

Let's Work Together to Reduce Pain - Caregiver Version

This fact sheet will help you and your child learn about using medicines (including opioids) for relieving pain. Knowing the facts will help you manage your child's pain with the goal of being able to continue daily activities with less pain.

What is pain?

Pain is an unpleasant sensation, suffering or distress. Pain can cause irritability, make it hard to sleep, reduce appetite, and make it hard to be active and enjoy life. Everyone can experience pain differently and it can change from day to day or with certain activities or even emotions (especially when your child tries to hold those emotions in).

It is important to know that most pain can be relieved!

Types of pain

It can be helpful to understand different "types" of pain. Although your child may be experiencing more than one type, it may help you to better describe it to your care team. Different medications work better on different types of pain and we want to do our best to ensure the medication prescribed will provide pain relief.

Acute pain is short-term pain. It comes on quickly, lasts a relatively short time and can range from mild to severe. It is caused by tissue damage or inflammation.

Chronic pain is long-term pain. It may last a few weeks or months or be ongoing. It may be constant or come and go, and it can range from mild to severe. Chronic pain can start as acute pain and then stay beyond the normal expected healing time. It is also called persistent pain.

Pain can also be described based on the part of the body it affects.

Nerve pain is caused by pressure on the nerves or spinal cord, or by damage to nerves. It may be described as burning or tingling.

Bone pain is caused by damage to a bone and it may occur in one or more areas of bone. Bone pain is often aching, dull or throbbing.

Soft tissue pain is caused by damage to an organ or muscle. It is usually described as sharp, aching or throbbing.

Visceral pain is pain that starts in internal organs such as the intestine or bowel. It is often difficult to describe or find the source of the pain. It is often linked with other symptoms such as nausea and sweating.

Phantom pain is pain or changes in sensation in a body part that has been removed. For example, some people feel pain in an arm or leg that has been amputated.

Referred pain is when one part of the body causes pain in another part. For example, a swollen liver can press on nerves and cause pain in the right shoulder.



How can I tell you about my child's pain?

At Canuck Place our team works hard to understand your child's pain. Some children/teens like to use the faces scale while others like to use numbers from 1-10. Your child may also have their own way of describing and rating their pain – we will work with you and your child so we can best understand and treat specific pain.

Managing pain

We have an amazing team to help manage pain but **the most important team member is your child!** Our team of specialized doctors, nurse practitioners and nurses will work with you to choose the right medicines to manage their pain. Sometimes it may take one medicine or a combination of medicines to best manage the pain — it can be a balancing act! We like to start off with low doses and slow increases in order to see how your child's body responds to the medicine and to watch for any side effects. We may also suggest some non-pharmacological (medicine free) ways to reduce pain such as heat/cold, massage, counselling and/or meditation.

Our team is available 24/7 to answer questions and help to manage your child's pain!

Communicating with your team

Your "team" includes your child (team leader), your family, caregivers and medical professionals involved in your care. Sharing information with team members and being open and honest about the pain will help to provide better pain management.

It is very important to listen to your child. Have you ever found they are saying any of these things?

- I can get through it I don't need any medication
- I'll just wait a bit and see if the pain goes away
- I'm scared to take an opioid
- I'm scared I will become addicted

There is no need for them to try and live life through the pain – they will have more enjoyment in activities when pain is under control. It is important to remember that when pain is left for too long it can quickly get out of control and become harder to relieve and manage.

Sometimes the thought of opioids can feel scary – especially if you have heard negative things on social media or if one of your family or friends has a strong opinion about it. Remember that the medication has been



prescribed by a specialized doctor or nurse practitioner who has given your child a *safe dose to effectively manage the pain*.

When your child takes the medication as prescribed they will not become addicted. The body needs the medication to block the pain receptors that are signaling the brain to tell your child that there is pain. Their treatment will be reassessed and their dose can be adjusted depending on how their body responds. For example, if your child receives a treatment that reduces their overall pain, then we may slowly reduce the pain medication if their body does not need as much medicine to manage the pain. Our team is always willing to explain this to family or friends if they have questions or concerns.

Tell your Doctor/Nurse Practitioner about all your child's medications

It is very important to tell us about all the medications your child takes. This includes any over the counter (like Ibuprofen, Acetaminophen, allergy pill etc...), herbal (including THC/CBD) health supplements. This helps to make sure your child is not prescribed a medication that they are already taking or one that interacts with their current medications.

Ask Questions when you have them. There is no such thing as a stupid question!

Here are some helpful questions to think about when you communicate your child's pain to the team

- What activities or movements can bring on the pain?
- Where is the pain?
- How intense is the pain? Does it radiate to anywhere else in the body?
- What does the pain feel like? For example: is it sharp, dull, and/or aching?
- What makes the pain better or worse?
- If your child is using pain medication, how much does it relieve the pain?

Sometimes writing the answers down is helpful for remembering when you speak with the Canuck Place team. The more you can tell us about your child's pain the better we can try and manage it. We can give you some tools to keep track of pain and what treatments or medicines work to relieve it. This will help us to make adjustments to your child's pain management plan.



