Just a Breath Away

STREAMS OF THOUGHT FROM A SEVERE TRAUMATIC BRAIN INJURY SURVIVOR

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I dedicate this book to my husband, Galen: my rock, my hero, my greatest love—then, now and forever. It was for him I clung to life; my old man, my sweet, saving grace. He swept me off my feet when I met him, all nineteen years of him. In those beautiful eyes, I saw truth. And for the first time I saw real love. I knew it in that instant: he's my "Forever Man," my soulmate.

It was the time of rebirth and discovery,

When hope and vision became a reality.

Through Him, all things are possible.

—KATHLEEN NEWHOUSE

Preface by the Author

Some of the names and locations in this book have been changed. The statements in this book reflect my opinions and views only.

This is my memoir. My sole intention in writing it has been to reconstruct and reclaim influential life-events in spite of the cognitive decimation my severe traumatic brain injury (STBI) has inflicted within me. As I document my journey, I am reflecting on my unique mode of recollection along the way. My interpretations and their accompanying emotions are only my own in these pages.

I understand that my recollection of the events in this narrative may be different from other people's memories of the same events. I am well aware that my perception of the facts may or may not seem entirely "accurate" to everyone. In many ways, the words in this book collectively demonstrate how my "STBI mind" interprets things today.

My words are in no way written with the intention to criticize or hurt anybody in any way. Likewise, every party involved in this book's production regrets any unintentional harm that may result from its publishing and marketing.

"She Will Never Be Found"

Treat the entire life, the entire person. It is proven: recovery extends far beyond the physical damage. It's the psychological effect that goes unseen, and far beyond survival. It involves tremendous strength, daily endeavoring, to pick up the pieces of a life that may never return.

Just to heal is a daily chore. Every box opened is a morning, unexpected. How do you prepare for something you don't understand? Something you can't see, nor have the consciousness to observe in yourself? How does one cope with the unknown?

Frightened and lost, most of the time, my brain is in a constant state of dizziness, confusion. In a drunken state nearly every waking moment. What does it mean to feel "normal?" Exactly what is this "normal?" Who sets the standards for it?

See the world as a survivor. Feel the effects of sound from another perspective. Few show on the outside, the physical side. They're undetectable at times. Our worlds only intersect at intervals, unknown. We touch wings, slightly, as each of us try to see the Other.

The life, STBI Survival is a family event. It's a never-ending, all-encompassing, world without escape. It affects each and every person you know and love. And without discrimination.

Inside broken skulls lie the same cells, the same lost dreams, same forgotten pleasures. Year after year, the search continues for the Lost One, yet no one has the heart to tell her that She will never be found.

—KATHLEEN NEWHOUSE

Introduction

I WROTE THIS MEMOIR to reassemble my history. I've written this memoir to help other Severe Traumatic Brain Injury (STBI) survivors, and their families, with what I have learned from my own traumatic brain injury. It's my sincerest hope that other STBI survivors and their families realize that they are not alone when they read my words. Hopefully, other survivors discover that there are others just like themselves.

My sincere wish is that they find solace as they realize that many others are in very similar situations. I pray that my own reflections, in the following pages, offer lasting, emotional support. More than anything, though, I hope my story resonates with other Traumatic Brain Injury survivors, so that they, too, can thrive, so that they realize they are still viable human beings despite their suffering.

I have painfully and carefully reassembled my story so that other STBI survivors realize that, although our brains may not work as they once had in the prime of our lives, there is real hope, that in time can make up for our cognitive plight. In writing this, I have rediscovered that the key to my survival has always resided within myself.

While reflecting on my recovery, I've discovered critical and recurring lessons other STBI survivors can benefit from. First and foremost is the power of patience. Survivors, find patience wherever you can and however you can. New perspectives, personality traits, and skill-sets emerge and crystallize—in time. Remember: your new life is more precious than your previous one. Make it your duty and privilege to live your new life as best as you can, despite your injury. Your new potential will surprise and astound you.

Do everything you can to accept that looming truth: you'll never be the same. All STBI survivors face this reality. And that's okay. Recognizing this fact is the first and terrifying step in the long path that awaits you as you reclaim your brain. I'm living proof, moreover, that accepting this truth is also the most liberating step. I urge you to find the audacity to say goodbye to most of the things you loved about yourself before your injury. Prepare yourselves to say "farewell" to all the things you liked to be—back then.

I've had to do this. I didn't really have a choice, either. No, I will never be able to play my music again, nor will I ever be able to perform as a concert-violinist ever again. I will never be able to compete in taekwondo tournaments again, nor will I be able to teach taekwondo again.

Survivors: please cherish every remaining semblance of the cognitive functionality you still possess so you can focus on developing them. Appreciate what your body can do today—moment by moment, millisecond by millisecond. Above all, create something beautiful with your new and changing abilities; never pity yourself. You can transform your disability into a superpower, but only if you actively pour yourself into the decision to do so.

As of this writing, I focus on honing my newfound superpowers every day. I'm writing. I'm painting. I'm thriving in ways I never imagined I'd be able to. As painful as my recovery has been, and as unbearable the pain and pressure in my head can be, I am still grateful for what I can do. Whether I'm having a challenging day or a less challenging day, I always make a point to thank God for each new day He has gifted me with when I wake up.

Begin your new life with gratitude. Right now, I have embraced my new calling, by God's grace. As such, this book's mission is to reignite broader advocacy for STBI survivors like myself. I pray that my words breathe more life into renewed awareness, empathy, and understanding of the STBI survivor's experience. As my narrative illustrates, comprehensive consideration of STBI survivors demands significant improvements in their current treatment. On a fundamental level, I'm arguing for a more practical ("realistic") medical approach that simultaneously accounts for the physiological and psychological needs of STBI survivors. Divorcing these two needs is socially irresponsible towards STBI survivors, plain and simple.

As my story unfolds, please keep in mind that there is a human being living within its lines. I pray that readers can find, and cling to, the humanity in my words. My memory can only be honored if others share it. This memoir only matters as long as progressive strides, however incremental, are achieved in, and for, the STBI recovery process. To accomplish this, my husband and I have worked very hard to start a new kind of STBI nonprofit organization. While it raises funds to benefit STBI survivors, its purpose is to springboard greater awareness of the STBI condition and to contribute lasting improvements to the quality-of-life of STBI survivors in facilitated recovery.

May my words inspire you, and your families, so that you extend your support to the greater STBI community. After all, a growing network of friends and families are suffering with you. May my story surprise and inspire you. My words are only written to empower you. I pray they breathe more life into your own. To those who wake up in despair, in solitude, you are not broken. You are part of our family. Together, we are not hopeless. We are not silent. Together we resound. We forge our words in this ecosystem, one at a time, and into the next chapter.

I hope my story becomes a part of your own.

CHAPTER 1

Welcome to my World

> It was sudden. A rogue asteroid crashed into my skull. Excruciating pain overwhelmed me with its magnitude. I blinked, and before I knew it, I was rushed into emergency surgery. Then, out of nowhere, a violent pressure clutched my brain. Like a large vice smashing a soft apple.

My world was crumbling from behind my eyes. Then came the impending doom. A myriad of voices blurred into each other. The doctors predicted that I had less than a five percent chance of survival, with the distinct possibility of ending up in a vegetative state. The thought of hope felt like wavering candlelight amid a growing sea of darkness. Time and space froze around me in slow motion.

> I was just a breath away from the other side.

Nearly-blind and forlorn, I woke up weeks later to an existence ruled by fear and pain. I yearned for the ability to recognize a coherent voice. A desolate consciousness devoured each one of my five senses, slowly but surely, like a hungry monster. I was powerless to stop it. I couldn't communicate in any way. Familiar sounds echoed from miles away. They drowned in the distance, unattainable. Only a few noises made any sense to me. Somehow, I knew that I was truly alone, like a lone prisoner wandering in a dark maze. I was trapped in the middle of an incomprehensible static. A depth-less void grew around me, and haziness consumed me. I reached towards a flickering light, but its warmth and brightness evaporated in the abyss. I can recall the specific confusion. Am I meant to be here right now? Is it approaching me, or I, it?

Am I the prisoner of an unforeseen beginning? This was merely the first of many strange and lonely steps along a twisty and interminable transformation. This transformation is also an identity: *Severe Traumatic Brain Injury Survivor.*

This new, nightmarish, and surreal existence was, in fact, real. I was a passenger, strapped in a turbulent roller-coaster-ride of self-rediscovery and reinvention. I wouldn't connect the dots until much later. Determination, perseverance, and, above all, faith in God enabled my survival.

What's more, these virtues were always there, like the artifacts of a former self, before my STBI. I fostered these tools as I learned to live with the new person inside my head. I harbored an intruder in there. She was apart from me and a part of me.

I wouldn't be able to reconcile my former life with my newfound identity until I could relearn how to communicate, all over again. It's only after my re-education, my re-literacy, that I've been able to share newfound, God-given talents. Today, I owe my determination to my newfound knack for painting. When physical torment and psychological anguish revisit, and it seems that the whole day or week is rendered hopeless, I focus all my energy on new beginnings. I embrace every sunrise like detective embraces every new mystery. Every tomorrow is a gift, a new canvas, awaiting the possibility within me—awaiting my next brush stroke.

CHAPTER 2

Early Life

> Letters written, never sent. Words behind the wall of seclusion, no eyes to see, no lives to touch, no hearts to break. Oblivion, mastered by the least of us, as we travel the path of most resistance. The mind races faster and faster, speeding through life at an alarming rate. The physical body has no chance of keeping up.

I WAS BORN IN 1954, in Long Beach, California. I spent my formative years with my mom, my dad, and two older siblings—one brother and one sister. Looking back, I wish that I could say I had a pleasant childhood, but sadly I didn't. The truth is: I almost didn't happen.

The conditions that led to my birth are as unfortunate as they are unsettling. My parents had an abortion a couple of years before I came along, which, by 1950s-American-social-standards, made "having" me a "mistake." That was the word my grandmother used, at least— "mistake"— as she struggled to explain my beginning to me later in life. She revealed just how close I was to becoming an abortion. Apparently, my mother lost a kidney to infection after her previous abortion. At the time, secret abortions were commonplace. They were also illegal and very dangerous. Back-alleys and seedy garages became unspoken havens for desperate and fearful couples with the dilemma. Of course, I have no recollection of my birth apart from my grandmother's.

I can however vividly remember my childhood. The clearest memories are of my family. When I try to remember them, my imagination is like a canvas, and each one of their faces comes alive from a swirl of colors. For some reason, the first person that takes shape is my father. When I revisit my past as a young girl, I can see my father just as he was. He was handsome and ominous. Wielding about two hundred and twenty-two pounds, and standing at six feet, two inches, his muscular build and dark, wavy hair easily drew attention from afar. He was often mistaken for John Wayne because of his looks and swagger—he was a rugged, "man's man," and he always had an unforgiving, gritty disposition stuck on his face.

He was obsessed with neatness. Looking back, he might have been manic about it. One of his many rules was that everything in our home had to be clean. Everything belonged precisely in its right place, and everything had to be immaculate. The trace of clutter was a punishable offense. He never showed forgiveness for the naturally, eventual messes my young siblings and I rarely left after playtime.

We very seldom misbehaved. Our toys were very rarely left out, our clothes were always hung neatly, and we always made our beds in the morning on our own. Food crumbs, fingerprints, and smudges were blasphemous. At the end of each day, my mother and siblings all suffered for it. My dad wasn't the typical disciplinarian of the era. When he was home, his misery cast a wide net over the rest of us. He would somehow find something to berate us about if we were in earshot. During his worst moments, if one of us happened to cross his line of sight, we were bound to hobble away in pain. It was either a slap, a kick, a punch, or a shove. It was as if my father looked for any reason to inflict his anger on us.

I think my father's memory haunts me the most because his presence was so overwhelming to me as an impressionable, young girl. He etched into my mind as a terrible, rude and scornful presence. As a kid, I remember thinking that my family, friends, and neighbors avoided him because they were all afraid of him. Each afternoon, I would anxiously watch the clock. I remember wishing that its hands would slow down so that it wouldn't be time for him to come home yet.

When it was time, the cold reality of his arrival would paralyze me. Without fail, he would always come back after painting used-car engines, freelance, and he would always bring a brooding cloud with him. As soon as the front door opened, his presence sucked all of the oxygen out of the house. I remember the shock that consumed us the second we felt the door shut behind him. I remember how instinctively my mother's posture changed as soon as the door closed. I remember her cowering in his presence from then on.

I can vividly relive the day my father made me feel guilty for wanting a puppy when I was six. I was walking down the main street late one summer day. A tiny Hispanic girl, probably just a little younger than me, immediately caught my attention. She was giggling at the puppy wriggling between her arms. I wanted a puppy, too. On my way back home, I started to consider my puppy. My new dream was short-lived by my father's obsession with absolute order. He would never consider letting me have a puppy. How would he? He only nearly tolerated his own children's' messes. How would he tolerate an unpredictable puppy? A dog was out of the question. Why did I feel foolish for the possibility of one?

I always seem to recall the worst days first. When I think about my childhood now, I only remember how I felt. The two resounding feelings that resurface when I try to reflect upon my girlhood are fear and guilt. My siblings and I felt like permanent liabilities. It can be as puzzling as it is unsettling to think about our existences as disgraceful youths under the dominating presence of our father. I remember carefully walking down our house's hallways, hands in pockets so we wouldn't be tempted to touch and sully the walls. If one of us did, or if one of our friends didn't get the spiel, we'd catch three different punishments. First, a beating: belt marks and bruises.

Then, more chores, followed by two weeks of "restriction." "Restriction" meant two things. One: healing our wounds in confinement. Two: hours with a bucket of ammonia water to wash all the hallways. Every inch of the expansive walls was expected to look brand new. The endless, ornate woodwork that accompanied them was supposed to be detailed. All this manual labor forced upon mere children, and because we dared to touch the walls in our own home. My house was like a prison, and my Dad was its warden.

I can't remember if I was five or six, but I can easily conjure the exact day I stopped seeking comfort from my father. I was sitting cross-legged in the front yard waiting to greet him when he got home from work one evening. I precisely sat on the edge of the walkway to the front door, so there was no way my father could miss me. When he finally arrived, I popped up and stepped forward, my front foot just slightly on the grass. I forgot where I was for a moment and dashed to greet my dad with a big hug. As I closed my arms and eyes, I felt an alarming slap, followed by an immediate shove.

Shock and confusion washed over me the moment I realized what had just happened. I had never felt that worthless before. This feeling was a new, more profound kind of dread. My father was furious because, in my excitement to greet him, I had inadvertently stepped on his delicate Dichondra grass. It was very sensitive: a unique sod that required careful maintenance. It was a poor choice for a family with young kids. The last thing I remember about that day is the red handprint on the front of my face in the mirror. Plus, two weeks of restriction. A new, interminable dread hung over me.

When I was seven, about a year later, there is a moment in which my father's memory turns into something even darker. To this day it's one of the most evocative memories I can recall. I was pulling weeds with him in the garden one sunny day. In a random outburst, he turned and grumbled at me: "The best advice that I can give you in all of your life, Kathy—and you better listen to me now—is never to have children." I didn't grasp any of it—neither what nor why he told me. I only remember the guilt: Why does he hate us so much? I was too young to comprehend the weighty implications in his warning. He was also apparently from an abusive family—and that this probably had something to do with an obsessive-compulsive disorder.

Perhaps his unfortunate upbringing and resulting psychological issues were not his faults. Why did he react to these things so violently? Wasn't it his responsibility to find a way past these traumas the day when he became a father? I've always wondered whether or not my dad acknowledged how his severity affected others. Did he think about this privately in his terms? Was I just a character in his story, or did we share one? Was he ever a playful child like I was?

In stark contrast to my dad, my mother taught me what love could be. Barely five feet tall, she had dark, curly hair, which she kept short, with a little length on the top to show off her coils.

She was slender but athletic and loved to ski. More than anything, she was a gentle presence. She never complained, even on days that she was sick or in pain. She was always patient and kind to everybody. It was almost as if she was trying to compensate for the brutality of my dad's presence. She was tender with my siblings and me. She'd always aim to encourage us even when she corrected us, or when she taught us a lesson. She showed us how to survive the scariest of life's moments: Find another way to look at things, even if they are bleak, and forge ahead, no matter what situation you find yourself.

She shared a deep and unspoken connection to all living things. She liked to scoop up little, injured animals, on the brink of death, and carefully nurture them back to life. There was always a new, animal orphan in our home somehow—a recovering squirrel, rabbit, or bird. I cared for them as secret pets until my mother returned them to the wild, but only when she deemed them able enough.

When I think about my mother now, only fond memories replay behind my eyes. She always made it a habit of coming to my room and sitting on the very edge of my bed. We would usually talk for hours at a time. When I was a tiny girl, I remember her mystically appearing to tuck me in every night. As I grew older, she'd give me company when I was under one of my father's "restrictions." She would always help me rebuild my self-esteem after my father tore it down.

She taught me the importance of well-timed play, too, somehow. I remember one day when I was a teenager: We were eating ice cream, which was a rare treat in our house. We were savoring the moment, when, all of a sudden, she flicked an entire spoonful of ice cream, hitting me square in the face. It dripped down my cheeks and formed little pools of vanilla stickiness at my feet.

I was rattled at first. I stood there breathless, my mouth agape. Then I gleefully remembered my father was out of town: relief. My mother, my sister, and my brother—we had free rein in the house! We didn't have to worry about him for once. The temporary absence of his physical presence meant the temporary lack of his negativity. The air in our home felt different for a fleeting beat. Unfortunately, these sprees always felt fleeting and were very rare.

I'm sure my mother's penchant for creative writing rubbed off on me. She wistfully penned fantastical stories about faraway kingdoms and magical creatures. The animals she saved became talkative characters—how they would enjoy their freedom but would always return to thank her. No matter how sad she became, they still managed to resuscitate her cheer. Ever since I was a teenager, I always reminded her to send me her writings so I could publish them for her. But she never did. I'm convinced that she was too afraid of my father.

My father had reduced her down so much she had no self-confidence left. It was second nature for my father to tear everyone else down to feel better about himself. My poor mom was the one who took the brunt of it. I do not think my father would have been able to handle her success. I imagine he made success scary for her. Writing would only be an emotional outlet for her, a routine, temporary, refuge. It got her through some tough times: It was that uplifting and inspired.

When she passed away in 2009, my father survived her. I learned that every single one of my mother's writings was casually discarded. Even worse, I discovered they were summarily thrown out in the garbage, and my heart broke in two. After all, she held the family together in spite of my father's destructive influence over us. How could my father disregard her writing, and so halfheartedly? An answer can be found somewhere in his torrid past.

I've learned that my father was pulled out of school by his father at the ripe age of eight so that he could work the family farm, full-time. He only had a third-grade education, and he felt embarrassed by this. As of this writing, I can only infer that my father transferred his to resentment and, eventually, anger. In stark contrast, my mother graduated from high school, and studied business in college, although she did not finish her degree. Next to my father, she was the educated one, although she never took credit for it.

On the contrary, she made it her duty to keep the peace between our father and us. She made all of the plans, paid all of the bills, and did all of the family book work. My father valued control over anything. He would always sit beside my mother to monitor the work her education enabled her to complete. He scrutinized everything she did. He acted like he had to have complete control over her and us. It was arduous, but she did what she had to do for her family in the end.

Because he worked so close to the Long Beach Airport, my dad was inspired to fly. He would watch planes of all sizes take off and land every day. Naturally, he became mesmerized by the prospect of flight. I was three when he earned his private pilot's license. Soon afterward, he bought a red and white "Cessna 150." Within a year, my mother received her pilot's license. A few years after that, they both earned their certified flight instructor's licenses. I remember when my parents sold the "Cessna 150" and bought a blue and gray "Cessna 172." It was a "tail-dragger" that could accommodate an entire family of passengers. Then my parents joined the Sky Larks Flying Club and jetting-off all over the country with their friends became a habit.

As we got older, they traded in their "Cessna 172" for a brown and salmon-colored "Cessna 182," which they housed at the Long Beach Airport when it wasn't in use. One day, when I was in the third grade, we flew down to the city, Fallbrook as a family. Back then, it was a sleepy, agricultural town, located in the middle of nowhere. It was known for its fruit. Sprawling fields of orange trees, lemon trees, olive trees, and avocado trees peppered its rocky hills. Once upon a time, Fallbrook was home to a popular stagecoach hub, which spanned as far north as Temecula to as far south as San Diego.

My dad heard an odd story: that twenty-two men built the airstrip at the Fallbrook Airport. He needed to see it for himself. When our family landed there, we found an artifact. An old, paneled station wagon was awkwardly parked to one side of the landing strip. A sign nearby read, "You can borrow me, but you need to check in with the office first." We wandered over to a little, yellow building that looked like something out of the

1920s. It boasted rounded corners and a stucco exterior. Home to the local realtor, it was the only building in the immediate area aside from a tiny grocery store and a distant tractor shop. After driving around the desolate hills surrounding Fallbrook for a few hours, my parents made their final decision.

They liked the serenity of the area so much, they eventually bought property and moved us there. Little did my folks know this new place entranced me. I was entranced by the intermittent barns along its green pastures, where cattle and horses carelessly flocked. I remember thinking, "Heck yeah, let's move here!" More than my fascination with horses, this new frontier meant an opportunity to try something new. Before relocating there, I thought, "Perhaps my dad was a happier person in this serene setting. Maybe then he wouldn't berate us so much."

Another Chapter

The house that my parents purchased was nestled in the hills of a smaller agricultural community, called Pala Loma. It was couched northeast of San Diego and in the center of a geographical triangle, between the towns of Pala, Fallbrook, and Valley Center. This clandestine neighborhood was teeming with a variety of fruit groves, which bore oranges, lemons, and avocados, but was short on local neighbors. One could drive for several hours in any number of directions and still not see another soul.

The property my parents purchased turned out to be a sixty-acre avocado ranch, so my dad promptly put us to work on the weekends and during summer and winter breaks. We eventually moved to "Pala Loma" a few years later. We worked very hard from then on, as if we were raised as ranch hands our entire lives. It didn't take long to discover new calluses and a "fresh-off-the-farm" smell to prove it. We planted avocado trees. We filled gullies. We carefully tended the fruit and the trees with fertilizer and the right amount of water, and we worked that ranch. We did everything on it for about thirteen years.

I remember dragging the most massive, most cumbersome hoses to spray weed oil between the rows of trees. They became incredibly heavy and grimy from the oil-and-mud-mixture, but I still found the willpower to move them and keep up with my brother's workflow. I'd learn this oil would be eventually banned in the U.S. because it's a carcinogen. There we were: handling the stuff, mixing it with our bare hands and maneuvering its hoses without gloves or respirators. Working the ranch was hard labor, especially for kids. We would never see a penny for our work on the farm, nor were our superhuman efforts praised in any way. There were times we felt like we missed out on our childhood, while our father greedily grew rich off of our hard work.

He passed away in 2013. Although he was a multi-millionaire, and many times over, he still died alone. The saddest thing is that he could have used his fortune to do positive things. The good thing about my childhood and teenage years on the ranch was that I learned a lot about avocados, which would come in handy down the line. While I am very thankful for the lessons about agriculture and my strong work ethic, the price I had to pay still feels disproportionate.

It still feels like my father hijacked my childhood and made us suffer unduly with manual labor while our family meagerly survived. Why did it still feel like we were scraping by? Perhaps it was his upbringing or the fact that he was born during the depression. Maybe he thought that we were in his debt because he gave us life. Perhaps it was sadism. Apart from the basic needs of food and shelter, my dad never bought us anything and never paid us for our tireless contributions to his business. He expected us to earn our own money on top of our already-time-consuming workloads: school, household chores, and the ranch. If we wanted to have clothes, or shoes, or work boots for the farm, we had to pay for them ourselves.

When I was a girl, it was challenging to earn money, so I had to learn to take what I could get. I remember being nine years old and riding my rickety, blue “hand-me-down” bike all the way across town, past all of the busy streets in Long Beach, to baby-sit. I was paid a dollar an hour to watch a two-year-old boy in addition to cleaning his entire house. It wasn’t a gigantic house, but it was demanding work for a nine-year-old girl. The boy’s mother would usually disappear for four or five hours. When she returned, she usually shorted me: three dollars when it should have been four or five. I never spoke up. I was afraid that she wouldn’t hire me again, so I took the money she gave me. The only thing I could focus on was buying a pair of shoes because the soles on my pair were worn completely through. I had one pair of shoes, so I had no other choice.

Even as a young girl I earned my own money for my own necessities. This taught me that I would have to work hard to survive. Getting ahead in life was another thing. I slowly became aware that I was missing out on so much of my childhood and teen years because I worked all the time. I’d see other teenagers on dates, and other kids are playing outside. I couldn’t help but notice overhearing other kids my age boasting about the vacations they returned from with their families.

On Mondays, I was dropped off at school. I would still be in my work clothes, unkempt from the ranch over the weekend. I wore them even though they were covered in dirt and wreaked of sweat and weed oil. It felt like I had a giant target on my back. Kids in my class, and on the playground, were cruel to me because of this. They called me names, like “stench,” and, “farmer girl.” I remember feeling like a leper. Ranking other kids based on how they looked and what they wore was common practice at that time. It was the early 1960s. Children were usually dressed “properly” and very precisely, like tiny reflections of their parents.

Most boys had slicked-back hair and wore collared, plaid madras shirts, which were always neatly tucked into their khakis. Girls wore cute, little dresses, had saddle shoes, and either proudly primped pigtails, braids, or pinned back locks. Then, there I was. A skinny, little girl in my siblings' old, unkept "hand-me-downs." On Mondays, I'd be in dirty, broken-in work clothes. Avocado-tree leaves peppered my hair. I was the perfect target for ruthless teasing by my peers, and I endured years of it.

Bus Rides: Noise Overload

The family ranch was far from everything, but other ranches. It was quite a distance away from my high school. I would take the bus every day, an hour and a half each way, after walking three miles to and from the bus stop. For much of the bus trip, there were only three of us: me and two other slightly younger girls from nearby ranches. I lived the furthest away from the school, so I was the first one on and the last one off.

I felt awful for the bus drivers. So many kids were rude to them. They were obnoxiously loud the whole time. They would yell and cause mischief every day. I remember teenage boys from the ranch and farm communities flinging anything they could get their hands-on books, gym clothes, leftover lunch items, and even trash. The foulest language would soar out of their mouths.

By the end of the trip, the bus was in shambles. There was always garbage everywhere, and spitballs plastered its windows. The bus driver had to clean that all up. The clamor was so unbearable that I had to keep my hands over my ears for the entire ride. The further I'd walk onto the bus the louder the noise grew. The mischief seemed to peak by the time I reached the back of the bus. It was for this reason that I always sat at the front. Altogether, I dreaded the bus ride. I had no choice.

I don't know why parents weren't ever made aware of their children's misbehavior. My best guess is the bus drivers were afraid of any resulting retribution that could implicate them. They were probably worried about keeping their jobs. I don't know how the bus drivers were able to carry on. To this day I'm unsure how they came back and kept doing their jobs every day, for the entire school year. I think I sympathized with them, because they, too, endured daily abuse. I admired their wherewithal. I think that their example galvanized a determination to break the same cycle within myself. I deserved to find a normal relationship. I deserved to raise my own kids, and in a loving home. I deserved a life without the daily-bus-driver abuse.

A Taste of Freedom (for a Price)

When I finally turned sixteen, it wasn't long before I got my driver's license. My father would let me drive his gold, 1963, Chevrolet Impala to school one day a week. It was a huge deal because he loved that car, and he was always so overly critical of everything I did. I wasn't sure why he trusted me with one of his most prized possessions, but it wasn't like I'd turn down an opportunity for some semblance of personal freedom. I remember that the power windows were perpetually stuck in the "down" position.

If I wanted to drive it, I had to put on a big coat, flip its fur-lined hood up, and cinch it as tight as I could against my head. I had to squeeze on cumbersome work gloves so my fingers wouldn't freeze to the steering wheel. It was a hysterical sight, but I did not care. I was just relieved that I did not have to take the bus for a day. Bundling-up was a small price to pay for peaceful, independent transit.

The trade-off was kind of ridiculous—each week I had to wash every single window that hugged our colossal house. Of course, they covered the entire front and back ends of our house. The surrounding walls were old adobe so thick that I'd have to climb into them to get to the windows. That's not all I had to do for the esteemed privilege of driving my father's car. It was my responsibility to pay for my gas and car insurance. I had to get a high enough paying job on top of my usual household chores, ranch work, and schoolwork.

I became a nurse's aide at a convalescent home in Escondido. It was a couple of towns away from my house. I worked at a hilltop facility, from three in the afternoon until midnight, five days a week. This job and all of my other obligations left little time for a social life, which was a difficult pill to swallow that age. Other teens were out having fun and socializing, and I was in an endless loop of work, school, work. I was drawn to the nurturing part of the job.

I considered studying to be a nurse in college, so this position made sense. I was mostly emptying bedpans, changing diapers, and feeding those who couldn't feed themselves.

When I started working at the hospital, I couldn't eat for the first two weeks because of an unmistakable smell—the sour mix of urine, vomit, and feces permeated everything. Even the food that they fed these unfortunate people was foul: pressed meat and gray slop that looked just as unappetizing as it smelled. There were only two aides and one-floor nurse to ninety-nine patients. There were two wards identified by the required care level of the patient: one for the capable, and the other for the incapable, who had to have everything done for them.

I remember thinking, "Oh God, please don't let me end up in a place like this when I'm older." Little did I know that I would find myself in a similar place thirty-five years later. Little did I know I would endure the apathy they did. Nor did I imagine I'd confront their internal dilemma: freeing a "capable" will from within an "incapable" body.

CHAPTER 3

Music for the Soul

> Held in concert with tape, my sheets of music with torn and frazzled edges, barely holding together. An emotional piece, a duet for a wedding, Bach's Concerto in D Minor for Two Violins is my favorite. It made my heart sing. Now, just dreams of memory…

I HAVE ALWAYS LOVED music. When I was young, I would sing in the back of each of my parent's airplanes. From the top of my lungs, I belted songs without care because no one could hear me over the noise of the engine. Nobody told me to shut up, so I would sing and sing and sing. These were the only times that I felt free, to be able to express myself vocally, in this case through song. To some degree, I felt like I was getting away with something. After all, it was a rare opportunity without the possibility of my father's repercussions. I discovered that I had an ear and a love for music—by myself. I could make musicianship my own, and its prospect liberated me.

In elementary school, I stumbled into an orchestra class where I fell "head-over-heels" in love with the violin. I started to play with a quarter-size violin at the age of seven and moved up from there as I got older. Although I could read music, I could play it with ease after a single listen. It just came to me naturally.

It turns out that I was actually quite gifted, or so I was told by my instructors. In all of the orchestras that I played in for about ten years, I was always first chair violin. When I was eight, one of my music instructors introduced me to the Long Beach Symphony Orchestra. I was hooked. I played in this orchestra off and on for ten years. Looking back, it was actually a little extraordinary. There I was, a young girl within a gaping orchestra pit. I wonder how others saw me then. I was a skinny girl, with a runny nose, who was attached to an enormous violin. I made sure I was always ready in the first position.

I was the protégée of Dr. Fred Ohlendorf of Los Angeles, my first superhero. He was an excellent symphony conductor with all the animation of Einstein. The classic mismatched clothes and wild salt and pepper hair. He was always disheveled. Items always fell from his vest-pockets, and he almost always wore a Five o'clock shadow However, he always seemed to have a sheet of music, half-crunched, poking out of his barely-closed, overflowing briefcase.

Dr. Ohlendorf was the Superintendent of Music for the Long Beach Unified School District. A real musical genius, he spent his extra hours with us kids, giving us hope through music. Thanks to him, we, the Suburb City Orchestra with a great big sound, were pretty good compared to others, especially for our young age. Incredible leadership and raw talent, all making beautiful music together, we worked for it because we loved it so intensely. With upwards of two or three hours of practice every day, we had put the time in and it showed. We felt confident in our abilities and were ready to perform when we needed to, which is half the battle. I remember how the stage swelled with young, musical talent that was forged by Ohlendorf's expert leadership. We definitely "brought it."

It was then, and it was incredible, the leadership and communication that developed between a group of individuals in the zone together. We spoke the same melodic language with our instruments.

> It is known. A rare signal, still—unspoken language. The language of the bow, the tilt. A sign from the chair and everyone plays in harmony... We look at each other with unspoken honesty: “Now is the time!”

The music filled my soul. It flowed through me as though I had played it before, perhaps in another lifetime.

The violin was my special tool. It was handcrafted and ancient. I remember its magical pull. Maybe it was the smell of its wood or the luster of its lacquer. With my fingers, I traced its markings along the maple streaks to where the frog of its bow hit the instrument and left gouges. It was played vigorously, and it showed. To this day I can still hear Bach’s Concerto in D Minor for Two Violins, the beginning and ending struck so hard and heavy, while the second movement was delicate and melodic, as the two violins shared a spirited conversation, back and forth. The depth of that piece has always touched my soul and made my heart sing—I loved that music, viscerally.

As an STBI survivor, unable able to play my violin, that Bach concerto reminds me of the musician I once was—a young concert violinist with her whole life, and possibly a career, ahead of her. I remember playing the music and being so emotionally touched by it even as a teenager. The highs, the lows of the piece, much like the ebb and flow of life. It was a hard piece to play, and it took many hours of practice to master its varied nuances. It taught me about discipline, dedicating yourself to a craft, to perfection and having respect for the essential things in life. Music has always been one of those rare things for me.

When we moved down south to Pala Loma, there was no orchestra, just high school band. I traveled 100 miles to Long Beach to play. The distance made life even more difficult. My family dedicated themselves to farming at that time. There weren't many realistic opportunities to play my violin except for sporadic weddings, funerals, and solo pieces for other events in Rancho Bernardo and San Diego, and occasionally in Long Beach. Because of the distance, it was so hard to get to Long Beach to be a part of an orchestra that my interest in playing violin eventually phased out.

At that point, I focused all of my attention on other instruments. I was always good at "making do" with what I had, so I taught myself the mandolin at the age of fourteen. My maternal grandmother had given me hers, so I plucked away until I mastered the instrument. I saved as much as I could for two years to buy a banjo. I considered it a fun tool, despite its cost, about twenty-four dollars, which was a considerable amount of money for a fourteen-year-old girl back in the year 1970. I also learned the guitar and eventually bought several six and twelve string versions, some acoustic, others electric. I even wrote music for the twelve-string guitar.

I wrote a plethora of songs with my guitar. I bet if I sold them, I would have done well for myself. In the early 1970s, I had no way to record or publish my music. I had no lasting way to share my songs with other artists. I was only learning as I went. I lived in the center of nowhere and was under the constant control of my father.

No wonder I felt like it wasn't worth the effort to explore my musical potential. I feared my dad would disparage my work, so I stopped trying at some point. I kept my music all to myself. My aspirations for music did have a value to me, even if they were unrealized. Music was an escape, a place of solace.

My siblings were much older than me. I had to get used to their absence from our home rather quickly. After they moved on, it was like I was an only child. That's when I would listen to a lot of music on my own, endlessly spinning vinyl on my record player. My two favorites were mainly Bach and Vivaldi. To this day I still can hear their music in my head.

