

# Chronic Pain in Children and Youth

An Information Resource for Teachers





Alberta Children's Hospital

In Partnership with







Calgary Board of Education



## **Chronic Pain in Children and Youth: An Information Resource for Teachers**

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## **Chronic Pain in Children and Youth: An Information Resource for Teachers**

#### What is chronic pain in kids?

Chronic pain may begin as acute pain and be a result of injury, disease, surgery orhave no cause. The pain is persistent or recurrent and lasts more than three months. It has been likened to a fire alarm that continues to sound even after the fire has been extinguished. Chronic pain has recently been identified by the World Health Organization (WHO) as a disease in and of itself as well as being associated with other chronic conditions and medical treatments. Headaches are reported most frequently with abdominal pain also being common. Substantial disability requiring intervention is likely to be experienced by 5 to 15 per cent of children and youth with chronic pain.<sup>1</sup> About 2/3 of kids with chronic pain eventually become adults with chronic pain.<sup>2</sup>





## Why is it important for teachers to understand their students with chronic pain?

In Canada chronic pain is experienced by 1 in 5 or 20 percent of youth under the age of 18, so there is a very good chance you are presently teaching or have taught a student with chronic pain. As there are often no obvious outward signs of disability, you may not even be aware that these students are struggling. Many of them are high achievers, and they can be reluctant to let on that they are experiencing challenges. In fact, pediatric pain has an observed relationship with perfectionism.<sup>1</sup>

More than 50 per cent of students with chronic pain miss significant amounts of school. School absence in general negatively impacts academic performance but when chronic pain is in the picture, achievement levels decline even more. Your students with chronic pain experience a poorer quality of life, disrupted family life, and substantially limited overall school functioning including peer and social relationships.<sup>1</sup>

Kids with chronic pain are twice as likely to die by suicide and are 20 per cent more likely to develop a substance abuse disorder as an adult.<sup>2</sup>

Physical and mental health professionals view school as being a child's primary occupation, the "work of childhood". It is seen as the most critical environment for supporting educational as well as social development.<sup>3</sup> A comprehensive, Canada-wide consultation process involving patients, families, and healthcare providers (Partnering for Pain)<sup>4</sup> resulted in more than 540 potential priorities around pediatric chronic pain research and care. Two of the top 10 of these priorities were:

- Priority #2: What is the impact of living with chronic pain on children's and adolescents' academic performance and educational attainment, and what strategies best support vocational planning for children and adolescents with chronic pain?
- Priority #7: What strategies for educating school personnel about pediatric chronic pain effectively increase their awareness, understanding, and recognition of the validity, impact, and treatment of pediatric chronic pain?

What does all this mean? Along with children, youth, and their families, healthcare providers in the field are eager and motivated to work with YOU! As teachers, they greatly value the unique perspective and potential resources you bring to improving the lives of kids with chronic pain.





#### What surprises people about chronic pain in kids?

We tend to think of chronic pain as something that mostly happens to older people, but in reality it "skyrockets" at puberty. Experts think that hormonal, physical, and emotional changes may play a role.<sup>2</sup>

The prevalence of chronic pain in kids has increased substantially over the past decades with hospitalizations increasing nine-fold between 2004 and 2010.<sup>2</sup> Because stress and obesity can be linked to chronic pain, experts question if increased screen time and lack of activity may play a part (think about all of those video gamers sitting in your classrooms).

There is no "cure" that ends chronic pain. The goal of treatment is not resolution of the pain but rather having the young person acquire and use pain management strategies that allow them to return to function with an improved quality of life. That means your students who have been receiving treatment will likely still experience some pain when they return to school.

#### Why do some kids develop chronic pain and others do not?

Biological, physical, and social factors all play a role. Biological factors include genetics, sex (chronic pain is more prevalent in females), hormones, and individual differences in how pain signals are processed. Low socioeconomic status is related to greater functional disability. Parent/child relationships and family interactions can be a factor. Culture, race, and gender have been shown to play a role when interacting with parent responses to a child's pain regarding the level of protectiveness and monitoring of symptoms. When parents have a higher level of catastrophic thinking, this can increase their distress which often leads to them limiting the activities of their children. As these young people would often benefit from more activity rather than less, this suppression of movement can increase the likelihood their child's pain will become chronic. Individual factors such as a child or youth's personality, physical and mental health, past experiences with pain and how people responded to it also play a role in how the brain perceives pain and thus the development of chronic pain.

