



**Opioid resource guide for  
PACT patients and their caregivers**

SickKids is committed to helping patients and their caregivers understand pain and the safe use of opioids. We are striving to provide quality information to help caregivers manage pain needs at home with confidence.



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# What is pain? [\(AboutKidsHealth\)](#)

Pain is the body's warning system, alerting us that something is wrong.



## **Acute pain**

Acute pain is called ordinary or nociceptive pain. It is a useful sensation because it protects us from hurting ourselves. If we did not feel pain, we might burn our fingers on the stove or not know when we have a serious injury.

Acute pain is what you feel when normal nerves send messages from the injured body tissues. This is the type of pain you feel from a needle poke for blood work, or from an inflamed or swollen joint. This pain is temporary. Acute pain goes away when healing occurs.

## **Chronic pain**

Chronic pain refers to pain that has lasted for at least three months. Unlike acute pain, chronic pain does not serve a useful purpose like warning us about something harmful. When a person experiences chronic pain, there may be abnormal messages being sent to the brain by the nerves, even when there is no damage or inflammation in the body.

Pain is very personal and subjective, so it is hard to know how another person experiences it. It can be difficult to understand a child's chronic pain as they may not have any visible signs of injury such as a cut, bruise or swollen joint. Likewise, it can be hard for a child to describe their pain to other people. It is like describing the taste of chocolate to someone who has never tasted chocolate before.

## **Pain can come from many sources**

- Pain from a tumour or mass: Your child may feel pain from a tumour pressing on bone, nerves or body organs. This pain may sometimes but not always improve with disease directed therapies.
- Pain from procedures: Cancer treatment often involves tests and procedures such as bloodwork and injections using needles which can cause pain.
- Pain from side effects of the cancer treatment: Some cancer treatments may involve surgery, and many involve chemotherapy medications. Surgery can mean cuts or incisions in the body that can be painful. Some cancer medications can have side effects associated with pain, such as mucositis and neuropathy.
- Mucositis: Some chemotherapies cause painful sores in your mouth and throughout your digestive tract (your gut, stomach and intestines).
- Neuropathic pain: This type of pain may be due to the effects of chemotherapy on nerve cells. Your child might experience this as burning, tingling, numbness, weakness, clumsiness, trouble walking, or unusual sensations in the hands, arms, legs or feet.

## **Pain assessment: Knowing if your child is in pain**

Sometimes your child will say when they hurt. They may use words like pain, hurt, boobo, sore or ouchie. Your child may point to the part that hurts or be guarded and try to protect the area.

If you feel your child can do so, you may use a 0 to 10 pain scale to find out how much pain your child has. Ask your child to rate the pain on a scale from 0 to 10 where 0 is no pain, and 10 is the worst pain ever. Mild pain would be 0 to 3, medium pain would be 4 to 6, and strong pain would be more than 7. You may also use a word pain scale asking your child if it hurts a little, a medium amount or a lot. Other kids may respond better to tools such as a faces scale which gives visual cues to help rate their pain. Other information you might want to ask your child, is what number of pain is manageable for them (it might not be possible to get pain scores to 0, but it is important to reach a number that allows them to do activities they enjoy).

For more information on pain scales please visit: [Pain scale](#)

## **Some children will not speak about their pain**

Some children may not complain or talk about their pain. Often caregivers can sense their child is in pain or they may notice certain behaviours that suggest their child is hurting. Examples include sad facial expression, kicking out their legs, thumb sucking, putting a blanket over their head, whimpering or being clingy, avoiding certain physical activities, or guarding and protecting parts of the body. A child in pain may also not engage in activities they would typically enjoy, (e.g., playing, eating, singing, etc).

If you are concerned about your child's pain control and management, you should contact your medical team for further support.

## **Managing pain**

With the help of your or your child's medical team, cancer pain can be treated or reduced so that your child can do the activities that are important to them. The sooner you speak up about your child's pain, the sooner it can be managed!

The experience of pain can be changed by interrupting pain signals from reaching the brain. These pain signals can be reduced or blocked anywhere along the pain pathway.

Pain can be modified using:

- medications such as acetaminophen (Tylenol) and ibuprofen (Advil) potentially in combination with opioids as described below.
- physical methods such as heat, cold, massage, and exercise.
- stress and pain coping strategies (e.g., relaxation strategies, distraction, positive thinking habits, meditation or mindfulness).

# What are opioids [\(AboutKidsHealth\)](#)

Opioids are sometimes referred to as “narcotics” or controlled substances. Controlled substances have additional layers of safety attached to them (i.e., your community pharmacist will ask for identification when you are picking up the prescription). Opioids are generally used for medium and strong pain. These medications, which include morphine, hydromorphone, oxycodone and fentanyl, change the way the body perceives pain signals. Opioids are classified as narcotics because they act within the brain and treat pain.

