

ONE FAMILY'S STORY

Learning to Live with Chronic Pain



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The first thing I heard when I came upstairs after tackling a mountain of laundry was Megan, sobbing behind her closed bedroom door. I pictured her, lying on her bed, clutching her stomach – or maybe her head. We had reached the point where everything seemed to hurt, all the time.

I wasn't sure what was more distressing: her tears or that I didn't know how to help her anymore. Nobody did, though it wasn't for lack of trying. Even Jake and Robby, who were 12, were as well versed about pain relievers as they were about video games and the leading scorers in the NHL, CFL, and NBA.



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I pushed open the door to Dan's office. His back was to me, his eyes glued to a document on his computer screen.

"Dan," I said.

He turned, startled, as if he'd forgotten he shares a house with other people.

"What's up, honey?" A pleased-to-see-you smile began spreading across his face. I almost smiled back, until the sobs reminded me of my mission.

"Did you hear that?"

"Hear what?" he asked.

"Your daughter, crying?"

He looked at me helplessly. "Megan, she cries all the time."

"She doesn't cry all the time," I said. Maybe four nights out of seven. Sometimes five. This week, seven. So, maybe Dan was right. But I couldn't bring myself to agree with him.





“If I could do something about it, I would,” he said, his voice tired and sad. I wanted to argue with him, to say, “*None of us can do anything about it, but that doesn’t mean we shouldn’t try!*” But what good would that do?

I left the office and crossed the hall, trying to compose myself. I could hear snuffles from Megan’s room, but nothing from Jake and Robby’s. No doubt they were glued to some video game, earbuds on to keep the pings and whistles from disturbing the rest of us. They were such good kids. Sometimes I felt guilty that a lot of my attention seemed to go to their sister.





I knocked lightly on Megan's door, then pushed it open before she could respond. Her back was to me. She was curled into a ball, hugging her long, slender legs to her chest. Her hair fanned out around her pillow and dropped off the edge of her bed.

How awful was it that I wished she were crying about a boy? That's what fifteen-year-old girls were supposed to cry about: heartbreak, and fights with their BFFs. Megan didn't get to see her BFF enough to fight with her – I wasn't even sure Maisy qualified as a BFF anymore, because they hardly ever got together. They saw each other on the rare days Megan was able to get to school, and I was pretty sure they kept up a texting relationship. Megan was so often in pain she rarely had the energy to do the fun things teenage girls were supposed to with their friends. No shopping. No movies. No sports teams. Back when Megan was in early elementary school, she dreamed of becoming an Olympic figure skater, but she hadn't taken lessons since sixth grade, when the headaches began.

And forget about boys. "They hate me, Mom," she would cry to me. "They think I'm making it up, that I'm pretending I'm sick. I'm not pretending. It hurts. Everything hurts."



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On more than one occasion she'd begged to be home-schooled. For the most part, she was, because her pain issues meant she spent more days at home than at school.

"What is it?" I asked, kneeling on the floor and stroking her hair. I no longer made the mistake of sitting on her bed to calm her: even the pressure of someone else on the mattress could set her off.

"My stomach," she moaned. "Mom, please, do something."

What? I wanted to ask. *We've done everything!* We'd been to the pediatrician, the family doctor, the **i** pediatric gastroenterologist, the **i** pediatric neurologist, the pediatric emergency room, and the walk-in clinic. No one had an answer. Some physicians treated Megan as if she were imagining her pain, and others acted like I was the worst kind of helicopter parent.





“How about hot compresses?” I said, trying to sound optimistic, though the days when a hot compress could make her feel better were in the distant past.

Before Megan could answer, Dan walked into the room.

“I think I’ve found a place for help,” he said, his voice unusually hopeful. “Did you know that there’s a pain clinic at the hospital, for kids?”

“Here?” I said. “In the city?”

He nodded.

I wasn’t sure what surprised me more: that there was a place in our city that could help Megan or that Dan was the one who had to find out, online, that it existed.





“How did you find out about it? And why hasn’t anyone told us about it?”

“I Googled – kids, pain, help. I don’t know why we haven’t heard about it, but it looks as if all you need is a doctor’s referral to get in. I’m sure Dr. Mehrali can do that,” he said, looking at Megan, who was listening intently. He rested his hand lightly on her shoulder. “It’s going to be okay, honey. We’re going to get you some help.”

