HOSPICE OF THE WESTERN RESERVE Pediatric Caregiver Training Guide

Caring for the Physical and Emotional Needs of You and Your Child

SECTION 2: PAIN MANAGEMENT

Contents

Pain Management	.2
Emotional Pain Management	.3
Common Myths About Children's Pain	.3

How Children Act to Pain	4
Medications	4
Suggestions For Giving Children Pain Medicine	4
Before Giving Your Child Any Medicine	5
Giving Medicine Via Feeding Tube	5
Addiction To Medication	5
Non-Medicine Treatments For Pain Relief	5
Home Remedies	5
Wong Baker Faces® Pain Scale	6
Neonatal Infant Pain Scale (Nips)	6
Face, Legs, Activity, Cry, Consolability Scale (Flacc)	6

Pain Medication Side Effects	7
Nausea and Vomiting	7
Constipation	7
Diarrhea	7

Pain Management

As a patient of Hospice of the Western Reserve, your child's comfort is our focus. Being pain free can often eliminate other issues. Your child may eat, sleep and participate in regular activities better. Feeling comfortable is the best way to help your child celebrate their day-to-day life.

Your hospice team will respond quickly to reports of pain and will make every effort to keep your child comfortable. Your doctor and hospice nurse will develop the most effective pain management plan by gathering information from you on how your child feels. You will be included in all pain relief measures.

To best serve your child's pain management needs, tell your hospice nurse everything about their pain. It may help to keep a journal. Write down the times when pain seems to be worse than others.

Be sure to tell your nurse about any other prescription medicines your child may be taking. Check with your nurse before using any over-the-counter or herbal medicines because they can interact with your child's prescribed pain medicine. Do not give your child medicine that has been ordered for another child or an adult.

Children, even infants who cannot verbalize their discomfort, are able to communicate pain in a variety of ways. Facial expressions, crying and body movements can all be signs of discomfort. Sometimes, a child may deny feeling pain to prevent taking bad-tasting medicine. In these cases, we rely on your instincts and close relationship with your child to alert us to their pain.

>) Call Your Hospice Care Team If:

- You think your child's pain is not adequately relieved or their pain has increased
- They complain of, or you sense, a new pain or sign of discomfort
- They experience side effects of medications such as constipation, sleepiness or an upset stomach
- They are not taking their medications
- You have any questions regarding you child's pain management plan

Emotional Pain Management

Many factors cause pain, and pain is not always physical. Emotional and spiritual pain are just as real as physical symptoms. For example, a child may feel sad about not being able to play like other children. That sadness can contribute to their physical pain. Anger, loss of control, loneliness and fear can all contribute to the experience of physical pain. Children will not always communicate these feeling through words and direct conversation. Instead, they will express their emotions through play, art, activities and music. Your hospice team will use these expressive experiences to better understand your child. Talk to your child about their feelings and encourage them to express their emotions through activities such as puppet play or drawing.

In some cases, a child may think their pain is punishment for something they did wrong. Positive reinforcement and assuring them that this experience is not their fault is very important.

Common Myths About Children's Pain

Myth: Infants do not feel pain.

Fact: Infants demonstrate indicators of pain through facial changes.

Myth: Children tolerate pain better than adults.

Fact: People tolerate pain better as they get older.

Myth: Pain is harder to treat in young children because they can't tell you where it hurts.

Fact: By the age of four, children can accurately point to the spot that is hurting them and/or mark the spot that hurts on a picture. Painful areas in younger children can be determined through close observation and assessment.

Myth: Children will tell you when they are in pain.

Fact: Children may not want to tell you about pain they're having because they may be afraid of getting shots or they may not like the taste of the pain medicine. They also may assume that adults know they're in pain and that they don't need to tell you. Adolescents may not want to take pain medicine for fear of it preventing them from being as active as they want, i.e., socializing with friends or driving.

Myth: Children get used to pain and/or having painful procedures done.

Fact: Children often remain quiet during repeated painful procedures because they see that crying upsets their parents. Other times, they become increasingly upset just anticipating receiving medicine. Honest, simple explanations of what your child will experience builds trust. Remind children that it is okay to cry. Your calm, reassuring presence is helpful.

Myth: You can tell how much pain a child is having by their behavior.

Fact: Some children in a lot of pain are very quiet. Others are very active. Some school-age children and adolescents become aggressive. Every child has a different temperament and coping strategy.

Myth: Narcotics are much more dangerous for children than for adults.

Fact: Narcotics are no more dangerous for children than for adults. Addiction to pain medication is rare in children.

Myth: Giving children narcotics will cause them to stop breathing.

Fact: Reports of decreasing respirations in children receiving narcotics are rare.

How Children Act to Pain

Every child shows signs of pain differently. Sometimes a child will display behavior related to pain as they anticipate feeling it. The following behaviors are typical indicators of pain.

