

# Episode 5 Pain and School\_v3

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## SUMMARY KEYWORDS

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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, everyone. Welcome back. Today's episode, we will be talking about pain in school. I am Brooke. I'm Sophia.

And I'm Fiona.

And today we're going to be having a candid conversation about chronic pain and school. This is an important topic, because for so many people, pain is something that affects every aspect of their lives, including school, which is where majority of the time, teens and adolescents spend their time, school can be very tricky to navigate with chronic pain. So the hope is that through this episode, you will learn tips and tricks for kids to be able to take steps in the right direction, but also hear about things that have worked for us and how pain has affected our lives and how we have not let it stand in the way of academic success. So I just want to open it up. How did you handle school and the beginning of your pain, journey.

Um, I think honestly, the first way I handled pain during the beginning of my journey is I didn't, and I would try and get out of going to school, it's not that I was trying to like make an excuse, I just didn't think it was possible for me to be in a place where I could go to school and deal with pain at the same time. And that was kind of because I wasn't dealing with pain. So at the beginning, I would definitely say I didn't really handle school and a because I didn't go and then when I finally when I did go, I felt like I wasn't really present. But over time, and like having someone like building a relationship with someone at school, who I was comfortable with and fully explained things to was really, really helpful. And I wasn't in a place to do that at the beginning of my pain journey. So my parents helped me with that, just because I was so young. So just like having a point person, I was able to make a plan that worked for me and kind of like went across all subjects.

That was definitely my experience too. Because I was in eighth grade when I first started having pain. So I was like a little bit young to kind of be completely advocating for myself. So my parents were pretty involved with working with my school. And then like you're saying, so if we're having a point person that helped me, it's funny, because you were saying at first that you weren't really dealing with pain and school and I had the same experience. But like the opposite, where I was trying to be at school all the time, and pretend I didn't have pain and trying to be at school all the time was of course making my pain worse. And it was, you know, like not a good cycle. So I did ended up also like not, eventually my parents were like, Okay, you need to not be in school for a little while. And then I like slowly transitioned into going like half days to school. And just trying to like build up the stamina almost to be in school for half a day and then like a full day and then start focusing on academics and stuff.

Yeah, so similar to Sofia, I started having pain. I was in ninth grade. So it was a few months after high school started. And it was very, very difficult for me. I remember mornings were always the worst time of day for me. So I would wake up with so much pain or I would not be able to sleep the night before. And when my alarm went off, it was like oh my oh my like cannot like believe it's time to get up already. And I found myself missing a lot of like first and second period classes, which was it was fine for the state that it was just electives in first and second period. So I wasn't actually missing academic content. However, that is just like not sustainable to always be missing. The same two classes like I must have been missing it three to four times a week as well as there are some days that I would leave early for a doctor's appointment And then some days where the pain got to be so bad that I would leave early anyway. And then I guess as my pain journey continued, I, it became very difficult to walk upstairs and walk around the school, it was a three storey building, so it was very difficult. And I actually didn't have a formal accommodation plan. Until my sophomore junior year of high school, I kind of just worked things out with my teachers, and I wasn't even sure if pain was something that would qualify for an accommodation plan. And I really didn't even know what types of accommodations you could have. Um, however, I did, definitely need to develop strategies, which will bring me to my next question about kind of What strategies did you use to get through the school day.

Um, I think for me, it was really, really beneficial to like have a place in the school where I knew I could go, like, if I really needed it, and like needed to be alone or needed to like, do exercises or something like that, I could do that. And that was just like, kind of like a comforting thing, at least for my anxiety. So I feel like that kind of helped some of my pain. But in terms of like strategies that I used, I definitely went on a lot of walks, and I would like go fill my water bottle and things like that. And I wasn't asked about it, or my teachers weren't supposed to ask me about it. And over time, like, when I got to a certain age, people stopped asking about it. And then when I also got to a certain age, it got harder to leave the classroom. So do things in my chair. And, like exercises, my chair, and I also tried to convince myself like, instead of like having a distraction, I would make school, the distraction. So I'd get, I try really, really hard to be as focused as possible. So I wouldn't think about my pain. And it actually kind of worked.