Dan was right: Dr. Mehrali had no problem referring Megan to the Pediatric Chronic Pain Clinic. She was happy to do so. “I’m glad we found a clinic that can help,” she said.





I was anxious about our first appointment. Part of me was hopeful that Megan would finally get the help she needed, but I didn't want to raise my expectations – or hers. What if this turned out to be another dead end, another case of “We can't find anything wrong with her, so clearly there is nothing wrong with her”? Or, worse, “These are just normal growing pains. And you, Mom, need to stop coddling her.” I couldn't face that one more time. And I knew that Megan couldn't, either.

But far from being the clinic of my nightmares, the **i Pediatric Chronic Pain Clinic** turned out to be exactly what we needed. That's not hype. It's not an overstatement. It is the truth. I felt like we were finally in the right place, and so did Megan.

“Tell us about your pain, Megan,” said Dr. Song, the physician, after he introduced us to the rest of the health care team at the chronic pain clinic. I could tell Megan liked the idea of having a team to help care for her – Bonnie, the **i nurse-practitioner**; Penny, the **i physiotherapist**; and Dr. Carvalho, the **i psychologist**. I liked it, too.



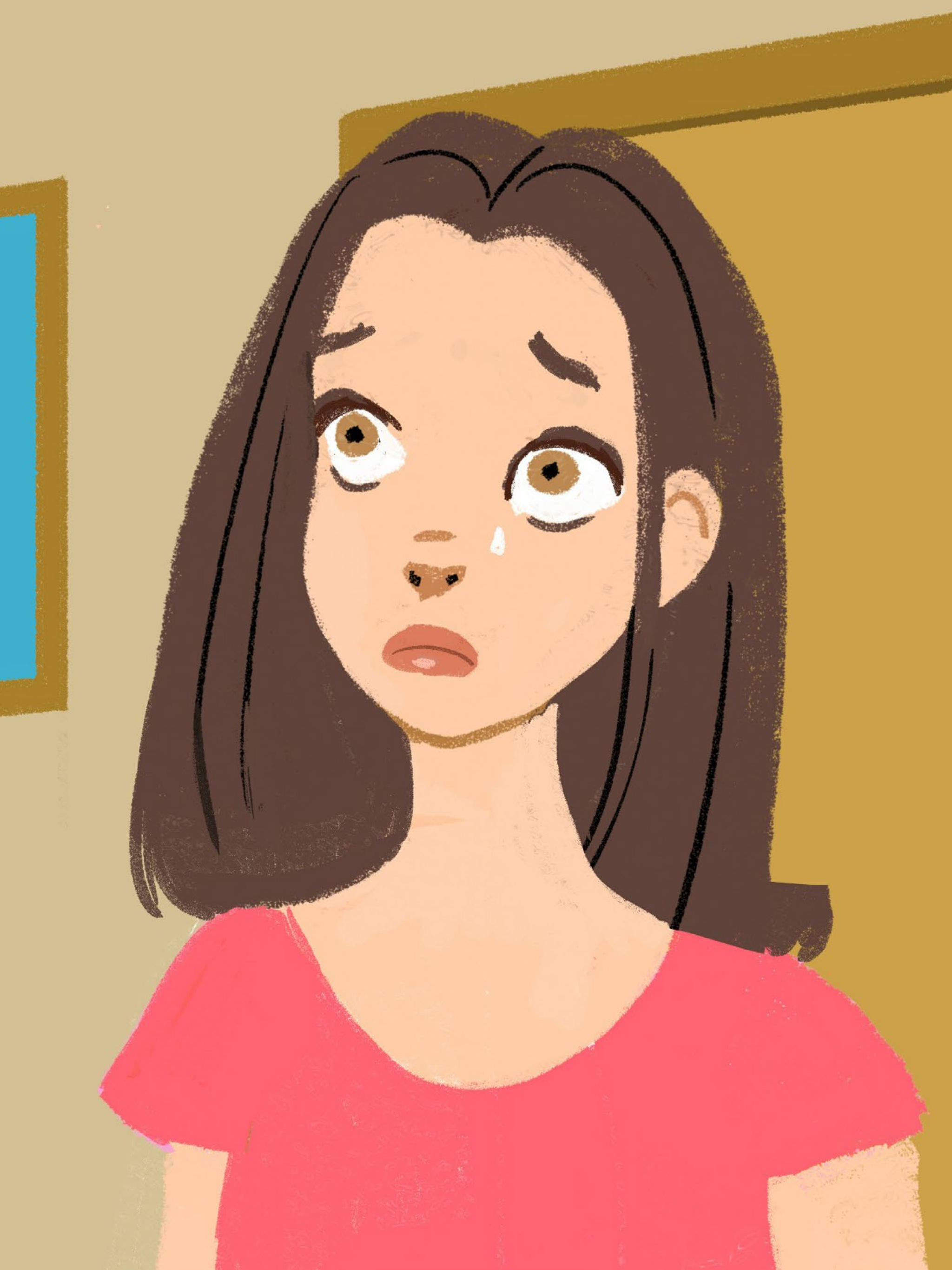


Megan explained how the pain had started with stomach aches when she was in grade six, how we tried changing her diet – more fibre, less fibre, no  gluten, no dairy – but no matter what she did or didn't eat, the pains continued. She told the team about her headaches, how she had them daily, usually first thing in the morning and at bedtime.

Tears filled her eyes when she talked about how she'd had to quit figure skating, and hadn't been able to join a single club in junior high or high school, how she rarely saw her friends anymore, and felt left out. Then, in a sobbing voice that made me choke back my own tears, she asked her first questions of the session, “Do you believe me? And can you make the pain go away?”

Dr. Song was the picture of kindness. “The answers are yes and no,” he said. “Your pain is real. Just because we can't see it doesn't mean it doesn't exist. Everyone in this room knows that you're not making it up.”





“But you can’t make it go away?” Megan asked, her voice a squeak. Dan and I each took one of her hands and held it. She squeezed my hand extra hard, and I squeezed back, trying to send her the reassurance that Dr. Song was reluctant to offer.

Dr. Song took over. “Chronic pain is a disease,” he explained gently. “Your pain is real. Our job is to help you to manage it. We want you to have a better life than you have since the pain started. We want to help you to meet **e** your goals, such as skating.”

The appointment lasted nearly two hours, but the time flew by. Megan, Dan, and I learned more about the **i** central nervous system than I had thought possible to absorb in an afternoon. We also learned about how pain exists in our nerves and in our cells, and that the same pain medications that work for **i** acute pain, like broken bones, often don’t work well for **i** chronic pain.





