

Living Through Traumatic Brain Injury

By

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The reality is...every family's experience with traumatic brain injury (TBI) is unique, depending on the specific circumstances and severity of the injury, immediate and long-term medical care, rehabilitation services, and the individual patient and family. But one thing is certain—TBI changes every member of a family. How families choose to react is the only thing that is in their power.

Our thirteen-year-old son, Paul, was struck by an SUV while riding his bike. He was not wearing a bike helmet and suffered severe trauma to his brain. In the emergency room, our son, not expected to live, was given last rites.

How do parents comprehend or cope with the possible death of their child or possible lingering deficits from such a traumatic injury? From our family's experience, I can say there is no way to understand or comprehend the **unthinkable**. Never, ever, could we have anticipated being in an intensive care unit, hearing the labored noise of the ventilator that kept our son alive. The wires, needles, tubes, and machines everywhere. Our son lying motionless, completely immobile. Never, ever, could we have imagined weakly standing there, our lives on hold, our lives in distress, our lives uncertain. Praying, praying for our son's eyes to open after weeks and weeks of him being in a coma. A coma...? We thought that sort of drama and suffering happened only in movies and books, but the reality was that it was our son on a hospital bed, decomposing right in front of us. We were helpless to help him.

Thoughts of "Why me? Why our child? Why did this happen?" ran through my head constantly. I knew these were normal responses to the possible death of our son, but if Paul did survive, it was inconceivable to accept the possibility that he could have permanent disabilities—loss of eyesight or hearing, or not being able to walk or speak, or maybe not even knowing his family.

My husband and I were totally unaware that TBI is more prevalent in the United States than breast cancer, HIV, multiple sclerosis, and spinal cord injuries. Every 23 seconds, someone suffers a TBI. It is the leading cause of death and disability for people between 15 and 24 years old. Educating ourselves on our son's diagnosis and learning more about this silent epidemic almost took hope away from my husband and I. But we refused to give in to the insanity of the situation, possibly in denial, staying by our son's side, hoping for a miracle. When Paul's eyes finally did open, we were ecstatic, but our euphoria was momentary as we realized our son could not speak, walk, or comprehend where he was or what had happened to him. We had no idea that we would soon be taking our son to a rehabilitation hospital (Franciscan's Hospital for Children) for long-term healing and therapy after therapy after therapy. We also had no idea how this would affect our marriage or our other seven children, who waited with both great anticipation and fear to see how their brother would fare.

I think most families are at a loss as to how to react to what may seem like insurmountable circumstances, especially if their child does not seem to be making much, if any, progress. I was no different. After the crash, I remember feeling isolated, lonely, and exhausted all the time. Bouts of anger and frustration surfaced. It was very hard to accept that recovery may be lifelong and that the person we knew may never be returned to us. We tried to remain hopeful, nurturing not only Paul, but ourselves and our other children the best that we could. We surrounded ourselves with positive people, hoping and trusting not only that the therapists would help Paul heal, but also that Paul himself would have the strength, the ability, and the willpower to succeed.

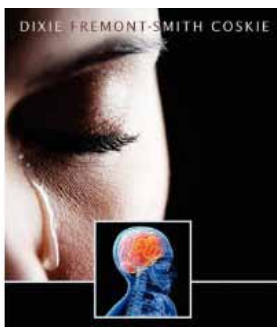
Brain injury does not go away. However, depending on the injury and with proper treatments and therapies, victims can at times progress and improve. My husband and I tried to keep hope alive, praying Paul would not "plateau" in his recovery. We celebrated any milestone: first time speaking, moving a finger, making eye contact, first time in a wheel chair... We advocated for our son's needs and the needs of our family, realizing it was not a weakness to know our limits and to ask for help. We also knew it was important to honor our other children's views of the situation and the process by which they had coped (to whatever degree) with the staggering changes we were all experiencing. We offered them support groups, counseling, and more informal ways to vent and share their thoughts and fears. We kept reminding ourselves that Paul was making progress, even if his gains were only incremental, and

we kept believing that he would one day be able to live a “productive” life. We kept pushing and fighting, knowing that Paul was one of the lucky ones—he was a miracle in progress. Through years and years of occupational, speech, and physical therapies, Paul regained enough movement, balance, and coordination to no longer need his wheelchair. Then he no longer needed his walker. And eventually, he was able to take steps that doctors had deemed impossible, walking independently to the podium to receive his high-school diploma.

At some point in life, everyone must face grief, suffering, and death. The only thing anyone can control is how they react to the events of life, including tragedies. Our family’s harrowing journey through TBI has led us to perceive life differently, knowing that no one is invincible and that everyone—despite any perceived or real disabilities—matters and is special! We have all come to know that family comes first and to never take anyone for granted. We now realize that grief changes and passes. After the fear, we emerged wearing an armor of faith, perseverance, and learned strength and determination. We try to live each day with meaning, integrity, thanksgiving, a sense of humor, and a lot of love.



THE
LIME
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Book Review



Unthinkable

A Mother’s Tragedy, Terror, and Triumph Through A Child’s
Traumatic Brain Injury
by
Dixie Coskie

Review by Sally Huggett

This was a book I could not put down. It should be read by every parent and every health professional. Dixie manages to capture with true passion what it is like to be a parent, and what it is like to be a parent of a child who suddenly has special needs. Health professionals would learn exactly what it is like from the parents’ point of view when a child is rushed into the emergency room and their life hangs in the balance. Having worked in the NHS myself for 14 years I know too well that we can focus on the job in hand and forget to care for the relatives. This is a fundamental aspect of holistic patient care. I love the way that Dixie shares with us her innermost private thoughts at the time she had them, by way of intertwining excerpts from her journal that she kept once her son had his accident. She makes it okay for us parents in similar positions to scream the question ‘Why??’. She explains the stages of grief, whilst reminding us that there is no prescribed right or wrong way, but that we may experience denial, anger, depression and finally acceptance. Of course, some of us may take longer than others to reach the acceptance phase. One useful aspect of Dixie’s book is that she writes ‘Tips’ for parents to follow. So this book is not only a heartfelt description of a mother and her family’s tragic journey, but it is also a practical resource. When reading this book you feel a deep connection to Dixie. You want to be with her and chat to her and give her a big hug. You want to visit her family and tell them how wonderfully they rallied round and made everything continue to work when their lives were in turmoil. So it is wonderful news when you read on and find out that Paul makes a good recovery, that he learns to walk again, that he has fun with his OT, and that he returns to school. Dixie finally feels her work is done, that all her children are in school and doing well, and she can take a breath and take up a hobby. Then we hear the wonderful news at the close of the book that you will have to buy the book to find out ...