ABISS

ACQUIRED BRAIN INJURY SURVIVOR SOLUTIONS

SURVIVOR STORIES



DAVE'S JOURNEY

It was early on a snowy morning when a minivan came through a stop sign at a blind intersection and T-boned us in our small Mazda. Both cars ended up in a field off the country road we were travelling on. My wife in the passenger seat had a badly broken left arm. The top of my head was scalped and I had severe internal bleeding from broken ribs rupturing my spleen. We were on our way to a funeral in Brampton and were to deliver a work proposal for one of my clients afterwards.

The trouble is I don't remember any of that. My first memory after this accident was 10 days later in hospital when I was being asked by a nurse if I knew my name, where I was and what happened to me. After a few days of this I caught on to the story and noticed the calendar on the wall in front of me so I could tell them what day it was.

> "MY FIRST EXPERIENCE WITH INSURANCE COMPANIES THAT I REMEMBER WAS BEING ASSIGNED A CASE MANAGER BY MY AUTO INSURER WHO MANAGED NOTHING AND IN FACT MINIMIZED WHAT HAD HAPPENED TO US.

I don't remember anything about a funeral or even my cousin dying. I remember working on a work proposal but nothing about scheduling a delivery so every memory connected with that day has gone including what must have been a painful experience and recovery in the first days.

So a drastic life-changing event happens and I'm a month in hospital. Still not well oriented and told I had a confirmed brain injury from brain lesions found in CT scans, I was sent home. My symptoms of flat effect, confusion and a tendency to have angry outbursts were classic to brain injury.

The impact on my family was huge. My wife was unable to continue teacher's college now becoming my primary caregiver. She had to deal with her own losses and injuries plus deal with a husband often angry and in denial at the same time be the insulation between that angry father and four children aged 9–18 together with being essentially the sole parent.

My first experience with insurance companies that I remember was being assigned a case manager by my auto insurer who managed nothing and in fact minimized what had happened to us. Having your health condition minimized by anyone is probably the most infuriating response of all. Having it done by the party you have paid for years to protect you in these circumstances fuels a reaction well beyond anger.

Soon after this I also got a letter from an insurance lawyer claiming I had been drinking at the time of the accident. Really? At 9:00 a.m. on my way to a funeral?? You have evidence for this??

When these types of things happen with your insurer it becomes obvious that their goal is to minimize insurance payments and not to fairly assess what your benefits should be.

Fortunately we had good friends who knew and recommended a personal injury lawyer who did very well for us. Mind you this was over a very financially stressful 3 years as we ate significantly into savings and retirement investments with no income. My environmental, occupational health and safety consulting business fell apart as I could not get new contracts nor apply myself in any sustainable way with very slow processing, bad short term memory and fatigue not to mention a tendency to show my frustration at inopportune times. I was devastated by my loss of ability to function in my work and extremely concerned about what that meant in terms of loss of income with a family of four to support.

The legal dispute with our own auto insurer was over whether my injury was classified as catastrophic or not. Apparently, I was conscious at the scene of the accident and Glasgow coma scores were high. Our lawyer had set a precedent in a similar case to consider more than Glasgow coma scores in considering brain injury outcome and got a significant settlement. That money in no way replaced what we had lost nor secured us completely for the future with four kids but it has helped a lot especially with our youngest. He suffered high anxiety at the time of the accident having almost lost both his parents and with only one functioning close to the way they used to. This was followed by marijuana use and unfortunately depression and continued anxiety led to oxycontin use. His opiate addiction recovery continues 17 years later. Progress is slow, expensive and emotionally soul-destroying for him and us as parents. The financial and emotional impact on an insured's family members is not considered at all by the insurer unless forced to do so in legal action.

I consider myself fortunate to have gotten my brain injury in an auto collision because I had access to and received excellent therapy and care from a great case manager our lawyer recommended, speech language pathologist, physiotherapist and occupational therapist who set and kept me on a course that continues to help me to this day. It has allowed me to seek meaningful volunteer work at my local brain injury association as well as a hospital rehabilitation centre treating people with acquired brain injury. I would not be able to have the sustainable, meaningful volunteer life I have right now without the kind of professional help I received. I may even have lost my family completely without that kind of intervention because a significant percentage of relationships fail with a brain injury.