CHAPTER 4

Meeting Galen

> It is my condition for him, that has worn me out. I have had to fight through the masses to touch the edge of his life. He, so in demand, so loved by each one who crosses his path. A righteous man of good faith, he listens to each and cares equally for all. So important, and so loved...But he sometimes forgets who loved him first.

My husband, Galen, was born in 1953 in Busan, South Korea, to a Korean mother and a U.S. serviceman, who was stationed there during the Korean War. When he was only two years old, Galen's maternal grandmother sent him off to an orphanage while his birth mother was away at work. It broke his mother's heart. She eventually realized that it was in Galen's best interest for her to give him up to an American couple who had inquired about adopting him. In those days, "Amerasian" children were shunned as outcasts in Korean society because they were not one-hundred percent Korean.

His Early Days

In most cases, these children were tormented, or thrown in the streets. They were abandoned by mothers, who felt ashamed in overly traditional and dogmatic Korean society. It was difficult for single mothers to make ends meet because of the scrutiny by other Koreans, especially the elders. So, it wouldn't have been a pleasant life if Galen had stayed.

Flower and Lawrence Newhouse adopted Galen with two other children. Flower and Lawrence were an "American couple." They were non-denominational ministers, and they happened to be traveling abroad. The generous couple found the living conditions in the orphanage to be very disheartening and knew that they needed to take action. So many kids were living in filthy and cramped quarters, many times barefoot with barely enough clothing to cover their bodies. They wandered almost freely within the compound, which included a couple of shanties that were abandoned during the Korean War. Food was scarce, so an overwhelming number of children were scrawny and looked malnourished. Realizing the fate of these children, the Newhouses saw it as their mission to rescue them.

In their lifetime, the Newhouses helped the Christward Ministry place five-hundred orphaned and abandoned Korean children into adoptive homes in the United States. After completing the appropriate legal documents, the Newhouses would fly the kids into the U.S. from Korea and hand them off to their respective parents. The Christward Ministry, with help from The Holt Agency, continued the Newhouse legacy of arranging thousands of adoptions. They have kept in touch with Galen over the years, which is a testament to the gratitude of the many adopted children, who have become healthy adults with their own children and grandchildren. To this day, these success stories express their thankfulness for Galen's parents, and what they have been able to accomplish.

In addition to being an ordained minister, Flower Newhouse, Galen's adoptive mother, was a clairvoyant and would often describe amazing visions and various states of consciousness. She was a Christian mystic, whose life, teachings, and personal insight into spirituality, have revealed a path to a higher awareness of God. Her students embraced her. Over her lifetime Flower wrote nearly a hundred books on the subject of mysticism. Her many writing and teaching interests included angels, the spiritual purpose of life, the hierarchy of perfected souls, the ongoing ministry of Christ, and what she described as the inner worlds. She dedicated her life to furthering Christ's mission. She even traveled internationally to lecture and do guest appearances, enlightening crowds of inquisitive parishioners.

It was Lawrence Newhouse, Galen's adoptive father, who wanted to help disadvantaged children. Along with his wife, the couple showed abundant warmth to the children they adopted themselves, and to the children they helped place in other foster homes. A tall, handsome, dark-haired gentleman with a pencil-thin mustache, Mr. Newhouse would spend a fair amount of time with all three kids. Soft-spoken and patient, Galen would often describe him as a gentle and caring man, who was deeply devoted to his wife and family. In addition to his dedication to parenting, Mr. Newhouse also handled the business side of the ministry and helped publish Flower's many books.

Once Lawrence Newhouse passed away in 1963, Galen's mother left most of the parenting to her household staff, as she continued with her ministry. To the caretakers, Flower was a star in the spiritual community, and they felt that Galen and his adopted siblings were a hindrance to her success.

After Mr. Newhouse passed away, Galen's younger brother had a difficult time with the loss of his father and was sent away to foster care through the Holt ministry orphanage. The remaining two kids stayed with their mother until Galen's senior year in high school when he left for boarding school. He became too much for Flower, or more accurately her staff, to manage, so off he went.

At boarding school, which was only several miles from the Newhouse's Southern California home, Galen spent his days in the company of offspring of the wealthy. It was a strict teaching environment with centered around military-style discipline, with little encouragement for anyone not focused one-hundred percent on college admissions. Feeling abandoned and let down by the only family he had known, Galen spent his time off hanging out with friends. He would often grab his body board and find solace in the waves at the beach in Carlsbad.

Without the encouragement of his father, or any substantial parental figure, Galen had little direction in his life at this point. He did not return home after he graduated high school, so he moved in with a friend in Las Vegas, working odd jobs to get by. College was not on his radar at the time, as finances and a sense of direction were both an issue.

A Blind Date, A Soulmate

In 1972, I was seventeen. My friend Debbie wanted to arrange a blind date for me and one of her boyfriend's best friends. His name was Galen, and he was moving back to Southern California from Las Vegas. When I opened the door at Debbie's house, and I looked at him with his long sun-bleached hair from bodysurfing and these beautiful almond-shaped eyes, I knew he was the man I was going to marry. We connected right away. I immediately felt comfortable with him like I had known him before.

Our relationship developed, and after only a few months Galen wanted to get married right away. I knew that I just was not ready. I was only seventeen-years-old, despite my sheltered home-life. I grew up thinking I would get married after college.

When my father found out about Galen, he quipped, "You're not going out with him. There are enough nice American boys for you here. You're not dating a Korean." So, I went to Debbie's house and spent the night with her every once in a while, and that's when I would go out with Galen, technically behind my father's back. I'm not sure how but about a year later, my dad figured out that I was seeing Galen. My mom was aware of it and told me, but my dad and I never really spoke about it. At that point, I was eighteen, and I knew that he had little to say about whom I could or couldn't see. I was still afraid of my dad and I knew that I could leave home if I wanted to. I also knew that I wouldn't be able to come back afterwards.

Over the next three years, when waiting to be picked up for a date, my mom and I would go into my room, close the door and sit on the edge of my bed until Galen got to our house. Although I was an adult, I was still living under my parent's roof and had to abide by specific rules and expectations. I also had to pay rent and continue with my chores, or there was all hell to pay.

If I left the safety of my room too soon, my dad was likely to find something he felt that I did wrong and would punish me for it, not allowing me to go out because of it. That was just his way.

Perhaps I should have moved out long before that point and lived with Debbie when she asked me to share a place. However, I was afraid to leave my mother. I was terrified of what my dad would do to her, so I stayed.

First Taste of Death

Our mutual friend Donna went in and shared an apartment with Debbie instead of me. They lived together for a couple years. I imagine they enjoyed their freedom. One day, Donna came down with a fever, and when her temperature spiked, we placed her in a bathtub full of ice. The ice bath didn't help, so we took her to the hospital. She ended up passing away from, of all things, chicken pox. The infection spread to her brain, and she got encephalitis.

I still remember her dad coming out to the waiting area and telling us that she didn't make it. We didn't believe it at first, as she was supposed to be getting married a few months later. We were all planning our weddings together as mine was happening in June, Debbie's in July and Donna's in August. It was so sad to see her fiancé put her wedding ring on her finger before she was buried. I'll never get over that site.

Chickenpox is apparently easier to endure as a child, but for adults, like Donna, it can be deadly; symptoms are often more severe in adults and can lead to hospitalization, even death.[1]

In Donna's case, it was just a matter of two days, and she was gone. For both of us, being that young and seeing death for the first time was emotionally arresting.

Then we had to go back to her room and pack up her things, which was excruciating. Looking back, to some degree, I realized it was a blessing for her. If she had survived, who knows how much brain damage there was or what kind of life she would have led. I would never anticipate then having to face a similar fate.

While living with my parents after graduating high school, I continued working at the convalescent hospital so that I could pay for my car, gas, and rent to my dad. I also kept working his avocado ranch without any payment and attended Palomar Community College in between everything else. I was studying both nursing and music and received my Associate's degree. In the meantime, Galen worked detailing cars while attending San Diego State University majoring in business.

Early Married Life

On June 21, 1975, Galen and I got married, four years after we met, and a day before my twenty-first birthday. We lived in a tiny apartment in Escondido but were very happy to have almost nothing except each other. We desperately needed money, so I took a break from college to help put my husband through school.

That's when I became a dental assistant and an office manager for a lecher. He only called himself a "dentist." I was confined to a dumpy little building in Escondido. I did billing, ran the front and back offices, cleaned everything, and sterilized all the instruments. The dentist would walk in the back door, sit down to work on a patient, and then leave for the day out the same door.

His careless routine was comical because of how automated it was. In the meantime, I was in charge of everything else.

This dentist was a disgusting pervert of a man who would always try to corner and grope me. Back then I had to develop the x-rays in the darkroom, and he would try to run in and close the door after him while I was in there. It was barely a closet space, and he worked so hard to be in there with me and rub up against me with his dirty, sweaty body. Although he was not a large man, his physicality and sexual aggressiveness scared the crap out of me. I was so young and quite naïve, and he took advantage of that. I was scared speechless.

If such unwanted advances had happened to me much later in life, I would have walked out the back door while threatening to tell his wife. However, back then, in the 1970s, most people tended to disregard a woman's word in favor of any man's in such situations. As such, I knew that no one would believe me, so I decided to endure the continual harassment. After six years of torment working for this dentist, I quit even though I was the primary income at that point and the job paid so well. Guess I know why, now.

Detailing Business

While I had the job with the dentist, Galen and I started our own business, which was an automobile detailing company. On Saturdays and Sundays we detail-cleaned motor homes, cars, and trucks. We made more money in two days doing that than the two of us made in a week in our day jobs. That's how we earned money for our first home in less than a year. We were living in a little apartment in Escondido but were saving as much as possible to buy our first place.

The one thing my parents had successfully taught me was the virtue of saving money. They never spent any money on us kids unless there was an absolute need and I picked up on the habit early in life. Without question, I deposited every penny I made since I was a child into a savings account. I never touched my savings, except to pay for basic needs, and later, our education.

Even with a healthy savings account, I was a careful shopper, looking for sales and getting by with just the necessities. We only bought things that we needed, and we made do with what we had until it fell apart, whatever it was. We didn't have any credit cards, and we would never buy anything on credit because if we couldn't afford it, we did not buy it.

When I married Galen, I had a decent savings account, but he was in serious debt. I remember walking into his, now our, apartment after our honeymoon and seeing about a half dozen pink slips all over his coffee table. These were late notices for everything from his utilities to his car payment. In addition to courting me, he would spend every cent that he made on everything but what he was supposed to, and there was never enough left to pay his bills. At that point in his life, he had absolutely no life skills or financial discipline.

I did everything I could so that we never fell into the same trap. When we were first married, I handled the finances. First, I paid off Galen's debt with my savings. After that, I would pay the bills and budget what we had, saving every little bit that we could. I knew that with discipline, it would eventually add up. I would go to the bank with as little as thirty-five cents and put it in our savings account, so we could eventually buy our first house. Galen would come home from work I would ask him to empty his pockets. I'd give him five dollars at the beginning of the week, and I wanted the change back. There were no exceptions.

Galen and I saved every penny we could and bought a new home in San Marcos in 1976, and moved in 1977 when it was finally completed. This two-bedroom, one-bathroom house was huge compared to our tiny one-bedroom apartment, and we had almost no furniture other than one little love seat and a water bed someone gave us as a wedding gift.

Starting a Family

After four years of marriage, we had issues conceiving a child. When we eventually considered the reality of adoption, we discovered that we were actually expecting. The timing was uncanny. Naturally, we were elated by the news. In 1980, we welcomed our first son, Trevor, and two years later, Michael came along. We skipped four years and then had Kellen, our preemie, followed by Alyssa ("Aly") two years later, our one and only girl.

After our first child was born, I rediscovered my life's purpose. Every time I checked on him in his room, his little face flooded my heart, then the rest of my body with an overwhelming feeling of lightness and positivity. It would just take my breath away. That was my small child, my "lovechild," and a gift from God. With each one of our children, I felt that way, and still do to this day. I so loved everything about raising our kids. Watching them learn and grow, and helping guide their minds and hearts to develop into beautiful adults. Galen and I felt blessed with our four beautiful, little beings. They gave us a new kind of resolve and shared in our unconditional love.

Neither Galen nor I came from the most effusive or loving families. Henceforth, it has been necessary for us as parents not to make the same mistakes our parents made. We decided rather early on that we would raise our kids with all of the love and care that we could manage. To be patient with them and to always make our kids our top priority. To the best of our abilities, we did just that.

As a homemaker, I was very active in all of our kids' lives while they were growing up. I managed their schedules, kept them busy with activities, made sure that homework was done, and doled out discipline when it was necessary. With my background in music, I tried to teach our kids how to read music and volunteered with each of their elementary schools twice a week to ensure that each of their classes had an excellent music program. I always felt that music is such a huge part of life and I wanted to be sure they had the opportunity to experience it.

I was also involved in the kids' sports including baseball and soccer, as well as their Future Farmers of America (FFA) activities. I would even volunteer to do all of the driving to be sure that none of the kids, ours or others, ever missed out on any opportunity. I would always have six or eight kids in my massive Ford Suburban and was their "mom" where I led them with songs and kept them occupied and entertained. It was a blast, and I loved what we did, and all of the kids loved me for it.

Galen and I had to make our way through college and had minimal direction or support from our parents, so we vowed to encourage our kids to seek as much education as possible. That's why we're very proud that all four of our kids went on to earn college degrees and are all successfully working in their respective fields. Trevor and Kellen are in management at West Pak Avocado, Inc., Michael is an airline pilot, and Aly is an elementary school teacher. Also, all of our children are married, and we're proud grandparents. Mila is Aly's little girl; Walker is Michael's son; Luke, our first grandchild, is Trevor's boy. As of this writing, we're expecting two more grandchildren—and very soon! As it turns out, I love being a Grandmother just as much as I've enjoyed raising our kids. Each new addition to our family is yet another lovely blessing from God.

One Step Forward, Two Steps Backward

When I met Galen, he didn't even know what an avocado was. Because of my thirteen years of experience as a ranch-hand, I knew plenty about growing them. I had a working knowledge of marketing, pricing, and business practices. I taught him everything I knew as quickly as I could. Galen's business acumen came in handy in 1977. We were approached by the owner of a fruit-packing house in San Marcos. My brother had worked for her in the past but had since moved on, and now she was looking for a partnership with someone who would come in and run the place. She offered 25 percent of the business and a fair working-wage while the candidate learned the ropes.

Galen stepped up to the plate, signing-on as the general manager. It turned out that he was a natural at running the operation. Galen had a knack for perfecting the various operational processes—produce-sorting, labeling, and packing. He even designed a more efficient method to pack and ship fruit. Galen had an uncommonly good rapport with the workers. They appreciated how respectful he was to them, and in turn, they worked as hard as they could for him. It showed. For five years, that packing-house ran like a well-oiled machine, churning out produce at a steady and profitable pace. Galen was to thank for it.

I remember the day we received news that our business partner's son landed himself in prison. When he was released, our partner instantly turned over her portion of the business to him. It was unprecedented to us. He wanted the entire operation to himself. He wanted Galen out of the way, so he fired him without thinking twice. Naturally, about nine months after that, company tanked. It was devastating to watch all the hard work we and effort go to waste.

One of the growers the company owed money to sued them in civil court. We had two babies at home and one on the way and didn't have a penny to our name, so we had to tap my retirement fund and sell everything we owned short of our home to hire an attorney to defend ourselves.

The case took several years to go to court. What's worse is that Galen was in court and unable to leave because I was giving birth to our third son. I was in labor, and the judge wouldn't accommodate Galen because of the timing of the verdict. Unfortunately, each one of the company's owners (Galen and myself included) lost the trial. What's worse, we each owed twenty-two thousand dollars, on top of legal fees, just to settle the case.

After the company closed its doors in 1982, Galen pulled into our driveway in his little pickup truck. I always thought it was a tiny piece of junk. He packed his truck to the brim with boxes. I remember noting his old desk chair, and a rattling old file cabinet buried under a sea of boxes. He unpacked what was left over from our involvement in the now-failed business.

I remember him looking crestfallen. For Galen, this was a significant blow. He has always been a fair and honest man. To this day, he has always been selfless. He has always put others first. It was unfortunate enough that he lost his livelihood, but being fired from a position, in which he performed so well, perplexed him. More than that, it shook him to his core. The whole ordeal left us both devastated.

Starting a Legacy

The next morning, November 2, 1982, Galen was up at 6 A.M. sharp, and we drove to rent a place in Fallbrook to begin our own packing house. Galen had an epiphany overnight realizing that we had the contacts and a good relationship with both growers and buyers. Why not start our own packing house? Thus, West Pak Avocado, Inc. was born. It was a small facility with just one existing packing line, but we worked it into an efficient operation. In the beginning, we rolled our sleeves up and got our hands dirty with everyone else.

Our first goal was to get things up and running. We would hire the picking crew to harvest the fields and would pull everything together, inspecting, sorting, labeling, packing, and shipping the fruit to our buyers. Business picked up, and the workload increased, so Galen reached out to his friend Randy Shoup, who eventually became our partner and helped turn our company into a veritable success.

We outgrew the five thousand square-foot Fallbrook packing house and, in 1991, we moved into a facility in Temecula, which was twenty-two thousand square-feet. In 2012, we moved to a more prominent facility in Murrieta, California, which we still own and operate today. This facility covers over one-hundred thousand square-feet and is the site of our current corporate headquarters. Today, West Pak is one of the largest avocado distributors in the world with seven facilities throughout North, and Central America.

We employ hundreds of full-time staff and support a large family of avocado growers throughout the Americas. To think that all of this, with West Pak, started because of my background in avocado ranching.

How to grow, tend, and harvest this tasty fruit and how to work with growers to achieve the ideal business solution for their crop. Galen realized the potential of the market, seized the opportunity and cultivated our business into the powerhouse company that it is today.

Balancing It All

Except for Sundays, holidays, and vacations in the summer, throughout our kids' entire childhood, we wouldn't see Galen until he finished all the business matters, which required his close attention. Six days a week he would spend toiling away, building his empire at West Pak Avocado, Inc. His devotion to his work, giving up time with family, was not done out of greed for the mighty dollar. At his core, Galen is not a greedy man, by any means.

On the contrary, he was, and is, driven to make things better for others. We spoke many times about his reasoning for working so hard. He saw it as his mission to take care of others. To grow the business and expand the opportunity for employment for others, so they too could feed their families.

It's often a stressful heap of responsibility on one person's shoulders. After business hours, Galen and his team would unwind by going out for a drink, or by grabbing a bite. They would get so wrapped up in their business banter that they'd often be out until “the last call.” These extended hours made it difficult to predict when he’d be home, which made it hard for me, on my own, to balance everything else involving our house and our kids.

I often thought of West Pak as the “other woman” in our relationship. Many times, when frustrated with being last in line for Galen’s time and attention, I asked myself why I stayed in the relationship. Like any marriage, there are times that you question leaving, and there were times I briefly considered it. When I hinted at the possibility Galen would say, “I have been left three times in my life, what’s one more?” I’d come around. I’d realize that I could never leave him. I loved him too much. Deep down I knew he also needed me.

We were partners, after all, and I would destroy that balance and sense of normalcy if I left. I also didn’t think he could survive another abandonment. His birth-mother had no choice but to give him up. His adoptive father died when Galen was young, in a sense abandoning him, and then his foster mother sent him away to boarding school. That’s too much for any one person to have to live with and I did not want to add to his anguish. The last thing I would ever do is hurt him. I had to reconcile the fact that Galen is the way he is with the fact that I cannot change him. So, I fall in line behind everybody else and take what I can get.

The Man I Know

Despite his unique upbringing, Galen turned out to be a very loving and giving person, which is why I married him. His nature is entirely stoic, not one to easily share his feelings, he has always been “the rock” of the family. Galen is also the most intelligent man I’ve ever met, especially when it comes to business operations and problem-solving. Nothing truly phases him. His ability to face the music and tackle foreboding decisions still astounds me. From Galen's point of view, every problem has a solution, and it's up to him to find it.

Galen is as stubborn as he is intelligent. There is no use in telling him how or when to do something. He hones in on a task and tackles it how and when he wants to. There is no use in stopping him. For example, Galen says that's he's retiring, but I know it's not a complete retirement. Even with somebody in place to run the company, Galen's still there. Still, with his hands in it all. Even after he "retires," I can imagine that Galen will continue as president of the company's board. That's just the way his willpower is. He won't let any of our hard work be mismanaged or squandered.

Galen continues daydream to me about us leaving for another place far away from our business. However, he is adamant about not selling our ranches or our Fallbrook home. I translate this to ultimately mean that if we are to keep our properties in any capacity, it means that we will be invariably stuck in our Southern California home base, overseeing their proper maintenance. That's just the reality I see in that. Neither one of us would ever trust anyone else to run our properties or to manage our estate again. It seems that in reality this ultimately means that we're not leaving at all. That's fine by me.

At this point, all I want to do is spend time with Galen like we used to when we were younger. Right now it's not about money or going to fancy and exotic resorts. It's not about owning more tangible "stuff." My priority is to spend as much quality time with my soulmate while we still have the time together.

> Be one with the sky and souls will collide. In the meadows, we meet in a dream. Love will redeem as one voice echoes through the forest. Who do we open our hearts to? What do we become? Where are we found? It's as though the Lost have withered away, buried in a deluge of forgotten dreams, and the search is long over.

CHAPTER 5

Callings

> When it's over, you finally give in, give up, call it quits, and say, "good night." I'm just so damn tired… Is it time to tap out and surrender the ring to the other competitor? She wants it more than I, and that's what it takes. You've got to want it, want it bad, so bad that dancing around the ring a few more times to deliver that final blow to the head seems quite simple at the present moment. Perhaps she needs the points, but I want them more, so I take them—it's that simple.

PHYSICALLY-STRENUOUS WORK HAS BEEN a significant theme in my life despite my best efforts. I first encountered it on my father's ranch, then with wrangling my kids much later. For six years, it defined aerobic dance for me. I surprised myself when I eventually became an instructor in aerobic dance choreography while I was pregnant. Once our avocado business took off and our kids were situated at school with their various interests and activities, I decided to tackle the martial arts. It's a somewhat unexpected story. Even to me, right now, as I write this.

One of my sons was bullied at school. His friend's mother suggested I put him in martial arts to give him the means to defend himself. We went down to a local church hall that held classes for taekwondo at night. I enrolled him, and I did my bible study on the sidelines as I watched him during class. As the lessons advanced, the sessions became increasingly spirited and physically intense. I was mesmerized by the various techniques and was swept up into the energy of the sparring sessions, that I found that I couldn't do my bible study any longer. I couldn't concentrate.

Instead, I kept watching my son and the instructor. I was fascinated with the cause and effect of the attack and subsequent defense and all of the nuances of the various blocks, punches, and throws. Finally, one day the instructor threw a uniform, which is called a *dobok*, at me and told me to put it on and try it. So, I did. It turned out that I loved it! At that moment, I decided that I was going to do this, and in less than a year I was a first-degree black belt in taekwondo. I worked that hard. I was in my forties. I was successfully balancing a busy home-life with four kids and achieving a high rank in a new sport, taekwondo.

Ever since I was a young girl, I'd go for something when I wanted it. As much as I still loathe him, my father has indeed bequeathed a vital virtue to me: If I wanted anything badly enough, I could undoubtedly get it, but only by investing hard work over time. Never in my life did the word, "failure" arise in my vocabulary. It just wasn't an option. In my father's home, the concept of "failure" was regularly met with sharp disapproval even harsh discipline. I was just so afraid of him that everything I attempted (violin, schoolwork, farm-work) became a matter of life or death.

During my third year in the sport, the head taekwondo instructor where I trained moved to Little Rock, Arkansas to work for the American Taekwondo Association. The timing seemed right, so a couple of partners and I purchased the location of the existing student-base of the school, which was in a local church. We rented a twelve-hundred-square-foot storefront space on

Main Street in Fallbrook, California, with great big windows across the front of the facility.

When the rest of Fallbrook had already shut down for the day, people would drive by at night and see my studio all lit up with classes packed with students. In the beginning, we taught classes to around a hundred students at any given time. We instructed a wide range of students, from a three-year-old black belt on our little tiger team to adolescents, to adults of various ages.

Within a year, we expanded operations by doubling the facilities and then two years later tripled the original space. Our staff also grew to include seven black belt instructors who would help teach.

Competition

After I had obtained my original black belt, I had started to compete in tournaments with the American Taekwondo Association, which was a requirement to advance in rank. In similar competitions, I did well enough to take home the trophy. I usually won either first, second, or third place every time I competed. Throughout six years, the awards would number into the hundreds. I'd even travel with about twenty to thirty students who would compete along with me. Traveling was especially important to me because I got to compete.

Each competition was another opportunity to earn enough cumulative points to qualify for the World Championships. It's the most prestigious competition for taekwondo. I'm proud to share that I have repeatedly placed in the top three in my division at the World Championships.

In the World Taekwondo Championships, competitors are matched within eight gender and weight divisions. Whoever accrues the most points wins each match. When an opponent is injured, or physically unable to participate in a match, they lose. If an opponent is "knocked out," they forfeit. Winning a match depends on several things: superiority, withdrawal, disqualification, and even a referee's punitive declaration.

Each sparring-match consists of three different two-minute rounds, with up to one-minute breaks in-between each round. These breaks are often cut short in some junior and regional tournaments. In taekwondo, advancement and rank depend on one's discipline and dedication. It took two years of competing to achieve my second-degree black belt, three years for third, and I was testing for my fourth-degree black belt when tragedy struck.

Breaking My Back (Literally)

In 2002, I broke my back. Technically-speaking, somebody else actually broke it. During a competition in Oxnard, California, organizers put me in the ring with a giant. She towered over me, at six feet, two inches, and had at least eighty pounds on me. I'm five feet, seven inches tall, and at the time I weighed maybe one hundred pounds.

Although I was a rather muscular and strong woman, this opponent was near twice my size and was two degrees and eight years of experience ahead of me. Because of our difference in size, weight, rank, and experience, there was absolutely no reason for the two of us to be paired together. Yet there we were.

I knew when I stepped into that the ring that day, that I wasn't going to take that match but I would give it everything I could and would have fun doing it. When I got the first point during the competition with a mere tap, it infuriated my rival. A simple punch to her abdomen and I heard the judges yell out, "one red," meaning that I got the point. I was merely having fun with it all and cracked a bit of a smile at the thought that she did not block my hit.

I could see on her face that she was out for blood. Her nostrils flared, her jaw clenched, and her frenzied eyes made told me she wanted to kill me. After all, this pipsqueak of a woman made her look bad on the mat, and she couldn't handle it. She tried to teach me a lesson.

Next thing I knew, my opponent attempted to kick me in the head. That type of blow was not legal in competition and could have killed me if she had connected to her intended target. Her massive leg swung across her body, and I turned and blocked it by raising my right arm. Her right foot deflected landing squarely between my shoulder blades on my back. I slid out from underneath her foot and fell to the mat, with her heel landing hard, dead center on my mid back. It was an "ax-kick" to my spine, and it immediately laid me out.

I heard a sharp snap like that of dry twigs and felt this sudden pain shooting through my veins like I was being electrocuted from inside my own body. A judge asked me if I was able to continue and, without flinching, I replied, "yes." My opponent was unusually tall. She looked like how I'd imagine a mythical Amazonian in real life.

She was on her knees, her back to the ring, acknowledging her wrong-doing silently. The momentary pause did not stop the match. I hopped up, flung my gloves, and bounced my feet back and forth. I was ready for another go.

It was over before it began. I remember the overwhelming pain. I fell back onto the mat in a quick defeat. When the beastly woman entered the ring, she waved to the crowd. Her massive arms towered high above her head, and everyone immediately cheered. When she won the match, she left as notably as she arrived. It was as if she left me in her wake without care. With one swift and illegal kick, my career teaching this or any other sport was over.

It's the nature of the sport that one does not question the higher ranks, so I accepted my fate and moved on. Many rules changed after that match, but for me, it was at too high of a cost. I lost a piece of myself to that day, and I've suffered for it ever since. To think, my mismatched opponent only received three months of probation for deliberately incapacitating me.

Quite frankly, we should have sued her, or at least, we were well within our rights to press charges. But we're not spiteful, nor overly litigious people at all. Besides, I had more significant problems on my plate, though I didn't know this at the moment.

Tapping-Out

Now that the match was over for me, my team carried me off the mat. Despite the sharp pain in my middle and lower back, and a burning sensation down the front of my right leg through the top of my foot, I didn't realize at the time how severe my injury was. I was likely in shock over the situation, both mentally and physically. I couldn't believe what had happened or allowed to happen, so much of the rest of that day was a blur. Another instructor made the three-hour drive home with me, and after he dropped me off at my house, I immediately climbed into bed. It was late, so I didn't want to wake Galen. He had no idea what had happened.

The next morning, I felt as if I couldn't move. My entire body ached, and it felt as if my back was fused to a board. There was also numbness, tingling, and some weakness in my legs and feet. I tried to roll over to one side and swing my legs down to the ground to get up. It was too painful to do on my own, so Galen helped me out of bed. Despite the immense pain, I tried to shake it off, to tough it out, but eventually had Galen take me to Scripps Green Clinic. My doctors insisted I rest if I wanted to heal properly. I needed to be immobile for six to twelve months. I had a business to run. I didn't want to consider their advice, let alone accept it. Above all, I've fashioned myself after a fierce warrior, like a powerful and relentless pro-athlete.

It turned out that I sustained compression fractures to my L3, L4 and S1 vertebrae—the last of which resides at the base of the spine, at the lumbosacral joint. Because this particular segment of the spine has several interconnected components, damage to this area is known to cause lower back and leg pain. Depending on the severity of the fracture, residual pain can linger long after it heals. In my case, the pain was immense, and my back couldn't sufficiently support my weight. I met a young neurosurgeon who convinced me that I'd be back in the ring breaking boards in weeks. She told me that fragments of bone, or "floaters," triggered serious waves of pain in my legs and back. In response, I underwent three neurosurgeries.

Each surgery tried to extract several pieces of bone—"floaters"—that were lingering inside of me for over two years ever since I broke that section in my back. Unfortunately, each attempt failed, so we concluded that there was more damage than the surgeon had initially led us to believe. At first, I naively trusted her. I did not do my research. I should have looked into my specific symptoms, their proposed treatments, and the particular surgeon's professional track-record before agreeing to her diagnosis.

Placing too much trust in the young neurosurgeon proved to a be a grave mistake. I would never make again. It turns out that this particular neurosurgeon had several malpractice complaints filed against her record. She is no longer practicing medicine, which makes sense now why the surgeries did not work for me.

In the meantime, I spent two years getting around either in a wheelchair or using a walker and suffered immense pain in the process for no reason. Two of my sons, Michael and Kellen, and my sister, LaDonna, a chiropractor, took turns caring for me during this time. It was quite a blow to my self-esteem to need this much help, physically. I was nothing but incredibly grateful for my family, who was somehow there to help when I needed it the most. I can't imagine survival without their contributions.

In 2004, another surgeon stepped in and revaluated my situation opting for a fourth surgery to add hardware to stabilize my back. It was clear to this doctor that my back needed to be secured so that it could hold my weight. He installed a series of surgical rods and screws inside my body. “Fusing” my back drastically limited my mobility, although it relieved some of the pressure between each vertebra so that the fractures could heal unencumbered.

This procedure gave me as much relief as I could expect considering the severity of my injuries. In addition to limiting my range of motion including bending from side to side and twisting, I’ve suffered through crippling pain every day since the break. My legs throbbed with pain. The little sensation I felt on the top of my feet, and around the hardware inside my spine, was noticeably diminished. This loss was very irritating. One of the screws even pressed up against my tailbone, which made sitting for long periods rather painful. It wasn’t until 2017 that I was well enough to have the hardware removed.

After the initial break, I could no longer participate in teaching, so I had to sell my school and retire from the sport. It was quite a blow to my heart. I ended up selling my portion of the school to my partner and bowing out. This was very difficult because I loved it so much. I was very passionate about teaching taekwondo because it marked one of the few periods in my life that I experienced freedom and absolute joy.

I remember feeling very accomplished with my successes, in a sport, and business. Through the school, I was able to touch many lives and build their self-confidence all while teaching them valuable lessons in discipline. Everything that I labored for was gone, and I felt empty, helpless and alone. In a snap, it was all taken away from me. Losing the school and ending my career in teaching was my first failure. Ever.

CHAPTER 6

It Started as a Headache

> This isn't a headache! It isn't just pain! It is a complete rapture of the skull. Total embrace, like the mechanical monster gone madly out of control. Pressure building to the point of explosion, near. Tension grows, anticipation causing brain matter to be subconsciously blown, like balloons are to eardrums.

It was August 2, 2006, a Wednesday. It started as a nasty headache with immense pressure in my ears that felt like my head was going to explode. At the time I wasn't sure what caused it, but the sensation was excruciating. I knew something was fishy. I could hardly swallow the prospect of not being able to drive myself to the hospital. I had to rely on my family despite my frustration. They insisted that I lay down with a cold compress on my head. I had to comply.

The next day, in addition to the head pain I was running a slight fever, and my neck was stiff. The vision in my right eye quickly deteriorated, and, before long, I started to see double. I also felt somewhat disoriented and was having trouble walking. When I tilted my head, even just a little, the pain in my skull would crest, and my ears burned like they were brimming with boiling, liquid lead. Rapidly firing lights started to flash in front of my eyes, and the searing pain became so unbearable that eventually, I couldn't keep my eyes open. Any amount of light was just too much to bear. The pain grew even stronger by the third day, and the Imitrex prescription for my occasional migraines wasn't working.

By Saturday, the pressure and pain in my head became so unbearable that I lost myself for a while. After resorting to extreme measures by screaming for help, our son Kellen stepped up and took me to the emergency room at Fallbrook Hospital. The drive from our home to the hospital was only about fifteen minutes, but it felt like hours. The constant stopping and starting, however trivial, were disorienting. The unnerving jolts as our SUV swerved through the steep and winding hills of Fallbrook. These were all contributing to my nausea. I absorbed every little bump in the road along the way. I remember wanting the movement of our vehicle to end and to get to the hospital so that I could realize some form of relief. By the time Kellan and I arrived at the hospital, parked and entered the emergency room, the pressure in my head was so immense that I was sobbing uncontrollably.

Kellen and I spent six hours in the emergency room facility where the medical staff focused only on my head pain. I remember that one young physician, who looked like he was maybe twenty-five, dismissively told us that I only suffered from "a migraine." I remember him being skinny and disheveled, like a man-child who slept in his scrubs the night before. I was perplexed because he didn't even bother to consider my various other symptoms. Besides, I'd had suffered migraines many times before and knew the indicators. This new pressure surging in my head and the pain that it left in its wake was no migraine. Between issues with my vision, my lack of balance, and the sensation of flashing lights, it was clear to me that I was suffering from something much more significant. I couldn't comprehend why no one understood what was so apparent to me, even in the stupor of my advancing pain.

Desperate for relief and with tears streaming down my face, I pleaded with the doctor with all the timbre and volume my hampered vocal cords could muster. I begged him repeatedly to help me, but he merely looked at me with a dead, emotionless expression and said, “Lady, you have a headache, go home!” He scribbled on his prescription pad with a few broad pen swipes and shoved a Vicodin script in my direction.

