

Symptom Management

Pain

From the first tummy cramp, to the “owie” of a skinned knee, parents hurt when their child hurts. The fear most parents talk about when they learn that their child’s condition cannot be “made better” is the fear of pain. As your child becomes sicker, it is likely that he will feel some discomfort and pain. However, it is a comfort to realise that your child’s health care team believes that pain relief is always an urgent need. Pain is never neglected.

The risk of pain increases when the child:

- * has a growth or swelling or inflammation that causes pressure on nerves;
- * has a condition that involves the nerves;
- * has treatments, such as surgery, that may cause nerve damage. surgery;
- * needs tests or treatments that involve needle pokes;
- * is constipated or has diarrhea;
- * is anxious and tense;
- * is tired;
- * is not getting enough pain medication.

Watch for these signs of pain

You know your child best. You know how your child shows pain. You know what gives her comfort and brings relief. Trust your instinct.

These are common signs of pain:

- * cranky and restless;
- * tense and stiff;
- * does not want anyone to touch or move him;
- * frowns, complains, moans or cries;
- * clutches a part of the body;
- * sleeping more or less;
- * rocks the body;
- * refuses to eat
- * withdraws from people or activities;
- * cries much more or less than usual.

Like giving food and comfort, taking away the pain, is something parents feels they ought to be able to do for their child.

Every person deals with pain differently. Parents are often the first ones to see the signs of pain in their child.

This pamphlet is the result of a collaboration between British Columbia’s Children’s Hospital and Canuck Place Children’s Hospice

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To find out more about the pain ask these questions:

- * *Can you point to where the pain is? Show me on your body or on your teddy.*
- * *Is it sharp like a knife or dull like a pinch or tingly or burning?*
- * *Does it come and go?*
- * *Is there any way to lie or sit that helps the pain go away?*
- * *What makes it worse or better?*
- * *Can you tell me how strong the pain is? If "0" is no pain and "5" is the worst pain, what number is your pain right now?*

If your child can't speak, observe and try to answer those questions by watching closely. Notice also what time of day or what is happening around the pain (feeding, bath time, morning).

How long does the pain last?

Parent voice:

For the longest time I could not get Maddy to respond to any of my efforts to track her pain. One day, her brother came into the room and sat reading beside her. When she started to squirm he said 'Is it hurting you?' She agreed it was and even told him about a hurting 'IT thing'. I realised then that 'pain' wasn't a word to which she related. She understood 'hurt' and saw the hurt as something coming into her body. We then made up our own story about the 'hurt thing' and what we were going to do to get IT out when IT came in. Tracking her pain was much simpler after that.

Preventing pain

- * **Keep your child relaxed and comfortable**
 - ◆ Keep the days as stress free as possible. Tension makes muscles tense and tires the child. Both of these add to the risk of pain.
 - ◆ Position changes and props like pillows, air/eggcrate mattresses, and sheepskins keep the body comfortable
 - ◆ Prevent thirst.
- * **Make sure your child has enough sleep and rest times**
(Refer to handout on Fatigue).
- * **Give your child things to do**
If a child is left alone or is bored, the pain may start. Use distractions like videos, games, books on tape, or visits.

Ask your nurse or doctor to give you some charts and pictures that might help you and your child track, measure and record the pain. You will find one of these sheets at the end of this section.

Managing pain

* Reassure your child with your calm

Someone in pain panics easily. Help your child remain calm by being calm yourself. If you are showing signs of worry and stress - e.g., talking quickly in a high voice - your child will be more tense. If you are crying, then your child will think his pain is really bad.

- ◆ Speak in a slow, low voice
- ◆ Relax your body, slow and deepen your breathing
- ◆ Slow down your movements

* Learn and practice simple distraction and relaxation exercises

You can use guided imagery, breathing, or singing / humming to get on top of pain or panic. Teach these to your child so you can use them yourself as well as coach your child through panic and pain.

