

Episode 3_Pain Myths_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.

In today's episode, we are busting myths about pain. To help us sort through all the information. We are excited to be joined by Dr. Bobby Riley and Dr. Rachel Coakley, a physician and a psychologist who are experts in pediatric chronic pain. Dr. Riley is an anesthesiologist and pediatric pain physician, the director of the chronic pain clinic in the pain treatment service at Boston Children's Hospital and the medical advisor for the comfortability program. And Dr. Rachel Coakley is the founder and director of the comfortability program, and the Director of Clinical innovation and outreach in pain medicine at Boston Children's. Both Dr. Riley and Dr. Coakley are on faculty of Harvard Medical School.

Hi, on today's episode, we begin by acknowledging that there are many misconceptions about pain. And sometimes these misconceptions can stop or prevent people from doing the work that is actually most helpful. I actually experienced this firsthand because when I was first diagnosed with complex regional pain syndrome, my first response to this was looking at my diagnosis. And Google gave me a whole slew of really scary information and facts. I only learned over time, that were not actually true. Nonetheless, I do know it is really hard not to believe the first article you read. I was just a kid tried to make sense of something I knew absolutely nothing about. I was eager to fill in the gaps of unknown and ambiguity. And in turn, I got in the habit of believing the first thing I've read or heard. But today we are joined by Dr. Rachel Coakley and Dr. Bobby Riley to do a little myth busting. But what is in isn't true about chronic pain. We're going to talk about some of the myths that we believed at different parts of our pain journey. And our hope is that our listeners learn a little today that will give them some hope and a way forward. Okay, let's get started with Myth number one. Chronic means lifetime. I was recently reminded of how confusing the word chronic is when I read a letter for my freshman yourself. So on our freshman year retreat, we were tasked to write our letter to our senior selves. And this letter was only to be opened after we graduated. When I opened my letter this past spring, I was shocked. The entire letter was about how I was never gonna get better because I had a chronic condition. And I spoke of my pain, like it was my fate and was completely sealed. I said I would never get better, nor

would I live a normal life. I thought I would never graduate high school, nor would I be able to go to college. And right now I'm speaking to you from my college away from home living a very full and active life. So I now know that I could not have been more wrong. But I do want to take a second to really define chronic pain, because I think part of the myth I believed has to do with understanding the definition of chronic pain. So, Dr. Riley and Dr. Coakley, I'm going to give you each a word and maybe you can help us make sense of what is and isn't true. Dr. Riley Can you define what pain means? And maybe Dr. Coakley, can you tackle the chronic part of the phrase? Sure,

I, I can definitely start out by going through the official definition of pain. And that is, it is an unpleasant sensory and emotional experience associated with or resembling that associated with actual or potential damage, which is a mouthful. What the definition is actually saying is that pain hurts. It's associated with all the emotions that go along with something that hurts and all of all of that is very person specific. Pain can then be divided into acute and chronic types. So acute pain is the obvious one to understand a perfect example is if you break your leg, you obviously are going to have a ton of pain, you'll go to the emergency department and get an x ray, which is going to show that you have this broken leg. And then you're going to get a cast and some crutches and after weeks of letting the bone heal. And once the bone does heal, the pain goes away. So easy peasy, right? Pain alarms, you have something dangerous, you fix that dangerous situation and the pain goes away. And that is the definition of acute pain. So I got pretty lucky. And I got to answer the acute part of this definition and the pain part Dr. Coakley, I'm gonna go ahead now and quiet down so that you can tackle the chronic pain part of the definition, which is not maybe quite as obvious.

Thank you very much. And I'm very happy to be here and be busting some myths along with all of you. So here's how it breaks down. Chronic when it comes to chronic pain, for sure can be a confusing term because Sophia, I don't know if this was true for you. But many people think that chronic means permanent. But by definition, chronic just means that pains persisted for three months or longer, it doesn't mean that the pain is permanent. Is that what you thought when you heard chronic?

Absolutely not. I thought that this meant like, lifelong forever and ever and ever.

I know it's such an important distinction. And the term is definitely confusing. I've met a lot of people who feel like being diagnosed with chronic pain means that they're going to have pain that lasts forever. But the reality is, it's just a descriptor, and it just means that the pain has already lasted for at least three months, it doesn't describe or predict when it will get better. What we know from research is that lots of kids do recover from chronic pain. So if you've been diagnosed with chronic pain, I want everyone to know that it means that your pain has gone on for several months, it doesn't mean it can't or won't get better. There's another really important characteristic, though, to chronic pain, different from what Dr. Riley was talking about. That pain of a broken bone is actually acute pain. And it gets better when the body has healed. So it's a warning sign for our body that something's wrong. Usually, in contrast, chronic pain means that the pain is not protective. It's not telling us about a broken bone, or about a problem that needs attention like that. And this is a really important distinction because we know that the pain is not protective. There's a whole different set of evidence based treatments that we use for recovery.

That's a great way to define those two words. When I first got diagnosed with chronic pain, I was really under the assumption that having chronic pain meant the way I was feeling at 14 years old was going to be the way I was going to feel for the rest of my life. So here's another misconception. When I was first diagnosed, I was also under the assumption that my pain would be fixed in a short amount of time, and that it wouldn't be necessary to implement other coping strategies that would prove to be more beneficial. I had nearly three years of chronic pain. Before I even figured out that I wouldn't necessarily be fixed by a pill. I would be fixed by a combination of coping strategies and lifestyle changes. It was a very long, difficult few years of waiting, visiting doctors trying procedures and undergoing surgeries, nearly all of which did not actually get to the central problem. Looking back, I think part of my experience was not realizing that not all types of pain can be fixed by medication alone. So let's call this one myth number two, medication is always the best way to manage chronic pain. Dr. Coakley and Dr. Riley, can you set us straight on this one?

