**SickKids VS Chronic Pain**

**Hannah** Before the accident, Lauryn was a happy, energetic kid. She was outgoing, made friends easily, and was a competitive dancer. But ten years ago, on a family vacation, Lauryn tripped and fell. In some ways, it was an unremarkable accident on the beach in Florida.

**Lauryn** He threw me the football, and I missed it. I was running for it and then I just remember dropping and I didn't really know what happened at that moment but as I tried to stand up I realized you know my foot is really bothering me. I must have rolled my ankle. When we get back we'll get it looked at but just going on the plane home like I'm sure it's fine.

**Hannah** But things weren't fine. Two weeks after Lauryn and her family returned from their holiday, Lauryn's foot still hurt. Her family doctor sent her for an x-ray, but the results showed no damage and only mild swelling. Lauryn was told to rest and use ice. Three months later, Lauryn went back to her doctor because her foot was still swollen and had taken on a purple color. She couldn't put any pressure on it and had started limping. This time, her doctor referred her for an ultrasound and an MRI, but the test showed no damage. She went back again, and her doctor suggested another bone scan. The results showed no damage, but the pain was all Lauryn could think of.

**Lauryn** I had had injuries before, so I considered myself to have a pretty decent pain tolerance to begin with, and I had never had a pain like that, where it was just so irritating. I remember saying, it feels like my foot's on fire, like it feels like it's burning.

**Hannah** We need pain for survival. As we grow up, we learn that when we have pain, we need to slow down and protect our bodies so they can heal. But sometimes for kids like Lauryn, there's a glitch in the body's messaging system. The injury heals, but the pain doesn't stop. Chronic pain can lead to structural changes in the brain and impact thoughts and emotions too. While medication and physiotherapy can help, it's often not enough. When pain becomes chronic, doctors need to rewire the brain.

You're listening to SickKids VS, where we take you behind the scenes of big breakthroughs to heal the future. I'm Hannah Bank, and this is SickKids VS Pain.

**Act One**

**Hannah** Today, we know that repeated painful experiences can cause structural changes in developing brains. Pain also sensitizes the brain to future pain, meaning that kids who've had multiple painful experiences often react more strongly to things like needles. It's crucial they receive proper pain management.

**Dr. Fiona Campbell** There's an appetite for change and a responsibility for us to really do a better job of reducing the burden of pain for all Canadians, but for me, particularly for children.

**Hannah** That's Dr. Fiona Campbell. She co-directs the SickKids Pain Centre with Dr. Jennifer Stinson. In Canada, SickKids is recognized as one of the biggest chronic pain clinics, and probably one of most research intensive. The Pain Centre also houses the Pain and Child Health Training Program. And because of this program, Canada also has the highest number of paediatric pain researchers in the world. Alongside their team, which includes nurses, psychologists, physiotherapists, occupational therapists, and social workers, Jennifer and Fiona have been practicing and studying pain for more than five decades combined. And they've treated thousands of children experiencing chronic pain.

**Hannah** Can you describe or maybe define what chronic pain is?

**Dr. Fiona Campbell** Chronic pain is simply defined as pain that has lasted for more than three months or recurs over a period of three months or longer. And while it can be related or secondary to tissue harm, it can also occur as pain in its own right without any tissue damage. So, analogies are sometimes helpful. And we will say to the kids, you know, When you're in school, do you ever have a fire drill? Yes. So, is the alarm loud? Yes. Is there a real fire? Is there are fire going on? No. So the pain analogy is that you may have had some acute pain leading to pain pathway activation, which has long since healed, and that you now have this pain signaling going on, even though there's no tissue damage. So, the problem is in the messaging system.

**Hannah** Unbelievably, it's only since 2019 that pain was even recognized as something more than a symptom.

**Dr. Fiona Campbell** The World Health Organization endorsed chronic pain as a disease in its own right, which had never happened before. So, the fact that this has happened really validates chronic pain as a condition in its own right, so it's de-stigmatizing. And it also allows us to track chronic pain in the population, because if you don't know how many people have it or how bad it is, how can you measure the impact on interventions or a policy?

**Hannah** Chronic pain can be so difficult to diagnose and treat, because it's often invisible.

**Dr. Fiona Campbell** There are also myths surrounding pain. Because we all have pain, we think, oh, why can't people with chronic pain just suck it up? They're attention seeking. Maybe they're lazy. Or if they're taking medication, maybe they have a substance use disorder.

**Hannah** And what is the impact of chronic pain on children as you've seen it?

**Dr. Fiona Campbell** They will have an impact on sleep. When you don't sleep well, you have difficulty coping. It has a big impact on mental health. So about 40 per cent of kids who have chronic pain have concurrent anxiety and depression. Having chronic pain doubles the risk of suicide in adolescence. So, it has a real burden on the mental health of young people. And this is also compounded by the impact it has on the physical health. So, the kids are unable to participate in their sports and hobbies. They have difficulty attending school. They can no longer keep up with their friends. So, they get dropped from their social circles. They become socially isolated and become lonely. So, it has a massive impact on all health-related quality of life.