He didn’t even look to notice that I couldn’t hold my head up long enough to take the prescription from him. Instead, he handed it to Kellen, turned on his heel and walked out the door. We’d find out later that this doctor’s inaction—he did not detect any of the other telltale STBI symptoms beyond head pain—eventually sealed my fate; he did not recognize the classic triad of symptoms for a brain abscess: disparaging fever, unrelenting head pain, and severely deteriorating vision.[2]

Consequentially, in a matter of days, our lives would change forever. When we left the hospital that very evening, my son, Kellen, and I discovered that our local pharmacy was closed for the day, so we were not able to fill the prescription for my pain medication. I was having a rough night. Galen was able to make it to the pharmacy early the next day to fill my order. By later that day, a couple of doses of Vicodin took the edge off the pain in my head. Or, so I thought.

Vacation from Hell

We always took a family vacation during the summer while the kids were out of school. We’d usually spend a couple of weeks soaking up the sun at our home on Lake Havasu or relax like a local on the Pacific coast of Mexico. 2006 was no exception. Despite my looming medical issues, on Monday, August 7, 2006, we departed for our vacation-getaway in Mexico, as planned. I endured the chaos of boarding and the tedious six-hour flight despite an extreme sensitivity to daylight, the rising pressure in my ears, and a searing headache. We traveled all day and reached Ixtapa in the late afternoon. Once we arrived at the resort, all of the curtains in our room were drawn, and I was promptly put to bed while the rest of the family went out to their favorite watering hole.

After a few hours, I awoke from a sound sleep screaming in agony. The resort management came over along with the police to find out what was going on. Other guests were concerned about what was happening, and not knowing what to expect, sent the authorities to deal with the situation.

The authorities witnessed me screaming in agony and cradling my head with both of my arms. They quickly realized I was in the middle of a dire medical situation. Galen told me later that I was acting strangely. I was noticeably incoherent and unresponsive. Worse, I was behaving as if I were oblivious to any person in close vicinity to me. Aly, our sixteen-year-old daughter, tried to help but my screaming was so loud that she ended up out on the patio with the door closed behind her.

The resort doctor promptly told Galen that I needed to go to the hospital immediately. Ambulances in that part of Mexico were scarce and under-equipped, so Galen had to take me himself. I understand that it took an hour to get me into the car to go to the hospital. I honestly don’t remember, as this was likely the immediate aftermath of the burst abscess in my brain. I didn’t know at the time, but bacteria were running rampant, utterly ravaging my brain tissue.

Searching for Help

After my family finally got me into the car, Galen drove me to the nearby naval hospital where the doctor from the resort greeted us. The hospital admitted me into a large, mostly empty private room and the nurses prepared me for my stay. The doctors first administered medications for my high temperature and performed lab tests to check for E. Coli and influenza viruses. About four hours later the results came back as negative. At that point, my temperature had dropped back down close to normal.

According to Galen, I could no longer respond to my name or identify him or the kids. My eyes became dilated and then rolled back into my head. The doctor suggested that Galen should consider immediately taking me to a better-equipped hospital in Mexico City or transport me back to the United States for care closer to home. The doctors were mainly worried about my impaired and worsening cognition, and they felt that they were unable to help me.

Not knowing how extreme my condition might be, there was a concern for the level of medical care that I could receive in a hospital abroad. Galen wanted me to have access to the best care and any specialists that I might need, so he decided to get me back to the United States as soon as humanly possible. He promptly called our emergency medical evacuation number through our travel insurance. The MEDEX Travel Assist, a service that responds to medical care situations while traveling, kicked in and arranged a medical-evacuation for the next morning. I remained delirious all night, which frightened my family about my chances of survival.

Emergency Evacuation

Luckily that night the physician who decides to grant emergency evacuations, did so, and the next morning the emergency evacuation team arrived at the naval hospital at 7:30 A.M. sharp. I was rushed to the Ixtapa Airport, and a personal “Learjet” was standing by with two emergency medical technicians to accompany me on the flight to the states. There was only room for one other passenger on the plane, so our daughter Aly made the trip with me while Galen, Kellen, and his friend who came with us on vacation flew home later that same day on two different commuter flights.

My plane landed at Brown Field in San Diego, and an ambulance was waiting there to take me to Scripps Mercy Hospital Trauma Unit. At 12:30 P.M. we got to the hospital, and I was wheeled straight into emergency intensive care. All of this unfolded before Galen could arrive in the states.

So, our eldest son, Trevor, who was only twenty-five at the time, had to step up to make any critical decisions and sign paperwork to admit me to the hospital and authorize any procedures. I was unconscious and intubated, so my Advance Health Care Directive automatically kicked in.[3] While the respirator kept me alive, a decision still had to be made, by proxy. To continue life-saving efforts or to pull the plug.

To this day, I feel incredibly guilty and grief-stricken that Trevor had to make such intense life or death decisions, especially for his young age. Although I taught my kids to be strong, it wasn't fair that Trevor had to carry that burden as to whether or not to keep me alive, let alone move forward with any procedures.

How was he to know that by consenting to keep me alive, that his actions would later compound my suffering and that of the entire family? How does a child, even one in his twenties, pull the plug on own his mother? It's too much weight for such a young adult to have to shoulder and I wish that I could have protected him from that situation. The "mother" in me frantically wished that Galen were there to save Trevor from the anguish.

CHAPTER 7

First Assessment

> Step into my world. In a snap, you are in another space, on another plane of the same life, a different track if you will, running simultaneously. Thus, the mass confusion. Which planet am I from? And on which one am I now? How, when, where? These doors never completely open for me. I know their existence. I know the ability to see time as levels – from outside of myself. I just don't know how to keep them all straight. It is like an algebraic algorithm, whose magnitude lies beyond my ability to describe. Just picture- space, vast, everlasting. Our world, but a speck, in the mix of things. Upon which your planes arrive, divided, as one.

My son, Trevor, met the ambulance at Scripps Mercy Hospital and gave the Intensive Care Unit (ICU) physicians the history of the events and my medications at the time. The emergency medical staff performed a CT scan and an MRI of my head soon after my arrival. In reading these scans, it became clear to my doctors that I was experiencing intracranial pressure likely caused by an infection. They told Trevor that, if I were to have any chance of survival at all, I would need surgery immediately to relieve the mounting pressure in my head. The same doctors also told him that I had less than a five-percent chance of surviving and that I would likely die or end up in a vegetative state without surgery. Trevor knew that I would face certain death if I hadn't received immediate medical attention. Without pause, he signed medical releases on my behalf, and I was rushed into surgery the same afternoon.

First Surgery

Dr. Sohaib Kureshi, the head of neurological surgery at Scripps Mercy Hospital, operated on me. The operation involved drilling two dime-sized holes in my skull on the right side. He made one lower and toward the back of my head, and he made one high above my ear. This procedure released the fluid from the abscess, which in turn reduced the pressure inside my skull.

Dr. Kureshi then installed a drain-like apparatus into my head to prevent any excess fluid from building up. Then, a surgical team performed lab tests on the drained liquid they collected from me to identify the exact type of infection afflicting my brain, and more importantly so they could prescribe the right antibiotics and antifungals.

After my surgery, Dr. Kureshi explained to Trevor that they discovered an egg-sized abscess in a difficult-to-reach area far inside my brain so he couldn't attempt to extricate it. That was not the end of the bad news. It only got worse.

It turned out I had an intraventricular rupture in the abscess, which was inside the ventricles between the frontal, temporal, and parietal lobes of my brain. The abscess burst a day earlier, likely while I was sleeping our first night in Mexico. This internal eruption released a virulent infection, which quickly enveloped my entire brain and its ventricles.

This is called ventriculitis, which is a dangerous infection of the fluid surrounding the brain cavity. It causes the lining of the ventricles within the brain to become inflamed. Ventriculitis can produce a whole spectrum of painful symptoms, including onset dizziness, incapacitating headaches, and even creeping unconsciousness; it can also be terminal if it is not treated immediately.[4]

I was facing unfavorable odds. All the doctors could do was to continue to relieve the pressure in my head with the drain and try to treat the infection within. Unfortunately, any assessment of the long-term damage to my brain would be deferred.

The evening of my surgery, after a long airplane flight, Galen and the rest of our kids joined Trevor at the hospital, and they all learned about my diagnosis. Naturally, they were devastated upon hearing the news. They could only pray for the best despite my overwhelming odds.

Post-Surgery

The next morning, the doctors focused on tracing the cause of the infection in my brain, the same infection that caused the abscess to rupture. Over the next twenty-four hours, doctors identified the exact strain of bacteria that caused the encephalitis—or, swelling—in my brain.

They then administered a substantial dose of penicillin. Encephalitis was the same condition that caused the death of my friend Donna in 1975. She had come down with chicken pox as an adult, and the swelling in her brain was far too much for the rest of her body to endure.

While I lay unconscious from the heavy post-surgical medication, Dr. Kureshi was concentrating his efforts on keeping my brain alive, his top priority. While monitoring me carefully, he walked Galen and the kids through each step and what to expect over the next few days. He reiterated to my family that my life was in severe danger from the infection caused by the abscess. He warned them to not to expect too much quick progress and told them to be patient and to take things day by day.

On Friday, August 11th, my family arrived early to speak to Dr. Kureshi. The doctor was alarmed that morning about my sudden spike in brain pressure, which is known as intracranial pressure (ICP) in medical terms. Dr. Kureshi noted that normal brain pressure is in the 1 to 10 mmHg range and that a healthy person had to stand on stheir head to register a measurement of 15 mmHg. At that time, my brain-pressure measurements hovered around 50 mmHg, and at one point spiked to 80 mmHg.

The penicillin was effectively killing the bacteria but was also increasing the pressure in and around my brain by creating a high volume of discharge. The drain installed initially into my head was not large enough to keep up with the debris volume resulting in rising pressure.

Dr. Kureshi told my family that I needed immediate relief and that there were only two main options. One option was to remove a section of my skull to relieve the pressure, but it came with the risk of permanent post-surgery brain damage. The other option was to do nothing and hope for the best. I would likely succumb to the pressure, and my brain would cease to function, rendering me brain dead.

Instead of risking surgery, Dr. Kureshi decided to put me into a medically-induced coma to lessen some of my brain activity. He explained that it was being done to give me my body a better chance to concentrate on fighting the infection. I learned later that my friends and family convened after the meeting to collectively pray for my survival.

By the next morning, Dr. Kureshi reported that my brain-pressure had dropped into the mid-20s range. Everyone was very relieved. Our collective cynicism turned into a small ray of hope. I'm sure that the three powerful drugs I on played a critical role—namely, the Phenobarbital (used to induce my coma), Vecuronium (used to paralyze my muscle activity), and Propofol (used to sedate me and reduce my pain). Galen joked that he didn't believe it was humanly possible for anyone in my situation to have any more tubes, and IVs, running in and out of their body. I must have been quite the sight.

Circle of Prayer

Sunday, August 13th was a special day because various local churches had me on their prayer lists and many family, friends and even former students were in attendance. I later learned that while I was unconscious, upstairs in the same hospital, my nephew, Adam, and his wife, Amy, were having their first baby. They had a beautiful girl named McKenzie. There was a stark juxtaposition between our two worlds. I clung to a previous life, while they ushered in a new one.

The morning was optimistic. My intracranial pressure (ICP) measurements fluctuated, from 8 mmHg to 15 mmHg. My "exit-tube" transformed from a white puss-filled line into a light-yellow fluid. It almost had the ideal, transparent luster of healthy-looking fluid. My doctors and nurses told Galen in his daily visit that they were encouraged with my progress. Everyone from caretakers to family breathed of relief, at least for the time being.

My ICU nurses expressed to Galen that my elevated heart rate was telling them that I was in pain, so they began administering Morphine on top of everything else. Things looked good, so they delivered what would be my last bag of Phenobarbital the following Sunday evening.

The day before, both nurses hinted to Galen that there would likely be more activity from the doctors on Monday morning. They explained that Mondays were busy days for some doctors, as they needed to catch up on events from over the weekend. Galen was hoping that there might something that would give a hint about my mental state.

On Monday, August 14th, my family arrived early to the hospital hoping for a sighting of my neurologists. This day is when they thought they were going to know my prognosis finally and understand the expected recovery. That idea flew out the window immediately when Dr. Kureshi told them that he decided to step down the removal of my medications slowly, so the transition did not shock my system. Suddenly everyone realized that I would take days to come out of my coma, not hours.

The good news that morning was that my ICP had dropped into single digits and the discharged fluid color was a light yellow. That afternoon the nurses deleted the Phenobarbital station and started to crank down the Vecuronium and the Propofol. Now it was time to wait.

Awakening

Galen called early Tuesday morning and the night nurse informed him that I was doing about as well as I possibly could. My intracranial pressure (ICP) remained low, and the color of my brain cerebrospinal fluid (CSF) was transitioning to a lighter shade.

Dr. Kureshi was in morning surgery, as my friends and family waited to soak up any news. After an hour and a half, he appeared and again reminded everyone that it could take several days for me to awaken from my narcotic-induced sleep. He told them to be patient.

The afternoon wore on, and Galen revisited me in the evening just before the shift change at 7 P.M. He was denied entrance at first because of all the commotion of a newly arriving gunshot victim. He finally managed his way in but found that all the emergency nurses were tending to the shooting victim.

Galen came straight over to be with me. He sat on the edge of my bed and reached out to touch my hand when out of the blue I opened both eyes and just stared at him. Galen said that my eye contact led him to believe that I recognized him. He thought I was responding to his voice with my subtle facial expressions. I'd raise my eyebrows and open my eyes wide when Galen spoke to me. I'd painstakingly try to track his movements when he changed his sitting position.

I'd learn later that these interactions both shocked and elated Galen, so much that he could hardly contain himself. Of course, the complexity of his emotions was lost at me back then. He would inform me later that he was driven to tears. He didn't want to alarm me, so he held them back. He just smiled broadly, laughed nervously and pulled my hand to his face to kiss it, repeatedly. When the nurses were able to return from helping the gunshot victim, they confirmed that I had awakened. Although I don't remember anything from this point in my recovery, according to the nurses, I had passed some early recognition tests.

In all of the commotion stirring about in my room, I had become agitated, so the nurses stepped out and allowed Galen to talk to me, to soothe me with his voice. Once I was calmed down, Galen rushed out and called family and close friends immediately, and he was uplifted even more in hearing the sheer excitement in everyone's voice. I was back, or so he thought, and for him, it was not one second too soon.

CHAPTER 8

Hope

Grace, beautiful grace, live, peace and serenity. Cover thyself from petal fall, as roses prepare for new birth. Buds beget beauty divine and color surrounds. The scent, it's beauty sleeps, and crickets sing while moons' tomorrow makes an exit for the Son's entrance. Peace again shines upon those who believe.

THE MORNING OF WEDNESDAY, August 16th was a whirlwind. Everyone came by to see me in the hospital. The nurse warned everyone not to get me too excited and not to ask me to move parts of my body for them because that was my job, not theirs. They reported that my lucidity was excellent that morning and my range of motion had improved from the night before. I was able to show selected fingers, had strong hand movement and some movement in my legs.

A Good Day

The left side of my body was performing much better than the right—this disparity would be addressed in later physical-therapy-sessions. At that time, my attending nurse decided that all my visitors needed to greet me on my right side from that point forward, or at least until there wasn't an issue with my body's other hemisphere. Dr. Kureshi stopped by that afternoon and was very positive. He said that he was much encouraged by my recovery so far. My nurse also commented that in her twenty-five-year career she had never seen such improvement in a patient who had such a slim chance of surviving such dramatic injuries. These comments gave my family hope and provided some much-needed reassurance.

After a long day with other visitors, Galen came in around 8 P.M. to say goodnight. I cracked my eyes open enough to make eye contact with him. Much to his delight, I reached up and grabbed his hand, which he took as my acknowledgment that he was there. I honestly don't remember this instance or much that went on during this part of my recovery, but more on that later.

My night doctors came by and expressed concerned about a small amount of stomach bleeding that appeared that afternoon. Other than the possible ulcer, they spent most of their time reviewing other medical issues besides my brain. Since their focus had shifted to my general health, Galen took it as good news and a step in the right direction.

On the next morning, Thursday, August 17th, it was reported by my nurses that I had a good night. I had slept soundly throughout the night except for the occasional checks by the night nurse. The good news was that these checks indicated that my right side was showing some slight improvement. I was starting to move my right arm and hand more and was exhibiting slightly better coordination. By the time Galen came by in the afternoon, I was tired from a busy morning. In addition to receiving a CT scan of my brain, I also underwent several tests—blood, breath and fecal—for my ulcer.

Galen was looking forward to hearing Dr. Kureshi's comments, as my nursing team was attempting to take me off the ventilator. They wanted to step down the amount of assistance the system provided to get my body to take over the function of breathing for myself. It seemed that I was having a hard time breathing on my own once I dozed off, which was not uncommon after anesthesia. The nurses offered reassurance that this was completely normal at this stage of my recovery and stated that once all of the medications from my surgery were entirely out of my system, I could start to breathe on my own.

In anticipation of the orders to remove the drainage line from my head, the staff raised the collection container higher than my head to slow down the flow. This action was considered good news even with my slightly elevated brain pressure, which was hovering around 20 mmHg. The cerebrospinal fluid (CSF) was now clear, and some of my IVs and monitoring systems were removed. I could finally leave the ICU.

Physical Side: Progressing

The next morning, I awoke in a different private room, with a television, no less. However, I was still agitated by the clamor caused by the “hustle-and-bustle” of the ICU. There were always loud beeps and buzzers and piercing alarms going off from the various pieces of equipment. The staff was perpetually on the move, checking on me in my room, or buzzing back and forth to the nurses’ station directly outside my door. The constant bustle was overwhelming. It was like I was in the center of a busy fishbowl. Hungry piranha peered in from behind the glass.

Although my cognitive functions had hit a temporary plateau, the left side of my brain was showing improvement. Two fortuitous CT scans revealed decreasing inflammation in my ventricles. It had been ten days since my surgery, and my family was very interested in when they would take out my ventilator tubes. They were also growing increasingly curious if I was able to speak once the ventilator was removed. Based on the early scans of my head, Dr. Kureshi had always felt that the potential damage to my brain would have affected the movement on my right side, as well as my speech. At this point, only time would tell.

I got my hair washed and had a bath and then fell deep asleep, continuing my slumber well into the afternoon. The doctors elevated my tube-receptacle to 15 cm over my head, and my intracranial pressure (ICP) remained in the 8 to 10 mmHg range, which was "normal." Their goal was to reach a receptacle height of 20 cm and assuming that my pressure held steady, they would consider removing the tube altogether. According to the nurses,

I couldn't leave the ICU until it was time for the tube to come out. Keeping it in meant the nurses had to monitor me more closely and frequently. Although I resumed routine liquid-nourishment, and my IVs were gone, my progress was difficult to gauge because my medical team insisted that I rest the whole day.

Resting Steady

After another weekend in the ICU and approaching two weeks of hospitalization, Dr. Kureshi seemed satisfied with my progress. According to my nurses, no news was good news, so they went about their ordinary course of business. They continued with my regular schedule of medications, feeding, turning my body position to limit bed sores, and general monitoring, to be sure that I was as comfortable as possible. Despite my stability, Galen had become frustrated and saddened that I had not progressed much with my cognitive abilities.

He noticed that I exhibited three distinct behaviors: excessive and deep sleeping, brief moments of clarity (usually for only a few minutes). I was able to sustain healthier levels of "awareness" because I was conscious for more extended periods. Being awake for up to an hour with fast eye roaming and an occasional lack of concentration was a milestone. The nurses reminded Galen not to get impatient because my brain was still very inflamed. Even with low bacteria counts, the inflammation could cause impairments with some functions including memory, speech and motor skills.

My internal sodium retention was also down and needed boosting, and I was still receiving four IVs of varying amounts of morphine, insulin, antibiotics, and a general fluid agent. Nourishment was two bottles a day of Promote with fiber to satisfy any hunger. Four tubes were running into my nose and mouth, a ventilator, feeding tube, gastric suction, and mouth saliva suction. I looked like I was "poster child" for the hospitals ICU.

Another Step (Backwards)

By August 22nd, I had shown enough improvement. It was time for the ventilator and intubation-tubes to be removed—and for good. I was transferred to a standard-hospital-recovery-room, on the 11th floor. However, the second I settled into my new space my body immediately responded by crashing—hard.

After my intubation, swallowing was painful. I wasn't even allowed to drink water. However, I was being pushed hard by the speech therapist to eat solid food for lunch. After managing not to choke after a few bites of food, I experienced acid reflux and ended up aspirating gastric acid into my lungs.

My doctors spent the afternoon administering breathing treatments and injections to improve my intake of oxygen because of the stomach acid burning in my lungs. By later that same day my lungs had become so congested, a natural reaction to the gastric acid, that I was placed back into the ICU, technically the non-surgical intensive care unit (NSICU) as a precaution.

I was breathing slightly better with less effort by the next day, showing increased amounts of oxygen in my bloodstream. However, a CT scan of my lungs confirmed a severe case of pneumonia. It was affecting one lung in the lower lobe and the other lung in the upper lobe. About the only good thing to report was that my vitals were steady and I did not need to be on a ventilator.

Although my recent blood cultures looked good, my cerebrospinal fluid tests did show signs of continued bacterial infection. My doctors decided to take a more aggressive approach and stepped up the dosage of my antibiotic IV treatments, which would stay for several more weeks. They needed to reduce the bacteria levels to avoid additional inflammation and potential damage to my brain.

Between some depressing setbacks—continued brain infection, and a new case of pneumonia—we all became overwhelmed with nagging concern. The time spent in and out of ICU those two and a half weeks was, if nothing else, a lesson in patience. This would come in handy later. It was the first of several setbacks during an extensive recovery.

My family found it hard to keep their spirits up at this point, and they were growing frustrated with what they thought was a lack of progress on my part. They were looking forward to me heading towards rehabilitation and eventually going back home. Back to a healthy life. Naturally, we all desired that to happen but needed to come to terms with what was considered reasonable as far as realistic expectations, especially in light of my condition at the time.

CHAPTER 9

Rehab in Sight

> To feel what condition my condition was in, there is a point that I can't tell there is a condition. This is where I have gone down that rabbit hole. No return. Too steep a fall, too fast. I'm lost and confused. I know I am but cannot break out of the box. Captured in my own injury, held against my will, I want someone desperately to notice that I am losing ground, headed for hell yet no one notices I need help.

BY FRIDAY, AUGUST 25TH, I was responding well to my various intensive treatments. Dr. Ballon-Landa, my infectious disease specialist, continued to prescribe new combinations of antibiotics to help improve my pulmonary condition caused by aspirating gastrointestinal acid. Between a battery of IVs and daily breathing treatments every three to four hours, I was breathing more comfortably, and my pneumonia only occupied one lung, instead of both of them.

According to the medical staff was assigned to me, I was at a point that I might be able to move on to a rehabilitation hospital soon, assuming that I kept up my current level of progress with my physical recovery. The rehabilitation hospital would continue my acute care, but more importantly would provide me with several hours of therapy a day to help improve my speech, memory, and my range of movement. My team at Scripps Mercy Hospital advised my family that I would most likely need at least several weeks in rehabilitation, possibly more, before going home. Once I was back at home, I would require full-time assistance until I eventually felt comfortable on my own. It sounded like it was a long road ahead, but at least my recovery was moving forward.

Cognitively, however, I showed almost no progress. Although I have a minimal recollection of this specific point in my recovery, I can remember having a hard time understanding the strange sounds everyone seemed to be sending me. People's words spilled from their mouths and evaporated into static. Some seemed more intent to break through to me, at times to the point of frustration. I didn't meet their expectations. Everything they enunciated made little sense to my ears. My room reverberated from the growing commotion, as if a hundred foreign languages clashed against each other, all at once. I only detected a few words of English in the din. They were like distant, muffled whispers.

I felt uncommonly blessed when random words popped out at me from the deluge of verbalized nonsense. This familiarity was cursory and rare. I fixated on mouths, especially. Reading lips helped me interpret sounds, but I quickly tired from the from the focused effort. Then I felt myself disengage entirely. From there, it wasn't long before I finally realized that I was not comprehending any part of any conversation. Later, I grew aware of my utter inability to interpret body language—eye movements, facial cues, and gestures were intimidating and exotic. This self-awareness was catastrophic. I withdrew, emotionally, and then I entirely resigned any lingering impulse I had within me to communicate at all.

Galen claimed that at this point in my recovery, I was somewhat responsive to the conversation in the room and that I even attempted to talk a few times as if I wanted to say something.

When I did, he said that my voice was weak, and the statements were not clear.

I do remember feeling frustrated that I was not able to call up words that I wanted to say let alone get them out of my mouth. It was so aggravating trying to communicate when the words in my head were jumbled, if not lost forever.

Escape that Funk

Because of a shortage of nursing staff on Sunday, August 27th, I was moved from the 11th floor back to the intensive care unit. My returning trip to the ICU, I was more alert, which made me more susceptible to the ups and downs of daily hospital life. The combination of flashing lights and the arrays of sounds from the equipment overwhelmed me. Then my whole being would become agitated and restless.

Galen brought in my iPod and magazines to help keep me occupied. He knew that these items would cheer me up and keep me busy but also understood not to put too much out for me at once, as too many stimuli could have been counterproductive. If I had too much in front of me, my confusion bound me.

Even though my pneumonia was improving steadily, the move back to the ICU felt like a step back at the time. My doctors quickly quashed that notion, pointing out that they thought that I was doing well enough to go on to rehabilitation soon. We just needed to keep a watchful eye on my pneumonia. They estimated that I would need a few days back on the 11th floor to rest, and by Tuesday or Wednesday of that same week, I should be ready to be transported to a rehabilitation facility.

Root of the Cause

While I was recovering from pneumonia, various doctors at Scripps tried to figure out the cause of my brain abscess. They used transthoracic echocardiography, a type of ultrasound, to examine my heart-valves and look for areas of infected tissue.

They also ran an MRI on the metal components in my lower back from my previous surgery to look for any signs of infection. In both cases, they couldn't find the cause of the abscess.

My medical team concluded that my abscess was probably caused by dental work. Just having my teeth cleaned may have caused some bacteria to break loose and migrate to my sinuses and then move upward into my brain. Today, many doctors prescribe antibiotics before their patient has dental work but back at the time of my injury, it was not a common practice.

In hindsight, the Fallbrook Hospital failed to see the obvious connection between my symptoms and my brain. The fever, head pain, and blurred vision are all textbook symptoms associated with having a brain abscess. I should have had an MRI of my brain first. Then they would have, by all accounts, found the abscess in my brain early enough to treat it with antibiotics. Maybe there was a real chance my STBI could have been prevented.

Remote!

Later that same day, my medical team moved me from the 10th floor ICU to the 6th floor, and then twice again on the 6th floor. I'm not sure why the musical chairs with my bed on wheels, but I finally settled into one room and stayed. All of my vital signs were within a healthy range: plenty of oxygenation and a steady heart rate. However, there was a little shake in my hands and right leg that were bothersome. Overall my physical condition, even with the lingering but improving pneumonia, was getting incrementally better.

My mental picture was still very complicated. Some words were starting to make more sense to me when being spoken to, but I was still eons away from having a meaningful conversation. I tended to lose interest in minute-to-minute happenings. However, the constant change of visuals on the television was able to keep my attention.

In person, I seemed to recognize people and somewhat understood what others were talking about, but I just was not that interested in what they were saying or what was going on at the time. Galen would comment later that I seemed distant and appeared spacey, staring off into the distance, even when being addressed.

What he didn't understand at the time, and I couldn't adequately communicate to him, or anyone else was that they made little sense to me. Whether he realized it or not, it was just as frustrating for me when Galen tried to speak to me, and I couldn't comprehend his noises. We were both aggravated by this, although we couldn't commiserate with each other at that moment.

"Monday Madness"

With everybody at Scripps back at their posts, the next day was a busy Monday. I had visits from my pulmonary, infectious disease, primary, and general practitioners, as well as my team of doctors from the ICU. There was also my RN and her assistant, my breathing treatment technician, speech trainer, physical trainer and a facilitator from one of the rehabilitation facilities, all in four hours. It was an exhausting day, but the great news was that my doctors were all pleased with my progress over the weekend.

Physically, I seemed to be on an upswing. My pneumonia remained a threat, but I was breathing steadily, and my blood, urine, and brain-fluid cultures remained negative for bacteria. I knew that things were not right mentally and I was confused and worried because of it. Galen was finding it more time intensive and more challenging to keep me positive and focused. He did know that I had a strong spirit and was trying hard every day, but he was worried that it might not be enough.

Vocalizing

On Tuesday, August 29th, my voice emerged more prominently to my speech therapist in the morning. He would mouth a word, and I would follow along trying to mimic what he was doing and eventually saying. The process was slow, but he was patient with me and didn't get aggravated when I couldn't follow along as the session progressed.

Later in the day, I completed about a half hour of physical therapy, which consisted of arm and hand exercises to build my coordination. That part of the session went well, but I was very weak when attempting to sit up or stand for a few minutes. My respiratory doctor swung by and explained that my pneumonia was "under control," and that he "expected it to be gone in a few more days."

That entire afternoon I slept soundly. In the evening Galen came by and made phone calls to family members and friends from my room. He said that I seemed very understanding of each conversation. Galen would dial a number, say hello to the friend or family member on the other end, explain where he was and then would hand the phone to me.

Although it was with a frail voice, I was able to take the phone and respond as if I was having a regular discussion with the person on the other end of the line. Galen found this to be quite unusual because since my injury it was rare for me to talk to anyone in person like I did that day on the phone. He took it as a positive sign.

I'm not sure why I felt more comfortable chatting on the phone. Perhaps it was because I usually relied on eye movement and hand signs to communicate and therefore, I choose not to engage verbally when in person. Talking on the phone may have just seemed more natural to me, as it required me to say something to the other party on the line to get a response.

Pick of the Litter

On Wednesday, August 30th, my case manager gave me the "green light" to move to a rehabilitation center, which would likely happen in a few days. In the meantime, Galen visited several potential physical rehabilitation sites for my recovery.

He after much comparison, he decided that Sharp Rehabilitation Center, in San Diego, was my best option. Galen tirelessly conducted research and concluded that they had a well-respected program.

The hospital was rated very highly in a majority of hospital surveys. The rehabilitation equipment seemed extensive, but the rooms were "first-class." Sharp is home to a specialized brain-injury department with uniquely appropriate therapy-equipment. So, the decision was made—Sharp it was! Galen and I were just relieved to move on to the next phase in my recovery process.

CHAPTER 10

Surviving Rehab

> I've never been here. Pain is different - stronger grip, both sides, but it grips my skull from the back of my head like two big hands wrapping around, squeezing ever tighter. My hand goes to the top of my head, where the pressure is applied by my entire arm. It helps for a moment, until the release of the grip, the opening of the nozzle. Then I can hear it coming, the blood rushes back, filling in empty space, like an un-crimped garden hose. It hits only walls— there is no escape for the deluge. The pressure continues to build, and the head gets heavier, the neck having a hard time holding upright.

On Thursday, August 31st, I was transferred by ambulance to the Sharp Rehabilitation Center in northern San Diego. The fact that I was able to travel meant that the immediate threat of my brain abscess and pneumonia subsided to a manageable status. The Sharp medical staff spent the day validating my medical documentation from Scripps and performing their analysis and plan of action for my rehabilitation. Other than some of the minor commotion getting me into the ambulance and back out again, I don't remember much about the process. Once in my new room, I slept most of the rest of the day.

Waking Up

The first day of September was my first complete day at Sharp. The entire staff seemed eager to get to know me and about the details of my injury and recovery. They would stop by and introduce themselves throughout the day, doing their best to make me feel comfortable and welcome. My new doctor on the floor was Dr. John Jahan, who specialized in rehabilitation therapy. He also came by to say hello and chatted with Galen and I about my rehabilitation, leaving a printout of my initial schedule.

It turned out that I had a well-designed and structured program, especially during the week. I started with occupational therapy in the morning, which was designed to help me master my day-to-day tasks like dressing, eating, brushing my teeth, physical coordination, and problem-solving. Anything needed to sustain me and frankly, all of the little things we all do day to day and take for granted.

Speech therapy followed around noon. These sessions involved the treatment of my cognitive-communication, voice, and swallowing disorders. In the early afternoon, I had physical therapy, which was more about my mobility and function and would help build up my strength, coordination, and stamina. On this day, my first day of treatment at Sharp, I received around an hour and a half of combined therapy work, which would extend to three hours come Monday.

I found it very challenging to control the speed of water down my throat when I swallowed. I was still getting my nutrients through a tube in my nose. It drained into my upper intestine. If I didn't swallow correctly, I choked. My doctors grew concerned and scheduled an "upper barium GI to check" for any potential blockages. They didn't find anything.

They decided to work with my speech therapist to try to strengthen my swallowing abilities. That way the tube could be removed, and I could consume food normally. Of course, I would have to keep the liquid nourishment down before getting to enjoy solid food of any kind. I would have given anything for a solid, substantial, home-cooked meal.

Later that same day, Galen attended a conference with my various doctors to review my current condition. They discussed the game-plan for my therapy. What was my schedule was going to be like, and how much time should my recovery take?

They were estimating about five weeks to get me to the point that I was strong enough and healthy enough to be released. The understanding was that I would still need to have help once I got home and would have to keep up a pretty strict series of physical therapy sessions.

In the conference at Sharp, it was discussed and highly suggested that immediate family should consider attending any of three education events that were offered by the facility each week. The classes covered areas of interest such as relationships, communication, how the brain works, mobility, family caregiver advice, and community resources.

Sharp also handed out a fascinating book called *The Journey Toward Recovery* by the San Diego Brain Injury Foundation which, Galen found very helpful. Although its findings have been updated since 2003, the following passage has proven especially insightful:

> Brain injury strikes 1.5 million people per year. That's one injury every 20 seconds. Approximately 500,000 of those injuries require hospitalization and close to 75,000 result in death. Between 70,000 and 90,000 survivors sustain injuries that are long-term or permanent. There are currently 5 million Americans living with disabilities from brain injuries. Although these figures are discouraging, they may help caregivers and friends realize that they are not alone.[5]

Struggling to Understand

Although I was in a rehabilitation hospital on Labor Day, it was still a special weekend for our family because we share several significant birthdays. In addition to my sister's and father's birthdays, Aly turned seventeen, and Trevor turned twenty-six.

I typically found this time of year to be so busy with kids going back to school and the two big birthdays for our children. This year I was not able to spoil them with gifts as I did in the past, so Galen stepped up and took care of everything for celebrating the occasion. He bought the cards and gifts, even handling wrapping them and arranged for decorations and cake.

To celebrate everyone's birthday, my family had a party in my room on Sunday where Aly and Trevor spent the afternoon opening presents. Because I was still on oxygen, we had a "no candle" birthday cake for Trevor, as Sunday was his special day. The nurse even managed to look the other way so that I could have a small taste of cake and a sip of milk, although neither were allowed on my chart. It was heaven!

As far as back to school, this was an especially tough time for me, as it was Aly's senior year and she was our last child in high school. I wanted desperately to be a large part of her life that year, but I knew that it was unlikely. As I watched her open her presents in my hospital room that weekend, I couldn't help but feel somber because she wouldn't get to have her mother present for such a life-changing event. It was bittersweet watching our last child take a momentous step forward in her life on her own. She came into her own as a proud and independent force. I missed being in the parent role for once.