Definitely. Dr. Coakley, I can start on this one. Brooke, lots of patients come to see us with this misconception that all they're going to really need is medication to treat their pain and then everything will get better. But it's like Dr. Coakley already mentioned, chronic pain is complicated. And unfortunately, there isn't a medication available to just stop chronic pain from being processed. That said, we do use medications to help. And the use of medication in chronic pain is typically going to fall into one of two categories. We're either going to use medications that are going to be used to treat triggers of the nervous system and examples would be things for inflammation or nausea. Or we'll use medications that are going to calm the overall nervous system down which we term neuro modulators. And this is really an umbrella term. All neuro modulating medications are going to be borrowed and are either going to be originally used as anti seizure medications, which certainly we do not think that pain is caused by a seizure. But as you might imagine, these kinds of medications are really good at calming the entire nervous system down, which includes the areas of the nervous system Process pain. Or we use medications in this in this category of neuro modulating medications that are mood stabilizing medications, which are helpful for treating pain, because the areas and the receptors that process pain and mood overlap in the brain. Now, the only other thing I think, that's really important to realize about any of these medications is that the use of these medications to treat chronic pain is going to be personalized. And it's really important that that patients work with their providers to determine which medications are the best to be used in in each patient. And that while medications can be useful, they don't work the same for everyone. And they are really only intended to be used to help patients participate in the entire multidisciplinary treatment plan, which we know is how, ultimately, we're going to get our chronic pain under control.

Okay, yeah, that makes a lot of sense. So I think for me, I think that our healthcare system seems to turn to prescriptions and medications as the first line of defense, headache, take some Advil, have a fever, take some Tylenol. However, in my experience, the medications I was prescribed for my chronic pain, actually did practically nothing to help me. Whereas the cognitive behavioral therapy, the physical therapy and occupational therapy I did and participated in really, really did help, obviously, Dr. Riley, as you mentioned, pain journeys are a deeply personal experience. So I do want to acknowledge that my experience, likely is not universal. So Brooke, and Bridget, I was wondering what your experiences were with medication.

So actually, I was prescribed pretty strong medication right from day one of having chronic pain, but taking the medication didn't really seem to do much. And in the end, it seemed to cause more side effects than the intended purpose. It actually really wasn't until I intentionally went to a pain rehabilitation program and adapted a more holistic, multidisciplinary pulmonary approach with physical therapy, occupational therapy, psychology, like Sophia mentioned that I really started to have the biggest breakthrough in terms of lowering my level of pain and resuming daily function.

So for me, unlike Sophia and Brooke, I did not start out my pain journey with taking prescription medication. I had doctors tried to put me on a whole bunch of different medications. And I got differing opinions from many professionals. So I decided it wasn't good for me. And I decided I didn't want to take them. So I actually did my I went to my pain journey without taking prescription medication. And I focused a lot on like active coping strategies, PT, OT psychology, but it did take me a while to get to that point. But I think like Sophia said, like everyone's experience with pain journey is different. And medication.

Yeah, for for sure. For sure. You know, as I'm listening to the three of you share these personal stories. It's really interesting that medication was recommended to you at different times, it didn't end up being part of your solution. But but it is for a lot of people. And I think, you know, I just want to comment too, on what Dr. Reilly was saying, you know, because the classes are the groups of medications that we use. I, you know, when you hear if you're not familiar, and you're not used to sort of talking about these medications, moods, mood stabilizing medications, or seizure medications, I mean, they sound like heavy hitters. And I think, you know, what people don't really understand is that sometimes they're used in really baby doses. And they're really used to sort of, as Dr. Riley said, get people to the place where they can engage and the word that everyone is tripping over, which is multidisciplinary treatment. It's a mouthful. But, you know, the thing is, I tell all of my patients, there is not a one size fits all kind of solution for the recovery of chronic pain and medication can be useful for some people. But it's part of the bigger picture for how we get people back on track. And usually, the best approach is to tackle the pain from as many angles as possible. If you listen to the first episode, you might remember that I use a metaphor to describe our treatment approach to chronic pain. And what I say is, when you've got chronic pain, you're like a tricycle with three flat tires. And to get going again, you have to fill all the tires. One tire might be filled with the treatments prescribed by a physician, but you still need to fill the other two tires or you won't go anywhere. So to see real and consistent progress. One tire has to be filled with the strategies that all of you have talked about some physical therapy and occupational therapy, and one tire has to be filled with the psychology strategies like cognitive behavioral therapy, and when all of those are filled, that's when we get people get back on the road again, and feeling better. So it really is this multi DISA puneri treatment that gets people going again, not a quick fix with

a pill, when I did get put on medication, even if it didn't help like my pain, really, sometimes it did help me tackle other problems. So I do think like, even pain, like it might not be our I mean, even medication, it might not be Tylenol or Advil, like you see with acute things. But I just think like, the cross between medication and chronic pain is just like another testament to how I don't know how not uniform chronic pain can be.