**Hannah** It's similar to Lauryn's experience. Over the next year, her foot is so sensitive that she stops touching it. She explains to me that the following winter, she has to wear sandals because the pressure of socks and shoes alone is too much to bear. And then her parents noticed a shift in her moods. She spent so much time in her room, so much time alone.

**Lauryn** My mental health went completely downhill. It was a very, very different experience and even my parents were noticing like this is a 180 flip from our happy-go-lucky child who would go talk to random strangers that they saw to not speaking, sitting in bed, not staying at school. I'd go to school for an hour and then I'd be in too much pain, couldn't focus and it led eventually to panic attacks. So I was, my anxiety was just too high. And in that sense, too, it was I don't want anybody to touch my foot or step on my foot. So, then I was isolating myself from everybody and everything. And as my journey went on, I got to a point where I didn't even end up telling my parents when I was in a lot of pain, I would just shut down because I knew that there was nothing that they could do and I didn't t want to put that burden on them. So, I just held it in.

**Hannah** Every doctor she saw said the same thing. There wasn't anything actually wrong with her foot, at least not physically, so there was nothing that they could do. For Lauryn and her family, hearing this time and time again was so devastating.

**Lauryn** So I hadAll of the tests possible in that time period. And I kept having to go to my family doctor, but you know, like this is not right. Like something is wrong. I get that these tests are coming back clear, but they're not giving me any answers. You have nobody believing you, and it gets so frustrating. And it gets to a point that it's just so exhausting. So that's when your mentality drops even further and you're like, okay, well, nobody believes me and nobody has an answer. So, I don't know what I'm gonna do now.

**Hannah** Eleven months post-injury and living in pain without a diagnosis, Lauryn's doctor referred her once more, this time to a neurologist. They told Lauryn they believed she had complex regional pain syndrome, or CRPS. They could prescribe her medication for the pain, they said, but also referred her to SickKids.

**Lauryn** I'm not one who likes taking medications. I've never been interested in it. And I didn't understand the science behind them, especially at 16. So, I was like, this is ridiculous. But having gone through everything without any answers, I was willing to try anything.

**Hannah** Trying anything also meant going for an appointment at the Sic Kids Pain Clinic, which is where Lauryn and her parents met with Fiona, Jennifer, and the team.

**Lauryn** We had gone into this room and the appointment I thought originally was daunting. It was six different physicians for three hours and I was like, oh my, like these people really want to talk to me for like three hours. I usually only talk to people for three minutes, so I was, like, they definitely want to help.

**Hannah** They confirmed Lauryn's CRPS diagnosis and were confident they could help her. But their approach to treatment was unexpected.

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**Act 2**

**Hannah** Even though Lauryn's pain made her feel isolated from her friends and family, she actually isn't alone. About 20% of Canadians live with chronic pain, meaning that there are thousands of teenagers across the country just like Lauryn, kids who are still living with pain long after their injury is healed. The same area of the brain that regulates emotions also regulates pain, meaning that pain can be driven by changes in the brain or nervous system in addition to physical injuries.

**Dr. Fiona Campbell** There are MRI studies that show that the amygdala, the hippocampus and the prefrontal cortex, which were all areas involved in emotional processing and cognitive function, can be affected by this change in structural changes related to impact of pain. So that's the effect that it has on the brain, but we also know that the brain is plastic, or it has this capacity of neuroplasticity, so capacity for change. So, can we rewire the brain or harness this plasticity to reduce pain? Yes, you can. There is hope, but it's hard because the treatment is painful.

**Hannah** Fiona and Jennifer agree that to effectively treat chronic pain in the long term, you have to lean into it. You have to get back to the physical activities that you were doing before it started. You have to get back to school. You have better sleep. But it's hard, especially if you're in pain. The SickKids Pain Centre uses a multi-modal treatment approach. They call it the three Ps.

**Dr. Fiona Campbell** The three P's being pharmacotherapy, physical therapy, and psychological therapy. Frankly, the most important work, assuming you can get some good mental health buy-in, is by the physiotherapists who get people moving again. And so, they will come in; the patients will come in for blocks of treatment with the physiotherapist supported by mind-body strategies, seeing the psychologist and sometimes with medication support as well.

**Hannah** Understanding that pain is a brain issue also highlights just how complex chronic pain really is. It isn't necessarily caused by a single injury or illness. So, one treatment on its own, like medication, probably won't be the cure. That's why the team at SickKids offers a range of therapies. Initially though, some patients and families are really resistant to this.