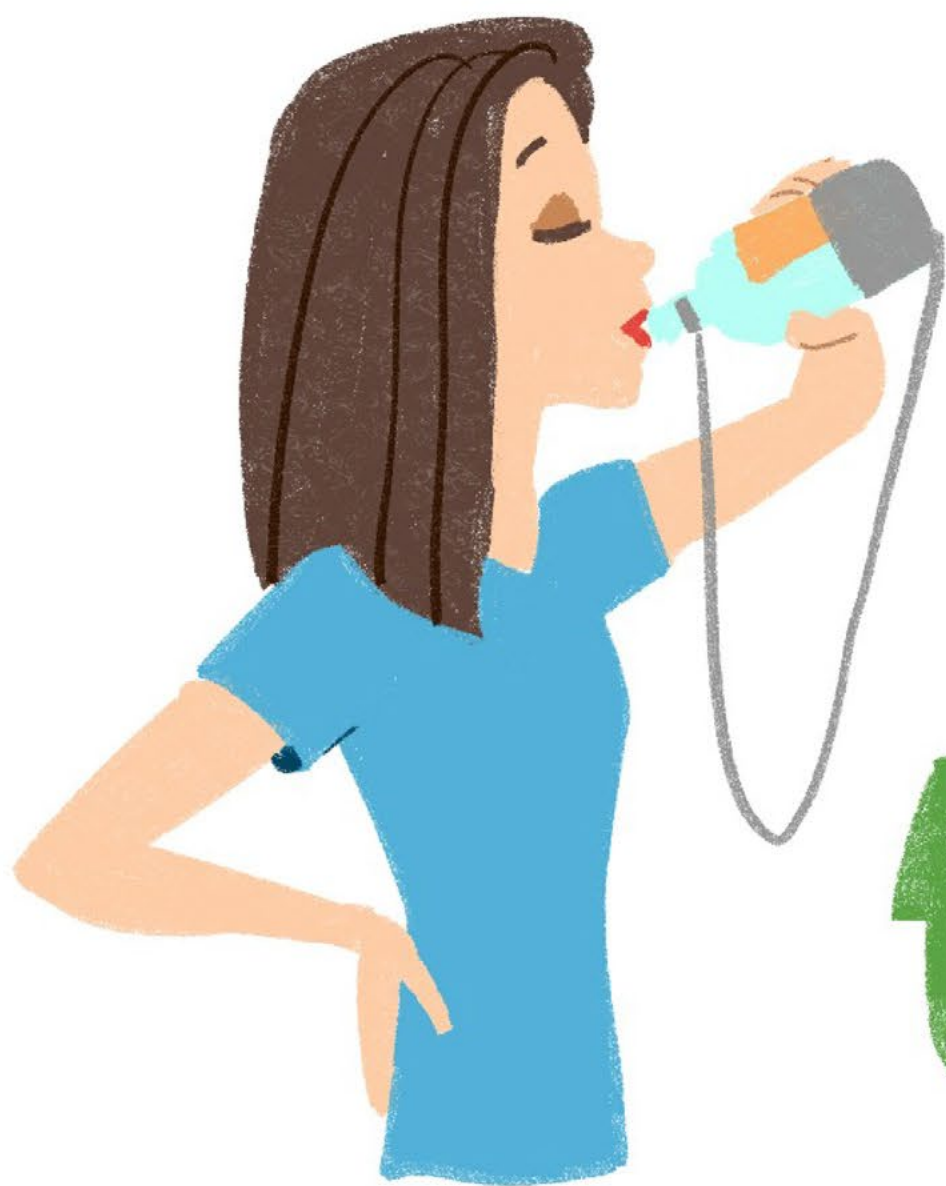
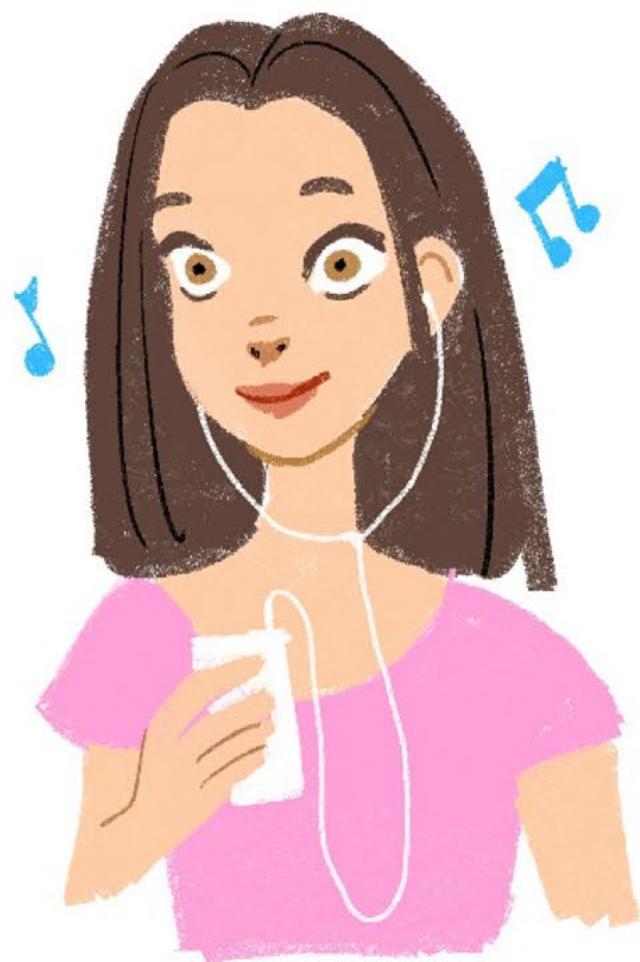
“Even taking **i** ibuprofen every day wouldn’t help Megan’s headaches,” Dr. Song said. “It’s okay to take it on occasion, but by the time your headache pain becomes chronic, it’s more about **i** irritated – or you can even call them ‘grumpy’ – nerves than it is about anything else.”

Who knew that too little or too much physical activity, sleep problems, stress, anxiety, and sadness can all affect the pain signals going to the brain? Well, the team knew. And now we did. Better yet, we had strategies.

To reduce the pain signals, the team recommended relaxation, gentle exercise, and plenty of **i** hydration. They suggested distraction in the form of listening to music, or doing **e** mindful breathing exercises. They gave Megan tips for changing her sleep habits, such as fewer naps, and turning off her electronic devices before bedtime. Equally important, they would help her change the way she thinks about life and her pain. It was, they said, all part of helping her.