So true. It's a tool. But it's not necessarily the only tool,

Sophia with saying that I think is just you made such a great point about like the correlation between chronic pain and medication. And that is a good connector to our myth three, which is pain is on your head, or because medication doesn't work, it must mean that the pain is on your head, or it's just anxiety. And this is something I struggled with a lot personally. For me, meditation did work and medication didn't. So it kind of gave me the idea in my head that pain was all in my head, it was just anxiety. And it was a huge myth I had to face about my chronic pain, which is just because you can't see it. And just because it doesn't behave like acute pain and regular pain, doesn't mean it's not real, or it's in your head. And it's just anxiety. Yeah,

I really resonate with this. And I think that this is something I also struggled with a lot because I had in my head that like regular pain or normal pain was acute pain, and that I had in my head that all pain should manifest the way acute pain does. And obviously, it was a hard pill to swallow no pun intended, that my chronic pain didn't manifest like this. And I did struggle a lot with thinking that maybe it was just all in my head because it doesn't look like every other situation I've seen pain in. So Dr. Coakley, I was wondering if you could help us out with this, and specifically help us out with how the brain body connection comes into play? And what does this mean? And how does this mean? The pain is not in your head?

That is a great question. And it's actually a really common question. And when I first meet you, I'm a psychologist. So when I first meet with patients, I have to start here and explain my role and helping to treat pain like this is the elephant in the room, right? Like, I have pain. And I've been referred to see a psychologist. How does that mean that the implication somehow isn't that pain is in my head, right? And so that's sort of where I start my conversation with people. One way that I do it is, is to use a computer comparison when I talk about chronic pain. And I often explain that chronic pain is like a software glitch. So imagine you have a computer that's not working. To fix the computer, we might first check all the hardware, right, you check to make sure it's plugged in, you check the wires, make sure there's no fray, you check the motherboard, you check the cooling fan, if everything looks good, if the hardware looks good, then you know that the problem is probably with the software and the computer that the messaging isn't working properly. Well, in human terms, it's kind of the same thing. This software that's not working, there's no hardware problem with chronic pain, there's not usually a broken bone, or something like that, that needs to be fixed. It's a software problem and the software and the human body is the communication or the connection between the brain and the body. So that communication is run by our nervous system. And what happens is that the nervous system can get glitchy it can get stuck in the pattern of producing pain because it thinks it's protecting you. And so the more the neurons in the brain are triggered to produce the uncomfortable sensation of pain in the brain, the easier it is for them to produce the discomfort in the body, and it creates this sort of unwelcome habit. We know that with chronic pain, the pain itself is this nervous system communication glitch, and it comes from the brain. But it's not the same thing as saying The pain is in your head. Because that makes it sound like the pain is not real. And for sure, chronic pain is real pain.

Hearing that pain is in your brain and is not in your head is really validating to hear somebody with chronic pain but also I can imagine for people who are a little concerned that it's in their head or if they're making it up understanding the background behind chronic pain, how it actually happened, and

how interconnected the brain body connection is, is really important and can really be life altering to here as somebody with chronic pain as that it's not something that is just they're making up or seeking attention, but it's something that it's happening in their body but it couldn't be fixed.

I I agree. And I think that validation is so important. And hopefully healing for people like the start of the healing is to realize that this is valid. It's a well recognized, well studied problem, and there are real treatments and solutions for it.

Yeah, and I think something that like in this field in general that I've had a lot of trouble with is, there's a lot that I was introduced to in my pain journey that I didn't know a lot about. And I didn't really understand. And because it was so new to me, as someone so young, I kind of defaulted to, oh, that doesn't make sense. So I'm just going to believe, like, the myths and the easy things to believe it was easier than going through the hard work of trying to figure out what was actually going on and what these recommendations actually entailed. Which I think brings me to our next myth. So myth number four is that meditation and mindfulness are silly. So before and even well, into my pain journey, I thought that practicing meditation and mindfulness to help my pain was weightless. I didn't think it would work whatsoever. And as someone so young, I really just thought it was kind of like, feeding into, like, pain being in my head, or I don't know, I just really confused me a lot.

Sophia, that is something I definitely relate to, especially with like meditation. I remember, I was so young when I was introduced to it as like a coping strategy for my pain. And it was it felt silly, like it's something you giggle about when you do it. Like whether it's like, sometimes it makes you do it in gym class. You can't sit still you giggle. It's funny. So then I was like, What is the point of me doing this? Like, how is this going to help me? And it took me a lot of tries, and I really had to give it a shot. And it definitely took me a couple of tries. And Dr. Cooley, this leads me to my question, which is what is actually happening when someone uses mindfulness or meditation? And why does this help with chronic pain?

I love this question, right, because all of this relaxation, this is a big part of what we do under the umbrella of psychology. And it's not silly, it like really works. And let me break this down for you a little bit. So the relaxation response is the term that describes what is happening in your nervous system. When you use relaxation skills. And relaxation skills can be anything, it could be diaphragmatic, or deep breathing. It could be mindfulness practice, progressive muscle, relaxation, guided imagery, all of those things fall under the umbrella of relaxation skills. So the relaxation response is a brain body reset, that creates a calming effect on the nervous system. And that helps the brain and body shift from a state of high alert, which is what happens when we've got chronic pain. It's like these alarms are going off in our body. And it really amps up all the activity in the nervous system, it shifts from that state of high alert to a state of calm and comfort. It's like sending the all clear signal through your nervous system, and is deeply relaxing. And it's great news, you sort of get a twofer. These same skills help to also reduce stress and worry in the nervous system to so you create the relaxation response when you combine slow steady breathing with a mental focus on like a relaxing place or a positive experience. Or even like with mindfulness, like an in the Moment object could be anything that you're seeing or touching or tasting. And by directing your breath and your focus, it calms your whole nervous system down. You can trigger this relaxation response when you engage in these skills for usually like 10 minutes, I would

