

Chronic Pain and the Family

A NEW GUIDE

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Chronic Pain in Children

WHEN I was a doctor in training, I spent a lot of time in the neonatal intensive care unit tending to sick and often premature babies. I was told, and I believed then, that these babies did not feel much pain since the nerve pathways that carry pain signals to their brains were not fully developed. This is probably not true—at least there’s no convincing evidence that it’s true. In fact, recent studies that involve monitoring facial expressions, movement, crying, and other responses to pain in babies and young children have revealed that they may actually experience more pain than adults do under similar circumstances. Such studies have prompted the medical community to rethink the experience of early childhood pain, but we still have a long way to go before we fully understand the effect of pain on children.

Although the literature on childhood pain is sparse, research studies have shown some important results. For example, the vast majority of children who suffer from chronic pain have close family members (often a mother or a father) who also live with chronically painful conditions. This may be true for a number of reasons. We know that some diseases have a hereditary component. In addition, parents who are invested in the medical system themselves might be more likely to take their children to doctors. And finally, it’s a well-known fact that children mimic adult behaviors; thus children who see their parents in pain may develop painful conditions and associated pain behaviors (for example, grimacing, moaning, or walking with a limp) simply because they learned this behavior from their parents.

Without realizing it, parents can actually encourage their children to develop chronic pain problems or can exacerbate an already existing

chronic pain problem. They can do this in two ways. The first is by being overly sensitive. This behavior usually begins early in childhood with a parent who is exceedingly concerned about the child's physical comfort—always checking to see whether he's covered by a blanket or is wearing enough layers of clothing. The overly concerned parent rushes to the child's side every time he trips instead of reassuring him that a minor bump or scrape is not a big deal. This over-sensitivity to the child's physical comfort can encourage him to become exquisitely aware of even the slightest physical discomfort. It also teaches the child that for any minor physical problem he will receive a lot of attention, and so the way to get attention is to complain of physical pain—whether or not it exists.

The second pitfall is the other extreme—the parent who does not validate and take seriously a child's pain complaints. The parent who does not appropriately comfort a child when she has an injury sends the message to the child that she's not important. This lack of validation of a child's very real experience has detrimental effects. It confuses and angers children. They know they're hurt, so why doesn't Mom or Dad pay attention? Why don't they care? To avoid encouraging pain behaviors in their children, parents should strive for an appropriate level of intervention and responsiveness.

Research has also revealed that children and adolescents who have chronic pain experience more emotional distress than their peers, including anxiety and depression. Similarly, young people with chronic pain have been shown to have lower self-esteem and more behavior problems than other children. Interestingly, the severity of pain is not necessarily predictive of whether children will experience these other problems. *In fact, what seems to influence children more than any other factor is how their parents cope and teach them to cope with chronic pain.*

Why Children Are in Pain

All children are familiar with the acute pain associated with shots at the doctor's office, skinned knees, sore throats, and bug bites. Others will have more serious injuries such as broken bones or lacerations that require stitches.

Many children are also acquainted with chronic pain, which in childhood can take many forms. It can be due to an ongoing serious illness or

condition such as sickle cell anemia, juvenile rheumatoid arthritis (JRA), or cancer. In these conditions, the pain may be constant but wax and wane in intensity, as is the case with more severe forms of JRA. Or it may be intermittent, as when a child with sickle cell anemia experiences a sickle cell crisis. Chronic pain can also result from repeated treatment-related procedures in serious medical conditions (for example, leukemia) such as obtaining blood samples (venipuncture), spinal taps (lumbar puncture), or bone marrow aspirations.

Even children who are not seriously ill might experience chronic pain from headaches, stomachaches, earaches, or various musculoskeletal injuries. In these cases, the pain usually occurs intermittently, as with migraine sufferers, who usually have long headache-free periods and then intense episodes of pain when a headache occurs. Dental work and orthodontia can also cause chronic pain for a period of time. In children who are competitive athletes, chronic pain may result from a single ongoing musculoskeletal condition (say, back pain) or from a series of injuries (for example, sprained ankles, knees, or wrists).

A thirteen-year-old girl who is a very high-level competitive ice skater came to my office with her mother. Mom did most of the talking. She explained that her daughter was in chronic pain from a series of ankle sprains. The girl practiced skating for four hours every day after school. She also played soccer, and in fact that's how she got most of her ankle sprains. It was clear to me after examining the skater that she had too much flexibility in her feet and ankles in certain directions and not enough flexibility in other places—this was causing her to roll over on her ankles and repeatedly sprain the ligaments. Appropriate treatment for repeat ankle sprains such as hers includes anti-inflammatory medications, icing the injured ankle, wearing an ankle support, obtaining shoe orthoses (which can be placed in skates and soccer cleats) to better position the feet, and attending physical therapy to improve flexibility and strength. It also involves avoiding activities that aggravate the injury while the healing and rehabilitative process is under way. But because this girl was an elite skater, described by her mother as someone who "someday may go to the Olympics," her mother refused to follow my advice and allow her daughter to take a short break from training. Two weeks after ignoring my advice, the girl once again rolled over on her ankle and this time fractured the bones in the lower part of her leg. This in-

jury sidelined her for much longer than she would have been out if her mother had agreed to follow my original recommendations. Interestingly, when I asked the girl (out of earshot of her mother) whether she was disappointed at not being able to train, she replied that she was delighted to have a rest.

