social, academic family. And now it's not something that I, like get super worried about because I know like, I know in my own self that my pain is real. I don't need to justify it to other people. And it's conversation that I can have if I want to, but I'm not required to.

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