say if I can get people to do five minutes of relaxation a couple of times a day, that's awesome. But 10 minutes, you're going to really set yourself up for success with this. And when the relaxation response is triggered, the whole nervous system stops paying so much attention to the hazard signals of chronic pain or discomfort and resets to sort of norm normal, calm healthy function. What happens physiologically is the heart rate slows and studies. breathing becomes deep uncomfortable, you move away from sort of that shallow chest breathing to that more deeper diaphragmatic breathing, your muscle tension relaxes. In places you didn't even know you were holding tension like your jaw or your hips or your back. And your thoughts calm down and focus as well. So all those ping pong racing thoughts, they settle down and get focused too. So any of the relaxation skills that I mentioned can be used, but also if sitting still and trying to meditate isn't your thing. You can use yoga to create the relaxation response. Acupuncture can help create that too, or even Reiki and massage sometimes can be helpful from that as well. One other question, though, I think is really important, I get this question a lot people say like, oh, I rest all the time, I'm totally relaxed, like I'm not stressed at all. Resting and the relaxation response are two totally different things. You can think of rest, like a quiet time without moving. You know, unrest happens when you're doing things like sitting on the couch or taking a break, laying quietly in bed, watching a show, you know, playing a video game that can be considered rest. And sometimes in the recovery from chronic pain, having planned times for rest is really important. But they don't trigger the relaxation response, they're not sending that calming effect through the nervous system in a way that helps the body reset from those chronic pain alarms. Does that make sense?

It's also really interesting, because as I'm thinking and listening to your response, and thinking about how much my meditation and mindfulness practice has shifted throughout, learning about it, in the beginning of my Pain Rehab journey, I've gone through periods of time where I absolutely love doing yoga, I've gone through periods of time where I love doing guided imagery, I'm gone through periods of time where I love doing progressive muscle relaxation. So really, is once you figure out what kinds of ways to relax your body that you like, there are ways to change it up. There's different types of yoga, there's different types of relaxation. I really liked doing meditations. In the morning, sometimes sometimes I like doing them at night. So it's really kind of a fun experiment to do, to figure out what works best for your body and what your body needs that day.

Of course, I love that idea. And I think it's a great place where people can really, you know, find what works for them and use that and be open to the idea that you might switch and try something new, when things get boring or dull.

Yeah, and I also think like, back to your point about like, the difference between mindfulness and meditation type of rest and watching a show type of rest. I think like, for me, something that was really interesting to realize was that, like, even when you're watching a show, you're not really like stopping when I'm watching a show, when my mom makes fun of me all the time. I'm also on my phone, I'm also looking at this, I just need to be doing everything, a million things at once. And while that might be helpful, from a distraction standpoint, it can be really mentally exhausting. When you never just have a time alone with your thoughts into like, really, like, I don't know, check in, I feel like I would take for granted a lot like how little I checked in with my thoughts and like, how little I checked in with my body. And that's was such an important life skill to learn like pain, no pain. I mean, whether it's like, I don't

know, like journaling, or doing a meditation or whatever it may be, I've really seen that like it's across the board, like really good just to like have times to check in with yourself. I

agree. I couldn't

agree with that more. Sophia, I think that's super important. Because it once you start to like get to that point, in your pain journey, when you're like managing your pain, well, you come to realize that all of these like tools we have in our toolboxes are meant for life to not just for chronic pain. And like you'll gradually see that as you progress in your pain journey. But it was something that like really shocked me too when I was like, Wait, this is for when like, I'm stressed out about a test not just for when like, my foot is hurting, like it really can be applied everywhere. And that is what I think is so great about these coping strategies, and mindfulness and meditation.

Oh, Bridget, I'm so happy that you mentioned you made so dear to my heart. Because I have to say a lot of times as we're encouraging patients to kind of incorporate some of these strategies. I mean, I don't see the eye roll, but I feel the eye roll. I feel like the thought is Oh, dear, you're going to ask me to do this added activity and I'm exhausted. I'm dealing with all of these stressors. And it's so helpful to hear you say, Listen, it's not just homework for this one thing, it will serve you well moving forward in all aspects of life, which I think is just a really valuable lesson for anybody to have learned. For sure.

Yeah, I agree completely. I think like, wow, this whole multidisciplinary treatment process has definitely been like not what I'm used to when it comes to treatment. I do think it showed me a lot of really, really valuable things and kind of just emphasized how much I would take for granted like yes, like I'm a student, but like I'm also a person who has a body that needs to be taken care of and exercise is important but also like mental exercise is also important and checking in in is like really beneficial, and I just don't think it's talked about enough. So I do think it was really good that this like, kind of pushed me in that direction. That is awesome. Um, but going back to our mythbusting, I do want to talk about our next two. And so, myths five and six are kind of related, but I do think it's important to look at them individually first. So myth number five is that pushing through pain is harmful, both physically and physiologically. So, for starters, I think that many people with chronic pain have been told they need to push through their pain, maybe do some physical therapy or exercise, even though it hurts, it's really important to push through because in the long run, it will pay off. But let me just say, is really, really scary. When you were being told that you need to try walking without your crutches. But every time you get around, you try to get around without your crutches, it feels like your bones are breaking under the weight. And I always thought that I was going to do further damage to my body when I was pushing through my pain. But at the same time, I thought I would make my pain worse if I didn't do anything at all. So it was really hard for me to find this balance. Dr. Riley, do you mind helping me out with this myth?