Status Report: Stagnant

As far as my overall condition at this point, the pneumonia was persistent but in recession. Overall, I felt pretty good and could tell that I was getting a little stronger. I was still medically restricted because of my feeding and antibiotic IV tubes. The hope was that by the middle of the coming week, I would have the feeding tube removed and be allowed to eat. I would also be fitted with a portable IV tube so that it was easier to move during my rehabilitation classes.

As far as I could recall, I mentally felt like I was running in sand and staying in the same spot. I had my good moments during the day, but most of the time I was either staring straight ahead or sleeping. For Galen, this was very frustrating because he wanted me to get better mentally, as well as physically. He witnessed that I was diligent with my various types of therapy but thought I was not trying hard enough to speak. I could communicate mostly with my hands and eye movements. My voice was still feeble, and my family hadn't heard more than a couple of words stumble out of my mouth.

I had been on the mend for about a week but had not made any significant breakthroughs. It would be a while before I could actually talk, or move the right side of my body, or be able to problem-solve. This meant I couldn't participate in a simple interaction with anybody even if I wanted to. Galen knew that it was quite a stretch when my medical team told him that I looked like I was a candidate to spend five weeks in rehabilitation. At this point, he concurred with their assessment and hoped that the staff could get my mind moving quickly.

Pedal to "the Meddle"

The first day after the Labor Day, the Sharp parking lot was full. Galen was able to spend some time with me that afternoon during physical therapy, which he found to be rather interesting. I had made enough progress to begin coordination and strength tests. The therapists would have me try and stand up on my own and then helped me balance myself between two parallel bars.

They helped me shuffle one foot forward, rebalance me, and then help me move the other foot. As if that wasn't demanding enough, I had to direct my movement along a straight and narrow path. It was an excruciating, cumbersome process, but I always expended all my mental and physical energies each time. I knew I still had a long way to go and managed to focus every last ounce of power on the process. Galen saw that. If I could keep this going physically, Galen would remain optimistic. I would daydream about the day he'd watch me harness enough strength to get in and out of bed by myself. I knew getting ahead of myself had its drawbacks. It was just hard for me to see the end of the tunnel every day, while I was plodding through the pain. I kept at it.

Although I was making strides physically and staying pretty balanced medically, Galen was growing frustrated that I was not progressing on a cognitive level. He found that I was strangely mute about it being almost impossible to get me to talk when I was face-to-face with someone. Hand me a phone with someone on the other end, and I was chatty for a reasonable amount of time. The medical staff couldn't give Galen an answer as to why this was happening but did encourage him to keep trying.

Unfortunately, though, I failed my swallow-test that morning, so removing the feeding tube was postponed yet again. It could only be taken out three days after I passed the test, so we're likely looking at another week, at the minimum. Galen and I were both so frustrated at the thought but did not have any choice in the matter.

Everyone's Opinion in 15 Minutes

On Wednesday, September 6th, the first big conference with my care staff took place. My physical therapists and nursing team reported that I was only able to perform 20 percent of average day-to-day activities and I needed assistance twenty-four hours a day, seven days a week. It was a sad reality right off the bat.

The speech therapist mentioned that I did not pass my recent swallow-test. So, a gastrologist moved my feeding tube from my nose to my side, and directly into my stomach. This repositioning was supposed to be “more humane.” Also, this change in tube position was better because I wouldn’t need to be fed through my nose anymore. It was cause for celebration—I hated how the tube numbed my senses. Repositioning my feeding tube relieved my speech therapist, who was, up to that point, concerned that the tube in my nose contributed to my lack of “daily interface” and speaking exercises.

My assigned general practitioner told Galen that I was progressing acceptably with all of my antibiotics and agreed with the speech therapist’s assessment for moving my tube feeding. My doctor was also concerned about my speech progress and lack of communication. He wanted to address the cause of my lack of communication at every level, so he ordered an MRI with contrast to see some of the finer detail in the speech centers of my brain. He also decided to reduce my pain medication, so that was not a factor in me being less alert or talkative.

My psychologist had not started his evaluation but was soon. He would review my physical damage to see how it related to the way I was acting, and his assessment would come later. The conference room contained over nine doctors, nurses, and therapists assigned to me to address the different levels of medical care.

They all agreed that they had not had sufficient time to evaluate me due to my late arrival the previous week and through the holiday. The staff was also surprised to hear that I communicated so well over the phone but had no expert explanation as to why.

The medical consensus was that my treatment timeline needed to be reconsidered. The team felt that I should get more out of my hours of physical, speech, and occupational therapy. After the assessment, my case manager estimated that I would need much more time in rehabilitation than the original five weeks. Bottom line: I was not progressing as quickly as everyone had hoped, so a more prolonged stay became an inescapable necessity.

Hitting Walls

After so many disappointments over the last couple of weeks, Galen hit a point where he had enough. Between the stress of work, having to handle everything at home without me and trying to support me while going through the recovery process, he hit a wall mentally. While sitting in a chair at the end of my bed, he uttered his disapproval.

Galen said that I had to try harder with my recovery or I wouldn't be able to come home. There was only one other option: to put me in a convalescent center, just like the one I worked in as a teenager. Deep down, Galen knew I didn't exactly like that place. He knew that I detested the idea that anyone should have to spend their final years there.

Somehow, Galen thought that he was motivating me to work harder by threatening to commit me to home, but instead, the notion crushed me. I was going through three to four hours of grueling therapy a day, working as hard as I physically could, even to the point of exhaustion. I never once turned down the opportunity to do a session. If anything, I'd ask for more and push myself through every obstacle.

There were things in my recovery, however, that I couldn't control, like the fogginess in my head, my lack of attention or communication when others were around or even my memory. Even with my handicap at the time, I knew that it was not my fault or entirely in my control. I found myself reduced to tears that night and withdrew to the comfort of my bed, hiding under the covers until sleep finally took over.

It broke my heart, and my spirit quashed. There were a few times I secretly wished that I had not survived at all. I just wanted to be released from my suffering. I just wanted to allow my family to move on. There I was, alone in my room, left to wonder and worry. Alone.

Sunshine and Fresh Air

On Friday, September 8th, our youngest son, Kellen, made a trip back home from the University of Arizona where he was studying international business. Galen picked him up at San Diego airport and brought him to the hospital to see me. As our other kids showed up later in the day, I became increasingly more engaged with my voice, actions, and expressions, as I was thrilled to see everyone. It became evident to Galen that my usual lack of communication revolved around my emotional state at the time. Since I was happy to have my family around, I responded better than I usually did and was more interactive with everyone.

My family also had an eye-opening experience with me and my physical rehabilitation team. My therapists had me get up and walk three times in one session. However, I was unable to do so without someone's assistance. I imagined it was excruciating to watch me struggle in co-dependence—I needed a nurse's diligent help to scoot one foot forward, and then, after a while, the other. However, I was able to pull myself up on the parallel bars and stand up on my own, which felt good. The lack of progress otherwise made it painfully apparent that I would have to be in the rehab facility longer than initially anticipated. Five or six more weeks, at least.

The highlight of my day was able to spend some time outside. This day was the first time I had spent time in the sun and open skies in over a month. I was rolled out in a wheelchair and pushed up to a table on the patio where I sat with my family while soaking up the sun. Although it took a long time for my eyes to adjust to the brightness, it was exhilarating to feel the warmth of the sun on my face.

Breathing in fresh air, which wasn't stale or "re-circulated," was very liberating. I could smell a hint of salt on the air from the nearby ocean. A gentle breeze delicately brushed my skin, and I could sense it. After a half hour, a nurse returned outside to wheel me back inside. My exposure to the sun was as closely monitored as my time outdoors. The nurse didn't want me to jeopardize my immune system. Nonetheless, my time outside marked briefly restorative peeks into a distant and thriving lifestyle.

Those Feelings

On Sunday, September 10th, I enjoyed an eclectic attendance of friends and family. Boy, did they lift my spirits! I exceeded my previous progress smiling and winking, with hand motions, and my general awareness of visitors felt keener. The moments I had in the sun during these visits also proved to be therapeutic. It was somehow a glimmer of hope in my otherwise tricky days. On Monday morning, the doctors moved my feeding tube from my nose to my stomach. The procedure left me sapped, so my rehabilitation team thankfully let me rest. Hopefully, without that tube in my nose, I would feel more confident and was raring to go on Tuesday.

At one point, Galen shared with me that it was frustrating for him to visit me at times. Apparently, I tended to show little interest in my visitors. He asked the doctors why I acted this way, and they suggested some reading material to help him understand. Among the most insightful information, he found is from chapter four, in *Journey Toward Recovery: A Brain Injury Guide for Families:*

> "Perhaps the most disturbing to survivors who have sustained a brain injury is the loss of identity. Many of us take for granted the things with which we identify ourselves; our job, our relationships, and roles. Imagine all of a sudden not being able to go to work, drive a car, cook a meal, play a game, help your children, go for a walk or even hug your family. Not only that, but you require assistance from others for even the most basic skills. Brain-injury survivors must come to terms with new

> limitations and new roles. We must reconcile a new sense of who we are and where we now fit in. The person she knew before the injury has been replaced by someone who is, in essence, a stranger. This can be more difficult to deal with than the physical limitations
>
> Many times, an individual suffering from a brain injury will experience feelings that others would consider natural, such as frustration, disappointment, and depression. However, injured individuals may also experience feelings that come as a surprise to family members and loved ones. Without the ability to care for herself, the patient may begin to feel useless and helpless. Having to rely on someone else to take care of one's basic needs can make the patient feel like a burden, no matter how good the caregiver is at assuring the patient she isn't.
>
> One of the issues that brain-injury survivors frequently encounter is that they do not appear physically disabled. Their disability may be solely cognitive. Without the physical reminders, others may not be aware of the patient's limitations and can act intolerant, causing the patient further embarrassment and frustration.
>
> The patient may or may not express these feelings; putting yourself in her shoes, and putting aside your own issues and wants, will help you really understand what the patient needs."[6]

The Conditions of my Conditions

My next progress report was on September 15th. My neurologist ordered CT scans and MRI tests. Their results confirmed a consistent trend. My recovery since the initial brain-swelling had improved consistently. Traces of infection appeared to be in recession, so a potent twenty-four-hour intravenous antibiotic was ordered by my doctor to be discontinued after the first week of October. I was still receiving 2,500 calories a day through a feeding tube but was not able to consume solid foods yet. For some reason, I still couldn't pass a "swallow-test," which was a prerequisite to begin eating normally and independently. My upper body strength was good, but I still seemed challenged with my legs and feet. My ability to walk was improving slowly but still had a long way to go to before being able to use a walker, let alone return home. The shaking of my hands was minor and deemed manageable, and the overall control of my body was incrementally improving.

As far as my speech, I could manage to converse on the phone, albeit in a feeble voice. However, it was still challenging to get me to communicate directly when in my family's presence. I could only communicate with the muscles in my face, the movements of my eyes, and subtle hand-gestures in lieu of not having a voice.

My medical team reported that I seemed to have mixed cognitive abilities at this phase of my recovery. I usually complied with a nurse's or therapist's request, even responded with gestures or a few words but other times I seemed less aware and responsive. I showed some indifference and lack of attention as visits stretched out.

When given choices, I was easily confused and then would sometimes withdraw emotionally out of frustration. The medical consensus was that most of my physical ailments seemed under control except for my ability to eat solid foods. I was still unable to function normally with walking or talking, which was chalked up as the direct result of the abscess damage to my brain. With continued intensive rehabilitation, my medical team felt that the long-term prognosis was good.

Halfway through September, the process of rehabilitation started to look like it was going to be a longer one than I expected. In the weeks that followed, my medical condition remained "stable." My vital signs were "positive," and there were no new "flare-ups" or "setbacks." Then, my progress started to ebb. It became unbearably clear that I was only recovering incrementally. My physical therapy was progressing on schedule (it was ramped-up to twice a day at that point) but it was still incredibly challenging for me. In my mind, my stagnant progress was the most significant roadblock hindering my release from the rehabilitation facility. The hope was to be soon able to start moving around in a walker, but I knew that I'd need to continue making baby-steps until I was ready.

CHAPTER 11

Walking Tall

> Hang on politely to anger. Never release it. Never allow the intimate you out to reveal the vulnerable part. Protect the fortress, lock the doors, and bolt the windows, protect your temple. Hide the real feelings, never let them be heard. Don't show that you—the gatherer, the keeper and fixer, healer, and lover—are scared, weak and in pain. I'm fearful to peek through the crack, in the blankets, from where I hide.

By Monday, September 18th, I could stand up straight from a seated position with little assistance. I still had issues balancing myself, so my physical therapist was at the ready and grab my arm once I stood up from my bedside or wheelchair. Once I could stand and balance myself, I could move my left leg and foot smoothly when walking. My left hand and arm responded as well as could be desired. My right side, however, wasn't nearly as responsive as my left side, which ultimately caused my body to move in a clumsy and uncoordinated way.

I was not able to feel, let alone lift, my right foot. I ended up sliding it along the floor, which took serious effort. However, even my right side did move slightly better after each therapy session. My rehabilitation and therapy team were confident that despite the slow progress with the right side of my body, I could look forward to walking on my own in a few weeks. At least that's what I was led to believe. In any case, the encouragement kept me motivated to move forward.

Progress Report, Recommendations

Galen talked with my case manager on Tuesday, September 19th, and she gave him a recap of an earlier meeting with my medical team. The team deemed that I was a "moderate to maximum assist patient." This meant I required assistance for every kind of activity, from personal care to therapy. There was a growing concern that I had not shown as much improvement as my medical team was hoping for.

That's when my therapists acknowledged that they were less experienced in rehabilitating brain abscesses. They wanted an outside opinion to see if a medical issue was slowing my rehabilitation progress. In the meantime, the inside impression by Sharp staff was that I was still four to six weeks away from being discharged to go home.

Dr. Kureshi, my neurosurgeon from Scripps, came by for a visit later in the day. He mentioned that recent CT scans had revealed inflammation in my ventricles, which he noted was not unusual for someone recovering from ventriculitis. Dr. Kureshi went on to explain that the valves between my spine and brain were scarred from my initial infection and did not let enough cerebrospinal fluid (CSF) flow back into the spine to be flushed out.

The fluid built up in my brain and created high pressure in my ventricles, which was impeding my recovery both short and long-term. Dr. Kureshi felt that reducing the cranial pressure either by removing excess fluid from my spine or inserting another brain drain could give the ventricles time to shrink and allow my brain to heal. His recommendations were passed along to my medical team at Sharp, and we waited to discover which option he chose.

Saturday, September 23rd, my doctors at Sharp Rehabilitation Center opted to insert a needle into my back to remove the excess fluid from my spine. The less intrusive of the two proposed procedures, the spinal tap was done in hopes of relieving the pressure on my brain, which would allow for improved physical therapy progress in the coming weeks.

My medical team hoped this procedure would make it unnecessary to insert another drainage line into my skull. It was a more invasive procedure that would involve yet more hair removal and insertion of a pipeline similar to the temporary drain I had implanted when I first arrived at Scripps Mercy Hospital. If needed, the new drainage apparatus known as a shunt was permanent. The idea was to help drain any excess cerebrospinal fluid but also keep a consistent and normalized pressure in my brain.

I remember feeling much more aware after the procedure that flushed fluid from my spine. That day, my head did not hurt as much as it usually did, and I felt much less foggy with my cognition. My hands did not shake, my legs felt stronger than before, and I was able to move around more easily. I felt a difference after the procedure. I just wished that feeling of “clarity” would have lasted longer.

Plodding Along

On September 27th, it was clear that my speech-therapy progress only incrementally improved. My voice was still weak, and I had yet to pass my “swallow-test.” Galen tried to get the speech therapist to realize that it was possible for me to talk if they got close enough to hear me. The therapist would typically sit in a chair past the foot of my bed, and it was hard for me to see him let alone make out what he was saying or was asking me to do.

Galen also asked the speech therapist to consider addressing me from my left side, especially with word association tests.

It was easier for me to see from that direction and I would try harder with my responses if they came closer to hear me.

On this same day, occupational therapy and physical therapy both went smoothly. My occupational therapist remarked that it was my best day since I got to Sharp Rehabilitation Center. I was able to answer basic questions and handled all of their tasks for me. Physically, they had me strapped into my wheelchair because I kept inadvertently trying to stand up, which I guess was a sign of progress.

Sunrise

On October 1st, Dr. Jahan stopped by during my physical therapy session so that he and Galen could have a good chat. He gave Galen mostly good news about my physical condition. It turned out that the fluid that had been removed from my spine the week before had tested clean. My overall blood cell concentrations were also very good and showed no signs of infection.

The most significant news from Dr. Jahan was the progress with two of my pre-brain injury medical conditions. Five years earlier, I had various back operations done, and I was prescribed different kinds of pain medication. I recalled the heavy strain they put on my internal organs, especially my liver. I was weary of pain medication in any form after that experience.

Fast forward to my rehabilitation with Dr. Jahan. He was happy to report a significant decrease in the dosage of my pain medication. This was a breakthrough. This decrease in medicine was possible because of my stay in a controlled hospital environment and my body's decision to focus less on the pain centers and transition its priority to my other problems.

According to Dr. Jahan, the phenomenon was like hitting your thumb with a hammer and then hitting your other thumb to reduce the sensation of pain with the first thumb. With the reduction of pain medication, plenty of rest in a controlled environment, and a steady and balanced quality diet, my liver functions were back to normal.

My medical issues at that point centered around a lower gastrointestinal tract infection, which caused elevated temperatures. I had a low-grade fever for three days, but that evening my body temperature climbed above 100 degrees Fahrenheit because of the infection. Galen and I hoped the doctors would get the issue under control before infection was triggered elsewhere in my body.

Check Me Out!

Tuesday, October 3rd marked Sharp Rehabilitation Center's bi-monthly review of "patient progress." Doctors updated my family on my progress. Dr. Jahan was pleased with my overall medical progress, and except for a stubborn fever, he felt that I was improving. He recommended another MRI and CT scan of my brain to update Dr. Kureshi properly.

The occupational therapist concluded that my progress in therapy sessions was too inconsistent and suggested that I continue in "total assist mode." The good news was that my physical therapist concluded that I had progressed to the point of using a walker during rehabilitation. I still needed some assistance. My right leg was still unable to move with a full range of motion. It was also difficult, even painful to get my feet to flatten out while I attempted to walk. Instead, I would balance mainly on the balls of my feet, which was concerning.

My speech therapist could tell that I was more responsive after the spinal tap. My core activity was improving, and my speech was becoming more evident. I could identify most objects and printed words and could even construct sentences and initiate conversations. He felt overall that I had progressed well over the last week.

My caseworker felt that our insurance might allow me to stay another week or two. The staff agreed that I was progressing and that two to three weeks of therapy was very beneficial to my overall recovery. The agreement was to fight the insurance company so that they would cover my stay.

A Surgeon's Work is Hardly Ever "Done"

Galen and Aly visited me on Thursday, October 5th to watch me go through my different rehabilitation classes. I was especially alert and operational on that day and went through my sessions with verve. The buzz in the hospital was that I was talking more and was hitting the call button and asking for assistance.

Galen also had another conversation with Dr. Jahan, who suggested a follow-up with Dr. Kureshi's office about the results of my latest CT scan. When Galen called, Dr. Kureshi said that he was concerned that my inner cranial pressure or ICP was still too high for his comfort. He was happy with my clinical results from the spinal tap, but the fluid level in my brain was now almost back to what it was before the spinal tap.

Dr. Kureshi felt that the best way to relieve the mounting pressure in my head and to preserve remaining cognitive function was to install a permanent pipeline into my brain that emptied into my stomach. This operation would entail a cut into the skin in the back of my ear area, and he would drill another dime-size hole in my skull and install a line with a valve. He would attach a thin line and run it underneath the skin into the stomach, which would automatically drain any excess brain fluid at all times. This brain shunt would be a permanent connection.

The downside of the operation was the potential for a complication during the surgery. However, Dr. Kureshi felt the risk was minimal. The upside was that I possibly could recover at a higher rate with a more standard brain pressure. The shunt would allow for a permanent solution to the fluid buildup, which was causing impairment with my cognitive abilities. Dr. Kureshi had been right on the money with my care so far, so we agreed to move forward with the surgery, which would take about ten days to schedule. This surgical procedure would involve transporting me to Scripps for the day to do the operation and then I was transferred back to Sharp afterward to recover.

Afternoon Assault

As of Monday, October 9th, it had been five weeks since I had been at Sharp Rehabilitation Center and Galen was worried that my recovery efforts had peaked.

My rehabilitation was steady but incremental, and I was incrementally improving every day, but no significant breakthroughs. He expected me to be walking more at this point and being more like I was before my injury. He knew that I was trying hard, but the slow process was weighing on him.

Good News! After two months, the antibiotic IV was removed. As a result, I no longer needed a PICC line, so it was also removed. We were all thrilled to say goodbye to the irritating I.V. machine, finally free from its constant alarms and noises.

I was still stuck with a feeding tube because I couldn't pass the "swallow-test." Galen would keep reminding me: if I could pass the "swallow-test," I could start eating and be able to go home finally. I was to the point where I needed to return home, and he thought that dangling this carrot in front of me would motivate me to try that much harder.

As the Shunt Turns

On Wednesday, October 11th, Galen spoke with Dr. Jahan about getting my shunt surgery rescheduled to an earlier date. The doctor had moved back the surgical timeline by fifteen days to accommodate Galen's schedule. However, we did not realize it would delay everything that much more. My medical team suggested that the sooner I could get the new drain line installed, the quicker I could get to the next level of my recovery. The doctor agreed with Galen's request and looked into an earlier surgery date.

In the meantime, the pressure was slowly building back up in my head. I barely held steady with my rehabilitation progress that week, but my attention span was diminishing. My hands began to shake. I tended to keep my left arm folded with the back of my hand against my chest, and my feet curled up, rendering my lower extremities somewhat useless. Dr. Kureshi ordered an MRI, and the results of the test confirmed increased fluid levels in my brain. All signs pointed to performing the surgery as soon as possible.

Dr. Kureshi decided to move forward and install the shunt and was able to schedule the surgery the next day. He claimed that it was a relatively simple operation with all of the typical disclaimers. The plan was that in the morning I was transported from Sharp Rehabilitation Center to Scripps Mercy Hospital where the surgery would take place. The procedure only took an hour or so. After a brief stint in ICU shortly after, I was sent back to Sharp to recover and later continue my rehabilitation.

The shunt surgery ended up taking place at Sharp the next day, as opposed to Scripps, but everything went as planned otherwise. While I was asleep in recovery after the procedure, Dr. Kureshi told Galen that he was pleased with the outcome. He added that he naturally hoped for the best but still made no promises that my condition would improve. The need for this statement, I imagine, is from his past experiences in his specialty and the sheer nature of being a neurosurgeon. He too knew that any hope for my recovery was in God’s hands.

CHAPTER 12

Breakthrough

> The ghost moved in and changed our reality forever. Forever.
> You can pray for healing, a return to this person they all but
> mostly forgot.

By Sunday, October 15th, my brain-shunt surgery was declared a "success" by everyone: my doctors, nurses, therapists, as well as my friends and family. Other than some localized post-surgery pain at the incision, I was feeling good and was quite aware of and responsive to other people. For the first time, I realized some form of clarity that day. I experienced the sensation of coming out of a significant fog or murky dream. I felt like a veil was lifted from my head, and I was able to see clearly, comprehend where I was and who was in the room with me. I especially remember thinking, "Wow... I'm alive... I'm back!" The moment was a miracle.

My visitors that same day saw me as mentally alert and very talkative, like my old self, and concerned more about them than myself. I acted like a person returning to consciousness after a concussion. Blinding confusion and long time-lapses punctuated the listlessness. It felt like I was slowly melting into oblivion, with little connection to others in the room.

Miraculously, I was able to take better control of my body movements. My arms, hands, legs, and feet were more responsive than before the operation, and my facial expressions became more animated and articulate. I even understood that this regained-control would immensely help my forthcoming physical, speech, and occupational therapy sessions. For the first time in months, I requested to sit on the side of the bed instead of lying down, which both delighted and dumbfounded my family. My request meant that I was more aware of my situation and had a better presence of mind to determine that I wanted to be situated differently.

Galen felt that I was exhibiting good humor, a sharp wit, and other strong emotional feelings. I was acting more like the woman he had married and less like the disconnected stranger who occupied my body since my injury. I think Galen was just thrilled that I wasn't just staring blankly and or becoming so easily distracted. My behavior that day was a win on many levels, and everyone, from friends and family to my medical team, was thrilled by the breakthrough.

The Buzz of Sharp

Tuesday, October 17th marked another patient-doctor conference, but this day was the first time that I was able to attend. When we all met, everyone sitting around the massive conference table was outwardly excited about my progress and ecstatic about my improved state of mind and physical abilities after surgery. According to my nurses, the news about my breakthrough was the buzz of the building. This development couldn't have been the first time they had seen such progress with a patient, but it sure was helpful from my perspective to be seen in such a different light—less like a hollow shell and more like a whole, viable human being.

My doctors in the meeting reported that medically everything looked good with the shunt surgery recovery going well.

The nurses noted that I was much more attentive to my daily personal grooming and could move around quite well. Heck, I could even brush my teeth, which was unheard of since my injury. Physical, speech, and occupational therapy all reported their approval and delight with my swift progress. They all agreed that I would still need a couple of more weeks of rehabilitation at Sharp but that there was a light at the end of the tunnel. It was soon going to be time for me to go home and the anticipation was mounting for both Galen and me.

Stubborn Problems

Even with my seemingly miraculous breakthrough, not everything with my recovery was ideal. I was not at 100 percent with my physical abilities or mental clarity, but that was to be expected based on the severity of my brain injury. I also had tremendous headaches that occurred sporadically throughout the day. The pain would start in the back of my head and radiate outward until it consumed my entire skull. With these headaches, sometimes my focusing ability in one eye was weakened, and sounds became deafening. At the time, we couldn't rationalize why the headaches recurred when they did.

I also had yet to pass my "swallow-test," which was aggravating for both me and Galen. The good news was that I was approved for limited amounts of thicker liquids, like milkshakes and pureed food with a semblance of flavor. The nursing staff also took some of the pressure off of me when they admitted that I could still go home with the feeding tube if needed. In the meantime, my speech therapist opted to use electrical stimulation of my throat to help improve the strength of my swallowing mechanics. Neuromuscular Electrical Stimulation (NMES) is when small electrical impulses are applied to the swallowing muscles in the throat via electrodes.

This new therapy was tacked on to my already-busy routine. I was already practicing regular swallowing exercises. Later I'd learn the NMES therapy significantly accelerated my regular muscle-strengthening activities. I will never forget how much I appreciated the ability to swallow in that painful period.

"SHUNT-Up!"

After three very positive days, on Tuesday, October 17th, my vital signs digressed, and my physical and mental performance dropped off dramatically. The mental fog came back, and I had a hard time keeping focused. I also felt sluggish, like I was running in sand, and my body felt heavy, and my extremities were somewhat difficult to move, almost as if they were weighed down.

By Friday, the 20th, my condition worsened and was cause for significant concern. It turned out that I was exhibiting the classic symptoms of "shunt malfunction": headaches, loss of previous bodily abilities, vision problems, tiredness, sore neck, wuthering cognitive function, and "foggy head syndrome." It wasn't long before Dr. Kureshi and Dr. Jahan were notified that my shunt was no longer delivering the results.

Disheartened at the setback, Galen set out to do some research. He looked into "ventricular shunts" and found that it is a complex world with several types. Galen discovered in his research that brain shunts are considered rather complicated beasts and their performance success can vary by as much as 20 percent.

Although we both felt confident with the expertise of Dr. Kureshi, Galen and I just wondered if the version he installed was a fixed, adjustable or a self-adjusting shunt. The next day, I was doing better. Half of my side effects had ceased or diminished, which left us wondering if this was the work of a self-adjusting shunt kicking in. We never did receive an explanation as to what caused the shunt malfunction.

One Foot, Two Feet

One of my other medical issues at this point in my recovery involved my feet. Being mostly confined to a bed for ten weeks had caused the muscles in my calves to shorten and tendons in my ankles to harden, which caused my feet to excessively point downward. Ordinarily, special boots are prescribed for bed-bound patients, especially if they are in bed for extensive lengths of time. My special boots, however, would often overheat my feet and were so uncomfortable that I often requested hour-long breaks apart from their confinement. The nursing staff thankfully obliged. However, they never put them back on. I lacked the presence of mind to remind them. So, within a few days, I, unfortunately, developed a "contracture":

> This occurs when "ordinarily elastic tissues are replaced by non-stretchy, fiber-like tissue as a result of reduced motion. This new, inelastic tissue makes it incredibly difficult to stretch that area, severely impacts a normal range of motion, and is often very painful.[7]

I had a couple of options to remedy the contracture deformity. I could try to correct my foot position in therapy, but that process could take many additional weeks of painful sessions if it were possible at all. Even afterward, there was no guarantee I would walk normally. At that point, my feet were frozen in place and couldn't be manipulated by hand. So, the only other option involved surgery. It turns out that my physical therapist was good friends and tennis partners with a surgeon who could help me unlock my foot position, so she stepped in on my behalf and asked her friend for help.

On Saturday, October 21st, with little notice or time to research, I was scheduled for another surgery. At 2 P.M. my Achilles' tendons were cut to release my feet, which were set into plaster casts, up to just below my knees.

After surgery, I was placed in the ICU temporarily and then moved back to my regular room around 6 P.M. At that point, I was awake and talking but felt weak and uncomfortable. I had two massive casts on my feet that spanned from below my knees down to my toes, but my feet did look like they were in the right position. We knew that is was going to hurt like hell for a while, but soon I would come to realize that this part of my recovery was by far the most painful.

For the most part, I was alert after my surgery, and the shunt seemed to be doing its job most of the time. I showed little or no sign of a hangover from the anesthesia but did ask the nurse for more pain medication. My feet and legs felt heavy and were throbbing with occasional stabbing pain.

As Sunday turned into Monday, new casts were applied. The first ones were too tight and the circulation in my legs and feet was being cut off. My legs swelled, and my toes turned a purplish shade of blue. It was one of the most physically torturous trials in my life, but I knew that I had to push through it. After the staff let me catch my breath for a bit, they had me up and walking around. It was excruciatingly painful, and the casts were so very heavy that moving around was near impossible. It was too much to ask.

The next day, although it was excruciating and felt like I was walking on hot embers, I was moving around. In therapy, I was using a walker and even managed to walk a couple of hundred yards. My feet were flat, and my legs were working reasonably well, both left and right. It was as though the pieces of the puzzle fit into place and all of the parts of my broken body were starting to work together.

The fogginess that was in my head seemed to have stayed somewhat lifted, so it appeared that the shunt was back to doing its job. My voice was also stronger, and my cognitive abilities were improving. I somehow surpassed the previous day's progress. I was overjoyed.

New Strength

Galen had a chance to go through physical therapy with me, and I'd learn that he found it quite remarkable. I'd learn that, to him, it as if I was a completely different person after my shunt was installed. I was able to follow commands easily, had a more extensive range of motion with my body and showed much of the physical conditioning I had my whole life.

The week before I could barely stand without help, let alone walk. My entire body felt like it was dragged around. I was finally walking on my own, albeit with minimal assistance. I was proud of myself because I could actually walk down the length of a twenty-five-yard hallway. This particular path was supposed to be my test-run course.

I surprised myself again—I traversed it twice. My physical therapist said that I was firm and demanding, so she gave me a tough workout. She wanted me to be in the 99th percentile of patients, who were able to walk out of the facility by themselves on their way back home.

Soul Foods

Thursday, October 26th was a great day at Sharp Rehabilitation Center. I took my swallow and eating test and passed with flying colors. All of the nurses and technicians were jumping with joy for my accomplishment. I'm not sure who was happier… the medical staff, or Galen, or me! The doctors left the feeding tube in place until I could demonstrate that I could eat the designated amount of daily nutrition.

With this in mind, I ordered chicken pot pie and pasta for lunch and a Salisbury steak for dinner. In addition to solid food, I was so excited to have little things like milk again. My taste buds were still very tender from the layoff of food, but I knew that it was just another step in my recovery. I would need to learn to enjoy the various tastes again.

My daily rehabilitation team worked me especially hard that week. The therapists even had me walking around the outside of the facility. I was escorted around the building, scaling ramps and stairs, upwards and downwards. It felt like such a great sense of accomplishment, and the team was very encouraging of me. With the three to four hours of therapy a day, my recovery was now coming along very rapidly.

The rumor from the nurses was that on Tuesday, during my patient conference, I would finally be assigned a discharge date. I learned that the big day would be someday at the end of the following week. These were pretty exciting times, and I was ecstatic because it seemed like things were finally going my way.

The Paradise in Cheeseburgers

The next few days I was tested on every meal for consumption. To have my feeding tube removed, I needed to eat at least 75 percent of each meal three times per day, and this had to happen three days in a row. There was a little confusion on the third day when my family brought in a cheeseburger from In-N-Out Burger, a local treat.

They placed the burger and milkshake in from of me and noticed that I was staring down at this massive amount of food. After glancing both ways, like he was on lookout-duty, Galen reached down and took a bite out of my burger. It took a while, but we worked together, and, well, got everything done. With my family's help, I passed the test and was allowed to eat the next night without the feeding tube. Hurray for small victories!

Seaside Reflections

On Sunday, October 29th, my recreational therapist allowed me to leave the hospital for four hours. My family picked me up and took me to the San Diego Bay, as I wanted to visit a much-loved restaurant for my favorite seafood, red snapper.

We navigated to the harbor and parked, and then Galen wheeled me to the restaurant from there. It was typical "San Diego weather," 75 degrees and clear. It was glorious, and it felt so good to be outside and away from the rehabilitation hospital.

Once inside of the restaurant, we were seated with a view of San Diego Bay and the aircraft carriers across the way. As Galen rolled me to the table, a wave of chaos hit me. The clinking of dishes, rattling of metal utensils, and chatter from other patrons was overwhelming for me. It was like dialing through a hundred different radio stations at the same time.

Loud talk shows, annoying static, and chaotic music alternated at random and insistently buzzed inside my ears. It was an environment that I was not used to, it was different from the sounds and ambiance of the hospital, and it was a scary immersion.

There were several people I didn't know. I remember feeling judged from within my wheelchair. It was like they could see through my disability. It was like they thought less of me because of it. Even with my family surrounding me, protecting me, I felt so lost and alone in a world in which I did not belong.

You better believe I thoroughly enjoyed a proper meal. Beyond that, I was just thrilled that my family came together to take me out somewhere away from the hospital, but I did not know how to tell them how scared I was. Galen did notice that I looked tired, so my family took me back to Sharp Rehabilitation Center at around 4 P.M. as I was ready to lie down.

Three months inside the confines of the hospital was an epic adventure overall. Galen told me not to expect such royal treatment the next weekend. After all, I was home to make my own decisions. After a moment of brief confusion, I nodded in agreement. That's when I knew I was finally returning home. Freedom at last!

CHAPTER 13

Homeward

> Break out, wake up my lost soul. Return to home within my heart. My crippled brain cannot find you. It cannot find me. On a plane, a stand above or below everyone else. I walk a space unseen by those who surround me.

