

# Children's St. John's Hospital

In partnership with the SIU School of Medicine



## Notes

## A Child's Guide to Helping Pain

Kids come to the hospital for many different reasons, but all children come to the hospital to get help for their bodies.

Some kids might not feel very well when they are at the hospital, or they may feel pain. What do you think the word pain means?

Pain means that your body hurts or does not feel well.

Do you remember a time when your body had pain?







While you are at the hospital you will meet many new people. These people are your hospital helpers. Their job is to take care of you and your body. It is important to tell your new hospital friends and your family if you are in pain or if your body is hurting. Remember, they are here to help you with your pain.



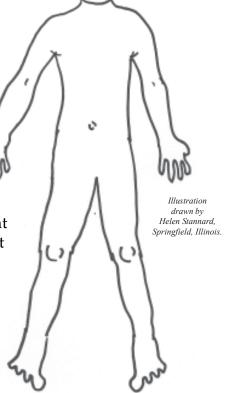
Some of the hospital helpers you will see are doctors, nurses, child life specialists and pharmacists. There will also be other families like yours.

If and when you are in pain, it is important to tell someone where you hurt.

Do you have any pain?

Make an X on the part of your body that needs help.

It is also important to tell your new hospital friends how your pain feels. When you tell them about your pain they can help. Below are some words that you could use to tell them about your pain.



Circle the words that describe your pain.

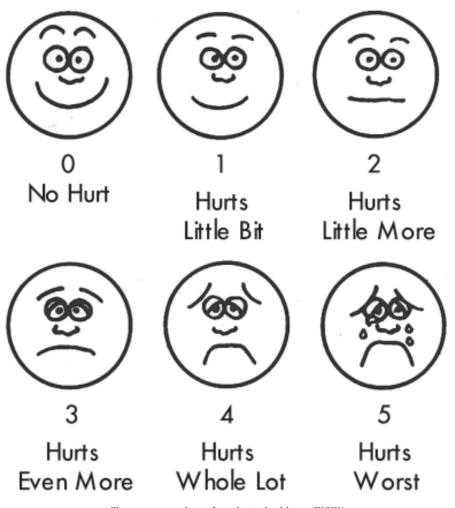
Aching Pounding

Thumping Throbbing Pinching

Stinging Pressing Burning

Your hospital friends need to know if you have a little or a lot of pain. They might ask you to look at the faces in the picture and tell them which face (or faces) looks the most like how your body is feeling. Remember, it is your pain so please be honest.

Color the face that your body is feeling the most like. It is everyone's job to help you with your pain.







The doctors and nurses might help you with your pain by giving you medicine that you drink or swallow.

Or you might get medicine through a tube called an IV.

How do you get your medicine when you have pain?



Draw a picture of you taking your medicine.

YOU can also help with your pain! How do you think you could help your pain?

Some kids like to stay busy doing something they enjoy. You might meet a child life specialist when you are at the hospital. The child life specialist can help you pick some toys or activities to help you with your pain. Circle the activities below that might help with your pain.



Sometimes when you are at the hospital, one of your new hospital friends might ask you to relax your body to help your pain. What do you think it means to relax? Relaxing means your body and mind should feel calm, quiet, and maybe even floppy. By relaxing your body, you can help your pain.

Here are some ideas to help your body relax.



- Wrap your body in a warm blanket or place a warm pack on the part of your body that hurts.
- Have someone rub your back.

Another way some kids like to help their pain is to learn to relax by taking long deep breaths. Here are the steps to taking a really good deep breath.

Step 1:

Close your mouth.

Step 2:

With your mouth closed, breath in through your nose very slowly.

Step 3:

Open your mouth.

Step 4:

Breath out very slowly and blow all your pain away.

Step 5:

Repeat steps 1 to 4 and take your time.

Sometimes it's fun to blow bubbles or a pinwheel to help you learn to take deep breaths. Have your new hospital friends or someone in your family practice taking deep breaths with you.