Yeah, definitely. Um, you know, I think that the first thing I want to highlight is that it makes sense, right? This concern, or this initial reaction to pain, it's actually built in as an instinct to react this way. Because pain is meant to be protective. And it goes back to the acute pain, when pain is serving to actually warn us that something dangerous is going on. So it's really a protective thought, Sophia, if we think back to that example that I used with a broken leg, The bone actually needs time to heal, right

resting, guarding protecting that part of the body and pain, when there's something dangerous that's present is the best first line approach. And so that's why everybody sort of reacts that way initially. But again, you know, this response is really only going to be helpful to address pain when it's a warning, and there is something dangerous, that's going on in acute pain. And as Dr. Cochlea mentioned earlier, once we've been reassured that pain is no longer protecting us from something dangerous, even though it is still just as hurtful, we then have to work on strategies that are going to allow us to go against our natural response to pain, which is that worry that something dangerous is going on, and that we might do more harm, and we need to protect the area. And so that's when we start to prioritize this slow return to the normal use of the area that's in pain and, and it's called active activity pacing. And we use it to restore daily function, where we use both physical and psychological strategies to accomplish our goal. And what we know is that increasing activity early as part of the recovery process, involves exposures to activities and situations that are going to kind of trigger that fear response initially, but learning to work through the situation actually help to increase flexibility in that natural fear response. And it's a really important part for recovery from chronic pain.

Yeah, I definitely think that that was kind of hard for me, it to shift my mindset going from, okay, we have this kind of universal belief that don't push through pain, you're gonna do damage to yourself, but then I was like, Okay, maybe like chronic pain doesn't behave this way. And so then I kind of got scared of the opposite. And so that brings us to myth number six, which, like I said, is kind of the opposite of the previous one, which is, if you don't push through your pain, and you kind of, I don't know, don't do anything about it, you're just going to be doing further damage and making maybe making your pain worse. So Dr. Coakley, I was wondering if you could help us understand why pushing through chronic pain, to a certain extent won't cause further physical damage.

So your question, it's such a good one. So if you had this question of like, maybe if I just, if I just pretend it's not there, if I just ignore it, like, if you don't do anything at all, I'll just you would you would think, right, like our intuition might be that I'll just get used to it, like, whatever. It's just the pain. It's just moved in. I'm gonna go about my life. But what happens is, over time, our body actually becomes more sensitive to the pain problem. So you would think that you could start to ignore it and just not give it much attention, and it would kind of go away on its own. You really have to be active in the recovery process. Sometimes just ignoring it can lead to being Morrison affective. So balance in this recovery is really key. If you remember that chronic pain is a glitch in the nervous system. The recovery process involves resetting this glitch. And that process is called desensitization. So our nervous system gets sensitized to chronic pain and get stuck in this really highly hypersensitive cycle. And we have to unwind it the other way, we have to desensitize it. And this involves exposing the nervous system to the sensations or situations that might be uncomfortable. And you have to do it little by little, nobody wants to, you know, goes zero to 60. And the recovery process that always ends up working against us. So little by little, you use D sensitization. And you can focus desensitization, on a particular body part, like, let's say you have a leg, that's painful we've got, or maybe it's numb or tingling, part of the desensitization plan might involve rubbing that leg, you know, many times a day to get used to the normal sensation of being touched and being rubbed. And this part of desensitization can be part of the physical therapy plan. But desensitization can also target the whole nervous system. And the tools and skills that come from psychology, those relaxation response skills that I was just talking about, think about it, that's unwinding the hypersensitive nervous system at the level of the brain. So that's an

important part of how we desensitize the whole body. And then when we combine that with daily exercise and activity, most people start to see a really big improvement in the hypersensitivity of their whole nervous system. And that's how that hypersensitivity is the glitchy nervous system we've been talking about. I'll also just say that the cognitive part of this recovery process is really important. You talked about that fear response, while pain always triggers a fear response, because it's supposed to be protective. So when those little hazard signals get to the brain, they trigger the amygdala, which is your fear response center in the brain. And that gets all fired up, it makes you not want to do the things that are part of the recovery. Little by little, you have to work cognitively, to retrain your brain to remember that this is an important part of a healthy normal recovery. And it may be uncomfortable, but it's not harmful. That helps over time, your brain learns that it can do things safely, and the fear response lessons and the pain response lessons. So sort of globally, we're looking to unwind this glitchy hypersensitive nervous system. And if we don't do it, sometimes things do start to get worse. So we want to really engage in this actively,

I might just add, you know, like one final add to that would be that the process of this desensitization or learning how to work through pain, like you mentioned, is it is it super scary, right? It's intentionally super scary. But if you can, if you can work closely with your pain provider with close follow up so that you get that reassurance that the activities that you're doing are safe, it'll really help build on that confidence and kind of help push forward in the whole process.

