

Managing Pain in Children with Medical Complexity



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Learning Objectives

After reviewing this Guide you will be able to:

- Identify signs of pain in your child
- Consider the pros and cons of different levels of treatment
- Adopt strategies to complement medical care

Introduction

Pain is very complex. Some pain is acute, which means there is a new cause of pain that will respond to treatment and improve. Other pain is chronic, lasting for months with on-and-off intensity. Both kinds of pain can cause discomfort for your child, and distress for the entire family.

This guide is intended to increase your understanding of why children with medical complexity can have recurrent pain, and how you can work with the medical team to make your child more comfortable. Some of the content is specific to the needs of families caring for a child with severe neurological impairment (SNI), but you will find that much of this material is applicable to other conditions, and especially to situations where the child cannot participate in assessing their pain.

Understanding Pain and Irritability

Irritability or agitation is the state of being unsettled and not calm. They are a signal of discomfort or distress. Pain can be a common cause of irritability or agitation. Other causes include an acute (temporary) illness or injury, a reaction to medication, or it can be related to emotions (anxiety, frustration, boredom, anger etc.). Irritability can also be caused by neurological decline or dementia.

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When distress occurs, you and the team will get a better sense of which symptoms tend to respond to the breakthrough care plan and which seem different. Call your primary physician if new concerns arise or if symptoms persist. For example, if there is a fever, it might make sense to first assess for a bladder infection. If you are worried or uncertain, contact the medical team—day or night.

Signs That Your Child May Be in Pain

Some common distress behaviors are:

- Muscle tensing or tightening at intervals: increased spasticity, stiffening of legs, drawing up arms, clenched fists, tremors or jerks, tense and still, kicking, thrashing
- Change in body position: back arching, rigid and stiff, head movement, thrashing
- Change in facial expression: grimace, frown, clenched jaw, distressed look, eyes wide open, or non-expressive face
- Change in vocalizations: crying, soft moaning, grunting, gasping
- Change in interaction: withdrawn, less active
- Skin changes: pale or flushed skin, sweating
- Can't be calmed: efforts to comfort the child don't seem to ease the symptoms

You and your child's medical team certainly want to consider all reasons why your child appears unsettled, including emotional ones. Is there a pattern of when these events happen? For example, do they occur on days when your child goes to school but not on the weekends? This could suggest that they are tired or stressed by the long day at school and more comfortable when at home. In that instance, you could work with a therapist and your child's school to get the child into a reclining position that might be more comfortable.

Knowing that your child is often calm, relaxed and smiling is the best way to know your child is well. Let the medical team know if this is often not the case. Then you can think together and make a plan.

Types of Pain

Tissue Injury Pain

Our bodies are made up of cells. Some of the cells combine to form organs (heart, liver, lungs, kidneys). The organs perform essential bodily functions. Other cells combine to form muscles, skin, bones and other parts of the body that handle less complex tasks. Injury or inflammation of this tissue is typically acute. The pain comes on quickly and will resolve once the cause has been found and treated. Causes of tissue pain can include a bone fracture or bladder infection.

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Your child will first be assessed for tissue injury and inflammation. These sources of pain are identified by taking a history, physical exam, and tests that involve obtaining blood and urine.

Pain that persists needs further assessment. The medical team may order an ultrasound of the abdomen to see if there are stones in the kidneys or gallbladder, and other tests based on information from the history and physical exam. Review your own family history for problems that can present with pain and share this information with the clinicians. Examples from family history include chronic inflammation of joints and muscles (arthritis) and inflammation of the intestines (inflammatory bowel disease). Share if you notice areas of redness or swelling on the body, or changes with the skin. Although some findings can be normal physiological variants that would not have a relationship to pain, others can be clues to an underlying medical problem. Don't hesitate to bring up your observations with the healthcare team. Others can be clues to an underlying medical problem.

Pain that comes and goes without an answer, or persists after treatment of problems, is a significant worry for caregivers. You may wonder if there are more tests to obtain. Or, if the clinicians start to talk about neuropathic (nerve) pain, how to feel certain that no other cause has been missed.

Your confidence in this process is as important as the thoroughness of the evaluation. Ask for a summary of all tests and what else needs to be considered. You can request an evaluation from a specialist if you have specific worries (for example, a gastroenterologist if you notice gut pain or a rheumatologist if you notice joint problems).

Neuropathic (Nerve) Pain

Neuropathic pain occurs when there is a change in how sensations in the body are processed by the nervous system. It is a form of chronic pain and is often experienced in repeating episodes of different intensity. Nerve pain can occur in children with neurological conditions or brain injury. It can also develop after injured tissue heals; for example, when there continues to be pain after complete healing from surgery.