Sometimes kids have different feelings about being at the hospital and having pain. Please share your feelings with one of your new hospital friends or your family so we can help you.

Happy, sad, scared, angry or confused might be some of the feelings you have. Color the picture of how you are feeling today.

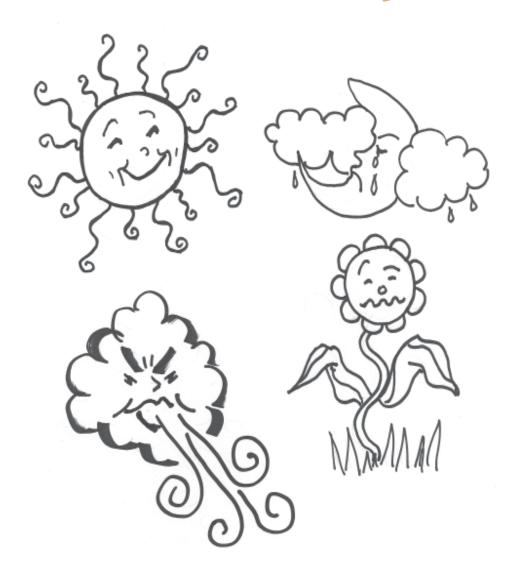


Illustration drawn by Helen Stannard, Springfield, Illinois.

Now that you know all about how to help your pain, let's go over the ways you can make your pain better.

- 1. Tell your doctors and nurses if you have pain and where it hurts.
- 2. Choose toys or activities to play with to help your pain.
- 3. Practice taking deep breaths to help your body relax.



Great job finding ways to help your pain! You are a super kid!

### Pain Episode 2

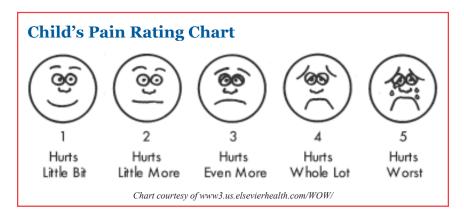
Time Pain Occurred				a.m.		p.m.
Child's Pain Rating (see chart)	1	2	3	4	5	
Child's Emotional State						
Type of Medication Given						
Time Medication Given				a.m.		p.m.
Time Pain Relief Occurred				a.m.		p.m.
Child's Pain Rating (see chart)	1	2	3	4	5	
Child's Emotional State						
Pain Episode 3						
Time Pain Occurred				a.m.		p.m.
Child's Pain Rating (see chart)	1	2	3	4	5	
Child's Emotional State						
Type of Medication Given						
Time Medication Given				a.m.		p.m.
Time Pain Relief Occurred				a.m.		p.m.
Child's Pain Rating (see chart)	1	2	3	4	5	
Child's Emotional State						

#### Your Child's Pain Record

Use the chart below to record and track your child's pain and pain relief. Tracking a child's pain and pain relief can help your child's healthcare team find the ideal way to manage their pain.

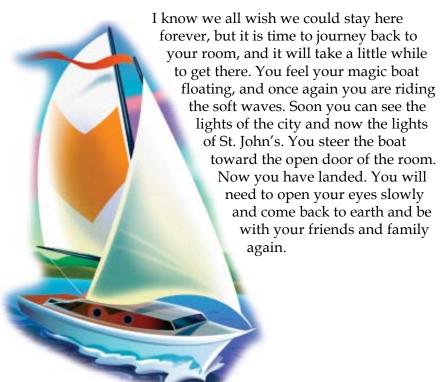
#### Pain Episode 1

Time Pain Occurred				a.m.	p.m.
Child's Pain Rating (see chart)	1	2	3	4	5
Child's Emotional State					
Type of Medication Given					
Time Medication Given				_a.m.	p.m.
Time Pain Relief Occurred				_a.m.	p.m.
Child's Pain Rating (see chart)	1	2	3	4	5
Child's Emotional State					



to choose where your magic boat goes on this journey. You discover that you can guide your small boat to your special place without any troubles.