That's so interesting. Like, I pretty much all the strategies I used were also in my chair, because I was really nervous about like bringing attention to myself, like I was already a kid that was in and out of school all the time. Like that was bad enough. So I definitely did the same thing with like strategies and exercises in my chair, but I never thought to make school the distraction. I should have done that. But I

mostly used stuff like chewing gum, although when I got to high school, we weren't allowed to chew gum. So this only worked in middle school. But chewing gum because it was like this really strong like stimulation, kind of distraction of like the activity of chewing gum. But then also like whatever flavor it was. And belly breathing, which I know I like mentioned in the first podcast episode, that it's like one of my favorite strategies to use basically, because you can do it in a chair and nobody notices. But I also had like a little bit of a safe space like you did, Sofia, where like, basically the nurse's office knew that I could come in at any point and just like sit in the back of their office and hang out, which I didn't do very often because again, I didn't want to bring attention to myself. But it was like you're saying really comforting to know it was an option.

That's so interesting, because I actually so I didn't know any pain strategies until right before my senior year of high school. So for the first three years of high school, I pretty much was going in coming school all for three years, I was pretty much in and out. I mean, my junior year of high school, I missed 40 days, I almost didn't graduate high school. And so it wasn't until I went to pain rehabilitation that I really learned how important it is to really kind of you not to miss school, but also to use so many different strategies. Mindfulness and belly breathing was something that I used almost every single day, my senior year of high school such as I mean, I would do 10 minutes when I woke up before I went to school, 10 minutes during my lunch break and 10 minutes before I went to bed. And then occasionally I would get up and walk around the building, but I started to use a lot more pain coping strategies when I got to college, and I was under a lot more pressure and a lot more stress. And some of the strategies that I use there was I really use advocacy as a big strategy. I would typically tell professors at the beginning of every class at the end of every semester, that I have chronic pain and I don't anticipate there being an issue but if there is this is what it would potentially look like. And to me that really signaled a very proactive way instead of reactive, so I really wanted to keep things, keep my teachers ahead of the game and keep myself ahead of the game, regardless. And then instead of having it be finals week, and I'm in a huge pain flare because of stress, and then teachers are like, oh, like, you can't, like Sorry, you have to take the exam. So I really tried to mitigate stress in that way. But I also really made it a point to allow myself plenty of time to get through to my college classes. But also really formally registering with the Office of Disability Services was extremely helpful. And then they're just also just like other little things like I would, if I was in pain, one day, I would actually use school as a distraction, and try to focus extra hard and really try to put all my attention on what the teacher was saying, or the professor was saying, which I actually found to be an extremely beneficial strategy. And that's something that I actually use now in graduate school, that if I'm having a difficult day, I will intentionally try to place all my energy on the task at hand. Yeah,

I feel like, like what you were saying about talking to teachers, things like establishing those relationships is been so important, because I found that like, like, I was kind of saying on the last episode, I kind of feel a little weird, like talking about my pain to people I have no relationship with, if they don't know me at all, and it's like one of the first things they're hearing about me, but like from what I've found is that teachers especially, are really ready to listen, and kind of respect the fact that you're advocating for yourself before it becomes a problem. And I feel like it also shows that you're committed to the course. And like, you don't want this to be an issue. But should there be one you're planning in advance? So there, you will have a plan, you'll know what to do. And I feel like that's been so helpful, just like as I got older, and I became more comfortable talking about pain and everything.

Yeah, I was really nervous in the beginning of high school, that teachers wouldn't believe me. If I would tell them about my pain. And I was really nervous that they'd be like, Oh, you're fine, like you were in class yesterday, or they would be like, Oh, I don't necessarily like, or even if they didn't necessarily tell me anything, that they wouldn't necessarily treat me with respect. But it actually was a pretty, pretty powerful experience. I was in the hospital for pain for a couple days, my junior in the very beginning of my junior year of high school. And I was so nervous the entire time I because it was a really difficult part in my English class. And we were reading a very difficult book. And there was a lot of very detailed book quizzes that I was missing. And I was so nervous, I didn't know how I was going to catch up. And then I talked to my teacher and I was transparent about it. And then I kind of later learned that her own child had pretty significant medical issues. So she ended up being way more accommodating than I ever could have anticipated. And I found that the more open I was with her and the more open my parents were because they helped me advocate at the time when I was in the hospital, it really was able to spark a productive conversation about it.

