

Autism and Hospitals: A Difficult Match

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As a resident, you always have that one patient who sticks out in your mind—the one who had some profound impact on your practice of medicine and your life outside of medicine. For me, though, it wasn't just one patient. It was one patient after another with the same challenge: autism. Having worked in the school system before medical school, I immediately recognized what was missing in the way physicians and the medical establishment approached children with autism. The hospital staff had no real understanding of these children and how their worlds worked. I first met Billy's mother on a crisp spring afternoon. I had been thinking about and searching for a way to provide the best care for children with autism when in the hospital. I wanted to hear what Eve, the mother of a young man with autism, thought about the issue. The following is Eve's story, in her own words.

Search-and-find missions are always wrought with unknown dangers. Billy's colonoscopy is complete and Dr D tells us to follow the nurse and attendants who maneuver the bed Billy lies in down the hall. We walk briskly to be next to our son's quiet body. In anticipation that Billy may grab and pull out the IV, his left arm is heavily bandaged like a cast. As we enter the intensive pediatric care unit, Matt and I are stopped immediately by a woman who identifies herself as the attending doctor. In a polite but curt tone, she informs us that we must wait outside the intensive care unit while the medical team situates Billy in his new room. We now enter a new and uncharted territory: a new department with new personnel, new rules, and limited knowledge about autism or Billy. Understandably, the medical team views Billy as a patient. But this 20-year-old young man has autism and a communication system that demands translation. In those short, precious seconds before the door closes and

separates us from Billy, Matt and I try to impress upon the doctor how extraneous noise, light, human movement, and the absence of a communication partner could sabotage the medical objective of completing a virtual endoscopy and that it would be prudent for us to escort Billy. The doctor, however, is not listening and has no questions, only directives. The doors slide closed, and Billy is whisked away.

The medical staff overseeing our son's case informs us that we must follow their protocol regardless of the fallout. This is the policy. But we are not the norm. In those few minutes, while we are barred from being with Billy, I know that even if he only semiwakens, the staff's medical experience will not equip them with the knowledge of how to proceed. Instead, an emergency will unfold as, bewildered and alone, Billy will use his free arm and hand to remove all foreign attachments, tape, and gauze from his body. Physical restraint and medication will likely preempt any effort to communicate because no one knows his language system. This is my nightmare. As these thoughts race through my mind, the nurse arrives and accompanies Matt and me to his room. My instincts are on high alert, and a brief snapshot view of the room compels me to direct. As the autism conductor, I fire out orders. "Close the blinds." "Dim the lights." "Speak softly or not at all." Pediatric intensive care protocol and routine procedures are about to careen into the equally gridiron world of autism. Despite all the drugs, Billy fights to wake up and take charge of his body. The staff do not understand his larger-than-life tenacity. Our immediate task is to keep Billy calm so that he will lie still for hours as the pellet passes through his lower intestinal tract. Despite my instructions, the nurses adjust his bed, reconnect the IV, and move back and forth through the flapping curtain. They act as Billy's wake-up call. No matter what potency, type, or variation of sedative administered, adrenaline surges through Billy's body.

Billy knows. His senses are not dulled but sharpened by the noise, the lights, and the pressure of the mounds of tape on his arm and chest. This is not going as planned. With every passing hour, different doctors, different specialists peer in, concerned and perplexed by what they observe. Matt and the nurse stand on one side of the hospital bed

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and I stand on the other side. Our hands are placed on Billy's chest and arms. We are not there to comfort Billy. We are there to restrain him while every 20 seconds his upper body struggles to rise and break our tackle.

We are his silent tormentors. Intimidation by force is the real sedative. Alert, Billy resists this assault continuously for 4 hours. With almost supernatural concentration, Billy waits to make his move. If the nurse leaves to update the chart or turns around to answer the anesthesiologist's question, Billy surges forward. If I leave for a restroom break or if Matt momentarily relaxes his hold on Billy's arm, Billy struggles to make a break. It is relentless. Into the third hour, my lower back aches and my feet are leaden; I just want to get the reading. This cannot fail. The cost is too high and we need answers. We need information.

But I am angry. Sedation was supposed to avoid this emotional catastrophe. A concerned doctor starts to order another sedative to add to the existing cocktail and I yell out, "No more!" I will not subject Billy to any more attempts to lure him into twilight sedation. The damage is done.

In the fourth hour, they complete the readings. The mission is complete. No longer a hostage, Billy sits up and with speed and dexterity removes all the tape, pads, and wires, as well as the needle from his vein. Blood pulses out, and Billy refuses the nurse's attempt to place a gauze pad on his vein. Billy's blood colors the white sheets and his T-shirt. Infuriated and betrayed, Billy looks at Matt and hits him on the head. Power, remorse, humiliation, and an incendiary rage blanket his face. Matt holds Billy back and gently says "no." We feel obliged to reassure the nurse that all is well, and Matt and I thank her for her exceptional help. She tells us to take our time. Billy can stay as long as he needs.

We are alone. It is dusk. The light softens outside the large square glass window. Billy sits on a built-in alcove

vinyl seat that nearly spans the length of the wall. I give Billy a pillow and our green afghan. We encourage him to rest, but he will not. Instead, he rails against what he doesn't understand. His wails are loud and deep. Matt and I silently ache. But Billy does not seek retribution. He seeks closure, and understanding. Sitting up on the bench, facing us but intently focused on his communication device, Billy replays his hospital experience over and over and over. He presses "hospital," "colonoscopy," and then he stops, cries and quivers, and begins the dirge again. Matt and I stand in a hospital room next to a bed of blood-spattered, tangled sheets and a grieving son, but we know we are blessed.

Billy does not avert his penetrating focus from the breach of trust that happened in this hospital room. No one ever told him what would take place after the colonoscopy. We had been assured that Billy would remain sedated and thus relaxed as the pellet passed through his lower intestine and the x-rays were taken. By all accounts, this medical process would be seamless. That was the plan. It didn't happen that way. Sitting on the bench, Billy faces the truth as he reviews the information on his device and evaluates the information he never received. As dusk becomes night, we cannot comprehend wholly what had occurred for Billy, for us, and for our family's humanity.

Several hours pass, and it is now evening. The doctors and nurses have gone home or are attending to other patients. We are alone. Billy stands up from the bench. We are all ready to go home. In a line of three, Billy, Matt, and I walk around the interior corridor of the pediatric intensive care unit. With his communication device strapped around his neck, Billy is composed and resolute as he walks straight ahead. As we exit, I turn my head, nod, and smile briefly at the doctors who watch our dignified procession move out the sliding doors. Billy is a class act.