I WAS DISCHARGED FROM Sharp Rehabilitation Center on Thursday, November 2nd, 2006, three months to the day from my initial melon-splitting, abscess-related headache. My first day home from Sharp was a joyous day but a worrisome one as well. I was afraid of being out of the hospital, as I was mostly on my own and I knew it. Galen stayed with me the first few days. Although I was informed that I would need a qualified, full-time nurse (caretaker), our housekeeper appeared instead. There was no call-button to push in case of an emergency, and there was no one on-call if I needed immediate medical attention. I was restricted to my bed. I had to be carried into the bathroom to use the toilet. I needed to be bathed. It was a worrisome period for me. I detested being alone and bedbound.

The first night back at home was especially difficult for me, as I was restless and awake most of the time worrying about how I was going to manage to be at home on my own. Although I don't remember doing it, I must have attempted to get out of bed at some point that night and had fallen forward. I found myself on the floor with my legs sprawled in two different directions and my face buried down into the carpet towards the foot of our bed. I was so weak that I couldn't muster the strength to turn over or lift myself up. My voice was frail, and I couldn't scream out with an audible volume. I tried and tried again to lift myself up, but the effort was in vain. No one could see or hear me, and I was unable to get up.

Crying, pulling at the carpet and full of fear, I then felt warm hands touch my back. A soothing voice, I heard the soft, sweet, nervous laugh I knew all so well. Galen, my hero, sensed that something was wrong and came to my rescue. He hoisted me onto the bed and wrapped me under the covers, tucking me in for the night. He combed the hair away from my eyes and softly kissed my forehead, and then said goodnight, yet again.

Reentry

As scary as it was, I must admit that it was otherwise a giant relief to be back in my own house. I tried to enjoy the small and familiar details of my home, which I sorely missed during the previous several months I was trapped in the hospital. If nothing else, it was blissful. To be in familiar surroundings, to enjoy the view from our bedroom window, to enjoy meals that had flavor.

In the four years since my back injury, my pain medication had eventually disgusted me so much my desire to eat faded. When I returned home after my therapy, however, I was on a comparatively reduced dosage of similar medication. I could independently manage to eat most foods, albeit in small amounts. This independence was critical. I knew that I needed to eat to build my strength back up again.

When I first arrived back home, I spent most of my days either stuck in my wheelchair or confined to the boundaries of my bed. I received a few months of outpatient visits by a nurse two to three times a week. The rest of the time, our new, live-in housekeeper, Maria, would bring me food or medication and take me to the bathroom to bathe or relieve myself. Maria didn't speak English very well. I felt helpless because communicating with her was so challenging. I could hardly understand or speak English, let alone Spanish. When she wasn't caring for me, Maria would spend her free time holed-up in our guest room if she wasn't also cleaning the house around me. Apart from her primary caregiving duties, Maria didn't engage with me beyond that.

While I appreciated her help, deep down I felt like our time together could have been better spent continuing with my speech therapy and physical therapy. It wasn't her fault necessarily, but my growing determination made me feel like I lost valuable recovery time every second I wasn't actively advancing my recovery.

My memory of this point in time remains sketchy, at best but what I do remember was being rather lonely. During the day I would mostly sleep, listen to my music or watch television to try and keep myself occupied. Except for Sundays or when taking me to occasional doctor's appointments, Galen was back to working long hours six days a week. He would often travel for weeks at a time for business so there were times that I would rarely see him. It was so scary for me, not knowing when he was back. My friend Debbie would stay with me sometimes during Galen's business trips, which was a tremendous help. However, I still longed for time with him and his attention, but I was unable to articulate my dissatisfaction when I would see him. Former students and other acquaintances did come by and visit me at first, but that petered out over the years. Our good friends Don and Delores Faulkner, however, came by several days a week for many years, sitting with me for hours at a time. They would bring anything that I needed from the store and take me out to lunch once in a while so that I could get out of the house. I am very thankful for them doing so much for me.

Psychologically, my self-confidence and the constant fear of what the future would bring caused me severe anguish. Galen continued to remind me that the pieces in the puzzle (in my recovery) would eventually come together. While I routinely prayed that he was right, I found it difficult to stay positive in the meantime.

I was a strong, independent woman once. Now I was evaporating in my bed. I was also missing so much of our daughter's senior year in high school, and I was not able to contribute to her various activities as I once had for our older children. At this point, our three boys were either away at college or out on their own, so Aly was our only child left in the house. However, because of her busy school schedule, and extra-curricular activities, I recall seldom seeing her then.

I learned later that she helped out with me after school as much as she could, but my memory of this time is not good. Instead, I recall only that our housekeeper would prepare her meals, clean her bathroom and do her laundry. Aly, otherwise, was mostly on her own, which broke my heart. We were so close when she was growing up, that we were like sisters. I was the ringleader of all of them, Aly and her girlfriends. They would pile into my Chevrolet Suburban, all seven or eight of them, and I would take them everywhere. I so missed those days!

The Agony of Adjustment

As of November 12th, I was having intermittent headaches that had lasted for the past week. The pain happened mostly later in the day or when I was laying down. It felt like the pressure was building in my head, and my brain was being squeezed all over in a large, skull-sized vice. There was so much pressure that it felt as if steam was going to burst outward from my ears.

In most cases, I would experience blurriness with my eyesight, to the point of double vision, and would have an increased fogginess with my memory and comprehension. I found it hard to concentrate and nearly impossible to remember much of what happened during one of the episodic headaches. Out of concern, a CT scan was scheduled to help figure out what was causing these incidents.

"Therap-EASE"

That week I started therapy at Fallbrook Hospital, the same place that missed my brain abscess diagnosis in the first place. After a couple of sessions, my occupational therapist decided I didn't need any further assistance in adjusting to home life. I soon mastered all the little day-to-day activities that one needs to in order to function—dressing myself, brushing my teeth, and brushing my hair—all on my own, again. She suggested that I continue speech therapy because it focuses on the cognitive aspects of my "mental training." She also recommended that I focus more on reading, and specific, psychological-development games, which would also improve my self-confidence as I recovered.

I had a few physical therapy sessions as well, but my therapist was hard of hearing. Couple that with my lack of strength with communication and it was a recipe for disaster. After a few unchallenging sessions, I decided that this facility was not working for me. I was so used the top-notch therapists at Sharp Rehabilitation Center, so together with my hatred for the Fallbrook Hospital, found the therapy efforts to be futile. Besides, it was hard to manage transportation, as Galen was back at work, and our housekeeper did not drive.

I couldn't rely on friends to take me all of the time and other family members were not always able to help. I needed to have a physical therapist come to the house a couple of times a week to help me gain enough strength to stand on my own and eventually walk. Unfortunately, it didn't happen, so I continued to spend my days in a bed or a wheelchair. I dreaded having to wear the ungainly boots to keep my feet straight. I had little choice, as they were essential to my physical recovery, so I merely had to work through it.

Low-Pressure Alert!

On Wednesday, November 15th, I had a neurology check-up. Galen and I left early for my CT scan at Scripps Mercy Hospital in San Diego, about a forty-five-minute drive from Fallbrook. Surprisingly, I was admitted for the scan right away. The hard part was waiting around for several hours after the scan until we could get in to meet with Dr. Kureshi. It was a forty-minute drive home without traffic, so it didn't make sense to take the trip back, only to have to turn around a few hours later. So, we decided to grab a bite to eat locally and managed to keep ourselves busy in the waiting room.

Dr. Kureshi would appear about five hours later. He reviewed my CT scan and said that he felt my shunt over-draining likely caused my headaches. Over-drainage occurs when the shunt allows cerebrospinal fluid (CSF) to drain from the ventricles more quickly than it is produced. Over-drainage can be very serious because over-draining can have dire consequences:

> "[It] can cause the ventricles to collapse, tearing blood vessels and causing headaches, hemorrhages (subdural hematomas), or a condition where the ventricles decrease in size until they are too small (slit ventricle syndrome)."[8]

My most recent CT scan confirmed that my headaches and memory issues were symptoms consistent with low pressure in the ventricles. Dr. Kureshi also confirmed that my shunt had a fixed valve and it couldn't be adjusted without surgery. He suggested that I go home and "take it easy," so my brain could safely adapt to the low pressure in my head. He explained that the brain is “an amazing organ that can adapt to thousands of variables,” and, consequently, he advised I try to “get used to” the headaches and other painful symptoms for as long possible.

For how long? He only hinted I endure all that frustrating pain for four to six weeks. If things still did not improve during this period, however, Dr. Kureshi cautioned that I would need another surgery to replace the valve inside the shunt. I’m not sure why an adjustable shunt was neglected. Regardless, I had no choice but to “try and deal” with the low pressure as best as I could.

For several more days after my last doctor’s appointment, the strain of the headaches and the symptoms of low pressure were taking a toll on me emotionally. The situation was distressing to me because I started off so strongly. A burst of mental and physical clarity consumed me when the shunt was installed in October, a few weeks earlier. However, recently I seemed to be getting physically weaker and more disconnected mentally as time progressed. I desperately hoped that my current situation was just the old ‘one step forward and two steps back’ routine that had been the story of my entire recovery. I wished I was able to take even more steps further.

Grattitude Day

It was almost Thanksgiving 2006, and I had hit a rough patch of road with my recovery. Since the previous week, my headaches had increased in frequency and had grown stronger in intensity than before. My condition became so dire that on Saturday, November 18th, Galen rushed me to Sharp’s Emergency wing, in San Diego. The doctors ordered and reviewed new CT scans and then upped my dosage of medication to help take the edge off of my pain. Once again, my symptoms pointed to an earlier diagnosis: over-draining of the shunt in my head. After six hours in the emergency room that day, I was exhausted and ready to go home to hope for a better day.

Those Damned Headaches

On Sunday, Monday, Tuesday, and Wednesday, my body felt like it was on a recurring and turbulent elevator ride. Each day I was jolted up and jolted down by my own body—the headaches, nausea, vomiting, and crippling pressure in my ears visited me in overlapping waves and dissipated without warning. When I dared to consider the possibility of a future with inescapable, daily headaches, I made myself a promise: if I didn't show marked improvement over the weekend, we would move forward and have the valve replacement surgery as soon as possible.

The operation would entail Dr. Kureshi reopening the incision in my head and replacing the current valve in my shunt with a new, adjustable one. The new valve could be adjusted for less drainage, allowing my brain to regain normal cerebrospinal fluid (CSF) and pressure levels. Once the valve was installed and adjusted, the multitude of pressure-related symptoms, including the debilitating headaches, were supossed to just go away, or at least, diminish.

Tuesday, November 28th was a better day. Galen helped organize my medications into a daily pill dispenser for easier access and then helped program the reminder on my phone so that I knew when to take my meds. The process seemed to be working. When I was sitting or lying down, the headaches were manageable. As soon as I got up or moved around, an extreme pain grabbed me. It seemed that as long as I held a position, I was somewhat okay, so I stayed in bed or rested on our couch for most of the day. We were in the middle of deciding what to do about my shunt, as the existing one was not working as expected. I showed signs of low-pressure headaches and nausea but did not know why or what caused it. Was it the difference in atmospheric pressure between my head and the drain to my stomach? Was the shunt malfunctioning? Would a different valve type and design make a difference?

Galen and I went over our options and decided that we'd wait out the surgery until we obtained additional information. We wanted to know what type of shunt Dr. Kureshi was going to implant and how much if any, improvement it was likely to make. We also wanted to know how we could minimize any potential complications. We hoped to get the answers to these and many more perplexing questions before we decided on the next step: surgery or no surgery.

Smooth-Sailing

In December we found ourselves trying to get back into a semi-regular weekly regime, though it was more difficult than it seemed. Between my medical issues and slow recovery from STBI, Galen's work, various activities with our children, not to mention the stress of daily life, things became quite complicated in our household. Top it all off with the tension of the holiday season, and it's a formula to freak out!

We were all very stressed, and tensions were running high, and it was easy to snap at each other. It was the first Christmas since my brain injury and the first time that the entire family was together to celebrate the holiday. Since this year was different, or I should say that I was different, it seemed to cause much tension and made the holidays challenging to get through.

The good news was that I seemed to be "pressurizing" slowly and each new day. I seemed to be improving, although it was incremental. My headaches remained but were of less intensity and duration than the month before. Nausea and low energy symptoms persisted, and we were trying desperately to find solutions. Dr. Kureshi planned to see me after Christmas, so hopefully, I had made enough progress to warrant a good report from him.

I was also getting used to my camber boots and was moving around slightly easier. These rubbery foam boots featured thick straps all the way up and down my leg and around my feet. The bottoms of my feet were sitting flat on top of the rubber soles and had no way to ventilate, so they became overheated very quickly. The good news was that I could unwrap the straps and slide my foot out of the boot. It helped when I showered, and the few hours I am rested at night.

During a checkup, my doctor tested my leg strength and pain level by having me stand without the boots on. I placed both feet squarely on the ground, grabbed the sides of the chair and lifted myself up, standing upright on both feet. It took a moment for the pain to catch up with me, and in a split second, searing pain shot through me as if I had stepped on and driven a giant nail through each heel. My right foot also wanted to curl inward much like it was before the surgery.

My legs buckled from the pain and I had to be helped back to a seated position. I've endured childbirth four times, and, yet, this new pain was somehow more severe and unrelenting. As much as I hated to admit it, I wanted the boots back on. I needed their support, although I knew it was a while before I could walk without them. I remember hating them, but I knew that I couldn't live nor walk without them.

Super Bowl Progress Report

In February of 2007, I still had significant problems with my shunt. The CT scans showed that my ventricles were like thin little slits instead of normal-sized canals. Everything was dire again. I was now facing a high risk of impaired mental function, loss of consciousness, and even death if my ventricles were left untreated. We did a little research and learned through various sources online that most surgeons install brain shunts with the aim of overflow versus underflow. Headaches, neck aches, nausea, and vomiting are common symptoms of an overflowing shunt valve. An issue arises when considering how a patient adjusts to an under-pressurized cranial area.

Dr. Kureshi gave me a difficult choice. Either I live with the side effects of an over-draining shunt, or I undergo surgery to install an adjustable shunt valve. It seemed like a natural choice, but we had to consider the risks associated with the operation.

I would need to consider the high probability of more pain, further hospitalization, severe complications, and acute infection that came with the surgery option. Plus, I'd need to face the genuine chance that the new valve would function more effectively than the one I was stuck with. It was one of the scariest risk-versus-reward dilemmas I'd ever navigate.

I was also frequently visited by a constant, and unforgiving earache. It can best be described as a pressure-vice, compressing both sides of my head. It started around Christmas and became progressively worse around New Year's Day, so we went to a new ear, nose, and throat (ENT) doctor for a diagnosis.

The doctor saw nothing wrong and advised us to go to a temporomandibular joint (TMJ) "jaw specialist," for referred ear pain. In the period from Christmas to early February, we had consulted with eight doctors for the ear pain including a dentist, a neurosurgeon, two practitioners, another ENT, an inner-ear specialist, and finally the TMJ specialist. We still did not have an answer. My TMJ specialist did find a ball of cotton lodged deep in my ear canal. It was left behind after one of my surgeries. It was not uncommon to fill a patient's ears with cotton to help absorb the sound when drilling into the skull during any brain surgery. It was bad enough that this piece of cotton had been inside of me for a while, but to add insult to injury, the TMJ doctor bruised up my inner ear canal getting it out. What a mess!

As time went on, I continued to suffer from what was assumed to be earaches. We could only guess if it had been the shunt or lingering pressure in the brain. However, earaches were not consistent with shunt or pressure symptoms. At that point, we were in search of the ultimate solution to my pain and looked to God to help us decide about the possible shunt replacement.

CHAPTER 14

Surgery on the Mind

> Hear me please—Again the holes in my skull that are left open for needle insertion to test brain fluid, are painful. A tube protrudes from here, wraps around my neck, down my chest center, and into my stomach. You can see this tube and follow it all the way into my stomach. It's here that excess brain fluid drains, relieving the pressure and softening the constant drone that drives my brain to a state of crazed contempt.

On Monday, February 12, 2007, I visited with my new neurologist, Dr. Shen Ye Wang, and my neurosurgeon, Dr. Sohaib Kureshi, who are both located in San Diego. My morning appointment was with Dr. Wang for my recent and continual ear pain. Besides a neurosurgeon, my on-going care required that I regularly consult a neurologist. Dr. Wang was referred to us by another physician at Scripps Hospital and seemed like a good choice for me.

After examining me, Dr. Wang couldn't diagnose any issues with my inner ear or identify the referred pain source. His opinion was that since the inner ear and brain were in such proximity, with both intertwined in function, my source of pain could very well have been the plummeting pressure in my brain caused by the over-draining shunt. He suggested we move forward with a "shunt-revision." Dr. Wang explained that if my earaches did not cease after the shunt revision, we could eliminate the low cranial pressure as a source of my ear pain and proceed with alternative treatments.

> "Your brain may not have properly preserved the short-term items in long-term storage yet. It's like your hard drive crashed, but the data is still intact." (Dr. Sohaib Kureshi)

That same afternoon we met with my longtime neurosurgeon, Dr. Kureshi. The purpose was to decide on my shunt revision. Dr. Kureshi suggested that since I had severe symptoms such as headaches and neck pain one hundred percent of the time, it was worth the risk of surgery for the potential upside of less pain. The primary dangers in shunt revision, as with all operations, carried an infection and internal bleeding complication factor of around one percent.

As he put it, "Nothing ventured, nothing gained," although he was quick to point out that nothing was guaranteed. Being careful not to overpromise, Dr. Kureshi stated, "Most of my patients that I have performed shunt revisions on, have shown some improvement."

Seizing the opportunity, I questioned Dr. Kureshi about my constant inability to verbalize words I was thinking but couldn't quite roll out into a conversation. Dr. Kureshi mentioned that my failure to smoothly recall words is due to the damage the abscess incurred in the speech centers of my brain. He said that he was still extremely pleased with the fact that I could speak and write and felt that my word recall would only improve over time. At that point in my recovery, I couldn't articulate a complete and coherent sentence to express myself, but I could write quite well considering my injury. The problem was that nobody would take the time to read what I had written thoroughly, so I gave up on that mode of communication.

I asked Dr. Kureshi about my short-term memory loss after my STBI. I couldn't remember much of what had transpired from the previous two years of my life. He informed me that the brain takes a long time to store away short-term memory and if there's an accident or injury, the brain may not have adequately preserved the items in long-term storage yet. When a computer's hard drive crashes, its data was still intact somewhere, but it's not accessible to the user. My brain had malfunctioned, and my memories couldn't be accessed.

I always imagined two parts of my brain with damaged nerve endings that no longer connected to each other. One side contained the information, and the other summoned it, but the data was lost in some vacant gray matter in between. I could visualize the electrical charges not connecting to each other, and I'd see sparks flying around and missing each other. It was quite a vision.

There was also my inability to remember daily interactions with people around me to which Dr. Kureshi said that after the injury, my brain was not as attentive and was trying to recover optimum performance. He reminded me it had only been six months since my initial surgery and that it could take up to five years before I could regain any of my previous physical or cognitive abilities back. His suggestion was to concentrate when someone was talking to me similar to the way I was listening to him during our visits. He felt that I would need to work on my concentration and over time I would regain most of my ability to remember. What Dr. Kureshi didn't know was that I had little interaction with other people at home, so my cognitive abilities remained extensively hindered.[9]

After my injury, much of my memory and cognitive ability was like that of a child, so in essence, I was starting all over again, and I desperately needed the human interaction to redevelop what I had lost.

> Everyone else around me should be embarrassed if they couldn't appreciate what I had gone through to survive. I should be proud that I had recovered much of my abilities and, above all, got that second chance so many people simply don't get.

Continuing the conversation with Dr. Kureshi, I told him of my tiredness, frustration, and embarrassment of my condition. I always felt self-conscious around other people, especially those I did not know and worried about what they thought of me. I explained that so many of my close friends, even family members didn't seem to understand me and was impatient with me or even dismissive of me. I always felt so inadequate even ridiculed when around them and found that it was easier to retreat from interaction and conversation altogether, which was both frustrating and depressing for me.

After a short pause, Dr. Kureshi abruptly stood up and with his head slightly cocked to one side, and hand movements abound, he proceeded to lecture me about what a miracle I was. In a stern voice, he reminded me of my close brush with death and the fact that I could have ended up in a state of "extreme retardation."

Thankfully I wasn't. Placing a reassuring hand on my shoulder, Dr. Kureshi whispered, "everyone else around you ought to feel embarrassed and ashamed if they can't understand or appreciate what you've gone through to survive." Then, he suddenly proclaimed that I should be "proud to have recovered so many of my abilities," and, above all, that I should feel lucky to have a second chance at life after my injury, which so many people in my condition before me have not been so fortunate to have.

Even with Dr. Kureshi's inspirational and impassioned consultation, I still felt anxious and confused about the amount of information that I needed to process. It was all disarming: the unbearable pain, the pending operation, the possible complications, another hospital procedure, another likely stay, the fear of potential setbacks, and worst of all, an uncertain future. Despite all this information and concern, Galen and I decided it was best to move forward with the shunt-replacement surgery.

Fits Like a Glove

On Thursday, February 22nd, I set aside my fear and confusion and had the shunt replacement surgery by Dr. Kureshi at Sharp Rehabilitation Center. The procedure started at 5:30 A.M. with pre-surgery preparations, and then I was wheeled into the operating suite around 7 A.M.

It turned out that the surgery was rather straightforward. The plan was to insert a new adjustable shunt valve in place of the fixed valve, which was over-draining and causing low pressure in my brain. The operation involved cutting into the area on my head where the first shunt was installed. Dr. Kureshi cut back the scar tissue, disconnected the siphon tube from my brain to the shunt and drainage tube to my stomach from the shunt. He then removed the old shunt valve and inserted the calibrated adjustable version in its place. He hooked up both ends to the new shunt and stitched up the incision in my scalp. Now I had the option and convenience of a valve that a doctor could fine tune as needed to assist with my comfort-levels.

Galen and other members of my family assembled in the waiting room at Sharp Rehabilitation Center until around 9:30 A.M. when Dr. Kureshi came downstairs to provide his post-surgery update. Dr. Kureshi noted that everything went exceptionally well with the surgery and that he was pleased with the outcome. He had to make an extra-long incision to get the new valve fitted correctly, but that was the only random event. Dr. Kureshi explained that he had installed an adjustable shunt for the fine-tuning features, which was set at a lesser flow state to slow down the movement of excess cerebrospinal fluid (CSF). Also, he added a gravity cut off feed, which would allow me to move my head up and down without as much head pain.

After the surgery and Dr. Kureshi's good prognosis was what we hoped was only a short hospital stay. Unfortunately, I had a rough night, and the next morning, as I bled through my surgical dressings, my headaches were so intense that I vomited without many pauses. Dr. Kureshi visited me later in the morning and ordered a CT scan of my brain to determine if everything since the surgery was functioning correctly.

He also ordered the nurses to redress my incision and had the staff pharmacist analyze the pain and nausea situation. Dr. Kureshi needed to get my pain and bleeding under control before sending me home. He explained that my brain had to adjust to the change in the shunt and that I had to allow the new adjustable valve to do its job. He also said that in time, the pressure in my head would equalize.

By Tuesday, February 27th, my surgical incision was slightly raised and giving me a lot of pain and discomfort in the back of my head. I also had a persistent headache but was unsure of its source, as my neck, back of my head, and all the way around both sides and front of my skull were affected. My pain medication was increased to deal with the headaches, which caused me to sleep most of the time or to be in a daze when awake.

The good news was that I had not been experiencing earaches or ear discomfort after the shunt revision, so we all knew that there was some progress. The big fear at that point was the threat of infection, as that could cause complications so Dr. Kureshi prescribed a round of antibiotics to help combat any potential infection.

New Shunt Report Card

One-week post shunt revision surgery and my earaches were gone entirely, but I did have some residual headaches. My appetite was decent, and I was sleeping satisfactorily. That was the good news. The bad news was that I still suffered severe headaches. They felt as if the top of my head was about to secede from the rest of my head. There was also pain from the incision, some dizziness, and at times I felt “weird,” or “off.” Almost like a constant state of drunkenness.

The best way to describe it is a lack of sensation with a delay in my sight. I would turn my head, and any person or object in my line of sight would have a trail of color, lightness or darkness that followed behind them. It seemed as if the pain had become the norm, so my brain overcompensated and wiped out or slowed down some of my other sensations to deal with it. I was aware of where I was and what I was doing, but I was looking through the bottom of a coke bottle to do so.

Overall, my new shunt did make a difference, as I had lost some of the original and painful side effects but gained some new ones including localized pain in the back of my head. There was confusion whether it was the surgical incision that was producing the referred pain or the ventricles in my brain.

At the post-surgery check-up, the first week of March, Dr. Kureshi was extremely happy with the overall appearance of the incision. He commented that everything looked great with no signs of redness or infection. I was much relieved when he removed the surgical staples, as they made sleeping on my back uncomfortable.

My progress significantly improved in the weeks after the shunt operation. I seemed to get fewer headaches and other complications. Unfortunately, some days, I did still get severe headaches, which were extremely difficult to manage. It was like I was back on the proverbial rollercoaster, some days rolling smoothly ahead while others were bumpy with uncontrollable highs and lows.

CHAPTER 15

Can't Catch a Break

> Sucked feet first, fingers clinging to the earth surrounding the dark hole. Dust flying, a dying trail leads straight to me. There is no imagination left. My eyes are open wide, and I can see it all. I just can't defeat the inevitable—the trip down the rabbit hole. Straight down, then round and round, confusion rises as the end seems never to come. Walls are left with the marks of fingernails scraping of dirt to catch me from further demise.

As of early April 2007, a lot had transpired during my recovery. The previous month was painful, and I went from a steady recovery process to spiraling downhill, yet again. Most of March I was plagued with severe headaches that would come and go. The pain felt as if my skull, especially my temples, were being sucked inward to the core of my brain. The sensation left a screeching sound in my ears and caused my whole body to tense up. It was like an extreme form of tinnitus. No matter what I did with cold and hot compresses and touching pressure points, the headaches wouldn't go away. When it first started, I couldn't for the life of me figure out what caused the headaches. And why did they just sporadically dissipate when they did?

At one point, I remember thinking that the pain would come and go with the tides, and that spurred an idea. Considering how powerful the gravitational pull needs to be to impact tidal changes, led to me ruminating about how powerful the earth's atmospheric pressure can be. So, I acquired a barometer and compared my room's atmospheric pressure with my brain-pressure. As it turned out, there was a notable correlation, although I had no luck getting any doctors to take my theory seriously. Anytime the barometric pressure dropped below 30 inches Hg (which was considered "normal" for our geographic region), I almost instantly felt a corresponding change in pressure inside my head. The noticeable pressure changes around me always preceded a massive headache. In fact, I could sense the change coming beforehand. I would yell at Galen, "It's coming! Get ready!" and the next day my entire head was buried under layers and layers of resounding pain.

I was already heavily medicated for pain. The headaches still had me in their grip, so Galen and I looked into other avenues to help deal with the pain. I found out about "biotherapy," also called "biofeedback," through a close family friend, figured that it was worth a shot. After all, I had nothing more to lose.

At the time of this publishing, medical researchers aren't exactly sure how or why biofeedback works. However, it has been consistently proven to promote a rehabilitative-like state of relaxation, which can be useful in relieving stress-related conditions. A "biofeedback therapist" helps patients practice specific relaxation exercises, which are calibrated to the patient and by the case to help patients reestablish control of impaired body functions. For example, a given "relaxation technique" could actually damper the particular brainwaves that activate during debilitating headaches.

By mid-April, I started receiving bio-therapy sessions twice a week at home. The technician that administered my treatment had already evaluated my brain damage through recent CT scans and was working with me to retrain my brain to operate "normally." In addition to decreasing the headaches, his goal was to improve my ability to retain and use current information.

My bio-therapy treatment involved forty sessions of biofeedback, which is a process where electronic monitoring of my brain was used to train me to acquire voluntary control of specific and critical cognitive functions. I had about twenty electrodes placed on my head, which measured my brain activity and displayed it as a stream of waves on a small screen. The monitor also emitted a high pitch hum that elevated in pitch when the brain waves increased in frequency.

In some cases, there was a flashing light that blinked faster with increased brain-wave activity. After doing several relaxation exercises including deep breathing, progressive muscle relaxation, guided imagery, and mindfulness meditation, I would concentrate on the sound or the flashing light. Through the technician's suggestions, I would imagine the sound decreasing in intensity or the light blinking at a slower rate until the sound or blinking reached the target level. Once achieved, I would concentrate on keeping it there. The idea was that eventually I wouldn't need the biofeedback equipment and could self-adjust by brain activity on my own. The experience had been very educational, and after these sessions, my headaches subsided temporarily. I also worked with a spiritual therapist or holistic healer whom I met through my hairdresser.

In the healing sessions, the therapist would sit beside me as I lay in bed and she would speak to me in a soft, reassuring voice. She'd rub her hands together, almost as if gathering up positive energy, and run her palms over my body, without physically touching me, while concentrating on my head, neck, and upper chest. As I relaxed, I could sense a deep but soothing heat that seemed to radiate from her hands. It felt as if she opened the pathways for "good energy" to "flow inward." I could feel what I can only describe as a tingling sensation or light electrical charge move all the way through my body, which subsequently felt almost weightless.

Even with my eyes closed, I realized such intense energy and a sense of balance, which gave me nearly immediate pain relief. A few times a month, we'd have her come in the evening, as her sessions calmed me, leaving me fast asleep after only forty-five minutes. I was so relaxed and in a state of balance that my slumber lasted all night. I would awaken to the light of morning feeling relaxed and refreshed with virtually no pain for anywhere from one to three days. It was such a great relief.

It was also wonderful to have someone to connect with not only on a spiritual level but also on a woman-to-woman level. My therapist understood that because of my pain, there were many times that I was on another plane and she would coax me back to Earth, to reality, without uttering a word.

There were countless times that my pain was so intense that I would use my imagination to leave my body and escape to another dimension. I would visualize the planes of this other dimension as large, flat ovals that rotate in a large circle. Expanding shapes spun around and pushed off of each other in different directions in random patterns. I would find myself moving from one plane to another when they came close to each other. I was not sure where each one would take me. It could be to a heavenly dimension that offered relief and enlightenment or to a dark, foreboding and soul-consuming place that was full of evil and despair. I just knew that I needed to keep moving to find my way back.

Intense Foot Therapy

After my Achilles tendon surgery and the effects of my foot nerve damage from my STBI, I was still having a hard time walking. Most of my right foot and leg was still numb, and it was excruciating to stand let alone walk. The pain would hit such a tremendous level that my legs would buckle, and I'd have to try to catch myself on something stable. Otherwise, I'd fall over. I was so afraid of falling when no one was around to help me that I didn't try as hard to walk as I should have to rehabilitate. Instead, I found myself staying in bed or seated in my wheelchair instead of moving around much.

I was still determined to get better, somehow. So, I did do my exercises at home the best I could while in bed or seated. However, this was not enough, so Galen and I looked into other options. We went with in-home therapy sessions, ordered special walking braces and stepped up my routine with more assisted walking. Within several days, I already showed improvement. We also applied to get me back into Sharp Rehabilitation Center, for more outpatient therapy. Galen and I both felt that Sharp was the best option for my professional long-term rehabilitation care.

During my first outpatient rehabilitation session at Sharp, I had a one-hour consultation with my physical therapist, who was quite lovely and was well acquainted with my condition. He analyzed me carefully and recommended a wide range of at-home and in-facility rehabilitation procedures, which concentrated on my ankles, feet, and balance. He estimated that it would take me several months to regain my balance and build up the strength back into my lower extremities. He was very optimistic, so I knew that I would do well. I always found the connection with the physical therapist to be critical to the success of the treatments. On that day I was relieved that I would finally get the level of care and intense therapy that I needed.

> My life is in complete turmoil, upside down and lost in the dark place. Nearly every day I wake the final time, at last. The band of darkness that followed me all night has turned to light and morning fog covers the earth like blankets of white.

Springtime Blossoms

As of May, I looked healthy, was eating well, exercising regularly, and appearing overall physically fit. I was also walking better with every day that passed. I was attending weekly rehabilitation sessions at Sharp Rehabilitation Center, where I was making strides but unfortunately still had issues with my right foot. It was still numb and did not respond as it should. My doctor had previously cautioned that it could take two years for full recovery. However, my right foot could have some residual nerve damage from the brain injury. I realized that it may never get better and that I would need a walker for a while and likely a cane for the rest of my life.

My cognitive abilities, however, were taking their sweet time to repair themselves. I found that I couldn't remember certain events, even on the same day let alone in recent days. My lack of cognition was the most significant disappointment because I was coming along so slowly in this area. It terrified me that I could get so easily disoriented and be so forgetful. I would forget earlier conversations or lose track of time, or quickly forget sequences of recent events. All of this turned me into a fussy, frustrated voice as I struggled to recall the near-past.

Once I was ambulatory, I could easily find myself someplace in the house and have not recollection of how I got there or why I was there. Years down the line I would even wander around our yard, out the front gates and then find myself trekking down the hill several blocks, even miles away. I'd become disoriented and then panic because I did not know where I was and couldn't remember how to get back. I'd be gone for hours and then finally someone would find me to bring me back home. They'd pull up in their car, which would scare me as I did not recognize the vehicle. Whether it happened at home from one room to another, or I wandered miles always, the lapses in time and memory was utterly terrifying for me.

We had visited Dr. Kureshi a few weeks earlier to verify that the surgical incision had healed properly, and without any traces of infection. During our follow-up, Dr. Kureshi also opted to adjust the valve in my shunt. He brought out a valve-adjustment kit, which came in a small case. When he pulled it from its case, he placed the open end of a small, plastic, disc-like cup over the shunt that was affixed on the very top of my head. He dialed in the exact degree of change, in this case, he opened the valve wider, by one unit of measurement. He adjusted it from 1.0 to 1.1 mmH2O, the unit of measure used in brain shunts. Dr. Kureshi felt that increasing the flow was better for me rather than to slow it down and reduce the cognitive development I had already made. I heard a small click, and the adjustment was made. Almost immediately I felt a change in the pressure in my head and a lessening of the head and neck pains.

Even at that point, it was not possible to measure my overall progress yet because I still had extreme headaches. The question was, were my headaches shunt-related or caused by something else? We noticed that after my weekly or bi-weekly bio-therapy sessions, I miraculously didn't encounter any headaches, even after very rigorous bio-therapy sessions. Also, taking medication like Valium, a central nervous system suppressant reduced my pain better than any strong pain medication.

We came up with the theory that my headaches may be stress and disorientation related, so we tried a new approach. First, Galen rented a home bio-therapy machine for daily therapy sessions, versus the just the ones I had been receiving from a technician once a week. Second, Dr. Druet, my pain management doctor, felt that he could help. He was an advocate of the theory of stress-related headaches. So, Dr. Druet prescribed some stress relaxation medication for me and wanted me to visit the office regularly to help manage the head pain. He felt that in a year or so, once I regained some of my cognitive abilities, I could regain enough autonomy with my body to be weaned off the medication altogether. It was a matter of getting through the pain of each arresting headache before the next one visited.

> I find myself falling again. I catch myself on walls or turn into corners. I landed on the bathroom sink and needed nine stitches. Here we go again...stitches! I sit on the bed's edge for a time so as not to fall as I rise. I have to plan my escape. Extreme fatigue begins from the point of waking in the morning. Forgetfulness more now than ever, in a matter of seconds, it's gone. Lost in time and space.