You now arrive at your special place. It can be at a beach with warm sand and blue waters. It can be in a cozy corner of a favorite room. It can be at a cool spot under a tree. Perhaps you will meet someone who is very special to you in this place. You can talk, or you can just smile and feel happy being together. Look closely at your special place. What does it look like? What things do you see? What things do you smell? Who is the special person that you meet in your favorite place? Spend a minute in your special place looking at everything around you or talking with your special friend. Enjoy feeling safe and relaxed in your special place. (Silent pause for 20 seconds.)



#### **Guided Imagery Scenario**

Sometimes children need adults to help them relax. One way to help children find whole body relaxation is by reading them a calming safe story with a soft, slow and comforting voice. Following is an example of a story you can read to your child to help them relax.

#### The Story of the Magic Boat Ride

Purpose: To encourage relaxation and a pain-free place

**Directions:** At the beginning of the activity, encourage the child to lie down in a quiet, comfy spot with the lights dimmed. Have your child close their eyes at the beginning of the story.

We are going to go on a make-believe magic journey. You will get the chance to imagine what your very own special and safe place looks like. It will be a place free of pain and hurts.

To get started, you need to get very comfortable on your magic boat. You might want to lie on your back or your tummy to feel most comfortable. Now close your eyes and take a deep breathe and just relax ... breathe in and out ... in and out. You should feel yourself all limp like a rag doll ... breathing in and out. Soon you will feel light as air and you will be able to float on your magic boat out the door and over into a beautiful lake. You can take a friend or a favorite pet or doll or stuffed animal. You feel very safe on your magic boat and cannot fall off ... magic holds you safely on.

You will begin to feel a soft breeze gently blowing across your face and ruffling your hair. You feel very peaceful and calm. You hear the waves of the water softly around you. You look around you at the beautiful dark night and the wonderful stars. You can almost reach out and touch them. You are happy because you know that you are going to visit the place you like to visit the most in the entire universe. Only you get

Age	Developmental Reactions to Pain	Relief Measures
School- Age 7 - 12 years Continued	Increasing need to be involved during proce- dures to gain a sense of control over body, for example, watching procedure	<ul> <li>Offer choices during painful procedures</li> <li>Coach the child through the procedure and remind them that the pain will not last forever</li> <li>Reward the child often for positive outcomes and cooperation</li> <li>Stress the positive outcomes related to the painful experience</li> </ul>
Teens 13 - 17 years	<ul> <li>Ability to verbalize, identify and describe pain, both physically and psychologically</li> <li>May experience extreme mood and behavioral changes resulting from pain</li> <li>Fear losing control over body and experience</li> <li>Fear threat of physical harm to body</li> <li>Difficulty with dependence upon others</li> </ul>	<ul> <li>Caregivers can request to remain with teens</li> <li>Prepare teen by providing explanation and encouraging questions</li> <li>Request a numbing agent* for procedures involving injections or needle sticks</li> <li>Encourage relaxation with quiet music, guided imagery, deep breathing or massage</li> <li>Involve the teen in all decisions related to their care and procedures</li> <li>Encourage socialization with friends and family</li> <li>Coach teen through the procedure and remind them that the pain will not last forever</li> <li>Stress positive outcomes related to the painful experience</li> </ul>

\* EMLA or ELA-Max cream

Age	Developmental	Relief
0	Reactions to Pain	Measures
Preschool 3 - 6 years Continued		<ul> <li>Reinforce that illness, tests or procedures are not the child's fault</li> <li>Involve preschooler in care and treatment by giving them a job, for example: "Put the bandaid on your skin."</li> <li>Provide distraction such as blowing bubbles or looking at books</li> <li>Request a numbing agent* for procedures involving injections or needle sticks</li> <li>Request procedure room for painful procedures</li> <li>Reward child often for positive outcomes and cooperation</li> </ul>
School- Age 7 - 12 years	<ul> <li>Can verbalize pain with descriptive words</li> <li>Fear of bodily harm increases with increasing knowledge of body's functions</li> <li>Concept of death developing</li> <li>Concept of time develops <ul> <li>Pain won't last forever</li> </ul> </li> <li>May deny pain to appear brave</li> </ul>	<ul> <li>Caregivers can request to remain with child during procedures</li> <li>Prepare child by providing simple explanations through play</li> <li>Request a numbing agent* for procedures involving injections or needle sticks</li> <li>Request procedure room for painful procedures</li> <li>Provide distraction such as blowing bubbles or looking at picture books</li> <li>Encourage relaxation with quiet music, guided imagery or deep breathing</li> </ul>