Yeah, I like my freshman year, I like didn't want to advocate for myself at all. I like decided, oh, like we're gonna leave this in the past. Because the year prior I missed like the first while of school because I was in a pain rehabilitation program. And freshman year, I was like, Okay, this is my first year in five years that I'm not starting school on crutches. And, or maybe it was four. And I was like, so I'm just gonna like, like, erase this from the memory like this never happened. And it kind of really a bit mean but because I ended up doing poorly, just like freshman year, like when you compare my grades to now to my freshman year experience, like they're very different. And I think like a large part of it is just I was not advocating for myself. I had no like in school accommodations, at least none that I allowed myself to use. And this year, like you were saying earlier, Brooke like I when the beginning of the year like I introduced myself to all my teachers will and I've been using it accommodations that like I actually need, and I have for a reason. And it's just like interesting to see like how much better I'm doing academically now that I'm not seeing pain as like, a swear word.

So going off of accommodations or things that you found helpful, what did you find to be helpful for you during high school and college,

um, like you were saying earlier said something about being proactive and reactive. And one of the big things that helped me was like setting up my day, and using strategies in the morning before I was going to class for I was going to school, so that I was like, starting my day in a pretty good place with as little pain as possible to like, set myself up. So I could be in a good place for my classes, and then maybe not have to use as many strategies or leave the classroom or something like that, or miss a class. And so doing that, and also going to bed on time, this is gonna sound silly, but there was so much pressure, like if I couldn't finish my homework, because I was in pain, I wanted to keep like pushing through and trying to finish it. But then that pretty much always resulted in me producing a kind of crappy product, that wouldn't really have been worth turning in anyway. And so learning to have like, kind of the discipline and myself say, no, go to bed, and maybe wake up a little bit early tomorrow morning and finish your assignment and have that be like more quality work, then trying to push yourself past what you can do today. So like setting those boundaries, and then following them for myself was really helpful.

Yeah, that's something that I actually do still is, I really kind of, I'm working on treating my schedule now more like the traditional work day schedule. And in graduate school, it's really difficult, that work can just get pretty out of hand all the time. So really kind of live setting boundaries on myself that I'll obviously work late, or get up early when I need to, but trying to be as productive as possible during working hours. But also something that really helped me was after I came back from pain rehabilitation. And this was probably one of the hardest parts about Pain Rehab for me, was to completely decreased my academic rigor load by a lot. And I mean, I was in accelerated and honors classes all three years. And everybody at the pain rehab program was like, you're going to take the lowest level class as possible. So you can focus on using the strategies and perfecting them pretty much. And I was terrified, I was so upset. I remember that being one of the hardest parts about the program. And I was super reluctant. I was like, I'm never gonna get into college, I'm not even gonna get into the college that I want to because I'm not taking all honors and AP. And I was shocked at how much more time I had to spend to take care of myself and focus on self care, and focus on things that actually brought me joy in my life besides doing homework, because that actually does exist. And in the first few months after coming home, you really start to build a new relationship with your body and yourself and with others, because the relationships are very different when you're in pain all the time. And I also kind of got to really solidify that foundation, before attending college, which really set me up for and I did end up applying early decision and getting into the college that I originally wanted to go to. So it all worked out in the end. And it really helped me build a strong foundation with skills that I was able to pull out of my back pocket at any time. And I wasn't afraid that they would not work or I've had a very strong foundation of skills.

Yeah, and I feel like the fact that like these are life skills is so comforting, because like, when I was younger, I didn't really I was I guess I was kind of reluctant to put in the work and like build these skills and like have these tools but now they're things that I utilize so much. And even like you're saying with the course load, like I've found, like this entire thing has like allowed me to like be nicer to myself. Like if I'm in pain. Like I don't need to sit there and do homework and produce something poor when I know I could do better on it. If like I think I'm just like kind of like fighting fire with fire and never really worked out my way. So I feel like one thing that I like really, really learned through all of this is just like, Be okay with, like, things not necessarily going according to plan. Unlike now, like I try not to have super, super strict plans, I like to like outline my day, but not plan it. And when I say I used to plan everything, I would write minutes on my planner, you're going to do this from this to this, and I never spent the correct amount of time on anything. And I would get really mad because like, obviously, if you're in pain, doing a homework assignment that's supposed to take an hour isn't going to take an hour, and it's going to take a lot longer. So setting these, like, strict strict limits for myself was really detrimental, because I always felt like I was letting myself down. And which then like makes everything worse. So I just feel like being nicer to myself. And this entire thing has like really given me the gift of being okay with things not going my way. And like just being a lot more go with