Your child’s healthcare team will monitor the dose they are given carefully. If your child has had opioids regularly over a period of time and their pain eases, they may be prescribed smaller doses which are reduced over time little by little – this is called “weaning”. Weaning is done to avoid unpleasant withdrawal symptoms because the body has become used to the opioid.

## Side effects

Like most medications, opioids have side effects.

### The most common side effects include:

- Sleepiness or drowsiness: This side effect tends to improve over hours to days after starting opioids or a dose increase.
- Nausea and vomiting: Try giving a small snack with medications or talk to your team about anti-nausea medications which may help.
- Constipation and hard stools: This side effect impacts everyone who takes opioids and will not improve with time. It often requires laxatives or stool softeners to manage.

### The less common side effects include:

- Difficulty urinating (peeing): If your child experiences this while on opioids, be sure to discuss it with your child’s medical team.
- Affecting your child’s mood: For example, they might feel hyper or very giddy, or they might not feel like themselves.
- Having vivid dreams or mild hallucinations (seeing or hearing things that are not really there).

Speak to your medical team if you have any concerns or questions regarding side effects.

Uncommonly, and if given in too high a dose, opioids can cause low blood pressure or respiratory depression, which is shallow breathing and a slow breathing rate. These side effects are very uncommon when opioids are carefully prescribed. Children need to be carefully monitored for these effects as these are the most serious side effects of opioids. There are ways of medically managing serious side effects of opioids.

Whenever your child is not in the hospital, keep track of the times and amounts of each pain medication your child takes. You can do this similar to how you would keep a diary, including notes about how much the pain has eased (using a pain rating score) and for how long. In page 14, of this package, you will see a dosage tracker for you to use to help you. Bring this tracker to your appointments to help your medical team make further decisions about your child's pain management plan.

## **What are short-acting opioids and long-acting opioids?**

### **Short-acting opioids:**

Short-acting opioids are designed to quickly control pain. They can either be prescribed regularly or on an as needed basis, also called "PRN". If your child hasn't been on opioids regularly, your team might start with short-acting doses, to determine whether a long-acting dose is required.

### **Long-acting opioids:**

Long-acting opioids are designed to slowly release medication taken by mouth into the bloodstream over a longer period of time. They are often prescribed to be given twice a day. The benefit of long-acting opioids is they provide a sustained level of pain control. When these are prescribed, they should be given regularly, regardless of your child's pain level at the time.

When short-acting opioids are ordered "as needed" with scheduled long-acting opioids, the short-acting opioids may be referred to as "breakthrough" doses. The hope is that long-acting opioids will control most of the pain, but if pain "breaks through" the long-acting opioids, a short-acting one can provide additional pain control. Your team may often combine use of short acting and long-acting medications because they can be given at the same time. The short-acting will provide quick relief while waiting for long-acting to take effect.

The names of these medications may seem very similar, please ask your medical team if you have difficulty understanding the difference.



## Addiction

People who are addicted to opioids are psychologically craving the euphoric effects of the drug. Addiction requires a specific context: Drug addicts are craving a “high” and nothing else; pleasure is their context. Though the drugs may be the same or similar, when children are given opioids to relieve pain, they are not usually seeking the “high” associated with the medication. Children are given the medication in safe, consistent and controlled amounts and it is rare to develop a psychological addiction.

## Physical dependence

Physical dependence occurs if opioids are taken for several days to weeks. If the medication is suddenly stopped, an uncomfortable “withdrawal” may occur. However, this can be prevented by gradually reducing (tapering or weaning) the medication as the need for pain relief diminishes. Progressively smaller doses will be administered until the medication is stopped. Physical dependence should not be confused with addiction. Medication taken on a regular basis should only be decreased or stopped under the supervision of your medical team.

## Tolerance

Tolerance occurs over time when a person’s body gets used to opioids. A higher dosage of a drug is required for the same level of pain control when tolerance develops, even though nothing else has changed. Your medical team may increase the dose if they think your child is becoming tolerant. As with dependence, tolerance should not be confused with addiction.

## Overdose

Parents often worry about overdose occurring when their child is given strong opioids. However, these medicines have been used for centuries and healthcare professionals know how to administer them with a great degree of safety. Overdose is extremely rare in children taking opioids for pain relief. In cases of inadvertent overdose, the child may be given an antidote called naloxone that works quickly to reverse the effects of opioids. For more information, please visit [Naloxone - Canada.ca](http://Naloxone - Canada.ca). Be sure to lock opioids in a safe place. Keep them out of sight and out of reach of children and pets. Return opioids that are no longer needed to your pharmacy for safe disposal. If you would like to obtain a Naloxone Kit to keep on hand, please ask your local pharmacy as it can be dispensed without a prescription.

