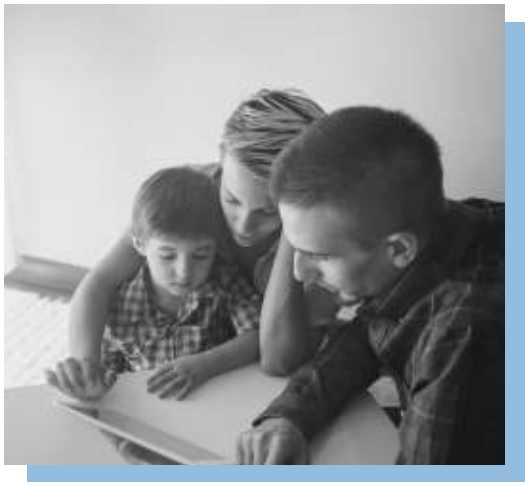
PAIN MANAGEMENT TIPS FOR CHILDREN LIVING WITH PANCREATITIS

Mission:Cure



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**.

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 his/her 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 child's pain level and activity over time. This will enable you to talk to your provider and also allow you to mark and prepare for the onset of a future pain episode.

PROMOTING PAIN AWARENESS AND STARTING THE CONVERSATION

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.**

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

Ask how your child is feeling if you notice that they may be going through an episode. By encouraging open dialogue and giving your child the space and confidence to express themselves, you can come up with your own language to assess pain. 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.

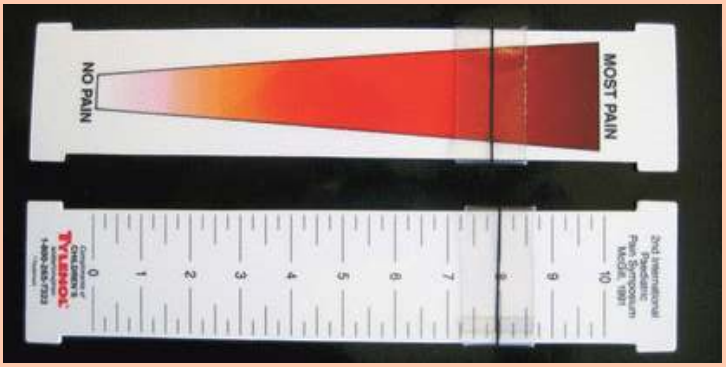
Look for physical changes such as accelerated heart rate, facial expressions, and body posture.



Observe their behavior, such as how they are acting, ability to focus, irritability, or changes in anxiety levels.



Color Analog Scale - (also known as CAS) is a way in which 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 from yellow-green, to yellow, orange, and finally red, 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 who understand the correlation of of increasing numbers with increased pain intensity. The higher the pain experience, higher the number they would associate with pain.

CONSIDER MULTIPLE APPROACHES TO MANAGE PAIN 2

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 three approaches:

Cognitive behavioral therapy (CBT) is a method of pain-focused psychology 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 psychologically in order to increase social functioning and offset the negative association between pain and daily activities.

Mindfulness techniques are useful to help control the physiological responses to pain such as heavy breathing, muscle tension and increased heart rate. Consider:

- Breathing exercises and meditation
- Distract your child from pain with their favorite books, music, blowing bubbles - things your child enjoys
- Comforting touch and positive affirmations

Physical Therapy is meant to build stamina, strength and confidence. Increasing your child's function is essential to decreasing their pain signaling, which can help them to maintain normal activities including school and social bonding activities.

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.

Uncontrolled persistent severe pain
Level IV

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.

Severe persistent abdominal pain
Level III

Level III introduces 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.

Moderate and consistent pain
Level II

Level II starts with continued use of Level I medications while introducing weaker opioids such as **Tramadol** for children 12 years of age or older. For those younger than age 12, **hydrocodone/ acetaminophen** is suggested for pain as needed.

Acute intermittent abdominal pain
Level I

Level I medications include **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.

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.

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.

NASPGHAN

Provider Creation Date: _____

PEDIATRIC PANCREATITIS PASSPORT AND ACTION PLAN

This patient has a known history of pancreatitis, and the current document is endorsed by the pancreas provider below. Please do not hesitate to contact them to discuss the pancreatitis action plan.