the flow. Yeah, something else that I've especially been thinking about pretty recently is that how would you talk to a friend who was in your shoes if a friend told you or a teacher? Or a teacher told you that? Oh, like they couldn't finish grading the papers? Because they had a really bad migraine last night? What would you say? Would you say oh, like, I'm so mad, you didn't get me the paper on time or like

you, the way that we treat others is so much nicer than the way that we treat ourselves. And that's definitely something that I've really learned throughout this entire process is that you should just give yourself grace, because what you're going through is something that many people will not go through. But also, it's not only something that's happening in your body, but it's something that's going to be a character building experience, but also a transformative life experience. So I really think that just kind of going in with the attitude is okay, like, if you can't do seven hours of homework today, and you can only get done four, then it's still four hours of work. But it's also how would you if a friend told you that and a friend was saying, Oh, I'm in like such terrible pain? What would you say to them? Would you say keep working, keep working? You keep working? Like? Of course not.

It's really interesting, because I used to, like have the mindset of like, you need to do seven and would be so upset if I only did four. But then it's like, if you do those seven. And then the next day, you're like, I did seven hours of homework yesterday, I need to do that. Again. This is the cycle I got into and then I got so burnt out and my pain was at an all time high because I wasn't sleeping enough because I was always doing homework, and still juggling everything else. And then the next day, I'd be exhausted running on three hours of sleep and do it all again. And like it wasn't helpful, because then I experienced such a burnout. And now I kind of like got into the mindset of like, you did four hours, you might want to have done seven, but like four is better than none. So you want to do seven every day, and then come to the day where you're like I literally can't open my backpack. No. So like, balance is, yeah.

Did you tell your teachers about pain.

So when I was in middle school, my parents were the ones telling my teachers about pain. And then when I was in high school, I kind of started transitioning towards like, me and my parents telling my teachers about pain. Basically, at the beginning of every semester, we have like a meeting with the teachers that I would have to sit down and be like, okay, hey, here's the situation like I did have an accommodations plan with my high school, so we had to go over that. And then obviously, when I was in college, I did it by myself. And that was probably the like, only time I ever felt really genuinely nervous about it. Because like you guys were saying earlier, I was pretty afraid that they weren't going to believe me or think that I was somehow trying to like take advantage of like the system to get more time or not have to like, complete all the work. And so I did having those meetings was really hard and talking about like, you don't of course when you have like accommodations, you don't have to tell your teachers, your professors, why you have the accommodations, but I always felt like I needed to somehow to like justify it. And while those were hard conversations to have it made my stress a little bit lower because I wasn't feeling as anxious thinking like, Oh, they're just gonna think that you know, I didn't come to class because I'm lazy or you know, any number of different things that then stressing about that would make my pain worse. So it kind of like having the conversations were hard but set me up have clear expectations between my teachers and professors and me, which made my stress better.

Yeah, I definitely had a similar experience. And I actually like went through a weird situation with this because as I saw, I go to a private school. So I never had to apply for a 504. And it was just like a conversation between my doctors and my teachers. But when I was taking standardized tests for college, like the AC T, I did need to apply. And I did need to submit everything. And I did need to



submit, like literally what felt like my life story. And I got rejected. And I was like, Does this mean that like, people don't believe my pains real and I kind of took it like way too, personally. But I never like had kind of like a piece of paper that was basically like, you're not deserving of the accommodations that help you. And that's what it felt like. And I like reapplied, and it got accepted. So it was fine. But I think like, emotionally that was really hard for me and kind of like, forced me to take a step back and actually think about, like, why I cared so much. Because I always say at least I say to myself, like you need to be enough for yourself, in the sense where like, you need to know your pains real because I went through a time like where I if someone said something about me, I'd start doubting myself. And I'd take it too, personally. And when you're letting everyone else's words like infiltrate what you think about yourself, it's just such a negative downward spiral. And so it was kind of like a weird moment for me because I needed to take a step back. And I was like, I tell people all the time, like you, like need to be enough for yourself. And like, No, Your pain is real. But here I am, like taking this piece of paper, this faceless like No. to heart. And yeah, so that was like really interesting. Because even after all of these years, I'm like, so comfortable talking about pain. And still like that really got to me.