“If I could make your pain go away tomorrow —” Bonnie began, but Megan wouldn’t let her finish.





“You can’t, though, right?” she said.

Bonnie nodded. “That’s right, Megan. I can’t. But if I could, what activity would you go back to?”

“I’d skate again,” Megan said, closing her eyes. I pictured her imagining herself flying around the rink at the club where she used to take lessons nearly every day after school. The image made me smile.





“You can,” Bonnie said.

Megan’s eyes popped open. The look on her face was a mixture of surprise and delight, with the tiniest twinge of fear.

“But how?” she asked.

This time it was Penny who answered. “You have to start slowly,” she explained. “You need to build up your strength. Listen to that voice that says, ‘if I do this any faster, or for a minute more, I’m going to pay the price tomorrow.’ When you hear that voice, you have to stop. This isn’t a “No Pain—No Gain” kind of thing. This is more of a “Know Pain Know Gain” deal.”

“I can really skate again?” Megan asked. I swear, I could hear her heart beating with excitement.

“You certainly can,” Dr. Song said. “And it’s good for you. Regular, gentle exercise can help you feel better – if you do it right.”

“Know my pains,” Megan said. “I definitely know them.”





She rolled her eyes, an expression that makes most parents of teenagers cringe. Seeing her make light of a condition that had defeated her for so long had the opposite effect on me. I smiled along with everyone else in the room.

“You will have gains, too, trust me,” Penny assured her. “Once you’ve started a routine, if you want, you can come back to the clinic and we can talk about it – any problems you’re having, what’s working. If you’re interested, I can put together an exercise program for you.”

“I’d like that,” Megan said, and this time the look on her face was one of pure happiness.

The Pediatric Chronic Pain Clinic was the best thing that had happened to our family since Megan’s pain started. As part of the program, she was signed up for Pain Class.



PAIN CLASS



Pain Class was a weekly program for kids. There were eight in Megan's class, six girls and two boys.

They were around the same age and had similar stories: unexplained and hard-to-manage pain, difficulty going to school, little social life, few (if any) friends. Once a week they met in a classroom at the hospital to talk about their issues with Dr. Carvalho and Bonnie, and learn more coping strategies. It was a  **cognitive behavioral therapy** and teen support group. The students earned high school class credits for attending the group sessions.

Pain Class also had a parent session. Dan wisecracked that we were joining the Pain PTA, but the program was no joke. None of the parents had met before, but because we'd had so many of the same experiences, we felt as if we'd known each other forever. I left each parent session feeling as if I'd made a dozen new friends and learned how to help Megan manage her pain. I even learned how to take care of myself so I could better support her.





PAIN CLASS

As Megan learned new strategies to manage her pain, we've noticed definite improvements. She's able to be more active, misses fewer classes, and is on track to graduate from high school. She's been hanging out with her friends, spending more time with them and less time crying in her room. At least once a week, she and Maisy go skating. That's freed me to spend more time with Jake and Robby. Last weekend I allowed them to drag me to Laser Tag. (I lost. Badly).





I often think of that first day when we met the team at the Chronic Pain Clinic, when Megan tried to find humour in the idea of knowing her pain. Looking back, I see that having a team of experts to support her offered her a kind of freedom that she (and her dad and I) had not imagined possible.

Know Pain Know Gain has become our family motto. As the whole team warned, Megan still has pain. Some days are worse than others, but those worse days are fewer and more far between. We're all better at managing the pain: between our team, the Pain PTA and Megan's class, we have developed  **skills to cope**, and have a plan.





Chronic pain never goes away – that’s why it’s called chronic, after all — but one of the most important lessons we’ve learned is that with the right **i** tools and strategies, Megan can control the pain, instead of the pain controlling Megan.

e And that’s the biggest gain of all.