* Show your sympathy and concern. Tell your child what you know, and what you will do, about the pain

Tell your child that there is a plan to manage the pain now and even if it comes back and is worse – she needs to know that something will always be done about it. Explain that there are many ways to manage pain. Stress that even pain that seems to be getting worse can be made less because of all the different kinds of medications.

* Remove the fear of the unknown – explain why the pain is there

If you don't know the cause, reassure your child that the doctors and nurses will look for a cause and try to make the pain go away.

* Lessen the fear of losing control (*"I can't handle this"*)

- ◆ Remind your child that she has managed many hard things before and that she can count on the support of family and doctors and nurses.
- ◆ Give permission to let go and cry or shout if that helps.

* Make sure "comfort" is not itself stressing your child

Sometimes things like stroking, holding, rocking or playing music are not soothing. They may add more touch or sound than the body can handle.

Learn how to use a calm voice and manner to reassure.

It is not fair to suggest that if you can distract the child from the pain then the pain is not "real." Think about it in this way. Pain is always the brain's decoding of a "nerve message." If you can distract the brain with other messages, the pain message will be less clear.

Feeling alone and helpless increases pain.

Explore with your child what he thinks the pain means. His thoughts will give you an idea of his fears. Do your best to reassure.

Your child needs to know that she does not have to show courage at all times.

Be aware that touch, sound or light, meant to soothe, at times may become a stress.

* Make the best use of medication to manage pain

- ◆ If the pain is there all the time, give medications every ... hours - “round the clock.” Don’t wait for the pain to return. You can give longer acting medications (medication that can be given every 8 to 12 hours) once your child’s pain is well controlled.
- ◆ Your doctor or nurse will give you information about the medications your child will take. Learn what side effects to expect and how to manage them.
- ◆ Swallowing medication or putting it through a feeding or g-tube (if there is one in place) is the easiest way to take medication. If your child cannot swallow, the health professional will show you other ways like suppositories, under the tongue, injections or infusions (subcutaneous or IV).
- ◆ Work out a plan to manage pain with the health professionals. This should include what to do for sudden pain or if pain “breaks through” between the regular doses. Review the plan if there are changes in your child’s pain.
- ◆ Ask questions and talk over your concerns about pain medication. You can ask to be part of any discussions about your child’s pain management.

Getting professional help when appropriate

Call your doctor or nurse during the day if your child:

- * needs more than 4 breakthrough pain doses in a day;
- * has pain even with the break through medication;
- * seems to need a new plan to manage pain.

Pain medication is most effective when the child takes it before he is in bad pain. There is no good reason to leave pain “until it gets worse” before taking the medication. The less pain, the less medication it will take to control it. The higher pain builds, the more medication it will take to get on top of it.

Give your child the break-through medication at the first sign of pain. Your child’s medication will be matched to the kinds of pain (burning pain, headache pain, shooting pain). The medications will also be matched, in kind and dose, to the level of pain from mild to stronger. If your child is on an opioid, such as codeine, morphine, fentanyl, methadone or hydromorphone, it is important that he also has medications to keep his bowel’s moving. (Opioids are very constipating.)

If you have not already decided on a plan, call your doctor or nurse as soon as you can if your child:

* has sudden and severe pain.

When you call, give your child's name, age, and diagnosis. Be ready with this information:

1. What kind of pain is your child having – where is it and when did it start?
2. What pain medications is your child taking – when and what was the last dose you gave?
3. Does your child have a fever? (Explain if taking a temperature is no longer part of your plan.)
4. What drugs/therapies has your child had?
5. Is this pain unusual for your child?

End note:

Many families worry about pain medication. They worry that their child will become addicted. Addiction is not an issue when opioids are used for pain. Once the pain goes, the need for the drug goes. There is good evidence to show this.

Another worry is that if they use strong medication now, there will be nothing to use later. The dose of pain medication, like morphine, can be increased as long as it is needed. The body can take very large doses if the dose has been increased over time.

The plan for managing pain:

In the event of sudden, intense pain that the normal plan cannot control:

Pain control is central to comfort and is almost always possible. The health care professionals on the palliative team are experts in pain control. You can rely on this!