Another primary concern was that I was falling so often. I tended to collapse in the middle of doing simple tasks, like brushing my teeth. Once, I bent down to spit out toothpaste and Bam! Down I went, falling forward without warning. I smashed my face and chin on the sink on the way down. I'd also black out and wake up anywhere from a few minutes to hours later on the floor. One time I spent three and a half hours on the bathroom floor before "coming to."

My tendency to fall, of course, was very dangerous, so Dr. Kureshi ordered an evaluation. The reasons I fell could have been related to anything, from plummeting brain activity to a central balance issue. Also, the next week I was scheduled to attend the Balance Center, located in the Sharp Rehabilitation Center. They would determine if this was a minor issue that could be solved with medication. They would decide whether rehabilitation was my best option.

June Doom, High School Cheer

In mid-June, Galen commented how exciting it had been observing how far I had come. But he was still concerned about how far I still needed to go in my recovery. Overall, I was slowly progressing and required more time, maybe even a lot more time, to overcome my inability to control my thoughts and emotions. I had collected a surplus of rage at my situation. I've always been frustrated with my slow recovery process, and I've felt self-conscious because of it. I've been continually plagued with unavoidable self-doubt.

There were times the pain and despair grew so immensely that I became distraught. I even contemplated taking my own life. I wanted to confide in anyone who would listen to me that I wanted to end it. It would have been easy to find our gun or swallow a handful of pain pills, but thankfully my faith overshadowed my suicidal thoughts. Somehow, I'd gather the strength to carry on. God was watching over me even when it felt like he wasn't.

Some of my emotional issues seemed to be resulting from the way my brain was relearning to process changes in my daily routine. The stress from all of the variables, decisions, pressures, and uncertainties was often bewildering and worrisome to me. Until I had the time to relearn what we all take for granted, then I would have difficulty in dealing with the symptoms. The constant muscle strains and tightening around the head and neck, stress-related headaches, and the ambiguity of what's around the corner were all effects of my uncertainty. The good news was that I would discover how to handle these things better as I learned to grasp the tools to control these actions. Unfortunately, it took years for this to happen. I was learning how to rewire myself. I had to reteach myself to control my emotions first.

My shunt operation healing, however, was progressing well and my only major surgery pain was from the original incision made into the skull for the fluid valve. Most bone cuts like mine take a long time to stop aching. My overall shunt operation success seemed fine. The headaches, related to the shunt operation, had gone down significantly. The slightest motion or head movement used to cause sharp pain, but this had since dwindled.

The reality was that the traumatic brain injury I received was going to give me lifelong problems. Dr. Kureshi commented that symptoms with shunts tend to be unfortunate and at times very challenging. I somehow had to get them under control to minimize their impact on my quality of life. How does a child do that? I had been going through a combination of biotherapy and spiritual healing treatments that seemed to be very successful. After each treatment, my headaches substantially dissipated, at least, temporarily.

Somehow these different processes worked on the internal control of my mind and allowed the brain to be calm and operate in an efficient and controlled manner. Unfortunately, these various treatments resulted in only short-term improvements, only for a few hours or a few days. It was significant enough to keep doing, as the training of my mind could hasten my recovery.

The throbbing pain in my skull was nothing compared my body's internal issues. The minute by minute control of the brain and how it operates was the prime factor behind me getting measurably better in the future. The Achilles tendon surgery had a mixed progression. My left foot had healed, and I felt stable on it.

The right foot, however, continued to be painful and unwilling to follow commands. I needed continued physical therapy to bring my right foot around if it was even possible. My natural balance was affected by my brain's inability to handle sudden movement or change of direction. Combine that with my problem right foot, and I was struggling to walk without assistance. On most days I relied on a walker to get around.

I was working twice a week with my physical therapist, Rose, at Sharp Rehabilitation Center, who was probably the most excellent example of an exemplary person you can meet in the physical therapy field. She had gone countless times over the top trying to help me in every possible way. She was on a mission to find every specialist, previous doctor, and associate, any of which could offer any help in my particular recovery. I just hoped that we could keep her around until I recovered completely.

Starting Over (and Over)

As of early August, one year after my injury, my shunt seemed to be operating within design specification, but I still had the side effects of the shunt. Headaches associated with the pressure. However, overall it was slowly improving. Dr. Kureshi installed an anti-siphon device during my shunt revision, which was designed to help keep it from over-draining.

The problem was that the anti-siphon device since installed had led to me blacking out on occasion. It was pure havoc: severe falls, bruised body parts, aches and pains, and worse, a roadmap of stitches. Plus, there were more setbacks. We had tried to limit my activities to decrease my chances of blacking out and had some success. I had even taken to wearing a softball helmet for ultimate protection when attempting certain movements. The major frustration was that I would always find a way to fall and hurt myself when no one was at home or hovering over me every second.

My speech was still an issue due to a lack of confidence and increased stress levels when talking to people outside of my immediate core. In some cases, if I was comfortable with the person, I was able to converse as if nothing had ever happened. It was when I was outside of my comfort zone that I would get self-conscious and start having difficulty in finding words or speaking smoothly. My inability to articulate was going to take time with a speech therapist's assistance.

Overall my mental and emotional functions were on track, except for my ability to remember short-term events. It was just something the doctors said happens with this kind of injury. We were told at an earlier date that it takes years for a person's brain to store long-term memories properly. However, to organize and efficiently store short-term memories turns out to be a highly complex process.

My understanding of external events was almost as good as before my injury. It just seemed that my brain was having difficulty deciding when and how it was going to sequence events during the day. At times I could remember everything that occurred on a given day, no matter how seemingly complicated events seemed. In the next moment, I would forget what happened seconds before or what day it was.

Psychologically, I was extremely frustrated that I was at that stage in my life. It was depressing when I entertained a reality in which I wouldn't fully regain 100 percent of my "former self" (my former combination of unique personality-traits). Going through something as horrible as an STBI, and quickly take away one's hopes and desires.

I was slowly trying to integrate back into society the best I could and was able to attend our daughter's high school graduation and our son's wedding the month before. However, at other times Galen and I traveled to places together like to Lake Havasu, Alaska, and Korea, and enjoyed time together. I was glad to be around for these moments. I just hoped that I could continue to improve.

CHAPTER 16

Long Road Ahead

> Little do they know that every minute of every hour in each and every day, I am in the clutches of hurt. Seldom is there relief, and after years of waking to the same sun, the drought continues. Like the crackling earth of a dry riverbed, I crumble under the pressure. Exhausted and humiliated, dragged from life against my will, the future is yet unknown.

I HAVE TRAVELED VERY far, from a distant time and place. One in which I was unable to walk without assistance. A time in which I couldn't care for myself if I wanted to. It has taken about five years or so to relearn everything from before, from menial physical tasks to holding a sustained conversation, to competent and autonomous walking. I had to be retrained to do mundane tasks: holding a fork so I could feed myself, squeezing toothpaste onto a toothbrush and then brushing my teeth, running a comb through my hair, even personal care.

All of the little things that others take for granted every day, like the ability to go to the bathroom, became new mountains I had to scale. Unable to feel the sensation most people do when they need to urinate, I have had to perform "self-catheterization" several times a day to relieve myself. It's not a pleasant experience but unfortunately a necessary one, and it took a while to master the process. It's also prone to causing urinary tract infections, so I have to be very careful.

I was suddenly at home, settling into a "normal" life. I managed to get to a point in which I was reasonably mobile, especially while my back wasn't hindering me. I was able to walk with the help of a cane, or a walker, on days where my strength languished. I even had a mobility scooter, which allowed me free passage to the bathroom and the kitchen. The other side of the house was reachable then, even despite my difficulty with walking.

Settling in at home after all of that time in a hospital, I took things day by day, finding joy in the little things like eating what I wanted when I wanted and relished the view from our patio on a warm sunny day. I was also working hard to improve my body and my mind. Religious about continuing my therapy, I was diligent with daily at-home workouts and worked hard with cognitive exercises such as flash cards with word definitions, memory games and concentration exercises.

I was also starting to write, which was a great release emotionally. I tried to take up reading again, which I so loved before my injury, but it was now an arduous task. Reading anything beyond a few paragraphs can be tough for me, as my mind can invert words or letters, even jumble the page much like with extreme dyslexia. I would push through and focus on a few paragraphs at a time. I started a project as needed and took breaks from it as needed. I resumed personal projects when I felt less tired, or when there was less pressure in my head.

My recovery is not without daily struggles, even more than a decade after my injury. Mentally, my mind has remained somewhat like an Alzheimer's patient[10] where I can't always remember anything short-term, and many of my thoughts don't connect. For example, I set out to the kitchen to get something, and I forget what I wanted to retrieve from there in the first place, and even forget why I ended up in the kitchen.

In many cases, I'd have a conversation with someone and then forget the next day what the discussion was about, or I may not even remember having the conversation in the first place. When writing, I form a thought and try to write it down, only to find that I wrote about the same idea the day before. Even with friends I've known my whole life, I have a hard time recalling names. I go to email or text them, and I can't even remember which keys to hit to access their information. It was infuriating.

In addition to memory issues, I have always had ups and downs with my brain shunt. The pressure in my head is compounded by changes in barometric pressure. I am prone, even to this day, to get extreme headaches and suffer memory lapses because of this pressure. Since my initial injury, I have had three shunt replacements, and I've switched doctors twice. What's more, pain still lingers in my skull, especially during atmospheric-pressure fluctuations as the weather changes outside me, and around me.

> You can feel it changing. Like personalities—multiple personalities. It's as though, like seasons' change, so does the personality. I can see it happen, not just feel it but see it from a distance. I watch it, as it occurs, on that screen, on the back of my eyelids. A black screen with bright letters or graphic pictures—the entire story is played out before me.

Devices called barometers are used to measure atmospheric pressure. They measure changes in pressure in inches of mercury (Hg). Barometric pressure varies with altitude and moisture with fluctuations in atmospheric pressure are commonly a sign of weather conditions.

I have found that a perfect day for me is when the barometer reads 30 inches of mercury (Hg) on the nose. In such a case, I enjoy being free of the pressure in my head, which allows me to experience incredible mental clarity. Words and thoughts come to me quickly, so speech and overall communication flows and I have a clearer recollection of recent events. The equalized pressure in my head also helps diminish any facial tics and tremors in my hands and makes me feel better overall on a physical level.

When the barometer changes even just by one-hundredth of a point, I can feel the shift of pressure in my head. It's a squeezing sensation that is followed by fogginess in my awareness. Quick and drastic changes or when the pressure is low, dropping below 30 inches Hg, affects my physical and more so my cognitive functioning. In extreme cases, I call it the rabbit hole.

It's like a dark, foreboding place that feels as if I'm being sucked in and held against my will. I am not able to fight it and find myself emerging from the hole hours, days, even weeks later, when the barometric pressure stabilizes, but I unaware of much that happened during the episode.

During this lapse in time, a different person emerges. Acting mostly on autopilot, this version of me carries out her day and even holds conversations with others. That's when—so I'm told—I have a propensity to swear, which is uncharacteristic of me. I can also apparently utter other kinds of inappropriate things. I'm not aware that I have done anything wrong until I'm informed afterward. It's like waking up after a blackout.

> I heard the obnoxious buzz-hum of the song my brain sings as it prepares for "the big one." I know the size of what's to come by the song it sings. Angry and dark, heavy and slanted signals a big one, so it's best to prepare. How does one prepare when the brain has no idea what to do or where to go? No one can possibly know or understand the world that opens at the time of impact.

Another thing that caused several issues for me was the vast amounts of pain medication that I was prescribed. From the onset, I made it a point to avoid taking any drugs I didn't need to. One of my early pain management doctors insisted I take them to "make it easier to manage my recovery." In addition to an array of medications for various pain issues for my back, head, and

Achilles tendons, my earlier doctor also put me a very high dose morphine patch. With all of these medications, I was so zoned out, and I felt as if I wasn't even alive.

The problem with any pain medication is that it's just so easy to take another one, and another one, and another. I see how people who have had an injury could become addicted. I also think this kind of medication can compound the recovery from an injury. In my case, there was an adverse effect on my personality.

They could make me feel uncoordinated, confused and disconnected mentally and in some cases, they made me agitated, and short-tempered. In other cases, the meds made me highly sensitive to the words and actions of others, which naturally affects my well-being. When I was overly sensitive, it always led to self-doubt, and at times, inevitable depression.

When I returned home from rehab, I found myself in a wheelchair staring out of my bedroom window. In my head, I was watching a girl who was also in a wheelchair, and she was looking out the window, but I remember thinking to myself, "That girl is going to die."

She was very slight, a mere eighty-five pounds, looking gaunt with sunken eyes with dark circles around them, and dull greyish skin. There was something about her that seemed unhealthy. Her dead stare conveyed that she was barely alive. In a moment of intense clarity, I realized that the girl in my vision was me. It unnerved me. It made me realize that the various pain medications were probably doing more harm than good. What's the point of living if there's such a glaring lack of clarity?

> It's not a life anyone wants to live. It's not worth it. Sometimes I pray not to wake up. It's the biggest sin I can ask for, but it's true.

Beside the possible side effects such as anger and confusion, many types of pain meds are known to affect the respiratory, gastrointestinal, musculoskeletal, cardiovascular, immune, endocrine, and central nervous systems.[11] Long-term use can also harm the liver and kidneys.[12]

The good news is that I have a pain management doctor that I feel comfortable with now. Dr. Druet has been quite supportive of my efforts to wean myself off of most of the medications. He prescribed Methadone to treat my moderate to severe pain, which also allowed me to stop morphine entirely and to step back on all of the other pain medications.

He started me on twenty tablets a day, and I worked my way down to three or four pills a day. It took about five years to do so, but I feel heroic for being able to step down to a manageable level. I am thankful for the increased mental clarity because of these efforts. By practicing meditation, acupressure, and breathing techniques, I am determined to keep the pain-medication use to a minimum.

> Each episode brings new dark boxes that open without discretion. You are the STBI. You are the injury's result, a walking time-bomb, ready to explode at any time. Tread carefully through this jungle, have patience in yourself and others. Perhaps they will learn some life lessons through you...maybe.

CHAPTER 17

Truth

> Broken and messy but kind. Lonely I am, almost all the time. Gone, what used to be mine. It's not what I asked for. No, this one! She slipped in the back door and remains to this day. For the girl I knew, reckless and bruised, she was never afraid to step out, to bring back the fire. The light that once filled the darkened sky, burnt fields remain in memory. What was and what could have been, these are the mysteries yet seen.

After telling my story as it unfolded all of those years ago, I now feel the need to come clean. The truth is that I have no memory of my brain injury, the initial surgery, coming out of the coma or about a half a year of my life for that matter. The most I could recall afterward was some of the time in a rehabilitation hospital in San Diego. There was no specific point that I "came to" but instead I have glimpses here and there that don't seem to follow any particular timeline.

I recall that at my worst I lost almost every capacity. I was mostly blind, having double vision and seeing only blurry shapes, I couldn't speak or communicate in any way, and I had no controlled use of my arms, hands, legs or feet. That whole time, I was virtually helpless, an invalid, as everything had to be done for me. The nurses would have to prop me up and change my position every few hours, as I couldn't do it for myself. I couldn't lift my head, and my arms and hands did not respond to me when I would try to reach up or perform little tasks like touch my face. It was like waking up to having both arms being asleep all night, and there's no way to turn off the alarm clock.

There was always a real sense of panic when immediate action needed to be taken. Neither my arm nor hand did what my brain was telling them to do. The same thing would happen with my legs and feet. I would think to do one thing, and it wouldn't occur, or that body part would respond in a different way than expected, sometimes even thrashing around.

I also couldn't eat, at least not without a feeding tube. The bothersome plastic hose ran through my nose, down my throat, and into my stomach. To this day I can still smell that nasty bucket of liquid that the hospital staff would pour into me for nourishment. It was a chemical odor much like protein powder, and the consistency was similar to thick mayonnaise. I imagined a sludge—an otherworldly, viscous, yellowish slime—emptying into the intake on my feeding system.

The bizarre concoction would slither down the feeding tube and fill my stomach until I felt like my gut would burst. I despised feeding time and dreaded the slime's nauseating smell. I instantly caught a whiff of the sludge on the poor nurses who had to schlep it over to me from the distant hallway. The putrid odor announced itself twice a day, every day. As appalling as it was, however, I knew it kept me alive.

Though I cannot recall exactly when or where this happened, during my first several semi-awakenings or moments of quasi-coherency, I remember feeling so incredibly confused and trapped. I wasn't able to move or communicate, and my brain was working overtime trying to figure out where I was and what had happened to me. All I knew was that I was a prisoner inside my own body. It was not responding as it usually had, even during the simplest, most rudimentary of tasks. It was like looking into a depthless crater—a dark and foreboding prospect.

> I woke up in a world that was unaware of who I was. I was unaware of who I was, but deep inside there was a box. This box held all the answers, and I just had to find it. There were many boxes, all different sizes, shapes, and colors. So many to go through in so little time. Would I need to open all of them, to find me? Could I open all of them, before I leave again? Do I want to?

There was one day after my first shunt installation, where I felt as if a dense and lingering fog had somewhat lifted. I felt reborn because I had a complete awareness of everything around me. I was incrementally in control of my thoughts and movements, but I felt completely empowered. I found myself ripping away at everything, trying to free myself from IVs and tubes. Although they had been in place for some time, this was the first time I was aware of them to the point of being annoyed by them.

Galen was standing over me, trying to help control my movement and calm me down. At first, I did not recognize him nor what seemed like a strange language that he spoke. The words were garbled and unfamiliar, yet he continued to repeat them. Although Galen's furrowed brow and targeted gaze showed concern, his tone was calm, and his assertive stance divulged that he was familiar with me, so I relaxed and allowed my mind to absorb my surroundings. As more of the fog lifted, I came to realize who Galen was to me and his words started to make sense, like pieces of a puzzle falling into place.

> Blank stares on rolling seats, empty mouths with empty hearts; in lonely rooms on dark starry nights. Bottles empty to nourish and keep alive. "Drip, drip." The sound that echoes in my nightmares That hollow cry. It's my story now. I write to you, oh Silent One; I write for you.

Isolation

One thing I recall about my time at Sharp Rehabilitation Center was that they had me so isolated from the rest of the patients. Maybe there was a purpose for that, but my room was at one far end of the facility and everybody else, the patients, the nursing station, and the entry for visitors, was at the other end. With enough space for two additional beds, I found myself in a vast echo chamber. Each sound seemed intensified and bounced off the walls and resonated within my skull. My bed was sequestered to the far end of the room. At least I was next to a window. Although, it was frustrating that the window's roll-up blinds were always in the "up" position.

Nonetheless, it was nice to see the sky finally. It wasn't long, however, before I found myself feeling utterly empty and alone like I was in a vast and barren ether. I felt severed from the rest of the world. The only time anybody else visited my room was when a nurse came in to complete their task. I would hear their footsteps or feel the change in air current as they walked past me.

Occasionally I'd see a faint blur of their colored scrubs contrasting against the drab beige backdrop of the room. They would gently touch my arm or work in pairs to carefully reposition my body, propping me up in areas with pillows. I'd also faintly hear them as they would chatter to each other. Sometimes they would even talk to me, but their voices or what they were saying were not always coherent. It was their delicate tone and the occasional use of my name that would spark a cognitive response in my head.

I remember when I was starting to comprehend my physical and mental situation and my surroundings somewhat, there was a point when some of the nurses would occasionally come in, grab a chair and sit with me as they took a break. Sometimes there were six of them huddled around me enjoying their lunches. Some days there were more and on other days, less or not at all. When they did come in, I just loved watching them and felt content when they were there. I'd hear them chatter back and forth between themselves, and sometimes they would talk to me, including me in the conversation. They would laugh and smile, and carry on and, even if I was not able to get involved, or understand what they were saying, I felt included and for the first time in a while, alive.

There were two nurses out of the group at Sharp that tried especially hard to connect with me. They would come by to say, "Hello," and checked on me more than the others did. They'd even spend the time to help me do little everyday things, like brushing my teeth and combing my hair. I remember feeling so grateful for the attention, as it made the overall experience so much more bearable.

Usually, the isolation and frustration with my situation left me feeling bleak and somewhat invisible to others. The connection that the nurses offered made me feel less like a burden and more like a real human being. I wish I knew their names or could remember their faces, so I could personally thank them and tell them how deeply they touched me.

Cool Hope

The first word I was able to say after my injury, or that I recall saying was "hope." The nurses would tell me always to have hope, and after having it repeated over and over again, that word became etched in my head. I would carefully watch their mouths form the word, sometimes they would repeat it slowly and succinctly so I could follow along, and eventually, I was able to emulate the movement with my mouth and produce the controlled sounds for myself. It was a milestone accomplishment, and I was proud of it. The only other word that I could muster was "cool." I'm not sure why that word, or how it came to be, but I guess that it was an easy word to recollect let alone say, so it became my go-to response for everything.

There was a gentleman in rehab who befriended me during the first week of his stay in the facility. He was a friendly man, a burly guy with sandy brown hair who was about my age, and he had lost part of his arm in what I would later discover was a construction accident. He came rolling up to me in his wheelchair and would try to spark up a conversation. I think that he wanted someone his own age to talk to so he reached out and attempted to make the connection with me. We hung around each other for two days, and it felt great to have a friend.

The problem was that the only word I could manage to say to him was "cool." Everything he said, every question, comment, expression, everything in conversation, my comeback was merely "cool." By the end of the second day, he grew frustrated with my limited answers. Perhaps he assumed that I did not comprehend or care, so he rolled out and moved on to find someone else to which to connect. That's what he needed, and although I was sad to see him move on, I was happy that he found someone else to talk to who was on his cognitive level. With my limited attention span and inability to communicate, I certainly didn't fit the bill.

The reality was that I craved a connection with other people, I didn't know how to find it or keep it. I was intimately aware of my limitations and was very self-conscious around others, especially outsiders. I also saw nothing to spark my attention long enough to keep it, except with my physical therapists at Sharp Rehabilitation Center. With them, I felt a connection not just at a physical level but emotionally. They seemed to comprehend how I felt and worked hard to connect with me through eye contact, thoughtful conversation, and deliberate physical interactions that would help me to gain confidence.

My therapists took the time and had the patience to explain each task during therapy sessions and remained by my side. They acknowledged my successes with absolute glee and encouraged me with inspirational words and gentle pats on the back when I failed. What I remember most is that the time each spent we me, their attention was 100 percent on me. Everything was done with my benefit in mind.

Having a connection with my therapists was the most attention that I would receive during my recovery, or at least remember getting. They were very perceptive about my mental, physical, and emotional progress. Their patience, sincerity and positive reinforcement gave me hope and made me want to try harder in my physical, occupational, speech, and other therapy sessions. I genuinely believe that the success I had in getting through therapy was because of them.

Different States of Being

After my injury, in time I came to realize that my brain was processing information at one level and responding or sending output at yet another. I felt like I was broken in two and living in two dimensions, instead of one. I didn't know which plane to live on and my mind didn't know where to go.

Nothing within my vulnerable, injured brain could contain the painful feelings that sometimes emerged. Continually spinning, my mind would spit out random memories and dark thoughts. Some recollections were from my abusive childhood, others were instances or even bad dreams in my adult life, and yet others I had never witnessed before.

No discernable pattern, nor reason explained how my particular memories were sparked. Nor was there any explanation behind the visions that seemed to pop up in my head on their own. It just happened. This lack of control was terrifying to me. There were also no breaks, no milestones or stopping points, just constant thinking, which led to pure mental exhaustion. I liken this experience to boxes of memory that opened, spilling random recollections and thoughts onto the floor of my skull, many times leaving what I envisioned as stains and clutter in their wake.

As time went on, I all too often found myself alone, so negativity built up as pain and confusion flowed from these dark boxes in my head. Day after day I was locked in an un-functional physicality, with a brain that was spinning out of control. It was like the metal wheels of old roller skates screeching to a stop on cement, the sparks flying, and the sound, deafening. Sometimes the lack of control was unbearable, and I had to learn how to calm myself and gain composure.

I would try to concentrate on my breathing, inhaling deep and holding for a four-count, and then exhaling and waiting for one, two, three, four, until I took my next breath. I'd also fixate on a specific point in the room and would attempt to call up a good memory. The problem is, I never knew what box would open or if the recollection coming out of this box was a good one or not. I would roll the dice and hope for the best.

CHAPTER 18

New Reality

> So often we are fighting to 'get back' to who we once were. It took me about a decade to figure out that we can't go back. We can only go forward. By acceptance of who we are today, we allow a whole new experience to unfold. We are made new! We are never who we 'were' but who we 'are.' Today is a new day, so be new within it.

THERE IS QUITE A difference between a traumatic brain injury and a severe traumatic brain injury. In the United States, 2.5 million people suffer a traumatic brain injury per year which can be sustained by a concussion; just being unconscious for five minutes can cause a traumatic brain injury and it can trigger issues that affect your entire life.[13]

However, a severe traumatic brain injury causes the loss of brain tissue. Each STBI survivor's experience is unique, as it depends on what part of the brain has been lost and or damaged. In my case, I suffered from the intraventricular rupture of an abscess in my brain. In turn, this led to ventriculitis, an infection of the cerebrospinal fluid (CSF) surrounding the brain cavity. The spread of bacteria in this fluid created pressure in my brain and ultimately caused permanent damage in the frontal, temporal and parietal lobes. This disaster affected my vision, personality, behavior and emotions, speech, writing and motor skills, understanding of language, short and long-term memory, concentration, self-awareness, sense of taste and smell, and overall judgment and problem-solving:

> Until only recently, it has been widely accepted that the brain had little ability to repair itself following stroke or other forms of brain damage. However, there is an increasing amount of medical research indicating that the brain does attempt to heal itself. Brain cells that are damaged, but not beyond repair, will typically "begin to heal and function more normally. Rehabilitation therapies stimulate sprouting of existing nerve cells, causing them to make connections to other nerve cells."[14]

How crazy is that! On top of that, it turns out that the brain can also recycle its own tissue to resume impaired functions left behind by its damaged regions:

> "Recent research also suggests that the brain may" [create new nerve cells through a process called neurogenesis. Stem-cell studies are now underway] "to see if this new nerve-cell growth can be maximized and directed toward the most damaged areas of the brain."[15]

When I saw my own MRIs, CTs, and x-rays, I quickly realized that the amount of grayed out or dead area was phenomenal. I was shocked by the degree of cognitive destruction I'd inherited. How does one exist in the wake of this fact? It's incredible what we can live without, or try to live without when we have no other choice. I survived. At least some of me did. It wasn't easy, and I wouldn't want ever to do it again. Once is enough for anyone. It's entirely way too much to process.

Who is in My Head?

During my whole ordeal, I wished that I had someone explain everything to me because I didn't know where the hell I was, or what was going on. When a survivor loses a part of their brain, as I did, they also leave behind a part of themselves. Some of this loss can be with the physical ability to function while other forfeitures can be with short or long-term memory.

I suffered a dramatic decline in physical coordination, cognition, and memory-processing. This turned out to be mostly for the short term though. It felt like an uninvited houseguest had moved right into my head without my consent. All the while I was asleep and powerless. A stranger hijacked my brain.

When someone has a visitor with them in his or her home, and he or she don't know the person, it can be very uncomfortable for the hostess. Imagine the scenario in a loop in your head. Visualize living with someone you don't know who takes a shower with you, goes to bed with you, and wakes up with you.

Who the is she? Nobody knows. However, it's not me. The once confident, highly social, and strong-willed, woman I once was, had disappeared. The new person: quiet, dependent, scared, and unassured, took over. I miss the old me.

> I'm not the pillar of strength you all think I am. I am not the picture of hope and courage you might believe me to be. Yet, I put on a good show. I've taken the fine art of pretending to great new heights, to protect those I love. I pretend that pain doesn't exist or at least that it's tolerable.

Not "Okay"

I may look healthy and act somewhat assured, but the reality is that I'm not the person that I once was and frankly, that needs to be okay. My friends and family and friends often tell me I look "good." They always remind me that "it's great to have [me] back." But I get the feeling they don't grasp what I've had to endure, and more importantly, just how much I've had to change. I tend to hear, "Well…you are better now…" Despite any good intention behind their a response, I find it to be among the most dangerous statements a person can say to an STBI survivor.

The reality is that I'm not okay, as it's too big of an expectation for what I've been through. Dr. Kureshi, my original neurosurgeon, had once told me that on a cognitive level it could take up to five years to get everything back that's coming back. It's been over a decade since my injury so I've had to come to terms with the fact that I'll never fully recover.

Once I finally realized that yes, I am handicapped, I have a brain injury, that's when things started to change for me. I have only recently accepted my STBI, so now I can settle into my current way of life and make the best of what I did have, versus dwelling on what I had lost.

Family Fortress

I do understand that an STBI can shake up the entire family. They have experienced a loss too, which can be difficult for them to grasp. The spouse and children of adults with brain injury have an additional burden of caring for the person who once was their nurturer; this situation may disrupt the family dynamic with emotionally charged consequences while role reversals can lead to resentment.[16]

As an adult survivor, I would think that children with an STBI parent would tend to feel abandoned and overwhelmed at the same time. They would have no idea how to deal with the situation so they'd likely distance themselves or do more harm by being impatient, even condescending or dismissive. I can imagine that it was hard to fully comprehend that the parent is not the same person who raised them and that their mind may be like that of a child.

Much of my personality has evolved since my injury, and my family had a hard time dealing with the change. My kids and all of my friends at the time didn't understand, perhaps did not like, the new me, so they withdrew. Not one of my friends from before my injury came around after a certain point. I was no longer their problem, so they chose not to get involved. I was too busy growing up all over again to realize how hard it was for them.

I know that my kids tried to help in my recovery efforts and to cope the best that they could, but to me, it was evident that most of the time they wanted to be somewhere else. I really can't blame them, as they were in their late teens through mid-twenties at the time of my brain injury and were pretty wrapped up in their own lives, as they should be. It's their young lives to live. I never expected them to stop their lives, to allow me to be part of theirs once in a while.

Even to this day, I believe that my kids don't understand why I'm not the same person that I was before. I get that they lost their mother all of those years ago and did not know how to handle what had happened. I sometimes feel that they resent me for the loss to some level, which can be disappointing. I miss them so much, and the connection we used to have but they've all moved on with their lives, and I feel as if I get pushed back, even held down, by their wake.

As much as the role reversal is hard, I can't stress enough how important it is for all family members to be there for the survivor. To accept and love them for who they are now and to not judge them on any short-comings caused by their injury. When the survivor makes mistakes, such as saying things incorrectly or not being as politically correct as perhaps they should be, tell them what they did wrong and help them to learn and grow. Be patient with them. Empathize with their situation. Teach them like you would a child because, in reality, a survivor is growing up all over again.

Unwelcomed Houseguest

During my initial recovery, I was thankful that Galen was patient with me and took the time to help the best that he could. He and his partner Randy were at a critical point in business dealings but between the two of them rearranged their schedules so that Galen could visit me in the hospital every day and attend every conference with doctors. I know that it was hard for both of them to manage that much time away from the business for Galen, but I am eternally grateful that they did.

When I was slated to be discharged from the rehabilitation hospital in early November 2006, the review-panel of doctors and caretakers at Sharp Rehabilitation Center informed Galen that I would require full-time care once I returned home. I recall one of the team members asking Galen point-blank, “Will she have full-time care when she gets home?” Galen answered succinctly, “Yes she will.”

Once I was back home, I found out that Maria, our part-time housekeeper was to be my full-time caretaker, which was a shocking revelation for me. Although she had previously managed some of the cleaning tasks around the house, this short, stalky Hispanic gal in her late 50s was grossly unqualified and ill-equipped to care for me.

I was mostly bed-ridden at that point and required much help with daily tasks and personal care, which is embarrassing enough as it is. Imagine having someone from outside of the medical profession, a person who usually cleans houses or packs produce in a warehouse, helping to bathe you, change your diaper or assist in inserting a catheter into a very private part of your body. Not fun at all.

In addition to not speaking English, Maria did not drive, and therefore Maria couldn’t do the grocery shopping, run errands or take me to doctor’s appointments. Galen had resorted to his regular work schedule once I was back home. He was gone at work for twelve to fifteen hours each day, usually six days a week. He was not able to do much more to help. I was left alone with someone with whom I couldn’t communicate. On top of it, this stranger in my home was not adequately attentive to my needs as a nurse or even someone who is trained as a caretaker.

Maria would clean our house and check in on me every hour or two. When it came to housekeeping, she wasn't very conscientious or thorough and would cut many corners. For example, I would see her mopping the garage floor, where our dog would often defecate, and then she'd bring the same mop into the house and use it on our kitchen and bathroom floors. It made me feel so angered and crazed that I had no way to explicitly communicate my dissatisfaction to her or even to my family. The words would jumble in my head, and I couldn't call them up quick enough to defend my position, so I ended up having no choice in the matter.

Maria was all that I had, and I found myself being miserable in my own home because of it. Rehab at the hospital was very different. I had around-the-clock care. I was suddenly expected to exhibit some form of independence at home. This marked a tedious transition. Having to suffer from what I felt was less than adequate care, especially when we could have afforded an actual nurse, was just inexcusable in my mind.

Full transparency—Galen and I have different recollections of this point in my recovery. He felt that I was bothered by having someone always hovering over me and opted to go a different route with my in-house care. Perhaps I became agitated when people were doting on me. It's possible that I sent each person away not realizing that they were there to help me, but I was psychologically like a child and did not know what was best for me. I know that Galen meant well, and always wanted the best for me but in hindsight, Maria was not the right solution.

After about five or six years with Maria, she was finally out of the picture, and we hired Patricia, who has been with me ever since. Patricia has been empowering to have around. She is very attentive and is a thoughtful, gentle and caring person. It turns out that she has two sisters with special needs, one who is much worse off than me, so she had the right type of experience for caring for someone with a brain injury. Once Patricia came on board, I came alive again and had a lot more progress. She gave me a different kind of hope.

"You've gotta laugh or you will cry!"

Coping, Informing

For the first year of my recovery, Galen documented everything in a blog that he posted for friends and our extended family to read. I do think part of it was an outlet for him, a way to vent, but most of it was a way to communicate with others about what was going on with me at the time. Posting updates on my progress freed him up to spend more time with me, and for that, I am very thankful. For the sake of others, the tone and content of the blog remain as upbeat and positive ever.

In reading the blog later, though not intentional, I found it to be somewhat misleading. Just weeks after my injury Galen proclaimed in a blog title, "Eureka! Kathy is Back!" In another post from that period, he said, "Our Kathy is back and not one second too soon." I know that Galen's sincere hope was for me to recover quickly and thoroughly. I know that he'd hoped I could go back to being the strong and capable woman I was before. Considering the slim chance for survival, and the extent of the damage in my brain, the likelihood of a full recovery was always bleak.

As much as I understand the need to stay positive and to hope when I read Galen's blog I wondered if he was in denial about my recovery. To me, his blog might have given readers false hope about me. Sometimes, when I revisit his blog, I feel like I was expected to fail. Maybe I'm over thinking it. I am fully aware, now, that Galen's intention has never been to expect me to fail. I can't help but feel like chunks of his blog resemble collections of unrealistic expectations regarding my recovery. I know that, on the contrary, he had the highest of hopes for me to recover as quickly as possible—that's just what having standards entails.

