

Understanding Your Child's Pain Disorder

What is Pain Disorder?

Sometimes children or teens can experience pain in their bodies, even when their bodies are healthy and have no disease or damage. This pain can last for a short or long time, and can range from mild to severe. Sometimes the pain can disrupt all of the areas of a child's life, and they can miss school, sleep more or less, get out of their normal routines, and avoid doing the things they used to enjoy. When this happens, it's called a Pain Disorder.

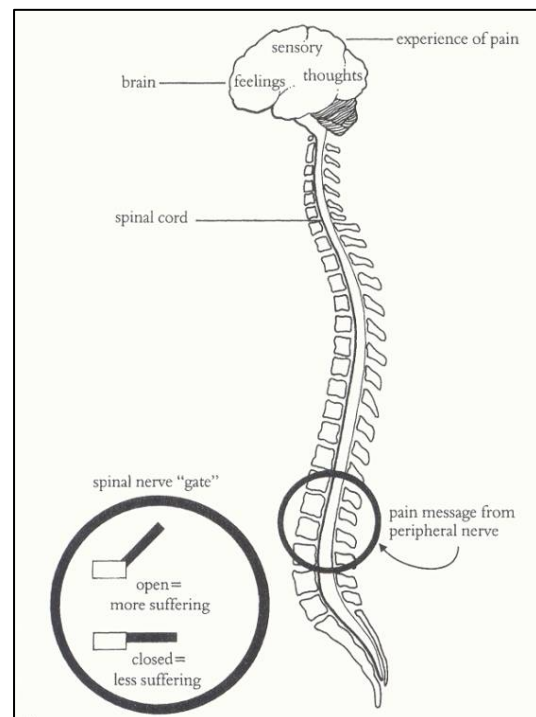
When a child has a Pain Disorder it is often very stressful for the whole family. It can be particularly frustrating for parents because they want to help their child to feel better and protect them from the pain. Parents sometimes feel that because there is not a clear and identifiable medical cause then doctors think the pain is all in their child's head. This is not true—Pain Disorders happen when neurons misfire in the body. Essentially the brain and body can get in a cycle of not communicating smoothly with each other and will send inaccurate pain messages. This process can happen for a variety of reasons.

Although many people have never heard of Pain Disorders, they are more common than you might think, and are experienced by many children and teens. We think of Pain Disorders as a chronic treatable condition. This means there is no single medicine that cures a pain disorder, but it is important to know that it CAN be treated. Most children learn how to get their pain under control and get back to their normal lives, but it takes work and time.

What Causes or Affects Pain Disorder?

Pain is experienced in very complex ways in the body. Nerves from all over the body run to spinal cord, where there are a series of "gates" that pain messages pass through to get to the brain. If these gates are open, then pain messages pass through to get to the brain, and the body experiences pain. However, if these gates are closed then the pain messages do not pass through to the brain, and the body is less likely to experience pain. Different factors affect whether these gates are more open or more closed. In a Pain Disorder, these gates get stuck in the open position, which allows lots of incorrect pain messages to pass through to the brain.

The following picture demonstrates how pain messages get to the brain through the pain gates in the spinal cord.



Many different factors can contribute to the pain gates being more open. These can affect how your child's body experiences the misfiring of neurons associated with a Pain Disorder, including any of the following:

- A triggering event such as an injury or illness
- Prior exposure to pain can condition the body to experience pain more strongly
- Sensitivity to sensations in the body
- Conditioning of the autonomic nervous system
- Behavioral habits like activity level, diet, and exercise
- Functional factors like school, activities of daily living, and scheduling
- Social or environmental factors like family life, how others respond to the child's symptoms, and social support
- Psychological and emotional factors like stress, psychiatric history, and reinforcement

What is the treatment for Pain Disorder?

- 1) Changes in the environment
 - Getting back into normal routines and expectations
 - Having a daily schedule as close to what the child had in the hospital as possible
 - Adjusting parents' responses to child's pain
 - Daily practice of skills learned in therapies
- 2) Behavioral Health follow up for:
 - Learning relaxation and pain management skills to help your child self-calm

- Helping your child to understand that her body is safe and she can participate in all of the activities she enjoys, even if she is feeling some pain
- Getting support and guidance for all of the changes the family is making in the home environment

3) Physical Therapy, Occupational Therapy, Integrative Medicine if needed

4) Consistent scheduled check-ins with primary care physician

How Can Parents Help?

Many parents feel worried or upset when their child has pain. This makes sense. One of your primary jobs as a parent is to protect your child from hurt or harm. You likely have been spending your time trying hard to do this while looking for the cause of his or her pain. When a child has a Pain Disorder, however, a parent's job changes a bit.

Now, instead of being your child's "protector", you need to be your child's "coach". This means that you need to find ways to encourage and support your child's return to normal activities and his or her recovery from pain. So, how do you do this?



