

# IMPACT

By

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Author - *Unthinkable: A Mother's Tragedy, Terror, and Triumph through a Child's Traumatic Brain Injury*

Five years of confusion, helplessness, and torment stung my nerves as I saw familiar terror in my daughter's eyes. I knew she was about to reveal something horrific. And finally, as the sobs escaped, she told me. Four of her closest friends had just been in a car crash.

They had been returning from a carefree day at the beach when their car lost control, flipped over and rolled down an embankment, which forced three of the teenagers through the windshield. Only the one wearing a seatbelt was not hurt.

She paused to take a long breath and I urgently asked, "How serious is it?"

Her voice cracked, "Not good. I heard James is in a coma." Breaking away from me, she began to pound the keyboard, instant messaging anyone that she could. As she hysterically typed, I asked questions, "Were they drinking? Speeding? Who was driving?"

"I don't know, Mom," she said, "But I almost went with them today." I quickly pulled her close to me. As I did, my mind flashed back to the day when our lives were forever changed. The moment when my thirteen year old son was struck by a car while riding his bicycle. He had not been wearing a helmet and suffered a severe head injury. I thought the wounds were starting to heal. But my daughter's frightened eyes had ripped through the scars.

Immediately my thoughts shifted to the mother of the injured boy. I didn't know this woman, but I understood her. I understood her anguish. Her confusion. Her loss. I knew it all too well. I wanted to find this mother and shield her from the horrors of brain injury.

You can't console a parent in crisis; the numbness that comes with trauma coats everything. And yet, reflecting on the images of my son Paul, lying in a coma, the only noise from the ventilator to aid his labored breathing, I remembered when the chilling realization hit me: even if he did survive, he possibly could be deformed, handicapped or impaired.

I instinctively wanted to phone James' parents. I wanted them to know they weren't alone. But knowing the chaos, the protective barrier that comes with crisis, I didn't. I knew they were trying to grasp the medical realities, demanding answers from the

doctors, doing anything they could think to improve their son's chances of survival. I knew they were inconsolable because I was inconsolable then, too. There is a powerlessness you feel when you see the child you brought into the world lying defenseless on a hospital table.

My husband, Steven, and I stayed by our son's bed side in shifts. One of us at the hospital, the other at home with our son's six siblings, allowing them to cry, and to ask questions, giving them whatever information we could in an effort to ease their grief. Occasionally we even timidly talked about life and death. When reality overwhelmed us, we simply prayed for Paul to live, to heal, and not to have any lasting repercussions.

Two months after our son's crash, Paul's eyes finally blinked open. He could not walk or talk or even remember who he was. With help from therapists, his family, and his self-determination and perseverance surfacing, he fought through days, months and years of rigorous physical, occupational and speech therapies. Today his efforts have paid off. My son Paul walks off-balance, but it is a blessing he is walking at all. His voice is slow and monotone, but the fact that he can respond and speak is amazing. Cognitively, his brain may move slightly slower, but it is beyond belief that he interacts with maturity, humor, and intellect. The left side of his body shakes due to ataxia, making it hard for him to accomplish simple tasks we all take for granted, but the reality that he is not paralyzed is miraculous. Paul has been on the honor roll and graduated from high school. He works full time, and his hobbies include paintball, golf and even bike riding. Nine years after our son was given last rites, we still see slight, incremental improvements, all of which have redefined what hope means to us.

I was told James had awoken. His mind was in a haze, but he was gaining more movement with his limbs. To my surprise, his mother phoned me – searching for guidance, reaching for support, telling me the intensive care administrators were suggesting sending her son to a rehabilitation hospital. Tears brimmed over and I tried to compose myself. I didn't know this woman, but our connection was real. I felt the relief in her voice that her son was alive, but I also sensed her fear, not knowing the future and the quality of life that James would lead.

Gripping the phone I said, "Connie, I know your uncertainty, but this is good news, the doctors have stabilized your son, now a rehabilitation hospital can begin to get his body moving again."

Hesitantly, she responded, "What if he remains in a catatonic state?"

Knowing she was fragile and on the brink of collapse, I spoke softly, reassuringly, "You're moving forward to help him to heal, there's hope."