Birth to 6 months

- Rigid arms and legs
- Loud, sometimes shrill crying
- Tightly closed eyes
- Creased eyebrows

6 months to 18 months

- Pulling at the part of the body that hurts
- Loud crying
- Facial grimacing often with eyes open

Toddlers and young children

- Loud crying or screaming
- Use of words such as "owie," "boo-boo,"
 "feel funny," "hurt," or "ouch"
- Thrashing of arms and legs
- Uncooperative or aggressive behavior
- Uncharacteristic clinging
- Putting arms out for hugs
- Restlessness and/or irritability

School-age children

- Tend to try to "put off" or "stall" a painful procedure by finding other things to do
- Stiffing muscles
- Grinding or gritting teeth
- Tightly close eyes

Adolescents

- Tend to vocalize pain when asked
- May be quick to temper
- May withdraw and be quiet

Medications

The best way to control pain is to stop it before it starts. If delayed until pain is severe, medications do not have sufficient time to work well. Our goal is to keep your child as comfortable as possible. Give them their pain medication on a regular basis to help prevent the reoccurrence of pain.

Medications come in different forms including liquids, pills, suppositories, skin patches, ointments and creams. Call your hospice nurse if you have questions regarding your child's medication or dosage.

Suggestions for Giving Children Pain Medicine:

- Have them suck on a Popsicle to numb their tongue and decrease the taste of a bitter medicine.
- The taste and smell of some medicines can be altered with:
 - Chocolate syrup or chocolate milk
 - Grape juice
- If they have difficulty swallowing medications in pill form, you can:
 - Change the form of the medicine depending on the need
 - Crush pills and give them with a small amount of pudding, ice cream or applesauce
 - Always check with your nurse before modifying medications.
- For infants and small children taking medicine by mouth:
 - Give slowly using a dropper or small syringe
 - Do not squirt a large amount of medicine in an infant's mouth all at once
 - Aim at the inside of the cheek rather than the back of the throat to prevent gagging
 - Blowing a small puff of air in an infant or child with neurological deficits face often produces a swallow reflex.
- If your child is nauseated:
 - Give them a small amount of a carbonated beverage before or after the medication

- If the medication has a bad smell, have them hold their nose and drink the medicine through a straw.
- When giving medicine rectally, insert the square-shaped end first.
- To halve suppositories, cut them in half lengthwise to get the most accurate dosage.

Before giving your child any medicine:

- Read the label to be sure you are giving them the correct medicine.
- Give the medicine exactly as ordered unless your doctor or hospice nurse tells you differently.
- Give scheduled medicine on a regular schedule, even if your child is not complaining of pain.
- Notify your hospice nurse if they develop any apparent side effects from the medicine or if the medicine does not seem to be working.
- Let your hospice nurse know if you are running low on medications (less than a two day supply).
- Keep all medicine out of reach of children and pets.

DO NOT:

- Give your child's medicine to anyone else, including other children
- Crush pills or modify medicines without checking with your hospice nurse
- Give more than the amount of medicine ordered
- It foll your child that medicine is "candy"

Giving medicine via feeding tube

- Flush oily medications with a carbonated beverage to avoid the medicine sticking to the side of the tube.
- Dilute thick medicines with a small amount of water to ease delivery.
- Mix "sprinkle" medications (medicines in capsules that can be opened and

"sprinkled" – always check with your nurse first) with a small amount of puréed fruit and water to keep it from sticking to the tube.

Addiction to Medication

Taking medicines to stop pain is a treatment, not a bad habit. Many studies show that pain medications used this way rarely cause addiction. It is very important that every child be supported with the right kind and amount of pain medicine.

Non-Medicine Treatments for Pain Relief

Medicine is important, but you can help control pain with non-medicine interventions as well. Gentle comfort measures, like the suggestions below, can help your child express their pain.

- Have your child "adopt" a doll, giving the doll medicine when you give it to them.
- Provide bubbles for them to "blow away the pain".
- Use distractions such as music, singing and playing.
- Rock them gently or sway back and forth (rather than bouncing).
- Use massage, relaxation or guided imagery with deep breathing exercises.
- Have them soak in a tub of warm water, or apply ice packs if they have swelling.

Home Remedies

Hospice of the Western Reserve recognizes and respects our patients' cultural differences. There are many traditional ethnic and cultural remedies for pain and comfort. Many are inappropriate for children and can have negative side effects or can interact with medicine children are taking. Inform your hospice nurse of any home treatments you are using. We will make every effort to accommodate your traditions and cultural practices.