<sup>\*</sup> EMLA or ELA-Max cream

Age	Developmental Reactions to Pain	Relief Measures
Toddlers 1 - 3 years	<ul> <li>Limited words to communicate pain in a meaningful manner</li> <li>Pain may be exhibited through behaviors such as clenching teeth or fists or rocking body</li> <li>Regressive behaviors such as bedwetting, thumb sucking and/or using minimal words may occur</li> <li>Aggressive behaviors such as kicking</li> </ul>	<ul> <li>Caregivers can request to remain with toddlers during procedures</li> <li>Familiarize toddlers with hospital and procedures through simple medical play with doll</li> <li>Keep favorite items such as blanket, toy or stuffed animal close to child</li> <li>Use toys such as bubbles and books to distract child</li> <li>Request a numbing agent* for procedures involving injections or needle sticks</li> <li>Request procedure room for painful procedures</li> <li>Keep routines as normal and consistent as possible</li> </ul>
Preschool 3 - 6 years	<ul> <li>Ability to talk about pain and fears</li> <li>Fear of bodily injury; may deny pain to avoid shots</li> <li>Self centered in thinking</li> <li>May view pain or shots as punishment</li> <li>Magical and fantasy thinking is common</li> </ul>	<ul> <li>Caregivers can request to remain with preschoolers during procedures</li> <li>Familiarize preschoolers with hospital and procedures through medical play with doll</li> <li>Encourage the child to handle medical supplies through play</li> <li>Provide preschooler with clear and direct explanations for procedures</li> </ul>

Continued from page 9.

#### Myth #6:

#### Pain medication is not safe for children.

- Children are typically under-treated for pain due to misconceptions about pain management and treatment.
- By following the American Academy of Pediatrics guidelines for pain management, children's pain can be treated effectively and safely.
- With adequate monitoring and following of appropriate dosing guidelines, pain medications are safe for children.

# **Age-Appropriate Ways** to Help your Child with Pain

Age	Developmental Reactions to Pain	Relief Measures
Infants Birth - 12 months	<ul> <li>Lack words to express presence, location and intensity of pain</li> <li>Indicates discomfort through body movements, facial expressions, changes in body state and crying</li> </ul>	<ul> <li>Caregivers can request to remain with infant during procedures</li> <li>Encourage sucking, lullaby music and gentle touching</li> <li>Assume natural swaddling position</li> <li>Request to use Sucrose during painful procedures</li> <li>Turn down lights and avoid loud noises</li> </ul>

#### **Myths about Children and Pain**

#### **Myth #1:**

Children and infants don't feel pain with the same intensity as adults.

• Some research indicates that by 29 weeks of gestation, pain pathways are well developed.

#### **Myth #2:**

Children cannot tell you where they hurt.

- Children between the ages of 4 and 10 years were able to indicate the site of the pain.
- As children's language skills increase, they are better able to describe painful experiences.

#### **Myth #3:**

Children will always tell you if they are really having pain.

- Some children may not share their feelings about pain because they are fearful that they might have to get a shot, take medicine or have surgery.
- Preschool age children may believe it is their fault for experiencing pain.

#### **Myth #4:**

If children do not look like they are in pain or can be distracted with video games or toys they are not in pain.

 Oftentimes children can be distracted from pain because this is their developmental way of coping with the pain.

#### **Myth #5:**

Children will become addicted to pain medication.