I agree. I think partnership with your with your team of treating providers is key here. This is hard. Yeah, it is

difficult and also from the patient perspective. And now Patient Advocate perspective, it's really important to recognize what into put those tools into play. Now when I wake up, and I can feel that it might not be a great day for my pain. My first instinct has been to now for the last five or six years. Okay, it's time to do some extra time on meditation, it's time to move your body today, it's time to spend some extra time taking care of yourself, because I know what the consequences are, if I don't. So when my pain is flaring, I usually make doing some kind of cardiovascular exercise that day, a non negotiable, I'm really into spinning right now. But if the weather's nice, I'll take a power walk outside or go to the gym. And be sure to stay out of the house and away from my bed. Because it is very difficult to resist that urge. But also recognizing that it's really important to listen to your body to finding that balance between what is healthy, and what is healthy in terms of how you should be coping with your pain in order to not necessarily spiral down into another pain flare.

Yeah, I think it's been like difficult for me to realize that neither of these myths five or six are true. And it's you need to find the balance between moving your body but not pushing yourself because you need to listen to your body and over time I've learned that you do have to push yourself. But you also have to pace. And you can't have one without the other. Like they're both absolutely so necessary. And yeah, I want to acknowledge that our pacing has looked different at different parts of our journey, the amount of had to push or pace has varied over time. And it still varies day to day, depending on what's going on in my life. But it's just non negotiable, that pacing does exist. And it's really, really important.

Sophia, I really liked what you said, about how pacing looks different at different parts of our pain journeys. Because like, we're always changing, like, our pain is changing, and it just isn't going to look the same each day. And like pacing, like really is like it's an art form. Like it's something you really master like personally, and you learn, like what's best for you when you're managing your pain. And that kind of brings me to our last myth, which is myth seven that we want to debunk is how you feel today determines how you will feel the rest of the day and tomorrow and the day after and the rest of your life. And I also think this kind of ties into that like term chronic pain, because when we think chronic we think, lifetime forever. And that's really not the case, it's kind of just the timeframe. So we'd like to bust this myth.

Yeah, and this feels really important and close to my heart. I mean, I think that we've all, at some point or another, have heard people talk about how chronic pain limits one's ability to do things in a very objective way. Almost like a video game, you have a certain number of lives, and you have to do a certain number of tasks in your game, or go on a certain number of adventures. But when you run out of lives, you need to wait a designated amount of time for your lives to recharge. It's almost like Candy Crush when you have to wait for your three little hearts to come back. So I'm wondering how much of this is true. And how much of this is a myth.

This one, this one was so real in my life for so long, I was really nervous about pushing myself and crashing the following day. I remember my junior year of high school, I was going to competitive dancer. And I had a dance competition where I was going to perform a brand new solo for the first time, I was really excited to perform this new routine. But I also didn't think I was going to be able to go to school the following week, because the pain would be so bad from all of the rehearsals and staying out the competition for 12 hours a day, and then going to the competition the next day. And really, and being able to perform with my best foot forward on stage. And this is really infinitely different than what I can do. Now I don't think of things that I do as if I'm not going to be able to do something tomorrow, or how that's going to affect me a week from now with my pain. Working out is a central part of my daily routine, when, for example, I mean the length of time changes based on a variety of factors. But pushing my self is not something I ever think about when it comes to choosing whether or not to work out or not to work out, for example. Sometimes it's 20 minutes, sometimes it's 45 minutes. But the point is that at this point, and where I am in my recovery, nothing ever really enters my mind thinking Oh, am I not going to be able to do something that I'd have to do later today? Or am I not going to be able to do something that I have to do tomorrow? Or am I going to be able to go to school tomorrow? Or am I going to be able to uphold my other commitments? So I want to hear from the experts? Dr. Riley? Is this true? Do our bodies have a finite number of things that we can do in a given amount of time? How is this different from the idea of pacing?

So let me jump in here if you don't mind. Dr. Riley, I'm gonna jump in and answer Brooks question. This is such an important question. And like you all I have, you know, heard people say that like, Okay, what I can do now is just, that's just it. And I guess I would say I never want to set a fixed limit for activity. Because of course, if we think that there's a ceiling to what we do, say I can only walk for 10 minutes, then we'll stop when we've hit it. And there's no growth. beyond that. And as you all have so eloquently shared throughout this episode, things change. There's lots of things that are in flux. And balance is key. And, you know, you find a way to sort of get what you need, all throughout your recovery. So day

to day, minute to minute, week to week, month to month, year to year things change. So rather than set a limit, I like to think of daily activity, especially in the early parts of recovery, being like a ladder, that we're slowly climbing. As you do a little bit more, you start to feel a little bit better physically And this improves your confidence and your motivation and your recovery. And this enables you to do a little bit more. And then you start to feel a little bit better, and so on. Slowly, slowly, slowly, as this process unfolds, up and up the ladder, you go, one rung at a time. The trick here is to move slowly and steadily and not get caught up. And what is often called the boom and bust cycle, you all heard of that. The, yeah, that's when you do too much on a day, when you feel like I might be feeling pretty good, or maybe my pain still there. But I'm really motivated to go to this concert or do this awesome thing, whatever you do too much on those days, climb up too many rungs on the ladder, let's say, and then you bust you slide all the way down the ladder the next day, and you don't do much of anything at all. And the end result is that you feel like you're not getting anywhere. So the process of building back slowly, like Dr. Reilly said earlier is called Activity pacing. And it's a really well studied and successful approach to increasing day to day function. When you pace activity, and you practice being active, even on what you might consider to be a bad day or a day with a pain flare. Over time, the body can learn that it can function, even when there is some pain or discomfort. And this is a really important aha moment for the brain and the body at such an important piece of the recovery. Because over time, the brain stops responding in a hypersensitive kind of way to the activity, it sort of dials it all back. And again, then you see that you're starting to make progress. So this is really, really important.