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Definitions

Acute Pain: Short-term pain caused by disease or injury. [Page 22]

Cognitive Behavioral Therapy: A form of psychological treatment that targets your negative thought patterns. You might have these thoughts about yourself or about things happening around you, in your environment. The goal of changing these thought patterns is to also help change your mood and unhelpful patterns of actions in which you may be engaged. [Page 32]

Central Nervous The portion of the nervous system that consists of the brain and spinal cord. [Page 22]

Chronic Pain: Chronic pain is any prolonged pain that lasts longer than the expected healing time (usually three to six months) or any pain that recurs at least three times in three months. This pain may be related to medical diseases such as arthritis, or may be a disorder itself such as migraines or functional abdominal pain. [Page 22]

Gluten: Proteins that are found in wheat, rye, and barley. [Page 20]

Hydration: To take in fluid. Often this term is used in relation to dehydration, which means the body does not have enough fluid (usually water) to keep it working. [Page 24]

Ibuprofen: Also marketed as Advil and Motrin, this is a medication that can be used to treat pain, inflammation, and fever. It is a non-steroidal

anti-inflammatory drug (one that is not a steroid, and that decreases inflammation/swelling) that works by reducing hormones that cause pain and inflammation (swelling). [Page 24]

Irritated – or You Can Even Call Them ‘Grumpy’ – Nerves: When chronic pain arises, your nerves can stop working properly. Scientific research has discovered that pain nerve cells in the nervous system can become extra-sensitive to pain, which leads them to over-react. Some nerves lose control and can irritate other types of nerve cells in the same region of the body. In chronic pain, nerves become over-sensitive and send false pain signals to the brain. These pain signals tell your brain that something is wrong, even when there is no injury. In other words, they set off a “false alarm” that tells you that you are in pain. [Page 24]

Nurse-Practitioner: Nurse practitioners provide direct care, focusing on health promotion and the treatment and management of health conditions. They have an expanded scope of practice and can diagnose, order, and interpret diagnostic tests. They can also prescribe medications and perform certain procedures. [Page 18]

Pediatric Chronic Pain Clinic: Chronic pain teams for children generally include specialist physicians, nurses, and allied health professionals (e.g., psychologists, occupational therapists, and physiotherapists). [Page 18]

Pediatric Gastroenterologist: A physician who treats and manages disorders of the gastrointestinal tract (e.g., stomach, intestines) in children. [Page 12]

Pediatric Neurologist: A physician who treats and manages disorders of the nervous system (e.g., brain, spinal cord, nerves) in children. [Page 12]

Physiotherapist: Physiotherapists are experts on how the body moves and what stops it from moving. As movement specialists, physiotherapists will use a hands-on approach to help you restore, maximize, and maintain movement for the rest of your life. [Page 18]

Psychologist: A psychologist studies, from a scientific viewpoint, how we think, feel, and behave, and applies this knowledge to help people understand, explain, and change their behavior.

A psychologist working with children should be trained in the area of child psychology. Typically, the psychologist will have received this training while in graduate school where he or she will have chosen the courses and training experiences to prepare for working within a particular specialty area. Sometimes, psychologists pursue specialized training after graduation by completing a post-doctoral fellowship. [Page 18]

Skills to Cope: Important information and coping skills learned by parents and children at the Pediatric Chronic Pain Clinic: [Page 36]

- A better understanding of chronic pain
- Regular relaxation exercises
- Gentle physical activity
- The importance of getting a good night's sleep
- Managing stress
- Being mindful in daily activities

- Eating regular meals including breakfast, and drinking lots of water
- Challenging unhelpful thoughts
- Talking to friends, family members, teachers and health care providers about my pain
- Putting it all together to manage those “pain flares” – so they won’t happen as often, be as severe, or last as long
- Living the life I want to live despite pain

Tools and Strategies: Here are some websites that list the locations of chronic pain clinics across Canada and the United States, and provide additional information about chronic pain. [Page 38]

Canadian Pain Coalition

<http://prc.canadianpaincoalition.ca>

http://prc.canadianpaincoalition.ca/en/pediatric_pain_treatment_facilities.html

American Pain Society

<http://americanpainsociety.org>

http://americanpainsociety.org/uploads/get-involved/PediatricPainClinicList_Update_2.10.15.pdf

Exercises

1. **Exercise #1: Happinesss, values and goals [Page 22]**

When a child in your life has chronic pain it is very difficult to see him or her unhappy and suffering. Quite often your child's life has had to take an unexpected and different direction. When starting to learn to live with pain it can be a helpful exercise to sit down with your child to gently and lovingly explore what it is that makes him or her truly happy and motivated. We invite you to write a few short lines to answer the following questions if you feel comfortable doing so.

What makes your child happy? ("Happiness" can include being content, satisfied, and feeling well and joyful.)

What are your child's personal values? ("Values" are generally understood to be qualities or behaviours that are important to a person, and that often guide a person's choices. For example, being healthy, loving, kind, sporting, artistic, and/or devoted to family.)