#### How is chronic pain treated in kids?

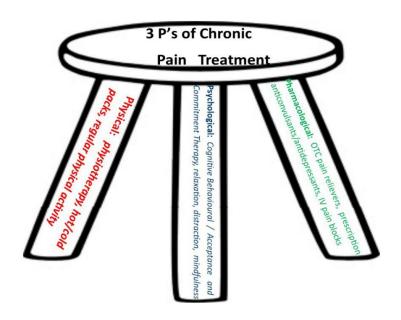
The *Biopsychosocial Model of Pain* is the predominant model used to understand and treat pediatric chronic pain. This approach recognizes that *biological*, *psychological* and *social* factors all interact and influence one another in terms of a child's pain experience. If there is an underlying cause for the pain, if possible that will be treated first.

Some pain experts also describe a related "3 P" approach to treatment: Physical / Psychological / Pharmacological. They use a three-legged stool as a visual metaphor.

A simple acronym for thinking about pain management strategies is:

RED: Relaxation, Exercise, Distraction

Drawing/sketching is an example of an activity kids like to do that is both relaxing and distracting for them. Listening to music is another example that can also be combined with exercise.



#### How is chronic pain related to mental health conditions?

Pediatric chronic pain can co-occur with a variety of mental health conditions; however, anxiety and depression/low mood are most commonly seen in youth with chronic pain. School anxiety (which is "meaningfully distinct" from other forms of anxiety<sup>5</sup> and will be discussed later in more detail) is a debilitating problem. Children and youth with chronic pain may also show clinically elevated levels of generalized anxiety, social phobias, separation anxiety, and panic/somatic symptoms. For example, a child experiencing panic/anxiety may feel stomach pain or the initial pain may scare the child and bring on feelings of anxiety. As time goes on, the two factors can become intertwined and it becomes difficult to distinguish the cause from the effect. Depressive symptoms have been associated with the link between sleep and pediatric chronic pain, as poor sleep often precedes chronic pain and further contributes to functional disability. <sup>1</sup>





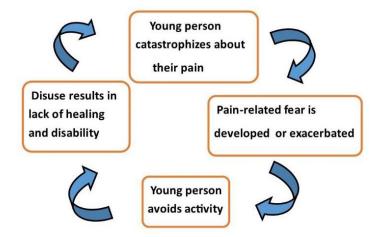
School anxiety presents as distress in these domains within the context of school:

- Cognitive (intrusive thoughts)
- Emotional/Behavioural (feeling frightened, worried)
- Psychophysiological (e.g. elevated heart rate)

These symptoms are mainly brought on by:

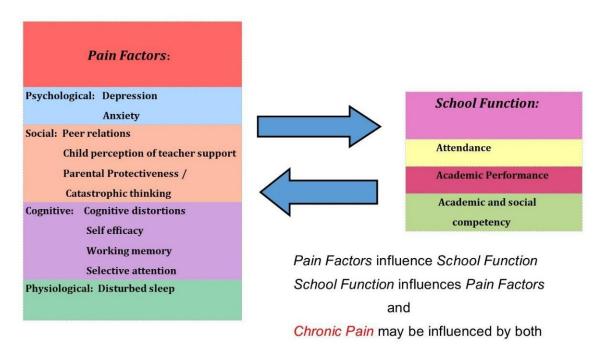
- Fears about poor academic performance
- Social rejection / isolation / victimization<sup>5</sup>

Cognitive factors may influence the youth's ability to employ coping strategies such as utilizing social support and managing pain catastrophizing.<sup>1</sup>