Not all children have parents who push them as hard as this mother, but many child athletes are nonetheless prone to chronic injuries and therefore chronic pain. They may sustain an acute injury (such as an ankle sprain) and either not allow it to heal fully before returning to play or not undergo any rehabilitative measures to keep the injury from recurring. Other children are at risk for the same types of overuse injuries that are common in adults. These injuries may be due not only to overuse of a particular part of the body but also to poor training techniques. For example, although cross-training (as when swimmers run to increase their endurance and give their arms a rest, or runners cycle to build up their lower extremity muscles and take a break from the pounding that goes along with running) has been shown to increase fitness and strength and help avoid injuries, coaches often do not employ this excellent training technique with children.

How Children Understand Pain

The Very Young Child

This age group includes children from birth to preschool age. Because the pre-verbal child is unable to vocalize where it hurts, parents must look for clues of discomfort. As children begin to talk, they can better communicate their pain or at least the fact that they have pain. Even so, it's impossible for children in this age group to be logical about their experiences. They understand things very concretely, and they believe that whatever they experience is obvious to others. For example, a three-year-old who falls down without any obvious injury may exclaim, "Put the Band-Aid right there where it hurts! Can't you see it?" Children in this age group typically have fantasies and believe in "magical thinking." They may view pain as a punishment for an action or even a thought they had. Very young children also believe that their parents have total control (that is, the ability instantaneously to make everything better). If they de-

velop chronic pain, they may assume that their parents are angry with them and that they are being punished. They may think that their parents could instantly take their pain away but choose not to.

Parents may not recognize pain in a child this young. This was the case with two-year-old Joey, who pulled his mother's coffee pot down and sustained second- and third-degree burns over 25 percent of his body. He spent several days in the intensive care unit on morphine and then was discharged to home with Tylenol with codeine. One week after his burn, his mother took him to the pediatrician and reported that he was "clingy." She didn't know what was wrong. She thought that perhaps he had an ear infection. The pediatrician watched Joey during the visit and noticed that he hadn't moved at all—very unusual for a child of this age. She immediately recognized that he was in severe pain, and she admitted him to the hospital for pain control. As soon as he was properly medicated, he began to move and was no longer seeking constant physical comfort from his mother. In the preschool-age child, changes in behavior are often more important than what the child is able to communicate about his pain.

The Older Child

As children reach school age, they become less egocentric and more logical. They begin to understand and describe their pain. By the time they enter school, most children have a limited understanding of the word *pain* and what it entails. Their reasoning is generally based on direct observation, and they tend to be very concrete rather than abstract. Children in this age group typically describe pain as "a sore thing" or "a thing that hurts." They believe that a person who is ill goes to the doctor and gets well quickly. Chronic illness or pain is confusing to them.

In addition to being more logical, school-age children are also increasingly aware of how their bodies function. They are curious and interested in understanding what's happening to them. They also begin to be aware of peer pressure and the fact that people may tease them for being "different." They want to fit in with their peers, and most children this age with chronic pain will recognize that they have a unique problem to deal with. This may cause them some distress and anxiety.

But school-age children do have significant gaps in their knowledge

and may have problems coping when they're in pain. Gretchen is a seven-year-old girl who suffers from growing pains—a fairly common problem in children ages six to ten, accounting for between 8 and 11 percent of musculoskeletal pain in this age group. Gretchen has the classic history of pain in both legs that awakens her at night and improves with reassurance, massage, and ibuprofen or acetaminophen. These episodes happen periodically and may be absent for weeks or months at a time. One night after a long pain-free period Gretchen woke up crying hysterically. Her mother reacted as she normally did, by giving her a massage and reassuring her that this episode of growing pains would be over soon. When she tried to offer Gretchen her usual medication, however, the girl became even more agitated and insisted that she didn't like the medication and that it didn't work. Her mother immediately realized that her daughter didn't remember taking the medication for this problem. Once Gretchen calmed down, her mother reminded her that she did in fact like this medication and that it had helped her in the past. Children in the throes of a painful episode may not be amenable to treatment that will likely help them; for this reason I recommend that parents talk to children about their condition during pain-free periods when they are better able to focus.

The Adolescent Child

Adolescents are able to generalize, reason deductively, and comprehend abstract ideas. Their definition of pain is generally more refined than younger children's, and when asked to describe what pain is they will typically respond with something like, "a physical sensation that occurs when the nerves are injured" or "something physical or psychological that hurts a person." Adolescence is a time when teens are excessively focused on their bodies and how they look and perform. It's a time when the "herd mentality" is at its height and children want to be like their peers. For better or worse, adolescents are harshly judged by their peers, and the need to fit in becomes a primary consideration. The teenager who has chronic pain, particularly if he or she has a condition that is physically obvious to others, may suffer dramatically during adolescence. Even if the condition is not apparent, there may be a stigma associated with reporting to the nurse for medications.