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MY DAUGHTER FEELS NO PAIN

Is it a blessing or a dreadful misfortune to be completely insensitive to hurt of any kind? Here is the firsthand story of a mother who had to weigh that fateful question

by MRS. JAY SHELDON
as told to FRANCESCA LIBERTE

MY LEGS TURNED to jelly and I had to sit down to digest the news the doctor had just given me about my daughter Mary, 11.

What he had said, in effect, was that you could drive a nail through her heart—and she wouldn't feel it.

"You mean you never noticed anything strange? There must have been some signs!" he insisted.

Numbly, I tried to think. Mary had always enjoyed excellent health. Then, recently, we'd decided to do something about a slight nervous tic she sometimes experienced. Our doctor couldn't explain it, but he said if anyone could it would be Dr. Richard Reuben, prominent pediatrician-neurologist. So here I was at Dr. Reuben's.

"Didn't it seem strange she never cried when you spanked her?" he asked.

"Lots of children don't cry when they're spanked," I said, defensively. "We always felt lucky that Mary wasn't a cry-baby. Her father used to call her his 'Little Stoic.'"

"That's interesting," Dr. Reuben said. "Maybe this is more common than we think. Many parents who feel 'lucky' that their children aren't 'crybabies' may really have children like Mary. Some die before the condition is recognized. Others grow out of it at an early age. Still others could live as long as Mary has—even longer—without anybody knowing something is wrong. Usually, however, there are signs."

Thinking more clearly now, I began to recall little things that did seem odd at the time—yet not so odd that we attached any special significance to them.

As a baby, Mary had cried only when she wanted attention or to be picked up—never over a bump or scratch. When her older sister cried over a fall or bruise, Mary would ask, "What's she crying about?"

When her tonsils were found to be badly inflamed and had to come out, Mary never complained about any pain, either before or after the operation. She never fussed about having a tooth filled or pulled, nor did torturously tight braces on her teeth seem to bother her.

Two years ago, riding her bicycle, she was struck by a car. She picked herself up and pedaled home without a murmur, despite a concussion that kept her in bed for two weeks.

Dr. Reuben nodded as I recalled these incidents. "That's more like it. Your daughter has what's known as 'painsymbolia.'"

"It's considered very rare," he continued, "and no cure is known—in fact, even the exact cause is uncertain. Actually, it's not really harmful in itself. It's simply that your daughter is insensible to pain. Impossible as it may sound to you, she probably has never felt an ache or pain in her entire life."

"She's lucky," I said, vaguely feeling it was the wrong thing to say.

"Well, not entirely," the doctor replied.

"I examined a boy last month who'd had headaches for a year. Nothing had helped—new glasses, dental care, antibiotics—and the pains were worse than ever. I found a tumor the size of an egg inside his head. If it hadn't been removed, it would have killed him within a few weeks."

"Pain is nature's danger signal. Anything from a simple toothache to a pain in the chest will give you a chance to fix things before it's too late. But if you never felt any pain in the side—"

He didn't have to finish the frightful picture. Mary, incapable of feeling such warnings, wouldn't stand a chance!

"But it won't help to worry yourself sick over this," the doctor reassured me. "You must simply be aware of the dangers involved, and be constantly on the lookout for trouble. Believe me, whether you know it or not, those first 11 years were the hardest!"

Even now, several months later, I still find it hard to get used to looking for signs of trouble. But I realize all too well what the doctor meant when he said the first 11 years were the hardest. In other children with a similar condition, the result has usually been tragic—and most often during the first 7 or 8 years.

ILLUSTRATION BY RICHARD GREEN



The car struck Mary's bicycle, but, despite her injuries, she pedaled home without a murmur.

That's when a child is most active and careless. Even more frightening is the fact that this is the period when other children pose an overwhelming problem.

A doctor told me of a little boy of 5, brought to him in pitiful condition. Bones were broken in his left foot. Both arms were covered with blisters. There were cuts and bruises on his body.

His little friends had discovered he didn't cry when he cut himself or got hit by a stone. Fascinated, they stuck the boy with pins, pinched him till he was black and blue, burned his arms with matches. Finally, an older girl dropped a heavy stone on his foot. And because he was "different," he's going to be a cripple for life.

Since learning of her unique condition, Mary has become a "new person" to me. I used to think she was being stubborn when she didn't cry if we spanked her. And I often wondered how she and Alice could be so different. Mary always took Alice's howls of pain with what I thought was a "hard" indifference. "It doesn't hurt, what are you screaming about?" she'd say when they got injections.

Her condition also explains why she is so much more "daring" than her older sister. Mary will attempt anything—and usually excels in whatever she tries, particularly in sports. The rest of us are definitely on the cautious side. Now I realize that she has never felt our need of caution—because she's not afraid of being hurt the way we are.

MARY, OF COURSE, doesn't feel she's "different" from other children. Never having felt pain, it's as difficult for her to imagine what it's like as for someone born color-blind to imagine what "red" and "yellow" are. To Mary, things she touches, or that touch her, are hard or soft, smooth or rough, and so on. If she touches the point of a pin in the dark, she knows it's a point because it feels so small.

This was not at all clear to me until the doctor explained that the sense of "pain" is entirely different from that of "touch," that we have more than five senses—and that the

sense of "pain" is an extra one.

The cause of insensitivity to pain isn't yet known. But since the sense of pain is lacking all over her body, not just in a localized area, doctors believe the network of nerve fibers and endings is all right—that the trouble lies in some part of the brain itself.

I had never heard of "painsymbolia" before I met Dr. Reuben. But since then, strangely enough, cases keep cropping up. A doctor tells of a man who's been coming to him for years with this condition. An old friend suddenly remembers a relative who was "like that."

And, Dr. Reuben explained, many cases may pass unnoticed simply because the children die—often because of this very condition—before anyone is aware of it. That's why if a child of yours doesn't cry easily under conditions that would seem to be painful, don't decide he's just plain "stubborn" or "brave." It's not pleasant to find this condition in a loved one, but once the condition is recognized the risk can be considerably reduced.

Frequent and regular checkups are imperative, and they must be thorough. Teeth, ears, throat, lungs, heart—everything must be periodically checked to make sure a normally "painful" condition doesn't exist.

X rays will show whether any bones are splintered, or reveal hidden growths. And of course the family should take careful note of any unusual swellings, and see that a doctor examines them at once.

Today if Mary even hints that she isn't feeling just right, she goes to the doctor immediately for a blood count and checkup. He has warned us that to take chances is to gamble with her life.

Painlessness has its blessings as well as its dangers. Mary might easily live to be 90 and be very happy, as well as free from pain. While if she were "normal," she'd suffer pains which all the rest of us suffer in the normal course of living. So in spite of my concern for her, I sometimes wonder whether Mary didn't get the better part of the bargain.

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