

10-year-old's death 'no medical mystery'

Parents expect no surprises at inquest into daughter's death

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For a Thornhill couple, the bottom line in their 10-year-old daughter's unexplained death is no medical mystery.

Lisa Shore was admitted to Toronto's Hospital for Sick Children Oct. 21, 1998 to control chronic burning pain that had plagued her after breaking her leg six months earlier.

The syndrome — reflex sympathetic dystrophy — is rare and difficult to treat. But it's never been known to be fatal.

So why did Sharon and William Shore's little girl die?

"We took our child's life in our hands when we went there," Sharon said. "Did the hospital kill her? We think so. If we had kept her at home and not gone to the hospital, she would still be alive."

The Shores, who had been coping with their daughter's bouts of uncontrollable pain for months, are convinced of that.

But there's a greater mystery to be solved.

How could one of North America's foremost children's hospitals have failed their daughter so badly?

The Shores hope a coroner's inquest scheduled to begin in Toronto Nov. 8 goes a long way to answering that question.

Deputy Chief Coroner Dr. Jim Cairns will oversee the inquest, which is designed to find ways to prevent a similar death from occurring.

Officials at the Hospital for Sick Children will not comment on the case until the inquest is complete.

Sharon Shore wants hospital staff — especially nurses who cared for her daughter — to tell their stories publicly.

"It's going to be very difficult to live through, but it's something that we have to do," she said. "If we don't go through with the inquest, then it gets swept under the rug."

About a month after their daughter's shocking death, the Shores demanded hospital records, relying on friends in the medical

community to analyze them.

"As soon as we got the records, we knew right away there were serious problems," Shore said.

Shore, who stayed the night with Lisa in her hospital room, believes her daughter may have had an adverse drug reaction that went undetected because her vital signs weren't properly monitored.

Lisa died sometime after 2:15 a.m. — about the time her mother fell asleep.

"The doctor's orders to monitor weren't checked," she said. "At one point, her heart rate skyrocketed ... The number was marked down on the chart, but a doctor was never called in."

In hindsight, Shore wishes both she and her husband had stayed the night, taking shifts to keep a more watchful eye over Lisa.

"If I had a recommendation for other parents, I guess it would be that they take

shifts and not sleep — make sure that their children are watched," she said. "If only someone had told that to us."

By the time Lisa died at the hospital, she had grown leery of the medical community.

And it was little wonder.

The beginning of the end for the Thornhill girl started with a broken leg — a

typical childhood injury.

An extremely active little girl, Lisa had fractured her leg while playing in her school yard about six months before she died.

Two days after a full plaster cast was put on at North York General Hospital, Lisa's toes turned purple and she was tormented by intense leg pain.

The hospital replaced the plaster cast with one made of fiberglass. But the mysterious chronic burning pain continued.

"She would be screaming in pain. She was uncontrollable," Shore said. "You couldn't even talk to her."

The Shores' frustration continued when doctors at Sick Kids failed to diagnose the cause of their daughter's pain.

Instead, they recommended psychological counselling, suggesting Lisa's pain "was all in her head".

"We never really had confidence in them from the beginning," Shore said from her Thornhill home last week. "It was deplorable — to say it was all in her head, that she was making it all up."

It wasn't until three months after Lisa had broken her leg that the Shores discov-





STAFF PHOTOS/SJOERD WITTEVEEN

William and Sharon Shore (above) stand in their daughter Lisa's (inset) bedroom, where the 10-year-old's school desk (left) sits with its top decorated with messages from her classmates.

ered the cause of their daughter's excruciating pain.

But it took a trip to Boston's Children's Hospital and \$20,000 in medical expenses to learn the truth. (OHIP refused to pay the medical bill, a decision the Shores are now appealing.) Doctors in Boston quickly ruled out a psychological cause for the pain and diagnosed reflex sympathetic dystrophy.

"They did it very, very quickly and very clearly," Sharon said. "They were able to tell us when it started and how it started."

The rare condition, which affects the sympathetic nervous system, often starts with a minor injury such as a fracture or a sprain.

An American medical organization, the National Institute of Neurological Disorders, states the syndrome is often misdiagnosed because it remains poorly understood.

"While many physicians previously thought that RSD was caused by emotional disturbances, they now agree that emotional problems arise from the physical limitations caused by RSD."

Unfortunately, some sufferers are tagged as complainers by family and friends and even their physicians.

Doctors in Boston were able to treat Lisa's pain by using "blocking compounds".

But when Lisa returned to Thornhill, she began to have relapses.

By this time, physicians in Boston had spoken with doctors at Sick Kids to confirm Lisa's condition.

Shore said although Toronto doctors now knew what was causing Lisa's pain, they attempted to control it with morphine.

Treatments can include local anesthetics, electrical stimulation and sometimes surgery.

"Morphine doesn't help with this," Shore said. "The morphine may have been way too much, given the other medications she was on."

Lisa's death has devastated the Shores and their two sons Devon, 10, and Aron, 7.

"It was especially hard on Devon because they were so close," Sharon said.

Sharon has found some personal therapy by developing a website for Lisa (www.lisashore.com).

It highlights Lisa, as well as the rare syndrome that inadvertently led to her death.

"She would have grown up to make a real difference in this world," her mother said. "She was the sweetest person. Little kids in the neighbourhood would come over just to play with her and her art teacher called her a peacemaker."