- Studies of pain associated with sickle cell disease or postoperative recovery found almost no risk of addiction.
- In a study of adults, less than 5 of 11,000 patients became addicted.

Continued on page 10.

#### Continued from page 7.

#### **Ketorolac (Toradol)**

- Anti-inflammatory medication
- Can be used for short-term pain and post-surgical pain
- Given through an IV or as an injection into the muscle

#### **Morphine**

 Given by mouth, through an IV, as an injection into the muscle or under the skin, or through a PCA pump

#### Miscellaneous Pain Treatments

#### **EMLA Cream and ELA-Max Cream**

- Minimizes pain before procedures involving needle sticks
- Topical anesthetic applied to the skin at the site of the injection at least 30 minutes to an hour before needle stick

#### **Sucrose**

- Sugar and water solution
- Given to comfort, calm and minimize pain for distressed babies up to six months of age
- Given by mouth on a pacifier or gloved finger

#### Versed

- Treats anxiety with light sedation and causes amnesia-like effects related to the procedure or surgery
- Given by mouth, through an IV, in the nose or as an injection in to the muscle

#### **Docusate (Colace)**

- Laxative and stool softener
- Given by mouth
- One side effect to pain medication may be constipation due to the pain medication (s), changes in eating habits and minimal activity.

#### Mild To Moderate Pain Treatment

#### Acetaminophen (Tylenol)

- Fever Reducer
- Given by mouth or through the rectum with a suppository

#### Ibuprofen (Motrin)

- Anti-inflammatory medication/fever reducer
- Given by mouth

#### **Moderate To Severe Pain Treatment**

#### Acetaminophen and Codeine

• Given by mouth

#### Codeine

- Given as an injection into the muscle, an injection under the skin or by mouth
- Sometimes used for severe coughing

#### **Darvocet**

Given by mouth

#### Oxycodone/Acetaminophen (Percocet/Tylox)

Given by mouth

#### Hydrocodone/Acetaminophen (Vicodin)

Given by mouth

#### **Fentanyl**

- Pain reliever for surgery and post-operative pain
- Provides anesthesia and sedation after or during painful procedures or surgeries
- Given through an IV, as an injection into the muscle or through a PCA pump

#### Hydromorphone (Dilaudid)

Given by mouth, through an IV or through a PCA pump

#### **Patient Pain Rights**

When your child is a patient at St. John's Children's Hospital, you and your child can expect:

- Information about pain and pain relief measures.
- A concerned staff committed to pain prevention and management.
- Health professionals who respond quickly to reports of pain.
- Your reports of pain will be believed.
- Up-to-date pain management.

# Common Pediatric Drugs Used for Pain Management

When a child's fears and pain are managed, their emotional and physical healing process can begin. It is therefore helpful to have an understanding of some common drugs that are available for your child during his/her hospital stay.

Listed on pages 7 and 8 are some of the common medicines used for children to help reduce and manage pain. Some are used to help calm and relax your child before certain procedures or surgery. Some are anesthetic (numbing) creams and gels that can be applied to the skin prior to certain procedures such as IV starts. Others are called analgesics that help manage mild to moderate to severe pain. Your child's doctor may order a patient-controlled analgesia (PCA) pump. A PCA is programmed to safely deliver the right dose of pain relief medication when your child pushes a button. PCAs are not appropriate for younger children.

All children are different and discovering the right treatment for your child's pain may take some time. Please recognize that a 100 percent pain-free outcome isn't always possible depending upon your child's condition, but minimizing the pain and finding pain relief should be possible. Your child's medical team includes doctors, nurses and pharmacists. The team is responsible and dedicated to seeing that your child's pain medications are appropriately dosed and administered safely to your child.

Please contact your child's healthcare team with questions about pain medication or the treatment of your child's pain.

When tests and procedures such as an IV start or dressing change need to occur while a child is hospitalized, you may ask that these procedures take place in the **Procedure Room or Treatment Room.** This is a room on the Pediatric floor that is specially designed for procedures. By having all treatments and procedures take place here, the child's inpatient hospital room can remain a safe place and one where the child and family can relax.