The following checklist includes some great ways to “coach” your child back to health:

- ✓ **Set an emotional example.** You may feel worried or frustrated as your child is working to recover from pain. This is normal. However, it is important to remain calm and try to manage these feelings, especially in front of your child. Your child will draw strength from your calm reaction and will be better able to deal with his or her pain. If you feel yourself getting tense or upset, try breathing slowly and deeply. You also may want to talk over your concerns about your child’s health with a trusted friend or health professional.
- ✓ **Encourage normal daily activity.** Going to school, doing chores, and participating in activities are all important for recovery. Participating in normal daily activities, even when in pain, gives your child a sense of control over the pain. As your child feels more in control, anxiety (and the associated stress response) will decrease.
- ✓ **Create a plan to gradually increase daily expectations.** Pain can disrupt your child’s activities—school, friendships, hobbies, etc. Your child will need your help and support to get back to his or her daily routines. Here are a few key steps:
 - **Step 1: Set a consistent daily expectation for participating in one area** (e.g., half day attendance at school, 30 minutes attendance at a club meeting or play date). Start with a small enough amount of time to ensure your child’s success and build from there.
 - **Step 2: Your child should attend the activity for the agreed upon amount of time each day.** This should happen regardless of pain or other symptom complaints. Your child should leave the activity at the scheduled ending time even if he or she is feeling well. Doing this will encourage feelings of success and help prevent symptoms from getting worse on the following day(s).
 - **Step 3: Your child’s progress should be re-evaluated weekly.** If your child has been able to complete the plan for the previous week without increased symptoms, then expectations should be increased slightly for the next week. You might increase time spent in the same activity or add a small amount of time on a different activity. Again, this added time may be as little as 30 minutes. Remember, slow and steady is the key!
- ✓ **Resist the urge to ask your child if she or he is in pain.** Pain is worse when children pay attention to it and better if they are distracted from it. Asking about pain encourages your child to scan his or her body, look for pain, and (usually) find it. If your child happens to be distracted from the

pain at any given moment, we want that to continue. It is perfectly okay for your child to come to you to tell you about his or her pain. However, if this becomes frequent, you might think about scheduling a specific time each day for a 5-minute “symptom report”. This can reduce your child’s focus on symptoms at other times of the day.

- ✓ **Improvement is first measured by increased functioning.** Your child is recovering when you see even a small gain in your child’s ability to do the things he or she once did (e.g., go to school, participate on a sports team). For most of our patients, the pain goes away *after* they are back to doing their normal activities.
- ✓ **Encourage positive coping with pain.** Gently remind and encourage your child to use skills like deep breathing, distraction, relaxation, positive thinking, etc. during pain episodes. These skills also can help prevent episodes if used before event that seem to trigger pain (e.g., eating, going to school, having a test). At first, your child may need more encouragement and help from you to use these skills (e.g., playing a distracting game or practicing relaxation skills with you). Over time, using these skills will become easier and your child’s self confidence will increase.
- ✓ **Use rewards effectively.** When your child is sick, it is natural to give lots of extra attention, affection, and privileges. You want to make your child feel better! But when a Pain Disorder is present, extra attention, affection, and privileges are best

used a little differently. Instead of using these things to make your child feel better when he or she is not doing well, you can use these things to reward your child’s efforts to manage pain and/or to meet daily expectations. Praising effort is very important. This encourages your child to keep trying and not give up. When your child is having trouble helping him or herself, or is complaining about symptoms, gently encourage more positive behaviors and walk away. But, remember to check in every few minutes to “catch” your child making an effort and offer praise! Offering special rewards or activities for reaching important recovery milestones (e.g., first time sleeping over at a friend’s house, first week of school with no absences) also can help increase effort.

- ✓ **Stay positive.** Use positive language and encourage your child to do the same. For example, you can say: “You are such a brave girl. I know that you will be okay.” This helps your child to focus on how well he or she can cope with pain, instead of how bad the pain feels. Remind your child how well he or she has coped with pain in the past. Talk about the pain being temporary and eventually getting better or going away. Using neutral words when talking about your child’s experience (e.g., pain “episode” versus “attack”) also can help make pain more manageable.
- ✓ **Encourage regular exercise and sleep.** Low impact exercise like swimming or biking is good for everyone, but especially for a child with a Pain Disorder. Exercise helps to improve the immune system and activates the pain relief response in the brain. Like everything, start small and

work up! Good quality sleep also is related to your child's ability to manage his or her pain. Your child should go to bed at the same time each night, get up at the same time each morning (even if she or he is not attending school regularly), and only use his or her bed for sleeping (not for doing homework or watching TV).



A Final Reminder: A long-term problem requires a long-term solution. Quick solutions do not work for chronic pain. Children who do the best over time make slow and steady progress in functioning first. If your child has been in pain for a very long time, it may take a similar amount of time for the pain to go away completely.