Choosing the most appropriate medication

When your child's doctor or nurse practitioner is choosing the medicine or combination of medicines, they will base it off the type, intensity (how strong) and frequency (how often) of your child's pain. It can take some time to get the right medication or right balance of medications for adequate pain management. Again, this is why it is so important to communicate your child's pain with your team!

When the medication is first started you might notice your child feels drowsy or tired – this can be normal. It is important that you tell us how the medication makes them feel and if it is effective. We usually ask that you give the medication a few days to see how their body will react to the medication. If their pain has been really bad prior to starting the medication it may take a little longer to begin to feel complete relief.

Types of pain medication

- Mild pain relievers, such as anti-inflammatories and acetaminophen
- Medium to strong pain relievers such as opioid medications
- "Helper" medications or adjuvant medication

Facts about opioid medications

Opioid medicines are pain relievers that have been used for many years. At Canuck Place, our doctors and nurse practitioners frequently prescribe: morphine, hydromorphone, methadone and fentanyl. Some of the differences of these medicines include:

Onset of action (length of time they start working)

- Immediate
- Delayed

Duration of action (length of time they last)

- Short acting (for a short time) these would be used for "incidental pain" like bathing or position changes.
- Long acting (for a long time) some opioids are designed to be released slowly and can last for 12-24hours.

Administration (how they are taken)

- By mouth (tablet, capsule, liquid)
- By injection into the fatty tissue in the skin, intravenously or (rarely) a muscle.
- By a patch placed on the skin that is changed every 2-3 days.

Possible side effects

These will be reviewed with you based on the medicine/s that is prescribed for your child. One side effect that is common amongst opioids is constipation. You will be asked to keep track of their bowel movements (frequency, consistency) and we will add a stool softener or laxative if it becomes problematic.



**Opioids may also be prescribed for other symptoms, such as dyspnea (difficulty breathing) or coughing. They work to increase vasodilation in the lungs (increasing the amount of oxygen that goes into your blood stream) and relax the muscles that can feel tight.

Adjuvant Medications

- **Steroids** (dexamethasone). These are strong anti-inflammatory medicines that may help relieve pain by decreasing inflammation. They may be used along with other pain relievers for nerve, bone, or other types of pain. It is usually used for a short amount of time only.
- **Antidepressants**. Treating any existing depression or anxiety can make pain easier to control. These drugs may also be useful in pain caused by nerve damage.
- Anticonvulsants. These medicines are usually used to control seizures, but they can also help control
 nerve-related pain
- Local anesthetics. These are medicines that can block pain signals in the body. A pain specialist may inject a local anesthetic to block pain.
- Muscle relaxants. Antianxiety medicines and muscle relaxants may be used along with pain medicine if pain is aggravated by tension or muscle spasms.
- **Bisphosphonates**. These medicines are sometimes used to prevent fractures in people whose cancer has spread to the bone. They can play a key role in relieving bone injury and pain.

Cannabinoids

Medical cannabis (THC, CBD or combination) may also be considered for pain management. Very little research exists on medical cannabis and its use in children. Canuck Place doctors and nurses will work with your child's health care specialists to prescribe medical cannabis for symptoms in which medical cannabis may have the best impact for your child. Canuck Place has a separate in-depth information sheet on the use of medical cannabis which you can request to learn more and decide if this may be a consideration for your child.



Using Medication the Right Way

It may feel overwhelming at first to learn when to give your child the pain medication and if there are combinations of medications, which one to take. Our team will do our best by giving you specific instructions for which pain medication to take and when. The medication may be prescribed as "regular" or "as needed" – it is important that you understand the difference. If you ever have any questions you can contact a nurse by calling the Kids Counter 24/7.

Regular or daily medications

Administer medication regularly at the intervals prescribed (or as close to possible to those times) to get the maximum benefit. If you delay the medicine for too long your child may experience avoidable pain, in addition it may be harder to get the pain back to baseline once it flares up. If you administer the medication too soon it could make them drowsier or affect their breathing. Setting a timer on your phone or watch is a great way to remind you when it is time to give the medication. If you forget a dose or have questions you can call the Kids Counter 24/7.

As needed or PRN Medications

These medications are to be taken if your child is experiencing increased pain or you will be doing an activity that you know will cause them pain. Sometimes they will be prescribed as "PRN" pain medication in addition to a "regular" pain medication. It is important to keep track of how often they require the "PRN" medication as it may indicate that we need to increase or change the "regular" medication. Please call the Kids Counter 24/7 line if your child is requiring more PRN medications to alleviate the pain.

Be Organized with the Medications

- Keep medication in the same place so that you always know where it is.
- Keep medication in the original prescription bottle so that you don't mix up the medications or strengths
 of the medications.
- Keep track of how much medication is left in the bottle when you notice you have less that 3-5 days left then let us know so that it can be refilled. Sometimes it can take a couple of days for the pharmacy to stock the medication so don't leave it to the last doses.
- Have any medications that your child is no longer using returned to the pharmacy for safe disposal.