

# Managing Pain in Children with Complex Chronic Conditions

IRRITATION / AGITATION / PAIN DUE TO SEVERE  
IMPAIRMENT OF THE CENTRAL NERVOUS SYSTEM



*written for Courageous Parents Network by*

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## INTRODUCTION

### Managing Your Child's Pain

Chronic pain is frequently seen in children with severe impairment of the central nervous system, or severe neurological impairment (SNI). This is a very complex problem to understand. Chronic pain causes discomfort for your child, and distress for the entire family. It can result in poor sleep and worsened health. This summary is intended to increase your understanding of why children with SNI can have recurrent pain, and how you can work with your child's medical team to make your child more comfortable. Take the time you need and use this information to help you formulate questions for your child's medical team.

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## Understanding Irritability, Agitation and Pain

- **IRRITABILITY** is an abnormal response to stimulus.
- **AGITATION** is an unpleasant state of arousal manifesting as irritability, restlessness, and increased motor activity.
- **PAIN** is a cause of irritability and agitation. Other causes include an altered emotional state, medication toxicity, and acute illness.

## Types of Pain

- **TISSUE INJURY PAIN** alerts us to injury or inflammation of tissue in the body. This type typically comes on quickly and will resolve once the cause has been found and treated. Examples of tissue pain include a bone fracture or bladder infection.
- **NERVE (NEUROPATHIC) PAIN** is a chronic form of pain, often experienced in recurrent episodes of different intensity. Nerve pain can occur in children with diseases or brain injury. Nerve pain can also develop after tissue injury pain has resolved; for example, healing after surgery or healing of the intestinal tract. Episodes can occur suddenly, with no explanation or known trigger.

## Signs That Your Child May Be in Pain

- **Muscle tensing or tightening at intervals:** increased spasticity, stiffening of legs, draws 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
- Your efforts to console or comfort the child don't seem to ease the symptoms

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## MEDICATION

### Reasons to Consider Requesting a Medication Trial

- Intermittent episodes of pain occur without a clear or consistent cause
  - These episodes have been occurring for more than three months
  - Some episodes may have an explanation, yet symptoms keep returning after treatment of various problems
  - The frequency and duration of episodes have a negative impact on your child's life
- Examples:*
- 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

### Medications (Generic Names) That Your Child's Medical Team May Consider

Do not administer any of these without a prescribed plan from the doctor.

- **FOR NEUROPATHIC PAIN**
  - gabapentin, pregabalin, nortriptyline, methadone
- **FOR AUTONOMIC DYSFUNCTION**
  - clonidine, gabapentin, morphine
- **FOR BREAKTHROUGH SYMPTOMS, AS NEEDED**
  - clonidine, lorazepam or clonazepam, morphine
- **FOR ASSOCIATED PROBLEMS, SUCH AS TREATMENT FOR SPASTICITY OR DYSTONIA**
  - baclofen, clonidine

### What to Expect While Waiting for the Medication to Take Effect

Waiting for benefit from new medications and worrying about possible side effects can feel challenging for many parents. Here are a few things to think about and explore with your medical providers:

- ***Consider the tradeoffs between lessening sedation and improving comfort.*** It is hard to be tolerant of sedation when you want your child to be both comfortable and awake. Is it more important to you to have your child be more alert while you are monitoring for improvement, or is it acceptable for your child to be sleepier for the first few weeks? This information can help your child's doctor determine how fast to increase the medication dose.

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- *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.

## The Goal is to Decrease Distressing Symptoms

Medications used for nerve pain can benefit many children, but for a child with an altered nervous system it may not be possible to be completely symptom-free. The goal with a scheduled medication is to decrease the frequency and severity of episodes. Some children have better symptom control with two medications (or three) that treat nerve pain.

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, as depicted in the figure below. The plan may include decreasing the number of medications, and/or decreasing intestinal tract distention that can help lessen the effects of too many scheduled medications.

## A CARE PLAN FOR BREAKTHROUGH SYMPTOMS

Here is an example of a care plan for managing breakthrough pain (symptoms like back arching and/or muscle tremors, facial flushing, leg stiffening, appearing distressed).

