

PAIN MANAGEMENT TIPS FOR CHILDREN LIVING WITH PANCREATITIS

WHY THIS MATTERS

Untreated pain can cause **anxiety, depression, irritability and exhaustion**. Pain can also cause changes in the brain that can make future pain worse. Children living with pancreatitis often have to miss out on school, daily activities, and social bonding opportunities due to pancreatitis-induced pain episodes that can last several days. These pain episodes can be isolating and may have **long lasting mental, physical and emotional impacts**.

PANCREATITIS PAIN

Pain is the number one symptom of pancreatitis. Pancreatitis pain is often classified as a different type of pain and has been described with graphic words such as "**powerful, dull, burning, ripping, bursting, stabbing, relentless**" and episodes, or flare-ups, have been compared to being "stabbed with a hot poker." This pain is primarily abdominal, sometimes radiating towards the back area and those undergoing a flare-up may find themselves doubled over or in a fetal position due to the intensity of the pain.



This handout is intended to be a resource for parents and caregivers caring for children living with pancreatitis. It compiles recommendations from various sources, including "Medical Management of Chronic Pancreatitis in Children" a position paper recently published by NASPHGAN (North American Society for Pediatric Gastroenterology, Hepatology and Nutrition) and other experts focused on pediatric pain management. The handout is broken down into three main sections: monitoring and tracking pain, multiple approaches to managing pain, and establishing a care management team and a plan so that a child living with pancreatitis can live a high quality life.

1 MONITOR AND TRACK YOUR CHILD'S PAIN

The first step to successfully monitor your child's pain is to have an **open and honest conversation with your child about their pain**. Not all pain is obvious. Therefore, it is important to look out for any unusual physical or behavioral actions that may be related to pain. Track your young child's pain level and activity over time and have regular conversations with your older children. This will enable you and your child to have informed conversations with their provider and also allow you to mark and prepare for the onset of a future pain episode.

There are three ways to find out how much pain your child has: by what they say, what they are doing and how their body is reacting. It is important to create a safe space for expression, and to acknowledge and validate your child's pain.

1 MONITOR AND TRACK YOUR CHILD'S PAIN

Use the **ASK, LOOK** and **OBSERVE** approach:

Ask how your child is feeling if you notice they may be going through an episode. Encouraging open dialogue gives your child the space and confidence to express themselves. Be careful to not dismiss or minimize their pain and instead acknowledge their pain ("I know you are in pain and I'm here to help."). If words are not enough, using a visual marker such as a color scale, the Wong-Baker faces pain scale or a numerical pain scale may be helpful.

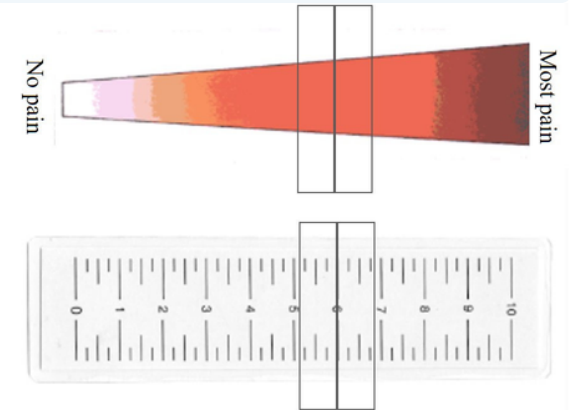
Look for physical changes such as:

- Fast heart rate**
- Grimacing**
- Body posture**

Observe their behavior, such as:

- Anxiety**
- How they're acting**
- Ability to focus**
- Irritability**
- Problems sleeping**

Color Analog Scale (CAS) - is a way younger children can associate colors with their levels of pain. It is considered both a valid and reliable self-reporting tool for providers to gauge the level of acute pain the child is experiencing. There are many versions of this color scale but the most common ranges from white indicating no pain to dark, deep red signaling severe pain.



Wong-Baker Faces Pain Scale - a common pain scale used in hospital settings. Children can point to the facial expression that best represents how they may be feeling at the time. This is a great way to connect emotional responses with physical pain experiences. Color is also sometimes used with this scale. In this example, green indicates no pain but as the colors darken, we can see changes in the facial expressions from smiles to frowns, with the last face in tears, indicating excruciating pain.