All information/suggestions contained in this form are not intended to replace the judgement of the treating physician

Patient Name:	**Diagnosis:** ☐ Acute Recurrent Pancreatitis ☐ Chronic Pancreatitis
Date of Birth:	**Parent/Guardian Contact:**
Pancreas Care Provider:	**Provider Contact:**

PANCREATITIS HISTORY

Brief History of Pancreatitis (1st episode, triggers, genetic/anatomic risk factors, surgeries/procedures, pancreatic insufficiency):

Patient Specific Acute Treatment/Medication Considerations:

Other Medical Problems/Allergies (☐ NKDA):	**Medications:**

PANCREATITIS ACTION PLAN AND RESOURCES

INFORMATION/SUGGESTIONS IN THIS FORM ARE BASED ON EVIDENCE AND EXPERT OPINION AT THE TIME OF CREATION AND NOT INTENDED TO REPLACE FUTURE MEDICAL ADVANCES OR THE JUDGEMENT OF THE TREATING PHYSICIAN

Workup

- **Labs to consider:** Complete blood count, liver function tests, electrolytes, lipase/amylase, triglycerides. Chronic pancreatitis patients may not have lipase/amylase levels that reach ≥3x upper limit of normal.
- **Imaging:** Complete Abdominal Ultrasound, Consider MRCP or CT Abdomen with contrast if concerned for pancreas complications.
  - Assess for fluid collection, biliary obstruction, and consider transfer to pancreas center if present.
- **Assess for signs/symptoms of organ dysfunction:** Hypotension, capillary refill, oliguria, metabolic acidosis, elevated BUN/Cr, elevated liver function tests, thrombocytopenia, cyanosis, pulmonary edema.

Treatment

- **Fluid resuscitation:** 20 mL/kg (max 1L) IV fluid bolus and assess if additional fluid bolus is needed based on heart rate, capillary refill, estimated fluid deficit. After bolus: ≥1.5x maintenance IV fluids (LR or NS).
  - Follow markers of hemodilution (BUN, hematocrit, urinary output – Goal 0.5-1 mL/kg/hr).
  - Once intravascular fluid euvolemia → decrease to maintenance IV fluid rate.
  - Monitor for fluid overload (e.g., pulmonary edema, heart failure).
- **Pain Control:** Pancreatitis can be incredibly painful. Analgesia management should be prompt and adjusted as needed to control pain, including the use of opioids when appropriate. Pain exacerbation episodes can occur without macroscopic pancreatic inflammation.
  - If mild pain and tolerating PO → avoid narcotic medications.
  - Opioid-sparing pain medications: Acetaminophen 15 mg/kg, ibuprofen 10 mg/kg, ketorolac 0.5 mg/kg. Avoid NSAIDs with elevated BUN/Cr.
  - Uncontrolled pain: Opiates are commonplace in chronic pancreatitis management and often used as adjuncts to opioid-sparing medications. Recommend judicious, but prompt, use of opiates for pain relief.
- **Nutrition:** Regular diet is OK if patient has appetite, is not vomiting, and pancreatitis is not caused by hypertriglyceridemia. NPO in the short term if moderate/severe pancreatitis, if ileus, or other contraindications for enteral feeding.

The first half of the passport consists of basic patient information including history of pancreatitis diagnosis, current medications, and treatment plans in place so that the new provider has a baseline for potential treatment.
The form should be filled out by the child's primary gastroenterologist and should be updated any time there is a change in symptoms or care.

The bottom portion of the passport includes recommendations on assessment and treatment. The passport is not intended to replace clinical assessment by the attending physician but rather should be viewed as a resource when seeking care beyond your primary gastroenterologist or healthcare provider.

Resources

- Medical Management of Chronic Pancreatitis in Children: A Position Paper by the North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition Pancreas Committee (full text)
- Pain Pain, Go Away: Helping Children with Pain
- Mission: Cure Webinar: Pancreatitis and Chronic Pain: How Can I Manage? with Dr. Tonya Palermo, Psychologist and Associate Director of the Center for Child Health, Behavior and Development at Seattle Children's Research Institute
- WebMAP Mobile - A free app developed by the Pediatric Pain and Sleep Innovations research team at Seattle Children's Research Institute
- Six Building Blocks: Chronic Pain Self Management resources. A list of resources compiled by University of Washington; they are not specific to children but helpful for caregivers to understand pain.
- Pain scales:
  - Color Analog Scale - "Reliability of the Color Analog Scale: Repeatability of Scores in Traumatic and Nontraumatic Injuries"
  - Wong-Baker Pain Scale
  - Numeric Scale via MedicalNewsToday
- The Pediatric Pancreatitis Passport was designed by the Pancreas Committee of NASPGHAN in collaboration with patient advocacy groups including Mission: Cure, National Pancreas Foundation, and Rebecca's Wish.