

## Managing Epilepsy in Your Children: One Parent's Perspective

by Mary Jo Hebert

When my children were young and learning to walk, I tried to remove every potential danger in their way. Drawers and cabinets were padlocked, stairways were securely gated, and every electrical outlet sported a protective cap. It was ages before our coffee table ever saw another cup of hot coffee. Over time, however, as with all parents, I was forced to acknowledge my limitations. There isn't enough padding in the world to soften every one of life's sharp edges.

Parents worry about their children. It's only natural. But when one of those children has a seizure disorder, a parent's inclination to worry never ends. And because seizures affect not just one person, but the entire family, those concerns spill over to siblings as well. My husband and I have three children: Andrew, 21, Nicholas, 18, and Louis, 13. Louis is developmentally disabled. He also has a seizure disorder.

For most of his young life, Louis's seizures had been well controlled. At 13, though, all of that changed. Adolescence had awakened in Louis a sleeping giant. Furthermore, what he had lacked in number of seizures over the years, he was more than making up for now with the duration and intensity of these new seizures. The unopened box of Diastat that had done nothing more than collect dust over the years, was now our single defense against a prolonged seizure. The problem was that none of us had any experience using it, least of all his then 17-year-old brother Nick.

When I answered my cell phone late one afternoon, something in Nick's voice told me that this was not his usual after school call inquiring about what's for dinner. The words came out in a hurry, controlled panic just under the surface, "Mom, Louis is acting strange. I think he's going to have a seizure. He's really scaring me."

The timing could not have been worse. The very next day, at precisely the same time a seizure was about to begin, Liz Foster, the Nurse Educator from the Epilepsy Foundation, was scheduled to meet with our family to discuss the use of Diastat. But all of that would have to wait now. Nick was home alone with his brother who was about to have a seizure, and training or no training, it would be up to him to handle it.

"Lie him down on his side. I'm on my way," was all I managed to get out before my signal faded and the line went dead. I was still a good 10 minutes from home. Whatever was going to happen was likely to happen before I got there. Sitting alone in my car, I felt utterly powerless and disconnected from the crisis that was unfolding at home.

Louis would be all right, I reassured myself. He was in a safe place. Emergency help was just a phone call away. The seizure would end. But who would support Nick? If this seizure was like the one before it, it could last well over ten minutes, and it would be up to him to intervene to try and stop it. Nick had always been his brother's greatest friend and strongest advocate. I knew that there was nothing in the world that he would not do for his brother. But managing a prolonged seizure alone was a frightening experience even for the most experienced. Would he

remember the medicine and be confident enough to use it? How would he get through it?

By the time I arrived home several minutes later, the emergency personnel that Nick summoned had arrived. I walked in to find Nick reporting to the paramedic that he had made sure that his brother was safe before running upstairs to get the Diastat. After waiting some time for the seizure to end, he said, he administered the medicine "just like it showed in the picture." Several minutes later, the seizure came to an end. "I took off his shoes, too, Mom," he offered. "I thought that would be a good thing." I told him that everything he had done was a good thing and thanked him for doing all that he could to help his brother.

A parent's desire to protect their children does not change over time. What does change is that, as the kids grow older, the stakes grow higher. Concern over teenagers who drive too fast or cars that speed around corners replace earlier concerns over the sharp edge of a table or a long open staircase. There is not one thing in the world that I would not do to protect my children. But there is one thing in the world that I cannot do to protect them – I cannot stop life from happening. I cannot separate the good from the bad, the hardship from the joy, the struggle from the triumph. And perhaps, in the end, there is no need to.

In an unlikely coincidence, Nick's girlfriend, Ashley, had a medical emergency of her own that day. After suffering a severe allergic reaction, Ashley's mother was taken by ambulance to the hospital. Hysterical, Ashley called Nick from her car phone. From down the hall, I could hear Nick's voice, strong, steady and reassuring. "She'll be all right," he said. "You are doing everything you can. There will be people who will help her." He spoke with confidence and authority. He had earned the right to.

Later that night when opening the door to Louis's bedroom, I discovered that Nick had prepared a surprise for his brother. In a stunning gesture of thoughtfulness, Nick had tied brightly colored helium balloons around Louis's bed. Messages like *tomorrow will be a better day* and *hang in there* danced high above the bed's frame. Louis, exhausted from his long day, appeared not to notice the spectacular display. But make no mistake about it. Nick's efforts were not wasted on me.

For me, those balloons carried one message more – high above our children's fear floats an enormous potential for courage. Courage to act. Courage to take charge. Courage to do what needs to be done. Within many families, the same brothers and sisters who toss a ball or tickle a rib can also dial 911 or time a seizure. Within our family, the hands that tie balloons to bedposts are the same hands that administer medicine in an emergency. They are capable hands. They are Nick's hands – the hands of brotherly love.

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