#### Family-centered care

St. John's Children's Hospital places a high priority on providing family-centered care to all of our patients. We believe that you play a vital role in the health and treatment of your child and as such we will make every effort to accommodate your family's unique needs so that your lives and routines are disrupted as little as possible by a child's hospitalization. A pediatric social worker and a child life specialist can assist you in meeting any needs that you may have.

When a child is hospitalized, it is often a stressful time for the entire family, including the child's brothers and sisters. St. John's Children's Hospital provides support for siblings who are confused or who are having a difficult time coping with their sibling being away from home. We provide age appropriate explanations of the child's illness and treatment, as well as activities that focus on the sibling's feelings and concerns.



#### **Child Life Services**

The goal of Child Life Services at St. John's Children's Hospital is to minimize the stress and anxiety often associated with health care experiences and hospitalization. The child life specialists at St. John's Children's Hospital work to achieve this goal through a variety of methods, including:

- Activities to encourage normal growth and development. While your child is hospitalized, a child life specialist will encourage and recommend some developmentally appropriate activities for your child that will normalize the hospital environment and allow them to do their "work" through play! These activities can be brought to the bedside or there is a Playroom and a Teen Lounge in the Pediatric Unit for inpatients and their families to enjoy.
- Medical Play. To help children become more familiar with the healthcare experience or a specific procedure, child life specialists often use medical play. During medical play, children see and touch real or pretend hospital equipment, learn its purpose and are allowed some control over the environment. When children are familiar with the objects around them, the objects become less threatening. Medical play is also a great way for children to express their emotions about their healthcare experience.
- Preparation for tests, surgeries and other medical procedures. Child life specialists use books, pictures, dolls and other materials to prepare children for procedures they will undergo while at the hospital. Through this preparation children learn what to expect, what they will feel, hear, smell, etc. and what role they have in the procedure. By including the child as a member of the healthcare team, we are encouraging them to retain some control and we are gaining their cooperation and trust.

#### **Pain Terms**

**Acute Pain** is pain that comes and goes. It may come on suddenly and be intense, but does not last long.

Chronic/Persistent Pain is pain that does not go away. Doctors may label pain as chronic if it has persisted for three to six months.

**Pharmacological Pain Management** is the management of pain with medication prescribed by the patient's doctor. The medication may be administered in the following ways:

- Oral or (PO). The child swallows the medicine and it travels throughout the body. It may be in liquid or pill form.
- IV or Intravenous. Medicine is injected into the tubing of the child's IV. Typically IVs are located in the hand, arm or foot. Medicine is delivered through the body by the veins.
- IM or Intramuscular. An injection of medicine is given to the child through a muscle. Typically the thigh or shoulder muscle is used.

**Non-pharmacological Pain Management** is the treatment of pain through means other than medication. These methods include:

- **Distraction**. This is used to take the patient's focus off of a test, procedure or their pain and redirect it. St. John's Children's Hospital has 'Coping Kits' throughout the hospital that contain toys and other objects that are likely to get your child's attention. Caregivers are also encouraged to bring familiar objects and toys from home to give comfort and familiarity to the child.
- Guided Imagery. This is a form of focused relaxation that can involve listening to music or someone's voice to allow changes in attitude and behavior and to encourage physical healing. There are several types of guided imagery available within St. John's Children's Hospital as well as commercially. Please talk to your child life specialist if you have questions or would like more information.

## A Parent's Guide to Helping Children with Pain

During your child's hospital stay, you may hear many words and terms related to your child's health and treatment plan. Listed on page 2 are some common terms used to describe pain and pain management. We want you to be well informed and confident in the care provided for your child. If there is ever anything about your child's care that you are unsure of or have questions about, do not hesitate to ask a member of your child's healthcare team.



#### **Notes**

# A Parent's Guide to Helping Children in Pain



In partnership with the SIU School of Medicine