Putting the phone down, I felt hidden emotions and images surfacing. Everything came back at once. Cradling my son's body on the cold dark pavement. The blaring ambulance, the helicopter ride, and the doctors stating, "Paul may not survive the hour or the next twenty four." I experienced the same fear I felt when I watched my child hooked up to

tubes, wires and a ventilator. And suddenly, my body began to tremble as I recalled the horror we faced whether to take Paul off life-support. And I remembered with shock, the uncertainty of when we eventually arrived at the rehabilitation hospital, seeing children disabled from birth, or accidents- and I remembered the physical therapy rooms, and the grueling days and nights fighting to gain back what was taken from Paul on that fateful day of the crash.

These parents didn't know the up hill journey and repercussions they would be facing, but I did. I wanted to spare them all of the grief my husband and I had gone through, but I had to keep reminding myself that there is no way to accelerate or soften the healing process. I wondered how they would cope, knowing the despair and agony they would witness. I wondered if they had it in them, to not give up.

The other piece of the equation, of course, is how would their son cope? We watched as my son Paul began to regain use of his limbs, and basic cognitive judgment skills. We encouraged him as he learned to sit up, roll over and to take steps. All the while waiting for the day he'd try to form thoughts, to process information, to speak. We were beside him reaffirming that he would get better as his brain sparked, sputtered, and played a cruel game of hide and seek.

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Months later, another phone call from James' mother revealed the same type of devastation I too had faced. Her son had maxed out his therapy benefits and her insurance company would no longer pay for therapies at the rehabilitation hospital. A decision had to be made whether to bring her son home, far from fully recovered, or send him to a residential educational setting.

Again her sorrow was evident as she whispered, "I know we haven't met, but I have heard bits and pieces about your son's recovery...what should I do, how can I best help my son?"

I said, "Every head injury and recovery is unique." I simply told her the decision boiled down to this: A) Bring him to a nursing home, and there is little chance he will advance in his recovery. B) Bring him home, be his sole caregiver, and fight through the special education bureaucracy at his local school. Or, C) Admit him to a boarding school or program with expertise in brain injury rehabilitation.

She was shocked when I again suggested the latter. But knowing the realities of bringing a brain injured child home, I somehow wanted to make sure she was making informed decisions that could best help her son in his recovery process.

Mentioning my experience, I told her we interviewed other facilities and spent hours with school administrators. Our instinct was to return our son to public school, with special assistance. At that point, our son was struggling just to remember "2+2 = 4." We needed to start a special program to help Paul relearn simple math, history, and English in a quiet

room. We searched for a personal aide to help reinforce his studies and to help him physically move through the crowded hallways. Due to Paul's lack of concentration and double vision, Paul listened to books on tape. A computer helped with his lack of motor skills and gave him a tool to write. We blocked out time on his school schedule so he could work with physical, occupational and speech therapists. And, his afternoons were spent, working with weights, cognitive workbooks, and swimming in the therapeutic pool, struggling to get better at a rehabilitation facility twenty minutes from our home.

Connie hesitantly said, "I want to bring my son home, but I'm not sure if I can cope with all the changes or what I'm up against."

Back then, to look at Paul some would have thought my son should be attending one of those schools for the physically and mentally challenged. Stubbornly my family saw him as challenged, but not handicapped. We wanted to see beyond his mangled body and mind; hoping for endless possibilities. Never having faced such a situation before, we stuck to faith – a faith adjusted to the situation at hand. We sacrificed our own needs and wants, wanting to surround Paul with the love he had always known. Paul sacrificed and endured too. He did not slip backward or plateau; he fought—like an athlete training for the Olympics.

Surprisingly, Paul recovered enough to be reintegrated into "regular class rooms" in a wheelchair. Not all head injury victims are as lucky, and I did not want to give this mother false expectations. But I shared with her that after months and years of heartache and struggle, Paul amazed his family, his teachers and fellow students when he walked to receive his High School diploma, taking steps doctors thought were not possible. Whistles, screams, tears, a standing ovation and Paul's smile had overpowered the room. Reflecting on this, I realized what to say to this mother; I knew I didn't have all the answers. I could only tell her from my experience. If she chose to bring her son home, be prepared for mood swings, anger, confusion, and the loss of independence. There would be a lot of driving to and from therapy sessions. And to be prepared that her marriage and her other children's needs would be placed on a back burner. She needed to know she probably would have late dinners, piles of undone laundry, and the gnawing gut feeling that no matter how hard she kept trying to get him better, it would feel like it was never enough. Then I said to this mother, whose grief and sorrow I connected with so tragically, "The important thing is this – choose what you think you can handle, and where you think your son can best recover – and then don't give up. Never, ever, ever give up. Pray and hope." I added, "For hope is what keeps the spirit alive and our souls in motion."

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