Yeah, Dr. called like, I have to say, I totally agree, I really don't think that there's a finite number of things that a body can do, I have actually found that the human body is incredibly resilient. And each of you is shared through the different life examples you just gave. And certainly, you know, the trajectory of progress during a journey with chronic pain isn't going to be a straight upward slope, you know, it's going to be more of that sawtooth upward slope line, right? There's always opportunity to rebound, right, both within like a single day, and then also within that chronic pain journey itself. And so I think it's by recognizing this. And then using the tools that we've been discussing, that you rebound quicker on those tough days are those tough weeks and keep moving forward up that up that ladder, like you mentioned,

yeah, it definitely is not linear, right, it doesn't just go in a straight line, there's definitely a you have to go into this knowing that there will be some setbacks, that there will be challenging days. And you don't let that sort of pull you all the way back down to the bottom. So you sort of keep trying to little by little build back up and get stronger and stronger. But I often tell patients that I work with it, like we're not looking at a micro level, minute to minute, hour by hour, day by day. But let's look over the course of a couple of weeks, if we can see that we can do a little bit more now than we used to be able to do that progress. And that's how we sort of charted our path forward.

And I think that reframing was really, really grounding to me, because I know for me, like, during my pain journey, I was very like, I don't know, achievement oriented, I want to say I was always wanting to check off more boxes and do more things. And obviously, that's great that I got to the point where I was like ready to commit and make the progress and do the things that I needed to do. But also like it at times clouded my judgment and kind of like led me to this all or nothing thinking at times where I was like, Okay, if I can't do absolutely everything on my to do list for the next two weeks, in one day, I failed.

And it's just like a really hard cycle to get in and leads to being very hard on yourself for no reason. And so I always found it very grounding, just to kind of like step back and like, think about how far I had come and how like, even if one thing even if I was upset that like 30 minutes of doing some physical activity was really hard for me that day. What at one point 30 seconds was really challenging. So I don't know, I think it's, it's comforting to know that there aren't a finite number of things that we can do and our bodies change and people grow in areas and yeah,

so true. So true. That's, we don't want to put any sort of, you know, arbitrary limits on what it is you can do. Yeah, you and you all are a testament to that for sure. Okay, I wonder, Dr. Riley, maybe you and I can turn the tables a little bit here. I wonder if we could end our mythbusting episode by asking our pure board members that are with us today. Sophia, Bridget and Brooke. A few questions you will have had the chance to ask us a lot of questions. And we have loved the chance to mythbuster with you and have loved hearing your experiences. But can we close by asking you some of our questions about your journeys? Cool. We, of course, would love to do it. All right. Dr. Riley, do you want to go first?

Yeah, definitely. I would say though, it has been so fun to help bust some of these myths. But here's my question for you guys out. So you've each had to contend with the different myths and in some cases had to learn the hard way about chronic pain recovery. Is there a time that you remember when things started to click, and you can actually start to see life getting better? And then I guess I have two questions. What was that turning point? Like for each of you? Was it kind of like a sharp turn? Or was it this like slow, wide turn in terms of the process.

So for me, it was my fifth day at my pain rehab program. And I went to this program nearly five years after having chronic pain. I was in the summer, after my junior year of high school, and which I missed nearly a quarter of that year, I was preparing to not go away to college, I was really preparing just to keep living my life as I was living it, which was not really doing much of anything, because I really didn't think this was going to work. At the beginning of Pain Rehab, I could hardly stand up, I could bear the hotel that we were staying at was across the street from the hospital where the rehab was at. And I could barely walk across the street to get there to go to the Pain Rehab, because that's how much pain I was in. So fast forward, the first few days are okay, they're just like coasting along. The fifth day was the hardest day. But it was also the day I remember making the biggest breakthrough. And I needed to put a lot of my old habits and a lot of my own conceptions about pain aside, and fully embrace the new tools and the new mindset that I was learning in this pain rehab program. Because I did not think that it was going to work. And I decided that I needed a mindset shift, I learned about all of the new tools that we have covered throughout the entirety of this podcast series. And I knew that this was going to be the way that I was going to live my life moving forward. It is now six and a half years after that, and I have not looked back since

book that's so great to hear and amazing, especially because you've been through your journey a little bit longer than I have. So that's just amazing to hear. Um, for me, things began to turn around after I left my pain rehab program. And it was quite timely because it was like right at the beginning of quarantine, I think we were the last group there for like a few months. And I was really able to put my strategies like into place during quarantine. And it was very, like timely for me because I had that, like three month quarantine where I was at home where it was like, Okay, this is where you focus on like, physically

getting better. And like, then everything else like that for the rest of that year, like through the summer and then going back to school in the fall. The whole world was doing things gradually. Like I went back to school hybrid. So it was very like I was in there every other day. So it was super, like well paced for me. And then it made it going made it easier going back full time. Like a whole year later in that like that spring. But I was like the whole world was gradual. And that was going to be my plan anyways, I've just fortunate to have like

the only one that had the well

Yeah, so like even though definitely quarantine had its like, side effects. its downfalls like, personally like helping me manage my pain, especially physically. And like doing like my exercise programs and all of that, like that time to myself was really important to help me get better. But that was like a whole year like so. Definitely that slow wide turn you mentioned Dr. Riley like definitely not that sharp turn, but I was very thankful for it.