WONG Baker FACES® Pain Scale



Neonatal Infant Pain Scale (NIPS)

FINDING		
Relaxed (Restful face, neutral expression)		
Grimace (Tight facial muscles, furrowed brow, chin, jaw)	1	
No cry (Quiet, not crying)	0	
Whimper (Mild moaning, intermittent)	1	
Vigorous crying (loud scream, shrill, continuous). If infant is intubated, score silent cry based on facial movement	2	
Relaxed (Usual pattern for this infant)	0	
Change in breathing (Irregular, faster than usual, gagging, breath holding)	1	
Relaxed (No muscular rigidity, occasional random movements of arms)	0	
Flexed/Extended (Tense, straight arms, rigid and/or rapid extension, flexion)	1	
Relaxed (No muscular rigidity, occasional random leg movements)	0	
Flexed/Extended (Tense, straight legs, rigid and/or rapid extension, flexion)	1	
Sleeping/awake (Quiet, peaceful, sleeping or alert and settled)	0	
Fussy (Alert, restless and thrashing)	1	
Within 10% of baseline	0	
11–20% of baseline	1	
>20% of baseline	2	
No additional O_2 needed to maintain O_2 saturation	0	
Additional O ₂ required to maintain O ₂ saturation	1	
	Relaxed (Restful face, neutral expression)Grimace (Tight facial muscles, furrowed brow, chin, jaw)No cry (Quiet, not crying)Whimper (Mild moaning, intermittent)Vigorous crying (loud scream, shrill, continuous). If infant is intubated, score silent cry based on facial movementRelaxed (Usual pattern for this infant)Change in breathing (Irregular, faster than usual, gagging, breath holding)Relaxed (No muscular rigidity, occasional random movements of arms)Flexed/Extended (Tense, straight arms, rigid and/or rapid extension, flexion)Relaxed (No muscular rigidity, occasional random leg movements)Flexed/Extended (Tense, straight legs, rigid and/or rapid extension, flexion)Sleeping/awake (Quiet, peaceful, sleeping or alert and settled)Fussy (Alert, restless and thrashing)Within 10% of baseline11–20% of baseline>20% of baseline>20% of baselineNo additional O2 needed to maintain O2 saturation	

Face, Legs, Activity, Cry, Consolability scale (FLACC)

	SCORING			
Categories	0	1	2	
Face	No particular expression or smile.	Occasional grimace or frown, withdrawn, disinterested	Frequent to constant frown, quivering chin, clenched jaw	
Legs	Normal position or relaxed	Uneasy, restless, tense	Kicking or legs drawn up	
Activity	Lying quietly, normal position, moves easily	Squirming, shifting back and forth, tense	Arched, rigid or jerking	
Cry	No cry (awake or asleep)	Moans or whimpers; occasional complaint	Crying steadily, screams or sobs, frequent complaints	
Consolability	Content, relaxed	Reassured by occasional touching, hugging, or being talked to; distractable	Difficult to console or comfort	

Pain Medication Side Effects

All medicines have potential side effects which are not considered allergic reactions, however not everyone will experience them. Fatigue, nausea and constipation are common side effects of pain medication. Side effects may worsen when first starting new pain medication and may take two to three days to improve. Please contact your hospice nurse with questions regarding side effects.

Nausea and Vomiting

Nausea and vomiting are common problems that may result from medicine or medical treatments, motion, constipation, infection, pain, anxiety or fear. If your child is nauseous or vomiting, notify your hospice nurse. An anti-nausea medication may be prescribed.

What can be done:

- Rest and limit position changes. Slowly sip Pedialyte or ginger ale; avoid caffeinated beverages.
- Continue clear fluids for 24 hours, adding Popsicles, broth, or Jell-O in small amounts every 15-20 minutes.
- Slowly introduce dry toast, crackers or dry cereal.
- Rinse their mouth thoroughly after vomiting and practice good oral hygiene.
- Take anti-nausea medicine as directed.

DO NOT let your child:

- Eat or drink 1-2 hours after vomiting
- 🗵 Eat heavy, fatty meals
- ☑ Be around strong smells
- 🗵 Lie down after eating

>) Call Your Hospice Care Team If:

- Vomiting recurs after resuming clear liquids
- Vomit is bright red or dark brown (looks like coffee grounds)
- Your child is unable to swallow

Constipation

Constipation often occurs from pain medication combined with lowered eating, drinking and activity. Keep track of your child's bowel routine and report any changes to your hospice nurse. If your child has not had a bowel movement after two days, your hospice nurse may advise trying a new medicine.

What can be done:

- Use stool softeners and laxatives as prescribed.
- If your child is not on a restricted diet, increase fluid, fruit and fiber. Fluids may be more effective if warmed to room temperature.
- Increase physical activity if possible.

Diarrhea

Diarrhea, or loose watery stools, can cause stomach cramps, weakness and, if persistent, dehydration. If your child experiences diarrhea, they should drink as much water as is comfortable. They may also drink other clear, non-caffeinated liquids, such as ginger ale or Pedialyte, and eat Jell-O or broth until the diarrhea stops. If diarrhea stops for at least eight hours, they may try eating dry toast, crackers, bananas, rice and continue clear liquids. Slowly add other foods in small portions, avoiding dairy products, fresh fruit and vegetables, and greasy or spicy foods until your child's bowels return to normal.

Helpful Hints:

- Keep rectal area clean and dry using mild soap and water.
- Do not take anti-diarrhea medication unless instructed by your hospice nurse
-) Call Your Hospice Care Team If:
 - Persistent diarrhea
 - Light-headedness
 - Fever
 - Your child is unable to urinate