Yeah, so I always kind of in the beginning of my pain story, I would have my parents talk to the teachers. And mostly just because I was way too shy and way too scared. But as I would say, starting senior year of high school freshman year of college, I really started advocating for myself, and I honestly found myself to be pretty open about it. I would, especially with my professors, I would typically just say like, hi, like I'm looking forward to your class this semester. I do have chronic pain. And I do have a formal accommodation plan that will be coming your way soon. But I just wanted to give you I guess, like a verbal heads up. And I honestly found that pain is nothing to be ashamed of. And everybody has something and it's obviously everybody's choice what they would like to share. But I also found that most of the time, like it wouldn't, like change anything, whether I told them my pain or not. And I would just want to be just like, I didn't feel as if especially in college, once I got very comfortable with myself, I didn't find that it was anything necessarily to hide. So yeah, like, I have pain. I also have, you know, brown hair. Yeah, exactly. Like I have brown hair, I have brown eyes I like I it didn't necessarily feature like become like as much of a defining factor in my life as it was in high school. But I also found that really, the teachers and professors really appreciate you being transparent, and not like by giving them all the details, but transparent and that you're being proactive. And that was incredibly helpful in grad school, and definitely a little different because I am kind of backwards. sophio recently talked about where I really want to leave this in my past. But I also know that it's very, very unlikely and probably not going to happen. So I've just kind of been dealing with it as it comes up. But I definitely have to go back and brush up on these skills a little, especially for the next coming years. But I also think, you know, we all go through ups and downs of RPM journey and sometimes it's easier to talk about it with certain people than others. And it's just, I guess, like a humbling reminder that I have to really, even though I've advocated for myself before, it's not always easy. And I really commend you all that are advocating for yourself at different stages of your life and going through different circumstances at different schools. Just because it even though It might not be what you want to do, it's ultimately serves you very well. So I have one final question for you all. If you were to tell your younger self something about pain and school, what would it be?

That just because you have to take a step back in your classes, it doesn't mean that that's forever, it means it's temporary and what you need in the moment, but you can get to where you want to be.

I think I would tell myself, that, although this was a really challenging experience for me, and it sounds weird almost to say this, but having pain because it was so informative for me, and especially with school has really shaped me into the person that I am now and a person that I do like, like, in high school, when I was having pain when I was in and out of school and having setbacks. It was really hard for me to like who I was, even though there were circumstances were really out of my control, it was just challenging. But all of those ultimately led up to me applying to the college that I went to, to studying neuroscience, which I majored in, to bringing me here to this place that I really love. And I'm excited about the brain and enjoy talking about pain and all these things. So even though it was like one of the hardest things that I did going through school with pain, I'm also like, grateful for it at the same time.

I agree completely.

Yeah, I would tell my younger self that you are going to learn so many skills along the way that will change not only how you view yourself, not only how you view education, and even how you not only how you change your career, I mean I started my whole life I decided I want to be I want to be a neurologist, and then after my pain rehabilitation experience, I was like hold up, I want to be a pain psychologist. But I would just tell myself that you're not going to be stuck in that treacherous and what seems like a treacherous endless loop forever that there is a light at the end of the tunnel

on behalf of the comfortability program. I want to thank Sophia, Fiona, Brooke, Bridget and Katie for their incredible work in writing, producing and recording this amazing podcast. We are so lucky to have the privilege of learning from you and working with you on the comfortability peer advisory board. I am also so grateful to my comfortability team, especially Dr. Amy Hale, who provided support and guidance to the pier board and staff throughout the project. Thanks to Dr. Hale, we all got a little zippier and felt a lot more confident. I also want to thank the Department of Anesthesia, critical care and pain medicine at Boston Children's for supporting this work, and the team at open pediatrics for the podcast post production. Finally, a shout out of gratitude to our strong and growing network of dedicated partner sites in the US, Canada and Australia. If you're looking for more great science backed information about managing chronic pain, check out our website that [comfortability.com](https://comfortability.com) We've got lots of helpful resources online including information about how to find a comfortability workshop near you. If you enjoyed the podcast and you want to help the comfortability program grow, so we can continue to support young people with pain. Please consider a tax deductible donation to the comfortability program through Boston Children's Hospital. How do you donate? It's easy. Just go to our website, the [comfortability.com](https://comfortability.com) and look for the donation button in the upper right hand corner. For more great content. You can follow us on Twitter, Facebook and Instagram. We are at the comfortability across all social media. Finally, I just want to say I'm so happy you tuned in to listen today. I know I speak for myself, our peer Advisory Board and the comfortability team when I say