Um, yeah, I've had a similar experience except after I finished my program and my intensive therapies, I would say I was kind of just like thrown back into the mix of school and everything and I was really excited to be there and I was kind of ready to just like turn a new leaf and obviously, part of turning this new leaf was putting my coping strategies into practice and it And I kind of I don't know, I at first, I think it was a little hard for me because I felt myself falling back into old habits. And I had this kind of like aha moment where I was like, Okay, now this is up to me. I've been taught everything that I need to know and do to keep going on my pain journey and become even more functional and everything. But now it was my responsibility to actually put into practice what I had learned. And it was really overwhelming at first. But also, I realized it was also kind of what I was waiting for, I actually had some power and initiative in this moment, in a journey that felt at times where I had very little power. And so turning it into, like, an empowering situation was really beneficial for me. And it was definitely hard to like, actually practice my coping strategies and put into practice everything I had learned. But over time, also, on my slow, wide turn, I don't know I really committed to what I had learned.

Amazing, and clearly, you and everybody else are stronger for it. I mean, those, whether you turn sharply, like Brooke did or take a wider route, I mean, it's just incredible. You all have found your balance in your own ways. So I'll wrap up with one last question for you. You know, you have all busted way through more than myths in your journey. Right? You've busted through so many barriers. I think in this course of this podcast, you've talked about school, and friends and family, and your medical teams and so many things, and all to get to the place where you are now, which are these like incredibly sturdy, amazing people. And where you all have this, like calm, cool confidence in your ability to manage pain or other symptoms that come your way. And, you know, what I'd say is, you've really all found the ability to have comfort in your life, even sometimes in the context of pain. And that is not easy. And it's also deeply inspiring. So I know that this took a lot of hard work. And I'm sure you all recognize that as well. Looking back, right from this like mile high vantage point that you all have now, what would you tell the younger version of yourself, the one at the beginning of the pain journey, who was struggling so much, and couldn't see that there was a path forward,

I think I would definitely tell myself that you have to want to get better at a certain point. And I understand that those first few months of a pain journey can be so hard because you just really do not understand what's going on. And it's definitely going to take time to get to this point. But once I realized I was like, I can't keep like living like this, like on my couch, like at home every single day, the same routine, like go home, like get home from school, take a four hour nap, go into bed later in my week, and then just repeat that cycle. I was like, I can't keep doing this. So that's when I kind of told myself like, I have to want to get better. And like use the strategies that I've been given and kind of just like, shut down. Like I was given, like minimal strategies. And then actually was when I went to the comfortability, and I was like, Okay, this actually works. And I had heard Fiona talk and I was like, Yeah, okay, like, like, I was like, Okay, this is great. Like, I can do this. And then a few weeks later, I got into the pain rehab program. But it's really just that mindset of like, you have to work and like, no one else is gonna put in that work for you. Because it is like your pain and like, you might have doctors, medical teams, family members, friends that are there for you. But they are not feeling it. So it's like, if you want to get better, like you have to put in the work. And you. Yeah, go ahead takes time.

So you are tell yourself, do the work. It pays off.

Yes. But be mindful and paced about it.

Yes, yes, yes, exactly. Not all at once. For me.

If I was to tell my 14 year old self, something about what these coming years would teach me, I would learn that I would say that commitment to chronic pain is not just for today. It's not just for tomorrow, but it's something you're going to have to integrate daily into your life. And it's at times it's going to feel hard and at times it's going to feel stressful of how you're going to get things done. But it's going to be worth it. It's going to be rewarding. Pain Rehab is going to be the most transformative life experience that you've had now. And you have learned to navigate so many difficult life situations that you wouldn't necessarily have had the opportunity to if you still were in the depths of chronic pain, you wouldn't have had chance to study abroad, you wouldn't have had the chance to pursue graduate school, you wouldn't have had the chance to pursue things that were never even an option when you were struggling so much with pain. So really taking it all in and enjoy the ride, because it's, it's gonna be long, but it's gonna be worth it.

So you tell your younger self take advantage of the resources that you have at hand like dive in? And you know, don't don't close yourself off to the opportunities that are that are there for you.

Absolutely.

Awesome. What about you Sofia?

I think for me, I would really enforce and emphasize how important it is to find the good. And the beginning of my journey, I feel like I kind of resigned to this hand that I was dealt and let pain have this kind of all encompassing power over my life. And in turn, I underestimated my ability to do anything about my life and my pain. But over time, I really found just how powerful my mindset and perspective

was in this process. And I know it's really scary to be diagnosed with chronic pain. And for me felt like my world was just completely flipped out upside down. There was nothing I can do about it. But I wish I could have told myself to find comfort in a clean slate instead of fear in one.

So that mindset becomes so important. Yeah. Wow, I am just in awe of all the hard work you all have put in and your courage in talking about it. With all of us. This is amazing.

I was gonna totally agree. I just I have to say thank you for sharing your stories and for the opportunity to bust these myths I really hope our listeners can find the same amount of inspiration that I've found. It's been wonderful. Just learning from you guys and hearing everything that you've had to share about your your journeys.

Well, thank you so much. And with that, I think we've busted some myths. We want to thank Dr. Riley and Dr. Hoadley for joining us today and from the comfortability peer Advisory Board. Thank you so much for listening.

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 thought 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 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 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