**Dr. Fiona Campbell** Some people will come saying we're just looking for coping strategies and we like to see the psychologist, or we just want physiotherapy or we're just looking a magic medication. So, after we've done the pain neuroscience explanation, we then talk to them about treatment. So, I'll just take a step back about what the clinic looks like. On the very first appointment there's the physician, physiotherapist, Psychologist. The nurse. We all are involved in asking the questions and then the physiotherapist and the physician will do a physical examination with the patient and that also gives an opportunity for the patient to disclose anything that they might not want to have disclosed in front of families.

**Hannah** Lauryn told me that she answered questions for almost three hours. And finally, there was a breakthrough.

**Lauryn** So I didn't really understand the concept of pain being neurological. The psychology side also was incredibly intimidating. And it's not even because it was a connection for the brain and the pain, but it was more because I had been told and basically felt like my pain was in my head. So, I was like, why are they wanting me to go see psychology if they're believing me that my pain is real, but they're telling me to go see a psychologist.

**Act 3**

**Hannah** Canada and SickKids are leaders when it comes to the study of pediatric chronic pain and its relationship to mental health. Sometimes it's about connection and leaning into the pain. And other times it's about distraction from it. That's where things like art, music and virtual reality come in. Thanks to philanthropy, sick kids can offer this type of pain care.

**Dr. Jennifer Stinson** Yeah, well, without philanthropic donations, the Pain Centre wouldn't exist, right?

**Hannah** Co-director of the Pain Centre, talking about Lauryn. In addition to her career as a nurse practitioner, she's also a research scientist in her lab called the iOuch Lab. It stands for Improving Outcomes in Child Health. Jennifer has devoted her career to improving outcomes in child health using technology. One of the lab's developments is a pain app called iCanCope, which was part of Lauryn's treatment. It's designed specifically for teens experiencing chronic pain, and it comes filled with a library of coping strategies that helps users with things like symptom tracking, logging where they're hurting, and rating their pain on a scale from one to 10. The app also encourages users to write down their goals, like returning to school and exercise.

**Lauryn** I had realized that once I started tracking my pain, I was finding trends where my pain became worse. And it would be if I was stressed or if I didn't sleep. And I was like, okay, so this is what they mean. It doesn't necessarily mean that my pain is make believe, but it just means that the mental state that I am in can actually impact my pain.

**Hannah** The iCanCope app really helped Lauryn identify her triggers, but also what soothed her pain. And it really opened her up to this community of people her age living with similar experiences, so she didn't feel so alone.

**Dr. Jennifer Stinson** The first time I met her, I knew she was going to beat her chronic pain. She just was so determined to get her life back.

**Hannah**: That's Jennifer again.

**Dr. Jennifer Stinson** I think with what we try to do is really focus on a rehab approach where we really, the top two things are aggressive physical therapy and psychological therapies. And those two things are done so that we can arm people to have what we call like a coping pain toolkit. So everyone's going to experience pain in their lifetime. But if we can arm them with strategies where they can use my body strategies to help. Reduce the impact of the pain, to try and cope with it. So sometimes we may not be able to get rid of the pain totally, but our goal would be to reduce the pain and improve their functioning so that they can get on with the everyday things that they want to and start enjoying their life again.

**Hannah** For Lauryn, managing her pain is part of her daily routine. But today, having lived with chronic pain for 10 years, she also drives, she completed her master's degree, she works, and she travels. She also volunteers as a patient advocate and educator and helps others navigate the paediatric health care system.

**Dr. Jennifer Stinson** And now she's a real strong advocate for the patient journey at SickKids. She's the co-director of the patient and family advisory committee at SickKids. So she's really an integral part of the pain center, and we just really value her perspective.

**Hannah** Now Lauryn can manage her pain. And while it hasn't disappeared, she's learned how to live with it.

**Lauryn** I've learned my triggers. I know what stresses my pain, what makes it better, what makes worse. So, it's a constant managing of my pain but I'm still able to do what I want within while still balancing my pain in my life. I am so mindful that my pain is very specific to me as is somebody else's pain is going to be very specific to them. And if I didn't have my parents advocating for me during my journey, when I was unable to, then I don't know where I would be. And I know that that's not always the case, but I'm very grateful that it was for me and that I had such a strong support system when I wasn't able to be strong for myself.

**Hannah** From SickKids Foundation, I'm Hannah Bank. Thanks for listening. To support breakthrough research in care at SickKids, please visit sickkidsfoundation.com slash podcast. And if you'd like this episode, subscribe and rate us wherever you listen to podcast. SickKids VS is produced by me, Liz Surani, Neil Palmer, Jasmine Budak, Charlotte Darcy, and Rebecca Ostroff. This episode was written by Liz Surani. Sound design and editing by Quill. Check out our show notes for related links and resources. Until next time.