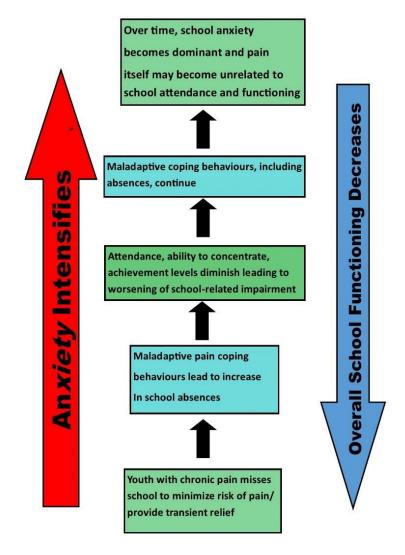
#### How do pain factors influence school function?

Physiological, psychological, social, and cognitive factors all interact to influence the key components of school function – the 3 A's: **attendance**, **academic performance**, and **academic and social competence**.<sup>3</sup> How a child or youth navigates the 3 A's also acts reciprocally to influence pain factors. These factors can also influence other pain factors and have an effect on school function and/or chronic pain.<sup>3</sup> For example, a physiological factor (sleep disturbance) affects a cognitive factor (working memory/attention) which then influences academic performance.



<sup>\*</sup>The above diagram was made from the work of Kailyn Jones et al., 2018

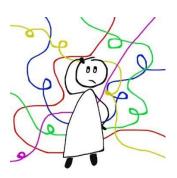
Overall, school-related anxiety results in poorer school functioning as well as withdrawal from athletic and social opportunities. Youth with chronic pain report feeling "less competent" in academic and social areas than healthy peers. Feer and social factors are important considerations as school refusal is increased when youth with chronic pain experience social challenges. A lack of competence in a particular domain and lack of responsivity from others have been identified as specific factors that can increase anxiety sensitivity and pain-related fear. Failure to address school-related anxiety may place youth with chronic pain at risk for an array of protracted physical and mental health problems. Interventions such as cognitive behavioural therapy, social skills training, and interpersonal effectiveness/assertiveness skills may be employed in an effort to reduce perceptions of isolation and improve school functioning.



<sup>\*</sup>The above diagram was made from the work of Gibler, et al., 2019

### What can make chronic pain in kids worse? What should teachers NOT do?

In a limited number of research studies, teachers were found to have dualistic beliefs about students' pain. That is, they believed the pain had either a physical **or** psychological origin rather than the holistic conceptualization that is the standard in healthcare. Teachers struggle to help in the most appropriate way and this may lead them to employ solicitous (protective) responses. Being overly solicitous is related to negative outcomes. Children and youth perceive excessive reassurance from caregivers as anxiety, which can make them feel anxious and intensify their pain. Discouraging responses from teachers or those expressing frustration/irritation contributed to an increase in pain intensity, disability and depression/anxiety. The relationship between the parent and teacher regarding how the student is being treated may be significant to the child's level of pain. Protective responses, such as minimizing expectations for schoolwork, may be perceived by youth and/or their parents as being associated with greater functional disability or school-related impairment.



## So, most importantly, how can you help your students with chronic pain?

The good news is that researchers found the most common teacher response to their students' chronic pain was **the promotion of well-behaviours and coping**. This response was predictive of a decrease in pain intensity/disability, somatic symptoms, depression, and anxiety. Current research shows that teachers' perceptions and expectations can significantly affect the success and well being of their students with chronic pain. Your support through positive responses can be a protective buffer against the adverse affects of chronic pain on school performance and an important avenue toward helping your students on a path to developing resilience.



More specifically, approach interactions with your students as **encouraging and monitoring** versus employing a protection response. Within an MTSS (Multi-Tiered System of Supports) framework, Tier 1 includes universal interventions of benefit to all students. As 23 per cent of students reportedly experience some form of chronic pain, these supports may help to reduce the likelihood of their pain developing further and possibly becoming debilitating. As many schools are incorporating Wellness Rooms into their buildings, these locations could provide a great opportunity for all students to access Tier 1 supports.