### Start with These Interventions

- Reposition and review for any personal care need
- Hold feeds if being given and vent gastrostomy tube
- If no stool during the day
  - Give a suppository if not yet given that day
  - If a suppository has already given, give enema as needed
- Give ibuprofen and clonidine
- Place the child in a calm, quiet environment
- If symptoms are not starting to decrease after 30 to 45 minutes, give lorazepam
- Call your physician if new concerns arise or if symptoms persist

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## Steps the Medical Team Can Consider Before Adding Medications

Resource for your child's medical team (AAP –American Academy of Pediatrics)

<https://pediatrics.aappublications.org/content/pediatrics/139/6/e20171002.full.pdf>

- Maximize the dose of other medications 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 and manage other contributing problems

## How Good is Good Enough?

These are general guidelines. This balance can help you and your child's medical team guide decisions to increase a medication dose or add another medication, if the episodes are too frequent or not responding well to the care plan for breakthrough episodes of discomfort/agitation.



|                    |                   |   |                       |
|--------------------|-------------------|---|-----------------------|
| <b>PAIN</b>        | Frequent episodes | Balance e.g. 3 or fewer severe episodes per week that require a drug (other than Tylenol or Ibuprofen) and benefit within 1 to 2 hours to interventions for breakthrough episodes | Fewer pain episodes   |
| <b>WAKEFULNESS</b> | Poor sleep        | e.g. Awake during most of the day, improved sleep   | Sleepy during the day |

You and your child's medical team will always be the best experts in navigating how to use this information. Seek experts if your child's symptoms are not easily improved. The expertise of a palliative care provider may be extremely helpful. You and your child deserve such expertise as you navigate problems that do not always readily respond to the medical interventions available, or do not respond as hoped for.

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## NON-MEDICATION STRATEGIES

Here are some pain management strategies to try as a complement to your child's medication regimen.

- **Comfort:** cuddling, rocking, massage, warm baths, music
- **Repositioning and supportive seating systems:** to minimize positional pain
- **Pressure and vibration:** weighted blankets, vibratory mats and pillows
- **Complementary and integrative therapies:** essential oils, Reiki
- **Lessen distention of the intestinal tract**
  - Treat constipation: try a suppository during a pain episode to determine if symptoms decrease after a bowel movement, vent the gastrostomy feeding tube
  - 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), successful pain treatment with a reduction in intermittent muscle spasms, limited movement of extremities, and general decline in activity



### Questions You May Ask Your Child's Medical Team

*Per Julie Hauer, MD*

- ***Are there tests that will tell me that this is nerve pain versus tissue injury pain?***

Tests can identify causes of tissue injury. Because there are not medical tests to confirm nerve pain, the best "test" is a medication trial.
- ***If the medication for nerve pain does not help, does this mean my child doesn't have nerve pain?***

Nerve pain can be difficult to treat in some cases, because the damage to the nervous system cannot be fixed or cured. But for some children, the combination of two different medications, or even three, can be more effective than a single medication.
- ***Should we do all tests looking for causes of tissue injury before starting a medication for nerve pain?***

The first tests typically look for the most likely causes of pain to treat. Sometimes it makes sense to start a medication for nerve pain while also considering some other tests.
- ***My child seems anxious. Do you think this is depression or anxiety?***

You and your child's medical team certainly want to consider all reasons why your child appears anxious and agitated. 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.

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- *My daughter has other problems that cause pain. How will I know when this is due to her spasticity (gastroesophageal reflux, recurrent clostridium difficile, tracheitis) versus nerve pain?*

Children with SNI are at risk for more than one cause of pain. Treating nerve pain can help the team understand how much this might be an underlying reason for some of the pain. Because the body tenses when it is pain, if a medication decreases nerve pain, it can help decrease muscle spasms.

- *How will I know when a breakthrough symptom is due to the nervous system versus a new cause of pain?*

**INFORMATION:** If you are worried or uncertain, call the clinic during the day and the on-call person at night. Over time, you and the team will get a better sense of which symptoms tend to respond to the breakthrough care plan and which features seem different. For example, if there is a fever, it might make sense to assess for a bladder infection if the cause of fever with pain seems different or is not clear.



## CONCLUSION

### Managing Pain is a Partnership

You, the parent, 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.