Perhaps this memoir can supplement Galen's journal entries on his blog, or maybe it's the other way around. How could he know the totality of my personal suffering at that time, however? Perhaps I'm oversimplifying it here, but I'm just trying to articulate everything I feel as I feel it. That's hard when perception, imagination, and memory all coexist in the same feedback loop inside my STBI brain. Maybe I'm too idealistic, despite this. That doesn't mean I don't feel extreme gratitude and appreciation for Galen's words. There's just more to it, I think. It's probably why I'm writing this now.

I realize a hard truth now, more than ever. It's always better to tell the cold, hard, complete truth to friends and family about a loved one's STBI. Have hope and stay optimistic, but realize and accept that STBI survivors change, often drastically, even after a best-case-scenario recovery. Facing the reality of a loved one's STBI has to start with those who are closest to them.

In this case, the spouse needs to find a way to come to terms with the reality of their loved one's diagnosis and prognosis. They should communicate to others that the survivor requires understanding, compassion, and support. That support includes being accepting of the new person that they have become and having empathy for how terrifying the situation is for them. To keep in perspective that although STBI affects the entire family, it has completely and utterly devastated, if not obliterated the survivor.

CHAPTER 19

Heavenly Visions

> The pressure in my head builds, as my hearing goes out. The pitch of the tone inside my head is high and loud. A sci-fi movie is happening right now inside my head. The Galactic Battle is in full swing, meteors at incredible speeds pass glowing red, purple and green. It's like a sound bubble encircled in rays of spectacular color blending as each one crosses to form a new pigment never seen. Each its own space, smell, taste, feel. A new entity.

ALTHOUGH I BECAME MORE aware of them as time went on, throughout my recovery, I would find myself in the throes of amazing visions. I embarked on fantastical adventures of the mind. I would catch glimpses of a greater universe, its stars, and planets. I peeked into previous lives, scattered moments in history. There were even places I had never imagined before. It was an eclectic mix of visuals. Only a few of them resembled recent memories and had made any sense to me afterward. Others are infinitely confusing, out of place, and random, like entropy.

In some visions, I would explore vast solar systems and mostly unfamiliar stellar bodies. The planets would rotate slowly as their surfaces erupt and swirl and their moons orbit in perpetual ellipses. I'd sweep across the surface of the celestial body and then head into the distance where the light from millions of distant stars flicker like beacons in the vastness of space. In other visits, I'm whisked away to witness the solar flares up close, as they sputter and arch in a fantastic array of luminance and unimaginable color. I see shades of purple, red, green, and orange against the dark vastness of space and awe at the brilliance and power of the sun's sheer magnitude.

In other episodes, I would see buildings and visit places that I've never witnessed before. I'd even observe earth at its most beautiful, healthy and untouched by man. Green forests and foliage growing up before me, lands once barren now flourishing with life. Next, I swim with the whales in a quiet Alaskan bay and visit with tree angles which would sing and dance for me, welcoming me to touch their gilded wings and join in the spiritual feast.

One memory from my youth tends to replay in my head. When I was a girl, I would ride through the clouds as large drops of rain pelt the windshield of my parent's soring aircraft. Blurry and wet, the view is the bluest blue you could imagine. A dark navy shroud transitions into white blankness, and then back to that shade of navy again.

Most of these visions visit me unannounced and at any point of the day. They were so beautiful and gave me such a sense of calm. In them I could see heaven in all its splendor with stunning whites and incredible blues and purples, but with shades of blue, teal and violet that merely aren't coherent in this earthly dimension.

During specific occasions, once in rehab in 2006, and twice at home a few years later, I encountered a powerful recurring vision in bed. I looked out past the foot of my bed, and in the center of this almost blinding brightness, I saw a figure that I sensed was Jesus Christ. The illumination was so intense that I couldn't see His face, only His outline. The vision had only darkness in front of it because the brightness from behind the figure enveloped and overtook Him. I knew in each of those moments that I was passing from this earth to the next dimension and that He was there to help me transition. I welcomed moving on and the thought of going home with the much-needed relief to my immense and seemingly perpetual pain and suffering.

Three times Christ visited me this way. He talked to me, touched my soul and then sent me back to earth. In my bedroom, he stood in front of the fireplace and with all his wisdom and brilliance, and he succinctly told me, "Not today." That's when I knew that I wanted to stay. I wanted to live, but I needed to recover. I had to carry on as my purpose here on earth was not yet complete.

> Just a breath away—so close, to touch the very space surround.
> Pure and silent tones move as travel we must, our wish desire.
> On waves blend blues to white, our souls' reunion. Gather as we again are one.

The understanding that I received while in the interim of passing, the reason He brought me back to earth, was to deliver a message to other people. To try to explain to others what it's like to be in an "STBI brain." Survivors have seen so much beyond this world and are trying to come back and to live life with some normalcy. It's challenging. To be able to understand another injured brain was helpful to other survivors, as well as their friends, families and loved ones. I want to be the one that gives them hope.

My utmost desire is for others to learn from my experience. Whether it's helping somebody else through something similar to an STBI, or comforting loved ones with their STBIs, I hope my insights help others empathize with survivors. I wish somebody would have explained some things to me when I was going through my recovery because it's terrifying. There is no way can you foresee, 100 percent, what will unfold, from one day to the next. I had made a promise when Christ sent me back, and I have every intention of keeping it.

> Things aren't different—they are totally rearranged. I haven't any idea where the rest of me went or who it is that keeps breaking my heart. Who is this strange one who wants so badly to keep a promise?

CHAPTER 20

Sketches and Brush Strokes

> No one is immune. Dragged from your mind's lock and key, a joke to share about the thoughts. Painting life as it happens in the survivor's subconscious. Oh, how different minds conceive rational thought.

BEFORE MY BRAIN INJURY, I was not able to draw. I couldn't even do a measly sketch of a stick figure. I can remember that my siblings were very talented artists when we were children. My brother could paint and draw while my sister was into interpretive art using a variety of mediums. From singing to violin, I had worked hard to be musically gifted. Now I couldn't even draw basic shapes, and I desperately wanted to master that in spite of that.

Sketching Experience

One day about two years after my STBI, I picked up a pencil that was laying around, and I started to sketch on some random piece of paper. I'm not sure why this attempt was different, but it just happened. At the time I couldn't tell you what I drew, as it was probably just some random doodle of whatever came to mind. The drawing was probably thrown out because anything “out of place” in our home became trash.

As weeks went by, I was compelled to draw on anything that I could get my hands-on including napkins, paper bags, envelopes, junk-mail—you name it. It felt as if I had something pent up inside that needed to get out but the vehicle in which to express it was not yet able. Weeks turned into months and stacks of doodle-riddled paper could be found tucked away throughout the house.

One day, I found a drawing on my nightstand that was set off to the side. It was a piece of inexpensive, white copy paper, likely brought home from work by Galen. I picked the paper up to examine it and realized that the drawing on it closely resembled a vision of mine during recovery. It was a little spooky, but it was oddly comforting at the same time.

I recognized the dark outline of the sketch from my vision—an unmistakable silhouette of Jesus Christ. Heavy shades of grey morphed into His familiar shape. I couldn’t believe that I drew this picture. After all, I could never draw before. Why was it different now? What was this crazy new talent that I seemed to master and how could I find more paper to feed my appetite to create?

Adding Color

Within a few months of discovering my propensity for drawing, I came across a box of oil pastels. I don’t know how I got them, but someone had gifted these joyful cylinders of color that were now a big part of my life. From that point on, color exploded onto each page and brought my artwork life. A faucet had been turned on and couldn’t be turned off. No blank sheet of paper was left un-sketched.

Once I began to add color to my drawings, I became even more inspired to create. It was like the added hues unlocked a whole new realm of possibility for me to discover and I could hardly contain myself. I felt as if there was steam spouting out of my ears and the top of my skull was coming off, ready to blow if I didn't relieve the pent-up energy in some way. My brain was churning one-hundred miles an hour, firing off what I envisioned as electrical sparks all over the place. It was just so much excitement and power that I had to release it, as it seemed as if my head was going to blow.

I began to draw whatever came to mind including stellar constellations or places on earth that I would later see in books. It was quite strange, creating pieces that only made sense much later. It was like living in a constant Deja vu state. Most of my art was inspired by scenes that I saw in passing to another realm. My interpretation of heaven, there were unimaginable shades of blue that were so vibrant and whites so pristine that there is not a pigment on this earth that could represent what I experienced.

These colors appeared to glow as if a light source of their own, radiating beams of brightness that seemed unending. The visions brought a sense of warmth and comfort like none other. It made me feel welcomed, safe and loved all in one massive sensation. The three times during my recovery that I tried to cross over, I witnessed many of these amazing, out of this world sights. Now, because of the addition of color, these visions were coming to life in my artwork.

"Brush Strokes"

For a somewhat brief period, maybe a week or two, I dabbled in watercolors, but the medium dried too quickly and wouldn't allow me to blend colors the way that I wanted. Instead, I tried oils on canvas, and that's where I found my passion. While oil painting, colors fuse together to make unique shades, and I can apply whatever colors I want to, layer by layer. Mixing colors of paint and adding multiple layers felt like I was blending nationalities and cultures, the most vibrant pigments of life. I find such blending to be immensely liberating.

The first complete oil painting that I created was a color version of my original sketch of Christ. From there artwork reflected other visions from when I traveled to the other side. Subjects included everything from planetary bodies and images from past lives into an eclectic modernism realm. Each painting can take several days to a week or more to complete, depending on the level of complexity and how I feel at the time.

In each case, the creation of my paintings seamlessly happens, evolves in front of me, and I don't do anything to change it. It's like my hand is being guided in the process, and a higher power is conducting my fingers. I can't exactly recall how I started each piece of art, but now there are easels and paintings everywhere in my home.

I have long since filled every bit of available wall space with my work so I have resorted to stacking finished pieces wherever I can. Leaning artwork in various sizes lines the walls in every bedroom and hallway several canvases deep.

I have also outgrown the corner of my bedroom that houses my easel and supplies. That's why Galen and I decided to build Studio of Hope, my own, separate, and self-contained workspace on our property. That way I can create anytime I want, even leave a mess if I'd like or stack artwork as deep as I can manage.

> The world, the universe, it's extreme, and every physical sense is out of this stratosphere. Living on the edge, as STBI survivors do, is something beyond imagination, like residing in a science fiction movie or seeing a film in color for the first time. It's beyond explanation because there's nothing on earth to compare it to.

Art-As-Therapy, Art-As-Escape

Sometimes the motivation to paint comes to me at three o'clock in the morning. There it is, an idea planted firmly in my head, and I desperately have to get it out. Other times I don't know what I'm going to paint at all. I touch the canvas, and it just happens. The inspiration manifests, coming forward almost as if it were on autopilot, and after several hours it starts to transpire into a painting. I honestly believe that it's not me controlling the end of my brush but rather a higher being.

I do find immense joy in painting. Whenever I think about it, I have a smile on my face. I look forward to it and try to paint almost daily, as it's a great creative outlet for me. When I'm in extreme pain, the only thing that tends to relieve it is sitting in front of my easel. My mind wanders and becomes preoccupied with creating art, and then the pain seems to drift away as I become entranced in the process of painting.

Starting with a Circle

Before adding any paint to my canvas, and any artist "worth their salt" will tell you that there is always a rough sketch. Everything I paint, every canvas, starts with a circle. You might not see it in my finished pieces because sometimes I paint over it. But the circle is still there.

It represents eternity because it never ends. It evokes both eternal life and everlasting love. I recognized its recurring shape in my visions when I was stuck between two divergent realities. The sight and realization of its meaning have never left me. It's like an element etched deep within my soul.

> The ethereal, that's another realm altogether. Everything you think you know, think bigger. Think greater, and focus on this truth—God exists everywhere, on everything.

Much like the symbolism of the circle, I believe that we never cease or die. We might leave this existence here on earth, but eternal life is in another dimension, a higher realm. For me that higher reality is Christ. God. For anybody else, it might be another higher being. It depends on your beliefs. For me, it's Jesus Christ, God, and Son of God.

It's reassuring to remember that I'm not alone on this planet. Jesus has been right there in my room with me, so close. Usually, I can only sense his presence. During my three face-to-face encounters with him, He filled my room with a radiant light. I cannot fully capture nor entirely emulate in my paintings. I cannot represent it here on this Earth, as there aren't any pigments to paint the colors that I saw. They do not exist here on Earth. I have tried to paint it from memory, but I can't. It's like it's too powerful. I don't think we're meant to do that. That's something for us to see later.

> What I couldn't describe, I began to draw. I couldn't speak with words so the things I couldn't say, color showed the way. Now I can't step away.

Visions and Emotions, Represented

All of my paintings have a story, and there's a purpose for every one of them. Most pieces of artwork stand on their own while others have themes. I find that I particularly enjoy eclectic and modernist styles. It's real. However, it also spawns a thought: who am I now on the inside?

> Talk, and no one hears. Act and people become unglued. Paint and everyone will be amazed.

“He Spoke“

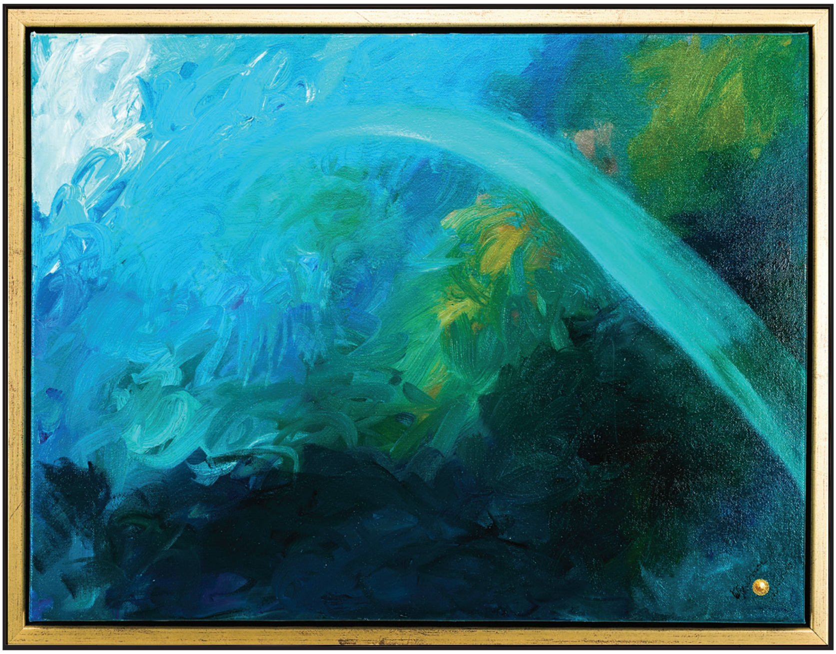
One of the very first paintings attempted, this unsigned piece is called He Spoke. It’s a color version of the original sketch of Christ.

"The Start of it All"

This painting is about the evolution of life. You start with green, which signifies growth, and as you become increasingly aware, you turn into the heavenly colors of blue. I believe that we are steadily growing until we evolve and become more Christ-like.

"Tiny Dancer"

Inside all of us a tiny soul is waiting to be moved and set in motion. This painting illustrates my better days and kindred spirit.



"Second Coming"

One of my early pieces, this painting represents Christ's second coming.

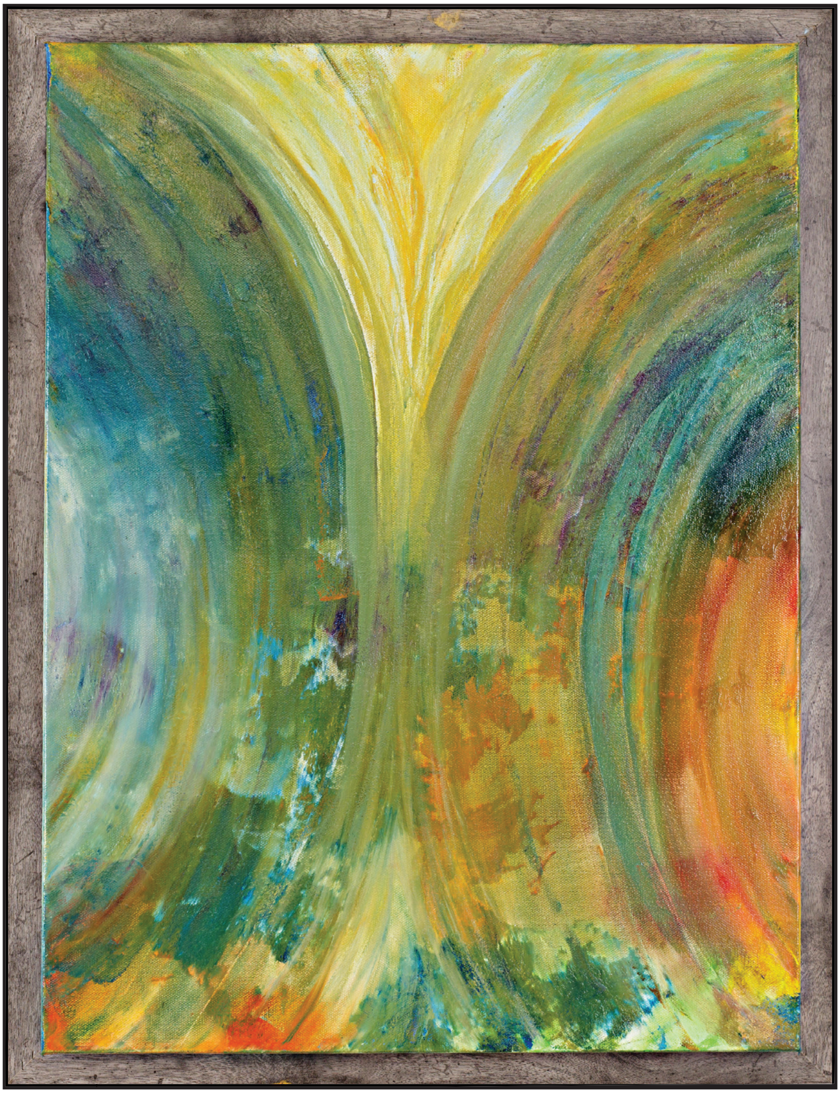
Kathleen Newhouse

"Pulled from Darkness"

A mental reality, this is where my mind goes on the very worst of days.

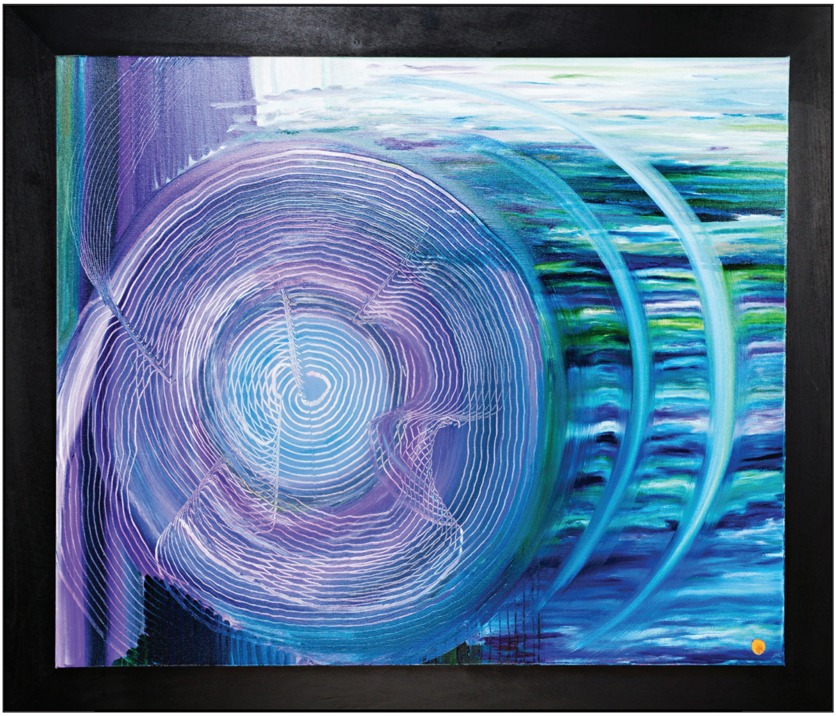
“Stairway to Heaven”

This is my first painting after a long period of Artist’s Block. I didn’t know if I was able to continue to paint, as nothing was coming, but now I’m back.



“Collusion of Souls”

This painting was a 42nd Anniversary gift to my husband, Galen. It represents our two souls, our true selves, coming together in internal love.



“Confusion”

Less textured on the surface, this is one of my most recent paintings. It’s buried in the canvas, like a smooth entry into a world. That is very profound to me. As I have evolved as a painter, my brush becomes less confined. Once I stopped controlling the brush and let the process happen, I feel like I get more out of it.

"Bridge to Sitka"

My favorite place—we stay on this island in Alaska every year. This image represents the footbridge leading to the isle. Look closely, and angels who fly around from one branch to another are watching.

"So You Think the Sun's Yellow"

People walk through life without really noticing anything. We look up and perceive the sun to be yellow and the moon to be white, but the reality is very different. The sun isn't yellow – the sun bursts and solar flares happen all day, and the colors are incredible shades of purple, red, green, and orange. We can't really focus on them because they're too bright and so far beyond our visual realm. It's a fantastic show. My soul has been there, and I remember it well. When I look at this piece, I can't help but smile.

CHAPTER 21

The Foundation

> May we work with love in our hearts and success in our smiles, reflected success. So much to do. A smile on the vision, today's silent rainbow. From the very tip of my brush, each silent stroke, a story, if we only listen. Visions released by the kindness of love. Art shared, each its own gift to one heart, or another.

FOR THE NEARLY TWO months that I was a patient at Sharp Rehabilitation Center, I often stared up at the stars at night through my window. There was little else in my vast, mostly barren room and my bed was positioned the long way next to a sizeable window that spanned most of the way up to the ceiling. At night, I was incredibly lonely in that substantial space, at the end of the hall.

Perception and Awareness

For what seemed like timeless jaunts, I squinted out my window, way up at the night sky. If I focused on one section of the sky long enough, even the faintest of stars would start to become visible to my delicate eyes. It was a magnificent sight when the heavens came into focus, with navy hues accented by a hint of purple along the edge of each distant galaxy. Stars twinkled and blinked, flickering as if relaying a message.

I would catch glimpses of angelic little beings in the branches of the massive tree silhouettes between my window and the night sky. They too would glisten and twinkle, leaving subtle trails of glimmering light wherever they'd go. Well aware of my presence, and me to theirs, the angels would flitter and hop from one branch to another, as if putting on a show to keep me entertained.

While marveling at the angels and gazing at the vastness of the universe, I prayed to our Heavenly Father, as I knew that He was watching over me too. Deep down, I always knew that God orchestrated my life-saving flight out of Mexico, and God, who had guided the doctor's hands to success in surgery. He's the one who slid my feet along the floor as I hoisted myself over the parallel bars and He who whispered in my ear, telling me to push past the pain with each painful step.

In my prayers, I asked for clarity and understanding but knew that all was revealed when He was ready for me to see. During our conversation, I thanked Him for saving me. I begged for the strength to push through. I promised Him that if I survived, I would find a way to give back to others, to help make a difference in the lives of other STBI survivors.

Many times, I've made the promise, although I didn't know for sure how I would or could help anyone else. Perhaps just speaking to other survivors or visiting them and holding their hands could help.

At least they wouldn't be so lonely or scared. The more I prayed, the more I understood that even the littlest of gestures was of great value to some else. So my mind was made up. First, I had to recover the best that I could. Only then could I set out to find some way to make a difference in the lives of others.

My New Calling

Over a decade later, I now understand that it's my calling to help others that are on this journey, the massive undertaking of surviving severe traumatic brain injury. I honestly want survivors to know that they are not alone and that although STBI is a tough expedition, it's worthy of surviving.

That's why I hope that others find this book and my words to be useful. As they flip through or scan the pages and they read, that they might see something familiar and say "Hey, I recognize that behavior," or "That's exactly how I feel."

I want to help them realize that once they get over the shock and the anger of their injury, they will flourish in their own unique ways. I want survivors to understand that although their brains may not be working as they once did, they will in time, make up for it.

They have to be patient and have faith that their new outlook, personality, and even skills will reveal themselves in due time. I want STBI survivors to understand that life is precious and that it is our duty and privilege to live it the best way that we can, despite our injuries.

It is also my dream to help and enlighten others about brain injuries, in general—not just the injured, themselves, but their families, supporters, as well as the general public. Through this book and other efforts, I hope to reach the masses by bringing awareness to STBI. I also want to find a way to start a forum of STBI survivors and their families, to give them a voice and a platform.

What's (Actually) in a Name?

Dr. Kureshi, my original neurosurgeon, told me that when I arrived at the Trauma Unit at Scripps in San Diego after my injury, I was just a breath away from death. That statement shook me. It lingered with me throughout my journey. I didn't realize I was that close to passing and it took a while for the notion to sink in. I thought to myself, "that's where I was, just a breath away," and realized that it would make an excellent name for a foundation. That's when I knew that I wanted to develop an organization to assist those who couldn't afford to exist during and after their STBI recovery.

I knew that I was okay because my husband and I were prepared for something like what happened to me. We are incredibly fortunate to have had good health insurance, and to be financially well off. For those who aren't so lucky, it is my greatest desire to help them. When I was in the rehabilitation facility at Sharp, I saw a lot of military STBI survivors and in many cases these people who fought for our country who had no support system. They are the most devastated by their injuries and in the most need of help.

They face being in financial debt for a very long time because of it, which can be overwhelming, if not devastating. It's a tough road, and it's not just what happens to the patient, the survivor if they can't get help it doesn't just stop when they get home from the hospital. It's extended for the rest of their lives, which can be financially strapping.

This has inspired Galen and me to start the Just A Breath Away Foundation in 2017. Most of the proceeds from the sales of my paintings, the sales of this memoir, and every additional fundraising effort will be used by the Just A Breath Away Foundation to help other STBI survivors.

My highest hope is that we can help offset the cost of a new wheelchair, or feeding system, or procedure for those less fortunate who are stricken by an STBI. Surviving an STBI requires a lot of one person, but not everyone is lucky enough to rely on a strong support system. We hope to step in and make a lasting difference, and in many small ways, too.

> It just happens, happens, happens, and it never stops. Just like the eternal canvas I paint, endless as one. There's a lull in

> time, a hole in time, a break for serenity to settle on the Sharp edges. Rounding the wind-torn pain with a soft edge, slide around the isles of a journey as cradled by one.

All those years ago I made a promise to God, and I am keeping it. I have an innate feeling that I'm not long for this world and I'd like to see all of this good set into motion before I move on. To publish this book, to have the Just A Breath Away Foundation realized and to have it do good so others can continue to do good even once I am long gone.

CHAPTER 22

Getting to Know Us

> Random everywhere, flying so fast and I can't keep up. I'll never be able to express all that is within these walls. Find someone who knows, who has been there. They know. I'm held without consent—captured, relentless, holding onto every attempt to progress. I know, I do. Help me explain what it's like to those of us who are caught up in the lost world.

As an STBI survivor, I believe that I have a fair amount of insight into what it's like to live with a physical and cognitive disability. After all, I survived a catastrophic injury that left me with damage to much of my brain. Since then I have overcome impossible odds and recovered much of my previous abilities. I've relearned how to talk, walk, and do all of the little everyday things we all need to survive. I now have use of most of my body, but my cognitive abilities, emotional strength and much of my memory are all still a work in progress.

Naturally, each survivor has their own virtues. By nature of their personal injury, their own breed of adversity defines them. However, having a severe brain injury, we survivors do have some common issues, and that's what I want to share in this chapter. I hope that friends, family, and caretakers come to understand what it's like for us. I hope that, in turn, they will collaborate to take strides, to help us on our journey through recovery.

We're Terrified

Unless you have been through a severe brain injury yourself, there is no way to comprehend how incredibly frightening the ordeal can be. Not just from the physical side of an injury, that's bad enough as it is, but from the comprehension side. It's simply terrifying.

Try to imagine waking up to a blaring white room, under buzzing fluorescent lights, and a cluster of strangers huddling over you like you were an art exhibit. They squawk and clamor at you leaning forward with animated gestures and expressions, frantically trying to communicate. Only you've never heard this strange language before, and you have no idea what they are saying. The barrage of words fired at you becomes drowned out by a loud blaring in your ears. It's like a catastrophic train derailment.

Your headaches all the way down to its core with pressure so immense that it pushes you to the point of seeing flashes of light until you half realize that these are flashes of consciousness. When you are conscious, your vision is very blurry at best. You see double. You see lingering auras following each person's silhouette as they move about the room. It's like a strange science fiction movie. It's also like an unending nightmare. Only, you have no choice when you can wake up.

Visualize waking up to such a scenario only you can't rationalize that something terrible has happened and that you're in a hospital. You can't escape the terror and frantically look for something that's familiar, only you may not know what familiar is. Panic sets in and every part of your being is drawn inward to escape the living hell. You shut down, retreat and only peer out occasionally to see if it's safe to venture out yet. It is the reality for many of us survivors, and depending on the severity of our injuries, it takes a while to feel safe enough to venture out of our shells, our inner “safe places.” Only in moments of calmness, when the swelling around our brains minimizes can we begin to emerge from within. Exploring our reality, taking stock of our injuries and relative state of being—these are all fleeting luxuries.

We’re in "There"

When it comes to an STBI, I cannot stress enough that we’re in there, somewhere. You may not think so, especially immediately following the injury, but we are present to some level, and we’re utterly baffled that you can’t see it. We may not respond as you’d expect and give the physical or emotional signs that indicate that we understand, but even with some of the worst injuries, there’s a spark of existence that we desperately want you to see and to acknowledge.

Don’t be hurt if we don’t recognize you or act as we once did. Our brains have been through severe trauma, and it will take time and lots of baby steps to figure things out. To realize the extent of our injuries and to discover ways to regain some form of normalcy after such a catastrophic event.

Even if you are not sure if we are there, locked deep inside of a broken brain, assume that we are and try hard to communicate with us. Instead of asking questions that we can’t possibly answer and confusing us with too much input, tell us that you are there for us and will be there to help get through the ordeal. Hold our hands, come up close and look into our eyes and be in the moment with us as much as possible.

Work hard to acknowledge us and restore as much dignity as possible. Such interaction can speak louder than words to a person in the midst of or recovering from, an STBI. However, don’t expect much from us at that point, and refrain from putting pressure on us to perform or get better, back to where we once were. Avoid the use of the term “better,” as in “you’ll be better soon." That kind of pressure can make matters worse for us and may leave us feeling frustrated and profoundly inadequate.

Starting Over (Again)

As we move into recovery, we will need a fair amount of physical therapy. We will, moreover, also need other kinds of treatment, too. Depending on our particular STBI, we may need to relearn much of what it took to get by every day as an independently-functioning human being. We will probably need assistance with the mundane, little things, like walking, talking, hand-eye-coordination.

We will need help reestablishing our physicality and coordination. Be sure to watch what our physical therapists do with us, how they physically handle us. Take note how our physical therapists connect with us, emotionally, and how they motivate us through our daily routines. That way, you can help continue their efforts down the line. This will make all the difference in the end.

Whether you are part of this therapy process, or not, please help us celebrate, especially the smallest of our achievements. STBI physical therapy is not fun. Even more willpower is required to master these exercises. Help us stay positive and motivated without revealing any disappointment or acting in any way that we may interpret as disapproval.

We also desperately want to please you. For you to be proud of our successes and to not lean on us as you once may have pre-injury. We need your accolades and acceptance of who we are and how hard we are trying.

Imagine that our mental state is like a child's. It's not that we want to be treated like we are children. We are learning everything we used to know all over again. In a sense, we are growing up all over again. It's all very surreal. It's very common an STBI survivor may not have the capacity to remember right from wrong, or how to do simple tasks. Most survivors are struggling to recall how to complete complicated tasks. We are not so different from children learning to play with others in preschool, or Kindergarteners learning their ABCs. It's like we are cramming decades of lost education in as short of a time as possible.

Even social interactions and learning appropriate behaviors and cultural awareness that typically comes over time. In many cases, our slate has been wiped clean, and we need you to help us to learn all of the little things that we all take for granted.

When you are teaching us, and reteaching us, please be extra patient with us. Please be understanding of our limitations. Find a way to be kind to us, despite how indefensibly we may act.

For the most part, remember: we can't control how we act or react. We are in the confusing process of relearning what behaviors are appropriate. Empathize with us, and you will gain the ability to help save our lives.

Emotionally Captive

There's no way around it: existence as an STBI survivor is alienating. There is no "normal" for us. We see things differently. We feel things differently. We hear and taste differently. Our very existence has been turned inside-out, into a complicated jigsaw puzzle. Things that were familiar before are not at all right now. Hurtful things tend to be much more painful. The world can be cold and unforgiving, but we do have a choice in how we interpret the chaos.

The STBI survivor is also always second-guessing themselves. We can't help that we feel certain ways and we have no idea how to handle it. In many cases, we are overly sensitive to everything around us and feel overwhelmed. Self-conscience and intensely fearful, we're acutely sensitive to how others think of us. To a significant degree, we lost our sense of self, and now certain situations, places, and people frighten us, often making any interaction intolerable.

> "Atelophobia"—the fear of not being good enough. Is that what perfectionists have and subsequent STBI survivors suffer from within themselves every day? The anxiety that exists when knowing nothing you do can ever be right or even come close to perfect again?

For the STBI survivor, the familiar is essential. The best solution, at least to start, is having a tight-knit group of friends and family that work together. Each new member who is introduced into the support circle, ought to understand that it will take an STBI survivor some time to get to know them again and to acclimate to the onslaught of changes ahead of them.

Make sure that the inner circle has received proper counseling on how to interact with survivors. Stay positive without being unrealistic or condescending. We do pick up on such matters as tone. Also, explain to those invited into that inner circle that we may not comprehend everything that is said, but we pick up on subtleties like body-language, tone, and the inflection of your words. We also may not grasp sarcasm and idioms, and sayings even overly animated gestures can be confusing to us.

When it comes to introducing survivors to new places, be aware the commotion can be overwhelming to us, and we can be oversensitive to the level of noise. Many survivors find restaurants, supermarkets, and malls to be loud, terrifying places that are near impossible to bear. Instead, opt for a quiet setting with fewer people, less noise, and limited distractions.

Pain is the New Normal

Every STBI means pain, although it's different for everyone. The pain itself is like its own disease. The effects are endless, life-changing and forever misunderstood. Alone with the continual disturbance that no one can see or understand, pain is silent and invisible to those who love and care for us. It does not make the pain any less real. STBI survivors: your pain can consume every waking moment and every action. Don't lose yourself in it. When there is severe pain, strong medication usually follows. However, these numbing agents can be as detrimental to our state of being as the pain itself.

Only it's in the opposite direction. That is not to say that someone in pain should not medicate for it, but instead to warn that being deeply medicated, especially when it's for a more extended period, can dig deeper into the cognitive fog and can cause less than desirable changes in our personality and demeanor. Just be aware that medication is one of the variables in our behavior.

> Pain builds character. Pain strengthens the will and reminds us of our convictions. Never give up, to look back with sorrow-filled hearts only stunts the growth of tomorrow. Forward are the days of growth and wisdom. But will I see them?

Worry, Despair and Anger

Understand that sometimes we wish that we didn't survive our injury. Especially in severe cases, when so our bodies have sustained so much damage. The pain, suffering and mass confusion is just too much to handle, and we wish that God had just taken us when he had the ideal chance.

