

The Most Memorable One



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I SHOULD HAVE told this story 25 years ago, during the final morning report of my internal medicine–pediatrics residency. Our medicine attending had asked us to share our most memorable case. After scanning my memory, I selected a fascinoma—the story of an elderly woman with profuse diarrhea who turned out to have a vasoactive peptide-secreting pancreatic neuroendocrine tumor or “VIPoma.” After a long diagnostic workup, our hospital team had been amazed to discover she truly had this rare condition, which I have seen only once, in that patient. Partway through describing her medical course, I felt a tugging inside, and the name of a young child bubbled up in my memory, followed by a series of vivid images from his hospitalization. I continued to tell the story I’d started, now with the uncomfortable realization that I was recounting an unusual medical case, whereas if I was the humanistic physician I aspired to be, I would be speaking about the most important human experience of residency. It was my very last day of training, and I had missed the boat. So, here I am, years later, hoping to correct that mistake.

Liam* was a 4-year-old boy with a sunny face and a loveable personality and the third youngest child in a family of 5 or 6 kids. He had some mild intellectual challenges but was otherwise healthy and full of life. His father and mother each told me, independently, that Liam had become the “favorite” child in the family because of his winsome disposition and because he needed a little extra help. They explained they’d had to work harder to help him grow up, and this had brought them closer to him. He had taught them that caring for kids with special needs can reveal a special kind of love to their families. Although I’d never previously thought about this, their words felt genuine, and ever since, as I have gotten to know families with children facing unique challenges, they have often shared with me that the slowing down, patience, acceptance, and appreciation of small wins that come with caring for these kids can help families broaden and deepen their understanding of love. Many parents have described this discovery as a kind of gift from a higher power, as did Liam’s parents.

One afternoon, when one of his older sisters was playing with him and carrying him on her back, she lost her balance and dropped Liam on his head, from a height of what could have only been 1 or 2 feet, the same height from which countless kids are accidentally dropped countless times every day all over the world. He got up and continued to play but soon after developed a headache and then became lethargic. Observing these changes, his family brought him promptly to the emergency department. Before long, he was comatose, intubated, connected to a ventilator, and hanging on to life itself. His computed tomography scan showed no internal bleeding but massive swelling of his brain. He had suffered delayed cerebral edema and fatal coma after minor head trauma, a rare but recognized condition affecting children and adolescents that no one has fully explained.

The pressure inside Liam’s skull continued to increase despite all known medical interventions, and over the following day became so high that he herniated his swollen brain. We feared he had slipped into the strange medical limbo of brain death in which his brain had ceased to function while some organs were kept alive by the machines in the pediatric intensive care unit. I watched the pediatric neurologist conduct the electroencephalogram required to make a diagnosis of brain death, and as she showed me the absence of electrical activity in that young child’s brain, it left a deep impression. It was the first time I had personally witnessed this transition from life to death in a healthy child.

Sensing my connection to Liam’s family, the pediatric intensive care unit attending invited me to explain the electroencephalogram results to the mother and father, a kind of professional compliment in a setting of utter sorrow. The parents, holding one another, took in this news without altering the expressions on their faces, asked the obvious questions about the certainty of the testing, and shook their heads in complete disbelief. Then we all began to cry, including the attending who silently reached beneath his glasses to wipe the corners of his eyes. I was unable to contain my tears and hoped they would somehow help the parents understand that I really cared and

was trying as hard as I could to imagine being in their place. Alongside my hope to support them, no doubt, lay an unspoken terrified and superstitious plea: “What must I do to be spared such agony?”

Liam was not a candidate for organ donation, because his was a coroner’s case, or perhaps for religious reasons; I do not recall. What I remember vividly was working with the parents to set a time to discontinue life support and developing a plan to bring in the extended family to say goodbye to him. His mother produced a large photo album filled with pictures of her vivacious and beautiful children, including our Liam, engaging in all the normal activities of childhood. She wanted us to know her son as he had been in life so we would have a taste of this precious gift God had given to their family, and then taken away so suddenly and mysteriously, in the mother’s words.

The parents left to prepare their family. I sat with Liam and his machines and tried to imagine this little boy as the one in the pictures. Sometime later, more than a dozen people entered the pediatric intensive care unit and filed into his room, including his siblings, all washed, combed, and dressed as though heading to church, along with grandparents, cousins, aunts, and uncles. Their priest accompanied them. I peered in from just outside the door. They surrounded Liam and his machines and took a final family snapshot. It was the first time I had seen a family photograph themselves with a patient on a ventilator, much less a child who had experienced brain death. I was overwhelmed by a sense of curiosity, fear, offense at this sacrilege, respect for the seminal moments in a family’s history, admiration, and voyeurism all at the same time. I glanced at the sister who had been piggybacking Liam when he fell. Her face bore a stunned, ashen, fearful expression that was quite distinctive, and I felt a deep surge of pain for that child. What I also remember vividly was that every single person in the room kept it together, first while the photograph was being taken, and then as the priest calmly administered last rites to Liam. Then he bid goodbye to the family and left the room. Once out of their sight, his face lost its composure and contorted into an expression of grief, revealing just how shaken he was. At that instant, as though on command, everyone burst into tears, with the wails of the children rising poignantly above all the others. Perhaps the parents had directed their kids to behave as though in church or at a photo studio, and when those instructions expired, their emotions poured forth like water from a fire hydrant. The family

remained as the machines were turned off. Liam was disconnected from the ventilator, and his body became as lifeless as his mind. It was one of the saddest and purest moments I can remember in the many remarkable experiences that inevitably occur during medical training and thereafter.

Little Liam left many lessons. His parents taught me about the extra love a special child can require and bring to a family. I discovered the cruel serendipity that a single small blow to a random skull on a random day can carry a healthy child to the brink of death in a few short hours. I was reminded that life is fragile and can move from robust engagement to hanging by a thread in a matter of moments.

I cannot recall discussing this profound experience with anyone in my work or personal life at the time it happened. Training teaches us to keep moving, and yet so many experiences, like Liam’s death, present powerful learning and emotions that ask to be explored, internalized, and taken to other patients and families.^{1,2} Perhaps this kind of yearning or need led the story to resurface on that last day of training when asked to present my most memorable case. Today, Liam’s tale reminds me to set aside petty concerns, laugh with my patients, hug my husband and children and friends as often as possible, focus on constructive acts, thoughts, and emotions, and work toward peace and reconciliation in these divisive times.

There. I have shared my most memorable story from residency. Perhaps it was wise to wait all these years, for, despite the passage of time and viewed through the lenses of countless other losses and lessons, the story of the life and death of this one little boy continues to resonate with a special clarity.

*Author’s note: Names and details have been altered to protect identities while striving to convey a genuine sense of this experience.

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REFERENCES

1. Vohra S. Learning to not move forward. *JAMA*. 2014;312:2215–2216.
2. Clay AS, Ross E, Chudgar SM, et al. The emotions of graduating medical students about prior patient care experiences. *Patient Educ Couns*. 2015;98:344–349.