Numeric Rating Scale - This is a scale best associated with older children (above 6-7 years) who understand serial ordering of numbers. Children can be asked to choose a number from 0 meaning "no pain" to 10 "the worst pain you can imagine" to rate their pain experience.



2 CONSIDER MULTIPLE APPROACHES TO MANAGE PAIN

Experts have found several methods to alleviate and cope with the pain that pancreatitis brings. For the purpose of our handout, we will focus on: **Non-Pharmacological Methods and Medication** that can be combined to better manage pain.

NON-PHARMACOLOGICAL METHODS

Non-pharmacological approaches to pain management are interventions that do not use medication to treat pain. There are several approaches to consider when trying to find what works best for your child and their specific needs. Below we highlight a few approaches:



Cognitive behavioral therapy (CBT) is a psychological therapy that teaches patients new ways to cope with pain by helping them understand their pain and providing them tools to minimize the impact of pain. CBT strategies focus on minimizing the physical sensations of pain and the emotional responses that can worsen it.



Relaxation techniques are useful to help regulate the physiological responses to pain such as heavy breathing, muscle tension and increased heart rate. This can include breathing exercises, imagery, and meditation.



Mindfulness exercises (e.g., focusing on the present moment, body scanning) teach children to notice pain without letting it take over their emotions.



Distraction by engaging your child with enjoyable activities (e.g., favorite books, music, drawing) can help divert attention from the pain sensation.



Physical Therapy is meant to build stamina, strength and confidence. Increasing your child's physical functioning is essential to help them to maintain normal activities including school and social bonding activities.



Social Support and Family Involvement can help to reinforce new pain management skills and encourage supportive communication. Social activities with friends and family can also serve as a distraction and emotional support.

2 CONSIDER MULTIPLE APPROACHES TO MANAGE PAIN

MEDICATION

Experts recommend a **layered approach to managing pain**. The advantage of this approach is that it allows for lower doses of each medication which decreases the risk of potential adverse reactions.

Analgesic Pain Management Ladder (adapted from the NASPGHAN position paper)

The NASPGHAN workgroup has developed this analgesic pain management ladder that incorporates **layering nonopioid with opioid medications**. The base of this chart starts with acute, intermittent pain and works its way up towards more severe, uncontrolled and persistent pain. Be sure to work alongside your child's pain specialist(s) as well as with a pancreatic specialist or a gastroenterologist to make sure these medications are right for your child.

| | |
|---------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Level I Acute intermittent abdominal pain | Medications like nonopioids such as NSAIDS or non-steroidal anti-inflammatory drugs (i.e. ibuprofens and naproxen) and acetaminophen which focus on relieving pain and reducing inflammation for acute intermittent abdominal pain. |
| Level II Moderate and consistent pain | Continued use of Level I medications while introducing weaker opioids such as Tramadol for children 12+. For children under 12, hydrocodone/ acetaminophen is suggested for pain as needed. |
| Level III Severe persistent abdominal pain | More potent oral opioids such as oxycodone, immediate release morphine or hydromorphone which are used off-label in pediatrics (331). Proper counseling on appropriate opioid handling is recommended for children and parents. |
| Level IV Uncontrolled persistent severe pain | If uncontrolled pain persists and child is no longer able to tolerate oral medications, it is recommended for the child to be admitted to an inpatient facility for pain control. |

3 HAVE A TEAM AND A PLAN

The best way to manage your child's pain is to be **proactive**. If possible, establish a team involving a pediatric pain physician, psychologist, nurse and physical therapist to help you put together an appropriate plan for your child based on their specific needs.

A good plan takes a tiered approach to pain management that includes a **mixture of pharmacological and non-pharmacological methods**, as well as a step-by-step plan to manage acute pain episodes.

To plan for acute pain episodes, complete the **Pediatric Pancreatitis Passport** with your child's primary gastroenterologist as soon as a pancreatitis diagnosis is confirmed. This passport is a portable resource that can be shared with clinicians who are not familiar with your child's medical history and diagnosis, such as at an urgent care or emergency department settings, so that prompt and appropriate treatment can be provided.



Download Pediatric Pancreatitis Passport