# Dispelling myths about opioids

[Hospice and Palliative Nurses Association](#)

The following information is designed to help dispel some of the myths surrounding the use of opioids.

## **Myth: Opioids cause addiction.**

**Fact:** There is a difference between physical dependence and addiction. Physical dependence is a state in which physical withdrawal symptoms occur when a medication is stopped or decreased abruptly after prolonged use. This is to be expected. Addiction is when people have poor control over drug use and continue to use the drug despite physical and social harm. “Addiction” describes seeking the feeling of a “high” when taking opioids. Addiction is rare in patients who are terminally ill when the goal of care is comfort.

## **Myth: Opioids may cause my child to stop breathing.**

**Fact:** When opioids are adjusted slowly to provide pain relief, respiratory depression is rare.

## **Myth: If a person takes large doses of opioids early in their disease process, the opioids will not be as effective later on when they need higher doses.**

**Fact:** There is no maximum dosage for opioids. A patient should get whatever dose is needed to provide pain relief. One should not focus on “the numbers” or dose but instead be focused on making sure the patient’s pain is controlled. Doses can be adjusted as needed during the course of the disease.

## **Myth: Giving opioids can hasten death.**

**Fact:** Research shows that the use of opioids does not lead to a quicker death. Withholding pain medication at the end of life is not appropriate when medications are available to relieve pain and suffering.

**Myth: Opioids cause a person to feel foggy and lose control.**

**Fact:** When opioids are taken as prescribed and on a regular basis, the feeling of being foggy or out of control should go away within a week.

**Myth: Using opioids means that you are a weak or bad person.**

**Fact:** Because there have been many stories in the news about people who abused opioids, their legitimate use for pain has been questioned. As a result, too many people suffer with pain who could be relieved with opioids.

**Myth: All types of pain respond well to opioids.**

**Fact:** Pain caused by bone or nerve injury (neuropathic) may need the help of additional medications along with opioids to provide better relief for these types of pain.

**Myth: You should not give opioids to a child.**

**Fact:** Children of all ages can receive opioids at doses appropriate for their weight and age and with adjustments based on physical condition.



# Where can I fill my child's opioid prescriptions?

The Paediatric Advanced Care Team or your child's oncology team will send an opioid prescription to the pharmacy of your choice. It is important to note that the person who is picking up an opioid or other controlled drug will be required to show a piece of government issued photo identification such as a driver's license.

## Option 1: Prescription can be filled at the outpatient SickKids pharmacy

**Shoppers Drug Mart**, 555 University Ave, Toronto, ON M5G 1X8



A full-service pharmacy, Shoppers Drug Mart is located on the Main Floor in the Black Wing. Drop in to find a variety of snacks, magazines, beauty and medical products. All drug plans are accepted and all proceeds support patient care.

## Option 2: You can fill your child's prescription at your community pharmacy

**Note:** your community pharmacist may not know your child's full medical history and may deliver different information from the PACT team or oncology team. The next section is a summary of information your community pharmacist may require. Please feel free to share this information with your community pharmacist to help them understand your child's treatment plan.

If you have any questions regarding the administration of your child's opioids, do not hesitate to contact your medical team or ask your pharmacist to contact your team.

Do not keep any medicines that are no longer needed. Check with your pharmacist about the best way to dispose of leftover medicines. These should usually be returned to the hospital or a pharmacy for safe disposal.

# What does my community pharmacist need to know?

## What is my child's diagnosis?

If sharing information with your pharmacist, you may fill in the blanks below with the assistance of your medical team as needed.

Dear Pharmacist,

My child is a patient of the Paediatric Advanced Care Team (PACT) at The Hospital for Sick Children (SickKids)

My child has a diagnosis of \_\_\_\_\_.

As a result of this diagnosis, they have been experiencing pain that is being managed by the PACT and oncology teams at SickKids. They have been prescribed opioids to help control the pain.

Some of these opioid doses might seem high, but the teams have put a lot of time and consideration to make sure that my child's pain is being treated safely and effectively.

If you have any questions or concerns about these medications or the doses that have been ordered, please feel free to reach out to my child's oncology team or the PACT team at SickKids.

**SickKids PACT contact number:**

**SickKids Oncology contact number:**

Thank you,

SickKids parent







**SickKids<sup>®</sup>**

For more information contact [www.aboutkidshealth.ca](http://www.aboutkidshealth.ca)  
or connect with your Oncology Team or your PACT Clinical Nurse Specialist