What's worse is that we know that you've thought the same thing. It's just human nature to some level, I guess, but it hurts us knowing how our injury weighs on you. This sort of back and forth of emotions induces anxiety in us. We have no idea how to cope with it. Most often, that stress, among other things, turns into frustration, and then, anger.

We're angry at our situation, wonder why our injury happened to us and are terrified of what the future may bring for us. We also hate being a burden on you, on our friends and family and we see it in your face when you worry about everything. Understand that we are also terrified. Consider the possibility that you won't be able to love or care for us anymore. Most of the time we feel like lost children, separated from their parents at the mall. We tend to think you're mad at us. We tend to think you blame us for our injury. We desperately want you to return to us and take us home.

We Didn't Ask for Any of This

Know too that we didn't ask for our situation. We can't help what has happened to us, and we'll likely not be the same person coming out of it that we once were. We can't get brain cells back, they won't go into remission as cancer can, but we can develop our brains in surprising ways and flourish as a new person, hopefully with you in our lives.

Be patient, be kind, get to know the new person in our heads, and be accepting of us, because the chances are that we were for you. We want to be loved just like you do.

We long to have someone engage with us and to make us the center of their attention. Perhaps this may sound a little immature and needy, but you have to remember that many of us are just kids in our minds, and children need more love and understanding than adults do.

What We (Actually) Want

With an STBI, we miss us too. During our recovery process we long to be whole again, for the way we used to be, but for many of us, we'll never be the same. With the amount, type or location of the tissue damage in our brains, it's just not a probability.

However, once we reconcile that we're going to be irreversibly different, we can learn to embrace the new versions of ourselves. We can then navigate daily obstacles with what we can control. We can still strive to win each day's small battles, and with continued assistance and acceptance, we can realistically achieve enough autonomy to live a fulfilling life.

How We (Actually) Feel About You

As survivors, we do know that our STBI and recovery is hard on you, our friends and family. However, we may not fully grasp to what degree. We also may not remember all that you do for us and may even seem ungrateful at times, as many of us cannot understand beyond our own needs. We're in this mode of recovery, which is mentally and physically draining and it's easy for us to be forgetful of the toll it's all taking on you. Don't take it personally.

The best advice I can muster for anyone close to a survivor is to get help, to find a way to step away on occasion and do everything that you can to help yourself survive our ordeal too. Otherwise, you may exhaust yourself, mentally and physically. Resentment is usually not too far behind such exhaustion, which makes matters worse down the line.

Regardless, please don't take it out on us and be aware that we may not understand when you step away. On some level, we are envious that you can. It may seem contradictory to suggest that you step away and then say that we'll be hurt when you do. Sometimes we lack the mental acuity to grasp this paradox.

It doesn't change the fact that you need to care for yourself first. Think of it as a safety announcement at the beginning of a commercial airline flight. In case of an emergency, put the oxygen mask on yourself first. Then you can help others. Good caretakers approach STBI survivors in the same way.

CHAPTER 23

What Needs to Change

> This is every minute of every hour of every day I am here on earth. 'Oh, I'm sorry,' with the look of pity in your eyes. I don't need pity. I don't want it nor do I respect it. I would rather have your empathy, please. It's a fact of my life. I endure to remain. The easy way out—end it. Just end the pain, and the misery is over. A long sleep without fear of waking in dire straits again, is that what ending this mess would bring? Or is the sin so great that every day from now through eternity will be spent just like this day, today? The mystery too great to chance, the cost of the sin, much too high to pay. The fear is never-ending.

FOR THE SAKE OF STBI patients, there are critical things that need to change. To start, I feel that awareness of this type of injury needs to take a giant step forward. The reasons why begin with the numbers. According to the Brain Injury Association of America,

> "over 2.5 million people are stricken with a traumatic brain injury every year, which averages out to one person almost every 13 seconds. Over 5.3 million Americans, or one in every 60 people, live with TBI-related disabilities."[17]

It may be surprising, but a severe brain injury can impact more than just the injured. Spouses, parents, siblings, extended and close families, and networks of friends may all find themselves deeply affected by a loved one's STBI. Beyond inner circles, there are healthcare providers, including surgeons, physicians, counselors, rehabilitation therapists, social workers, and personal care attendants as well as special education teachers and those who prepare America's future healthcare-workforce.

Beyond that, there are insurance companies that issue auto accident, individual, and health, disability, life and reinsurance policies, attorneys of all types, including personal injury, insurance, and disability claims, civil rights, discrimination, wills, estates, and trusts. On the government side, some agencies administer health and social programs and vocational rehabilitation not to mention employers of all types.[18]

Traumatic brain injuries touch the lives of many people, which means as a society we need to prepare ourselves for the realities that come with prevention, awareness, and recovery. The statistics tell us that much needs to be done to help those afflicted with a traumatic brain injury, and it all starts with education.[A]

It was highly beneficial if people understood TBI and STBI better from a medical perspective and took steps to learn how to relate to somebody who's going through it, whether they are a survivor or a loved one. It's such a terrifying ordeal, especially for the survivor, and they need to be the highest priority. Not just medically, but ethically.

Medical Misconceptions

A lot needs to change on the medical side. However, I'd like to start with one area that I take very personally, the technology for intraventricular brain shunts. I sincerely do hope that there is a study underway somewhere in the world that delves into the correlation between barometric pressure and brain shunt

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"Endnotes" on page 218

design and operation. As explained in earlier chapters, I have found that the effectiveness of the various shunts I have had installed, even adjustable ones, have been significantly affected by any shift in barometric pressure. The worst-case scenario being during quick barometric changes or with low pressure.

Many doctors seem to reject this notion, but until they live with one installed in their brain for a while, I don't think they have the right to dismiss it outright. As patients with a chronic issue like this, we deserve to be at least heard and our input considered, hopefully, passed along to the manufacturers of the devices. That way more testing can be done to try to understand the shortcomings better and to work to find a solution. How else can technology develop for the better?

Although the concept that some shunts can be adjusted is terrific, it does absolutely no good when the process for changing shunts is so invasive, cumbersome, and dangerous. For example, I can only have my shunt valve adjusted by a doctor with the appropriate, and likely proprietary, apparatus for adjustment, and in my case, that doctor is not in my proximity. Since barometric pressure can vary hourly, and often quite drastically, wouldn't it be logical to give the patient a way to adjust themselves in the process? All I can say is that there has got to be a better way!

I'd also like to see changes in how medical professionals address their STBI patients. In my case, I was able to sit in on some of the following progress report meetings during my rehabilitation process and was astonished when I was treated as if I were not present in the room. The entire conversation was addressed to Galen, and I was referred to as "she." I'm not sure if addressing the survivor's spouse, or designated power of attorney, in front of the survivor is helpful. This almost always comes across as inconsiderate. This needs to change.

I understand now that the doctors, therapists, and nursing staff were used to the routine of reporting to Galen. My medical directive had kicked in, and he was my power of attorney while

I was disabled. Once I was able to attend the meetings for myself, regardless of my level of comprehension, the medical staff should have at least included me. Indeed, Galen would eventually understand if they addressed me directly in all of their decisions—about my own future. I'm not sure what harm it would have done. It would have done wonders for my self-esteem up to that point. Just picture it. There I was, at the head of a gigantic conference table, in a room overflowing with O.R. scrubs and white lab coats. One-by-one, various medical professionals reported their findings, from the previous two weeks of my rehabilitation, exclusively, to Galen.

It may surprise some people, but now I can paraphrase what my doctors shared with my husband, unbeknownst to me. They told Galen, "Well, she did this," and, "She can't seem to do that." It is mind-boggling that I was present for most of this, even though I wasn't consistently conscious of it at the time. I was stuck sitting there, overhearing everyone in the room talking about me as if I weren't there at all—as if I were an inanimate object—on a distant shore.

Besides, who the heck is "she?" Why don't they talk to "her?" Why don't they talk to me? How about,

"Kathy, when you did this…" or, "Kathy, when you did that…" None of this "she" stuff. I'm right here, guys! Address me, please. I may not understand everything at first, sure. This is why my selfless husband, Galen, is with me in the room, as well.

I am still a sentient human being. I am self-aware, so I know I deserve the same respect everyone else enjoys. A little bit of consideration and respect go a long way with me.

Regarding "respect" and "dignity," I want to address daycare in medical facilities. Granted my recollection was from over a decade ago, but some of the things I witnessed or endured should, nonetheless, be considered. If more people grasped what going through the recovery process requires, and how humiliating it is, then perhaps better policies could be put in place to help the next generation of survivors.

What was tough for me was watching another patient, who was worse off than me, wither away. While waiting in between physical therapy sessions or even just in the day, the aides would just set patients aside, parking them in the hallways in their wheelchairs. Patients would slump down in their seats, their feet and hands curing inward, with their head and eye position looking downward – as if in despair, like they'd given up.

When left alone like that and ignored like yesterday's garbage, it wears on a person's psyche. I witnessed, even experienced no interaction from staff and no encouragement for the patients during these "in between" times during the day, every day. In my head, I could hear other survivors screaming in agony, hoping that someone would try to connect with them. The entire process of recovery should be a time of building up the patient, giving them attention, love, and respect, not allowing them to wither away in a forgotten heap.

> I understood, I knew in my injury that things just didn't fire like they used to anymore. But I couldn't make them understand me. Others on the floor knew too. Without even using their words, we just spoke with our eyes, through our souls.

In my case, some of the nurses truly understood how to handle STBI survivors and took the time to try to connect with me. The problem was that they had so many patients that it was hard to spend that much time with each one. I should tell you—those who did spend the time, who made an effort to connect, really made the difference for me during critical moments.

Although I couldn't effectively communicate it, I appreciated everyone who spent time with me, especially the little pockets of time. I'm eternally grateful to everybody who brushed my hair for me or helped me brush my teeth or took the effort to make eye contact with me. These heroes treated me as if nothing were wrong with me at all. They made me feel human again. I felt empowered by those interactions like there was still hope. They reminded me that I wanted to carry on.

"Coming Clean"

On the subject of bathing, I have two issues that I would like to address. The first involves being transported to the shower room at the far end of the long hospital hallway, completely naked. There I was all curled up in a ball, trying desperately to hide certain parts of my body from prying eyes, not so much with the nurses, but with visitors and other patients in the same ward. I couldn't command my hands, legs, and feet to cover sufficiently, so there I was on full display for all to see. I vividly remember the feeling of embarrassment and felt abused for the lack of basic human dignity. It's humiliating, and it needs to stop.

It's easy for others to think that we patients are not aware of what is going on around us, but some of us are coherent enough and are humiliated for the loss of dignity. Deep inside we're disgusted by the lack of respect we're shown in such moments. In the case of the aides wheeling us down the hall, all they had to do was throw a towel or gown over us so that we're not on full display.

What's with this whole "one bath a week" thing? Despite the "naked hall of shame," every time I was bathed I felt a little more whole. We all experience it. It's that just-showered freshness when we feel clean and somehow more alive. Why couldn't this happen more often during my recovery? I'm not talking about little sponge baths. Those are temporary. I had no choice. My new life started in diapers. On top of that, I sweat profusely in each day's therapy session. I remember feeling embarrassed by how unclean my new body made me feel all the time.

Every bath was its own little luxury. Each day, after treatment, my pain was rewarded with a clean body. It was glorious. For a short while, I wouldn't smell like sweat, and my clean hair didn't stick to my head. More frequent bathing would have helped boost my morale during the most trying moments of my rehabilitation process. If I could have felt just a little bit better about myself, I'm convinced I could manage to push my body's limits even further during therapy. I would've jumped at any additional advantage back then, no matter how inconsequential it seemed.

Rehabilitating "Respect"

It's difficult for survivors when their friends and family don't fully comprehend rehabilitation and the process of recovery because they don't see what the patient has suffered through. To outsiders, a patient may appear to be okay, how they looked before their injury. But on the inside, the survivor is ripped apart emotionally and struggling.

Surviving a traumatic brain injury is difficult, and the process of recovery is a daunting task. When a survivor is going through rehab, the work is constant. The therapists get us up in the morning and move us into the therapy room right after breakfast. We typically spend about an hour each in physical therapy to build our strength and stamina, speech therapy for communication, and occupational therapy for helping us do all of the little tasks of everyday life.

We have short breaks in between each session to let us catch our breath. When the therapists finish for the day, the aides put us back into bed and let us sleep. They promptly get us up the next day to do it all over again. It's hard, exhausting work and is a full-time job to recover from our injuries. It's not just the physical impact of the trauma, it's the consequences for mental health as well. There are many therapists we have to see every day, and they're so upbeat and are so willing to help us, but it's a grueling process that seems never to end.

All of the facets of rehabilitation and therapy should not just be for the patient, but the entire family. I think it was wise for all adult family members to work with the survivor's physical therapist once in a while, to sit in on the sessions, so they realize what's involved but also to help carry the process forward once the survivor is back at home. Most therapists are happy to demonstrate what needs to be done at home to continue the momentum of recovery.

While the family needs to step up and do their part to help the survivor, the rehab facilities need to provide the tools for the family to do so. Friends and family are so traumatized by what has happened to their loved one that they may not be in the right state of mind to sort through what needs to happen.

If a team of professionals says, "Hey your family member needs help, and this is how you can best help them," then perhaps family members might be more likely to help in the long run. At the same time, it's essential to offer the family therapy of their own, so they can not only understand how to work with survivors but realize that they're not alone in the ordeal and that they can get through it with proper help.

To initiate such a program, I would think that a social worker or a case worker was assigned to the rehab facility. A protocol was put in place that called for a mandatory meeting with the entire family at least once and asks them to step up. In addition to signing them up for various tasks, the facility would also offer at least an introductory counseling session for the family. That way they can cope better and in turn be more helpful to the survivor.

Friends and Families of Survivors

I want friends and more so family and caretakers to realize that the hardest part for survivors is to be understood by others. We would like you to make every effort to comprehend what we are going through and how scary it is for us. Try to understand the STBI survivor better, to know what to expect in their recovery and to find creative ways to step up and help. To address the various needs and to make a difference in someone's recovery.

It's so important to build them up, not tear them down. To make a positive difference and encourage them to try, even when it all appears hopeless at the time.

As I was a parent to my children, teaching them to be an adult, I'm asking you, to be there for the survivor. To show them from ground zero once again so they can become the best they can be. We need your love, we need your support, and we need your understanding. All survivors need extra guidance as they venture back into adulthood. It's crucial that you understand that and accept that.

I believe people need more compassion, patience, and empathy. Realizing that STBI survivors will never entirely recover who they once were, that it's not their fault, is as saddening as it is necessary.

Consider that it's their situation to share. No matter how hard they try, the old version is gone forever, wiped clean from their memory. This new person is like an emerging child. This child needs your help. Focus on "getting to know them." They are now, without any presumptions, and take special care to show them you respect who they are now.

My Letter to STBI Caretakers

For the STBI survivor, it is about embracing his or her particular journey. However, for the STBI caretaker, it's about being there to support survivors as well as humanly possible. First and foremost, STBI caretakers need to have empathy for their survivors. They ought to imagine what survivors are feeling and going through and to respect their humanity and individuality.

To caretakers, I humbly offer the following pointers. Turn everything off when you go home, but when you're on the job with an STBI patient, and they are suffering in front of you, try to be present-minded with them, and only them. Do this no matter how busy or understaffed you are.

Realize that you've chosen this profession because it hopefully is your calling. Everyone can help STBI survivors. Tell them that you know they are going to be okay. Remind them that their frustration, loneliness, and pain are is natural and expected. Tell them directly that you understand what this means for them, or at least do your best to do so. All of the kind words and the simple gestures mean the world to somebody who is held hostage by their brain.

> It never stops, the circle of information. The lightning strikes that pierce my brain without notice. Flashes of light, words across the board, written in a soft font, capture my attention. Even the dark notes begin in a pretty font, but leave you hanging in the dark with broken letters and misspelled words. A tragic scene of sorrow, the story that can't be told.

Improving Communication

In many instances, the STBI survivor is unable to communicate efficiently, and they can subsequently become frustrated and withdrawn. Therefore, friends, family, and caretakers need to collaborate with each other. Better communication relies upon a unified spirit among them whereby teamwork and clarity are paramount as they play their respective roles helping those in need.

I've put a lot of thought into the following list of questions to ask yourself if you are a friend, family member, or caretaker of an STBI survivor; each self-query addresses recognizable STBI symptoms (namely, memory loss, confusion, and communication difficulties):

- Is this environment too bright, loud, chaotic, distracting, or confusing?
- Is this room crowded with people?
- Did they understand what I said?
- Did I talk slow enough?

- Are my instructions clear and concise enough?
- Am I speaking too loudly or using confusing phrases?
- Can I simplify this conversation by speaking in shorter, more precise sentences?
- Is it only possible to ask “Yes” or “No” questions?
- Did I use slang, puns, idioms, sarcasm, and/or humor that is/are confusing?
- Are my gestures too distracting for him/her?
- Will pictures, illustrations, or whiteboards help?

Everyone Can (Actually) Help

The best overall advice that I can offer others facing my condition is this: if you can find the courage, find any STBI survivor and lock eyes with them. Even if they don’t look back into your eyes, speak to them as you would any perfectly healthy person. Instead of tip-toeing around the elephant in the room, be as empathic and honest as you discuss the reality of his or her condition.

Of course, you never want to overwhelm. Above all, remember to encourage and build him, or her, up. Your encouragement is far more impactful than you may initially think. It can mean the difference between a survivor’s day ending in hopelessness or hopefulness. For the sake of STBI survivors everywhere, friends and family of STBI survivors need to step up.

Family and friends of STBI survivors, please be decent and do for survivors anything they cannot do for themselves that you can. Really love them. Be there for them. Try to empathize with their fears. If their injury scares you, set your fear aside. Close your eyes and imagine how they feel at that very moment.

How to converse with STBI survivors:

1. Always include them in daily conversation. Have a conversation with them that focuses on them. Never exclude them from social settings. Once in a while, make them the

center of your attention. If nothing else, STBI survivors want to be "in on it." Inclusion is the focus.

2. Be as patient as you can. There are no miracles. Just realize the person has achieved when they achieve it and acknowledge it. Consider saying, "Look how far you've come," or "good job," not, "Look at all the crap you've caused." I would have loved to hear, "I'm proud of you," just once.
3. Compliments instead of criticisms. Encouragement and love always accomplish more than hatred and kneejerk frustration. Please think of the life lessons we learned from our mothers as children. My mother never put me down or treated me less-than. She lovingly helped me learn. She always reminded me that there is still a different way of looking at things. My mother would encourage me to try things and not worry if I failed every once in a while. She'd say, "Let's try it this way this time," or, "Maybe this is a better way to see it. She'd even console me with similar humanity: "Oh honey, don't cry, everybody does that..." My mom was a paragon of encouragement, and I think we should all learn from her.

Psychological Support

I also sought alternative psychological therapies after my rehab. I found that personalized sessions were the better way to go for me. However, many people can't afford this luxury. They are stuck with the dearth of group therapy options their local community or charity groups offer. Although I do appreciate the effort and opportunity, I found my group therapy sessions to be a waste of time.

We'd only sit in a circle and wait. The person in charge always seemed to phone it in. They would ask pointing to one survivor, "What happened to you?" and the next, "What happened to you?" and so on. Every flipping week it was the same thing, the same stories, around the table they would go and talk about their woes, but never anything came of it.

Frankly, they brought me down, so I quit. If there were just some form of follow up to each survivor's story, suggestions to cope or ways to help the situation at hand, then maybe the sessions would have been worthwhile to me. Now, that's not to say that group therapy is not or cannot be helpful. I'm just saying that for me, with this tactic and this person at the helm, it was not effective.

During my initial hospital stay and in the early stages of my recovery a group of phycologists visited me to assess my cognition. Unfortunately, several of them barely acknowledged my humanity. It seemed like most of them apathetically sat at the foot of my bed and rifled through their paperwork. Some would even ask me a generic question or two about how I felt, albeit cold and dispassionately. I couldn't see very well as it was, let alone make my eyes focus past the edge of my bed.

In a perfect world, somebody—anybody—would sit with me, ask me how I was feeling, and genuinely listen to my responses. In time, I do think that I would have become comfortable enough with a therapist to vent my anger, frustration, and confusion with my injury. Who else was going to do it for me? My family certainly couldn't know how. Plus, the other doctors, nurses, and rehabilitation therapists were usually already preoccupied with my more immediate medical issues.

I believe that I would have had a quicker and more fulfilling recovery if I had regular sessions with a therapist. To anyone else in my position, I would highly recommend pointed one-on-one therapy for the duration of the recovery and then family sessions beyond that. Naturally, a person cannot be forced to have counseling, but when integrated into a comprehensive rehabilitation program, I do believe family members were more likely to either attend the sessions themselves or at least recognize the need for the survivors.

CHAPTER 24

My Message to STBI Survivors

> Never doubt yourself. Others will doubt you, and that's enough for one to deal with. Disbelief is another measure to wonder in this state of mass confusion. "She looks great. She must be okay." A world of one, so contained that the only one given a key is another survivor. They may be on a parallel line, running right beside you and you don't even know it.

WHETHER FROM A FALL, vehicle accident, assault, medical issue, or in my case, a tiny microbe that finds its way north, there are many causes of STBI and an infinite number of outcomes. It's hard to understand why misfortunes like a brain injury can happen to decent people. I have always wondered how it's even possible that God looks down at all of the cruel people doing disgusting things in this world. How can evil people thrive while terrible things can happen to genuinely good people? It just doesn't seem right. Somehow here we all are.

In my case, I'd like to think that I have led a virtuous life. I worked hard, honored God and tried diligently to be a decent person. I was always honest, helped others where I could, and strived to be a fair and understanding human being. I married a

Godly man, birthed and raised his children and sought to teach them to be kind, to give back and always to be good, caring people. In spite of all of my efforts, faith, and strong convictions, I still found myself on the journey of STBI.

There's something unforgettable that STBI survivors have to learn throughout their journeys. It's important to note that I didn't wholly accept my situation or learn to work past my injury until I let go of the anger. I harbored my rage for a long time. I told myself that my injury did not have to happen. I blamed the world for it: If only that doctor listened to me and set aside his ego, he would have detected my classic symptoms of a brain abscess before it was too late. Then I wouldn't be stuck in this excruciating dimension. An MRI and some antibiotics would have done the trick. Then my family wouldn't prematurely lose their mother, grandmother, sibling, and wife.

It's incredibly hard to live in a shell of what you once were when you fixate on everything you've lost—on all that has made you who you are. Your thoughts, personality, and memories wiped clean. The anger makes it hard to want to be here on earth anymore, but yet we must be, as it's our mission.

After all, becoming an STBI survivor changes you indelibly. It forces you to focus on the things in life that matter most. A meaningful life has nothing to do with this physical world. The accumulation of possessions and the objective, outer-world around us—is just secondary. It's just "stuff." None of that is essential or "real" in the grand scheme of things. It's bittersweet: we work so hard to obtain tangible items in our lives. But we can't take any of it with us when we die.

I have worked to acquire material things my entire life. It turns out I was working for fool's gold. At the time of writing this, my husband and I have all of the wealth imaginable. Frankly, we have everything we need. I'm talking about the intangibles. Other than the love of others, all you truly need is your health. That inescapable adage in my brain is right. We all heard that saying from our parents and grandparents while growing up and it never really phases you until it affects you:

> "If you don't have your health, you don't have anything."[19]

Carry On (Despite the Darkness)

> Just think: it takes just one odd turn, in a series of events, in one moment passed, to pave a road leading to every new event we experience in this life. Every journey planned and every experience foreseen. It's how we perceive these moments that make us stand or fall. Do we change our behavior, or do we remain stagnant in the realm, just beyond the reach of reality? Lessons for all to learn, but how many will truly see?

It's an arduous journey and those who can make it deserve a medal because surviving an STBI is statistically improbable. It's a tough thing to survive, to live through and a very different world to live in once you have recovered. To successfully heal, you need to get over yourself, as sometimes it can be a real pity party if you let it. Wallowing in pity is most often a waste of time. You have to rise above it. It's not always easy, and that's where the fight comes in. You've got to carry a big stick, and not be afraid to use it.

I know that my survival is a miracle and I don't have any problem saying that word. I am God's miracle. I honestly doubt I could have accomplished surviving my STBI on my own. I am one of God's children just like you are and we are all capable of withstanding our injuries if we have it within our hearts and minds to do so. We can do anything if we allow ourselves that ability.

My parting words to you are for your encouragement. Be brave, fellow survivors. Be strong, if not for yourself, for your loved ones, who have prayed so diligently for your survival and have hoped for your meaningful recovery beyond anything. Accept that you are loved first and foremost by God. Remember that your family and close friends also love you. The STBI-survivor community loves you! We intimately grasp what you are going through. If you find yourself without help along the way, look to any STBI survivor to fill-in the hole in your heart.

My best advice to you is to forgive freely and to let go of all the anger. It's best if you find a way to cope with the fact that you have a brain injury and a fair amount of your previous personality is now gone forever. Know, too, that this journey offers other gifts. You have yet to discover new abilities, new skills you can master, and new ways to thrive, all of which the old you could never imagine. You might also get to know other STBI survivors on entirely different levels, and witness how harrowing our new lives are.

Know too that there is something bigger than all of us out there, another level of being that is far beyond this earth. There are different planes of being, parallel realms that offer incredible experiences for those who dare to see. This life is temporary but is none the less part of our master journey.

I have peeked behind the curtain of death to see the other side. It's horrifying only at first. It is also a wondrous place of unimaginable beauty and peace that is not of this earth. In due time God grants us admission into His kingdom. Everyone's expiration date varies. Never be afraid to give in when he calls you. Give in to the hard truth. Your fate is ultimately not up to you. Relinquish yourself to this providence. Free yourself.

> Learn to let go. Of the anger. And surrender yourself. To God's constant grace and absolute wisdom.

We are all granted gifts with life,

And some are quite incredible.

But when God takes them with tragedy,

We're left bewildered and lost.

To wonder is natural,

To pity is to waste.

Move on after the shock wears off

And the senses regain their stamina.

For tomorrow brings new words,

Fresh ink on your page.

—KATHLEEN NEWHOUSE

How to Help

I welcome you to visit the Just A Breath Away Foundation website and to cruise through the virtual gallery of my artwork. You can also read my blog, follow us on social media and consider offering support wherever you can. Whether it's a donation, providing a useful resource or a kind word, every bit is appreciated and welcomed!

A 501(c)3 non-profit organization, Just A Breath Away Foundation has been established to increase awareness of severe traumatic brain injury (STBI) and to raise funds to help survivors and their families. Through the sale of my paintings, this book and other fundraising efforts, all proceeds will be donated to others in need. Please visit justabreathaway.org and join our Circle of Hope community.

JABA
FOUNDATION

Please visit justabreathaway.org and join our Circle of Hope community.

Glossary

CT scan. [Computerized Tomography Scan.]

Unique X-ray imaging technology that generates a cumulative composite of interior-organ topographies by aggregating a comprehensive array of inter-dimensional cross-sections within a localized focus. Dependably expedites the identification and diagnosis of internal brain-injury symptoms that include the following: hemorrhages, hematoma, fractures, and contusions.

Also called CAT scan and Brain scan. Compare MRI.

encephalitis.

Irritation, inflammation, and swelling of the brain. Caused by bacterial, viral and parasitic infections. Actionable diagnosis requires medical-imaging, blood analyses and often an invasive spinal tap procedure. Symptoms include chronic lethargy, stiff-neck, increased sensitivity to light, headaches, confusion, fever, nausea, vomiting, and even unconsciousness. Severe cases warrant ongoing physical therapy and speech therapy to treat the following: incoordination, hearing loss, speech impairment, memory loss, seizures, and hallucinations.

See also ICP.

GCS. [Glasgow Coma Scale.]

Clinical procedure used to practically evaluate the magnitude of neurological damage from a traumatic brain injury. Assigns a score to the degree of consciousness retention among brain-injury patients by assessing the following: verbal acuity, motor-skill responsiveness, and eyelid control.

Also called Glasgow Coma Score.

ICU. [Intensive Care Unit.]

Specialized hospital department that treats the most critical and severe injuries and ailments. Priority is to recover and sustain normal homeostasis functioning. Requires highly trained professional teams to maintain careful, intimate, around-the-clock monitoring of its patients, seven days a week. Its overall purpose is to keep patients alive.

Also called Intensive Treatment Unit; Critical Care Unit.

ICP. [Increased Intracranial Pressure.]

Substantial and treacherous upsurge in cerebrospinal fluid pressure around and on the brain. Caused by sharp declines in blood flow to the brain. May lead to severe spinal cord damage. Designated by fluid-pressure measurements of 16 millimeters mercury (16mmHG) and above.

Compare encephalitis; mmH2O.

MRI. [Magnetic Resonance Imaging.]

Method of mapping radiological snapshots of internal human anatomy into an array of pictures to track periodic fluctuations in healthy, functioning vital organs. Large, tubular machine that emits powerful radio-wave frequencies through magnetic fields to diagnose spinal-cord health and brain tumors over time.

Compare CT scan.

migraine.

Chronic and severe headache marked by intense and prolonged pulsing and throbbing. Causes severe sensitivity to sound and light, nausea and vomiting. Can last hours or days and cause incapacitating bouts of pain in the temples and forehead.

mmH2O.

Short for millimeters of water. Standard unit of measure adopted in VP shunting, which monitors and curtails increased intracranial pressure (ICP) caused by mounting cerebrospinal fluid (CSF) around the brain. A scale that assigns numerical values to degrees in water pressure per millimeter of water. More specifically, a system that quantifies magnitudes of increased intracranial pressure (ICP) per millimeter of excess cerebrospinal fluid (CSF).

See also VP shunting; encephalitis. Compare ICP.

PICC. [Peripherally Inserted Central Catheter.]

Special tube inserted into a patient's vein that delivers medication and nutrients into their bloodstream over an extended period, often for weeks or months at a time. Also, a means for important blood tests. Requires regular flushing and cleaning because it can cause blood clots over long periods. Categorically invasive and uncomfortable for patients. See also encephalitis; ICP.

Compare VP shunting.

STBI. [Severe Traumatic Brain Injury.]

Highest classification of brain trauma, which results from extreme head injuries by internal or external forces. Characterized by persisting damage to the following neurological and psychological abilities: language, vision, hearing, taste, touch, smell, short-term memory, long-term memory, attention, motor skills, coordination, impulse-control, and time-management skills. Induces chronic depression and anxiety, unpremeditated aggression and a range of personality disorders.

See also CT scan; GCS; ICU; ICP; MRI; stroke; TMJ; ventriculitis; VP shunting.

stroke.

Sudden and severe disruption of healthy blood flow to the brain whereby its critical oxygen supply plummets and subsequently damages and kills its cells beyond repair.

See also encephalitis; ICP; ventriculitis.

TMJ. [Temporomandibular Joint Dysfunction.]

Broad category of chronic disorders involving the temporomandibular joint, which links the lower jaw and skull together. Caused by trauma to the head, namely to its accompanying muscles, tendons, and joints. Symptoms include ear-ringing, jaw-clicking, dizziness, hearing damage, headaches and restricted movement of the mouth and jaw.

ventriculitis.

Hazardous inflammation in the brain due to infection in the ventricles. Leads to personality disorders, chronic vertigo, dizziness, headaches, fever, seizures, stroke and even death.

See also stroke; VP shunting. Compare encephalitis.

VP shunting. [Ventriculoperitoneal Shunting.]

Highly invasive, urgent, and risky surgical procedure that enables efficient discharge of excess cerebrospinal fluid (CSF). Risks include acute infection, intracranial swelling, seizures, hematoma, and permanent brain damage. A catheter is fed through a hole drilled in the skull and into the brain's ventricle. A second catheter is fed behind the ear into the abdomen. A valve is installed behind the ear to connect both catheters under the skin. The valve automatically adjusts to increased intracranial pressure (ICP) and routes excess cerebrospinal fluid (CSP) into the catheters and abdominal cavity. A reservoir on the valve collects excess cerebrospinal fluid (CSP). After installation, VP shunts require periodic and careful maintenance to minimize the significant risk of infection.

See also encephalitis; ICP; mmH2O; PICC; stroke; ventriculitis.

Endnotes

1 “Facts about Chickenpox for Adults,” National Foundation for Infectious Diseases.

2 Brook, “Brain Abscess: Clinical Presentation,” secs., “History,” and “Physical.

3 State of California, “Health Care Decisions,” Pub. L. No. AB-891, § 4701.

4 Agrawal, Cincu, and Timothy, “Current Concepts and Approach to Ventriculitis,” 100-104.

5 “Brain Injury Facts and Statistics,” Brain Injury Association of America.

6 Reiter, Dwight, Kessler-Heiberg, Munroe, Pahr, Coughlan, and Curran, Journey Toward Recovery, 37-42.

7 Ma, “Contracture Deformity.”

8 “Risks of CSF Shunts,” United States Food and Drug Administration.

9 “Talk. Read. Sing. It Changes Everything,” First 5 California.

10 “Alzheimer’s Disease: Symptoms and Causes,” Mayo Foundation for Medical Education and Research.

11 Baldini, Von Korff, and Lin, “A Review of Potential Adverse Effects of Long-Term Opioid Therapy.”

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14 What Happens Immediately After the Injury?,” Mount Sinai Medical Center.

15 Bentz, “Can a Brain Heal Itself after Stroke?”

16 Rocchio, Challenges, Changes, and Choices: A Brain Injury Guide for Families and Caregivers, 15.

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18 Ibid.

19 “Chuck Pagano Quotes,” BrainyMedia.

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Helpful Websites

ALCS Stroke Information & Resource Guide:
www.acls.net/stroke-information-and-resources.htm

Americans with Disabilities Technical Assistance Program:
www.adata.org

Brain Injury Association of America:
www.biausa.org

BrainLine:
www.brainline.org

Caregiver Action Network:
caregiveraction.org

CDC on Brain Injury Awareness:
https://www.cdc.gov/headsup/resources/index.html

Centre for Neuro Skills:
www.neuroskills.com

Defense and Veterans Brain Injury Center (DVBIC):
www.DVBIC.org

Defense Centers of Excellence for Psychological Health and Traumatic Brain Injury:
DCoE.health.mil

Family Caregiver Alliance:
www.caregiver.org

FAQ Social Security Disability:
ssa-custhelp.ssa.gov/app/answers/list/c/105

Guide for Family Caregivers:
Disability.gov

Learning Services:
www.LearningServices.com

Military and Veteran Caregiver Network:
MilVetCaregiverNetwork.org

My Grey Matterz:
www.mygreymatterz.org

National Rehabilitation Center:
www.naric.com

National Stroke Association:
www.stroke.org

PsychArmor Institute:
www.psycharmor.org

Real Warriors, Real Battles, Real Strength:
www.realwarriors.net

San Diego Brain Injury Foundation:
www.sdbif.org

Social Security Disability:
www.ssa.gov/pgm/disability.htm

TBI Survivors' Network:
tbisurvivorsnetwork.ning.com

US Department of Labor:
https://www.dol.gov/odep/topics/Stay-at-Work-Return-to-Work.htm

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VeteranCaregiver.com

Well Spouse Foundation:
www.wellspouse.org

What is Brain Health:
brainhealth.nia.nih.gov/

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Survivors

Are here

For a reason.

And I've

Found mine.

—KATHLEEN NEWHOUSE