What are your child's goals? (Goals are specific, realistic targets. For example, to graduate from high school, visit a friend once a week, swim ten laps, do a random act of kindness.)

2. **Exercise #2: Mindful breathing [Page 24]**

The following is a brief exercise that you and your child can try. This exercise can help prevent stress and pain from building up. You can do the exercise together by having one of you read it out loud if you wish. The exercise can last as long as you want and you can do as much as you want. It can take a few minutes or ten minutes or longer. There is

no one way to do this exercise, so you should feel no pressure to “get it right.” Practicing will help you get more out of it and some people will do the exercise once a day. The important thing is that it is not a chore. This exercise should be done in a safe place where you can take a break. You shouldn’t be driving or operating machinery at the same time, for example. Start off somewhere that is quiet and where you will not be disturbed for 10 minutes or so. Perhaps you can also switch off your phone. You can sit in an upright chair or cross-legged on a cushion on the floor. The important thing is that you and your child are comfortable and warm. Wrap yourselves in a blanket if you like.

After a while you and your child may want to do this on your own and this can be a good idea, too.

The exercise.

Practice saying these words slowly, using a gentle and calm voice. You can add your child’s name in places if you wish.

This is a special few minutes. You don’t need to rush. This is time to be kind to yourself. It involves just a little work but with a little practice this could really help you feel better.

Sit comfortably. Make sure your back is straight but not stiff. Your head can relax and tilt forward just a little. Rest your hands gently on your lap or on your knees. Gently close your eyes... Take one deep breath in and then breathe out, making a noisy playful sigh “Ahhhhhhhhhh.” Do this once again. The first one was practice. Now wiggle your jaw just a little to see if you can relax your jaw muscles. Smile for a few seconds, even if you don’t want to, and then just

relax your face muscles. Gently move your neck and shoulders, relax and let your muscles go soft. Just do your best. There is no such thing as 'getting it right.'

Now gently place one of your hands on the middle of your belly. Now breathe slowly, through your nose. Take deep breaths. Feel those breaths deep into your belly. At the same time, count slowly to five. Do not worry if you do not make it to five. Before breathing out, hold your breath for a count of three.

Then breathe out slowly. You can repeat this two more times if you wish. Slowly breathe in... Hold for three... Breathe out.

Then let your breathing go back to normal. Don't worry about counting. Just take relaxed, normal breaths. Feel the warm air flowing through your nostrils. Notice the gentle sound that your breathing makes. Gently breathing in...and out. You might want to imagine that you are sitting on a warm, sunny, quiet beach. Imagine the waves gently splashing on the shore. Just like the rhythm of your breath ... gently in and out.

Maybe you would like to imagine sitting under a tree in a quiet, warm garden. Imagine the warm breeze rustling the leaves. Your breath is like the breeze...

You might notice thoughts coming and going in your mind. Maybe these are sad thoughts from yesterday or worries about tomorrow. This is normal. This is what your mind does. You can let these thoughts go. Do not struggle with them. Imagine your thoughts are like clouds floating across the sky. You can watch them and let them go.

Notice your breath again. Notice how warm it is... Notice which of your hands is warmest... Slowly breathe in and out... Notice which part of your body is hurting most... If you are comfortable, take your warm hand and place it gently over your pain...breathing in and out... Notice the soothing, loving warmth of your hand... and leave it over your pain for a couple of minutes...maybe longer... It is okay to care for yourself. It is okay to soothe the pain...

Gently open your eyes...relax your hand to your side. Look around. Slowly move your arms and legs...and gently stretch. When you are ready, you can get up and move around. You can say ‘thank you’ to yourself for spending a few moments looking after yourself.

3. Exercise #3: Collecting your thoughts [Page 38]

‘Dear Pain Team’ - Wanting the best for your child.

If a child or young person in your life is suffering from chronic pain, we invite you to sit down with them and write a short letter. This might be best done after you have read the e-book. This is not a letter you would send in the mail but a letter that you keep in a safe place so that you can talk about it together. One idea for an opening line is “Dear Pain Team,” but we encourage you to write whatever feels comfortable. The letter doesn’t have to be long. You might get started by writing a few lines on the following:

What is the most important thing you would like the pain team to know about your child’s pain?

What is it that you hope the pain team can do to help your child?

**KNOW PAIN
KNOW GAIN**



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"Thank you to the families for participating and sharing their stories"

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