Because there are no medical tests to confirm nerve pain, the preferred “test” is a medication trial. How your child responds to the medication can help the team understand the under-lying reason for some of the symptoms. Reasons to request or consider a medication trial include:

- Pain that comes and goes without a clear or consistent cause
- Symptoms keep returning after treatment of various problems that have already been identified
- Three or more episodes per week, each lasting more than one hour
- A cycle of daily episodes for one week out of every 3-4 weeks
- Episodes occurring for more than three months

Medications used for nerve pain can benefit many children, but a child with an altered

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nervous system might never be completely symptom-free. Some children continue to have breakthrough symptoms, even with two or three medications for chronic pain. For some two scheduled medications and an effective care plan for breakthrough symptoms is the optimal balance.

Medications

Your child may have more than one cause of pain making them uncomfortable and irritable. Some medications are known to benefit two or more of the following problems, information to review with the medical team:

- Neuropathic pain
- Autonomic dysfunction (dysautonomia, autonomic storms)
- Spasticity
- Dystonia
- Anxiety or depression
- Dementia
- Delirium (when hospitalized for an acute illness)

What to Expect While Waiting for the Medication to Take Effect

Waiting for the benefits from new medications and worrying about possible side effects can feel challenging for many parents. It can take 2-4 weeks for the benefit to take effect. Here are a few things to think about and explore with your medical providers:

- Chronic pain is exhausting. Increased sleeping in the first week can mean that the medication is working and your child is better able to sleep. Let the medical team know if you feel that it is more important to have your child more alert while you are monitoring for improvement, or to have your child sleep more in the first few weeks. If your child remains sedated (sleepy and unable to stay awake) and you would like them to be more awake, ask the medical team if a medication dose can be decreased. Pain treatment from one medication can change the effect of sedation from another drug. It may make sense to continue the medication that best achieves pain reduction.
- Pain treatment will not prevent your child from experiencing and displaying pain from a new cause. You will know if your child has a new cause of pain that needs to be identified, such as pain from a urinary tract infection.

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Steps the Medical Team Can Consider Before Adding Medications

- Maximize the dose of medications already being used for chronic pain
- Review and modify, with your input, the care plan for breakthrough symptoms
- Review constipation management and risk for overfeeding
- Review management of other contributing problems, including spasticity and dystonia

A suggested resource for your child's medical team from the American Academy of Pediatrics (AAP):

<https://publications.aap.org/pediatrics/article/doi/10.1542/peds.2017-1002/38764/Pain-Assessment-and-Treatment-in-Children-With?searchresult=1>

Chronic Pain Treatment

For many children, treatment can provide benefits over years and even decades. Adjustments may be needed from time to time, and particularly when there is progression of the child's condition. As the condition progresses, it is possible that an intervention will become too stimulating. Sometimes the best way to improve comfort is with less treatment. For example, if the child becomes less active they will need fewer calories, and decreasing their calorie intake may improve comfort. Cough assist and Bipap are other examples of interventions that may become more difficult to tolerate while not providing the same benefit that they did in the past.

Take the time needed to reflect with trusted members of the medical team. Remember the years of benefit with the intervention as you consider if this benefit is slowly being lost. The expertise of a palliative care provider who specializes in pain management may be extremely helpful. You and your child deserve this expertise as you navigate problems that do not always readily respond to the medical interventions available, or do not respond as hoped for.

Strategies to Complement Medical Treatments

There are complementary and integrative therapies that may help the nervous system remain more relaxed. These are some that can be used on a regular schedule (not just when symptoms occur):

- Essential oils
- Reiki
- Massage and deep pressure therapy
- Stretching
- Pool therapy / whirlpool
- Vibration
- Music therapy
- Acupressure / acupuncture

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You can also help your child be more comfortable with these steps to ease pain:

- Comfort: cuddling, rocking, massage, warm baths, music, calm and quiet environment
- Personal care: review for hunger or wet or soiled diaper or undergarment
- Repositioning and supportive seating systems
- Pressure and vibration: weighted blankets, vibratory mats and pillows
- Decrease feeds for a period time to lessen distention of the intestinal tract
- Treat constipation: try a suppository during a pain episode to determine if symptoms decrease after a bowel movement. If a suppository has already been given, try an enema
- Vent the gastrostomy feeding tube
- Hold tube feeds temporarily
- Assess for overfeeding: calorie needs can be overestimated by 30% or greater in children with SNI who have a low body temperature (less than 95°F/35°C), successful pain treatment with a reduction in intermittent muscle spasms, limited movement of extremities, and general decline in activity

Conclusion

Managing Pain is a Partnership

You, the caregiver, know your child best and will always be the most sensitive to their symptoms. Be assured that you and the medical team, working together, will be the best guide to the care plan that makes the best sense for your child, and to approaching decisions each step along the way.