Multi-Tiered System of Supports (MTSS)		
Tier 1 Unive	ersal Supports	
Curricula to support	Sleep hygiene	
healthy lifestyles:	• Exercise	
	Healthy eating	
	Stress management	
Teaching mind/body skills	Relaxation strategies	
to all students:	Mindfulness practices	

You can also advocate for and support specific interventions and accommodations recommended for students with chronic pain. Based on my experience working with students in the Intensive Pain Rehabilitation Program and the published literature, the following accommodations typically help kids with chronic pain:

### Accommodations and Interventions Teachers Can Use to Support Students with Chronic Pain

- A gradual school re-entry plan (especially for those students who are school avoidant)
- Reduced course load
- Extended time on tests
- Flexibility with assignments as long as curricular outcomes are met
- Flexibility with due dates. Chunking assignments down so that deadlines are more incremental can help to keep students on track and accountable without overwhelming them.
- Providing an extra set of textbooks or access to online textbooks to reduce the need for the student to carry a heavy backpack
- Providing a copy of class notes can help a student with chronic pain to focus on the content being presented rather than trying to listen and write
- Frequent breaks. These breaks can be used to build in coping strategies (Relaxation, Exercise, Distraction) which allow your student to be more productive during dedicated work time.
- Providing a private/quiet place for your student to go in the event of a pain or anxiety flare. It can be helpful for your student to have a private signal to communicate with you, so that they can leave class without drawing attention to themselves. This is where the *monitoring response* can be important. If the student is leaving class excessively, you may need to revisit thisaccommodation.
- For students experiencing headaches, listening to music with headphones or wearing sunglasses to manage light can help them deal with environmental stimuli.
- Have a consistent "go to" school staff contact who understands chronic pain in children and youth. A staff person who will proactively do frequent, regular checkins with the student with chronic pain can go a long way toward helping them to be successful with school functioning and becoming a strong and resilient learner. Establishing this relationship of trust and support with the student and their parent(s)/guardian(s) may be one of the most important things you can do to contribute to their present and future success and well being.







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#### What sources were used in the creation of this document?

- <sup>1</sup> Paul C. Jones & Katherine S. Salamon (2019): Treating Pediatric Chronic Pain in Schools: A Primer for School Psychologists, Journal of Applied School Psychology, DOI: <u>10.1080/15377903.2019.1619646</u>
- <sup>2</sup> Chronic pain in kids is more common than you think, by Raina Delisle, in *Today's Parent*, April 30, 2020 https://www.todaysparent.com/kids/kids-health/chronic-pain-kids/
- <sup>3</sup> Kailyn Jones, David Nordstokke, Gabrielle Wilcox, Meadow Schroeder & Melanie Noel (2018): The 'work of childhood': understanding school functioning in youth with chronic pain, Pain Manag., www.futuremedicine.com
- <sup>4</sup> Partnering for Pain Identifying the Top 10 Research Priorities in Childhood Chronic Pain in Canada.; 2019. http://bit.ly/2NSYY7p.
- <sup>6</sup> Sarah Nelson & Deirdre Logan (2019): What's the right answer? Parent and youth perceptions of teacher responses to pain behaviors in the classroom, Children's Health Care, DOI: <u>10.1080/02739615.2019.1603995</u>
- <sup>7</sup> Sole E, Castarlenas E, Sanchez-Rodriguez E, Galan S, de la Vega R, Jensen MP, Miro J. Chronic pain in the school setting: the teachers' point of view. J. Sch Health. 2018; 88: 65-73.
- <sup>8</sup> Sara King, Jessica A. Boutilier & Jill MacLaren Chorney (2018): Managing Chronic Pain in the Classroom: Development and Usability Testing of an eHealth Educational Intervention for Educators, Canadian Journal of School Psychology, DOI: 10.1177/0829573516674308

#### Who compiled the information in this document?

My name is Rae Miller. I am a Calgary Board of Education retired teacher who worked with kids in pain for over 29 years at Dr. Gordon Townsend School. It has been my privilege to work with students attending the *Intensive Pain Rehabilitation Program* (IPRP) and the *Rehabilitation and Education Program* at the Alberta Children's Hospital in Calgary, Alberta.

For general information please contact: contact@kidsinpain.ca.

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