Insurance companies have now been successful in drastically reducing auto insurance benefits with our government. It is reprehensible that there is automatic treatment of insured accident victims as if they are freeloading moochers or even criminally taking advantage of their situation but to now reduce monies available to them for treatment just adds insult to injury!

Dave Gaylor - Motor vehicle accident December 12, 2000.

JULIE'S JOURNEY

I am just like each one of you. I was someone's partner, the mother of two beautiful children, the daughter of amazing parents, and a sister. I was the family organizer and the family caretaker. I was a personal trainer and a yoga/fitness instructor. I did not lead an adventurous life. I did not participate in any high risk activities (with the possible exception of trying to get my kids to clean their rooms). I led a pretty routine and boring life. Just like every other parent, most of my evenings were spent chauffeuring my kids to their activities. I was happy... WE were happy.

> "LITTLE DID I KNOW THAT I WOULD SOON FIND OUT WHAT HELL REALLY WAS AND THAT IT WAS WAITING FOR ME ONCE I WAS RELEASED FROM THE HOSPITAL AND SENT HOME.

All of that changed on October 21, 2010 when I crossed paths with a drunk driver. I awoke from a coma five days later. My first memory is nine days after the crash. My daughter, Gracie's, doctor came into the room to explain to me (yet again) that Gracie was not going to survive her injuries. Apparently, my husband, family, and multiple doctors and nurses had already told me this... multiple times over multiple days.

Besides 16 spinal fractures, a skull fracture, six pelvic fractures, a dislocated and shattered left foot, broken ribs, jaw, teeth and fingers, I also had a Traumatic Brain Injury (ABI); a coup contre coup midline shift severe traumatic brain injury to be exact.

I had woken up with a broken brain in a broken body with a broken heart.

I'd woken up with a broken life.

Lying in that hospital bed all alone in the dead of night, I was sure that I had died in the crash and woken up in Hell. Little did I know that I would soon find out what Hell really was and that it was waiting for me once I was released from the hospital and sent home. Hell for me came in the form of "Treatment Denied" and Satan came in the form of an insurance adjuster who stamped it on almost every treatment plan sent to her. In the first nine months of being home, I had 10 IE's (including one to see if I really needed grief counseling). With all of my injuries, I was forced to endure hours of excruciating car rides. Despite the laundry list of injuries, it took ten months to get a catastrophic designation.

Ten months of waiting to find out if my injuries, which left me in a wheelchair without the use of the left side of my body were bad enough to be eligible for rehab therapies that would help me walk again.

Even though I had obvious memory issues, difficulty finding words, had lost the ability to comprehend the written word, could no longer organize my thoughts much less my family,

struggled to stay on task (or even identify the tasks that needed to be done, lost most of the use and sensation in my left side, and struggled to control my emotions I was denied any cognitive rehabilitation based on one IE with a neurosurgeon of the adjustor's choosing.

I spent five minutes with the man who had me count backwards from 100 (not a skill I lost), had me flip my hands bilaterally (something I still can't do today) and had me listen to him talk about how his car was damaged when it was hit by a drunk driver while parked empty (so he understood where I was coming from). Because he wrote, "Mrs. Wynen can expect a full recovery from her injuries.", I was denied treatment despite the fact that no one, NO ONE, recovers fully from my type of brain injury. Even though she had denied other types of treatment, this denial hit me the hardest; it was my lowest point.

I was no longer a partner... I was a burden. I was no longer a mother to my one surviving child… I had become the child that she needed to look after. Instead of caring for my aging parents, they were now caring for me. I was no longer a fitness professional… I was a patient relearning how to move my hands, feet and legs. I was no longer the family caretaker. I was now a patient that required a team of people to keep me upright, focused and moving in a forward direction.

I had lost me. The 'me' that I had known, raised and cultivated for 42 years no longer existed. I had been surveilled. My child had been surveilled. I had been accused of Fraud more times than I could count for the simple act of trying to put the pieces of my shattered life back together. I was being treated more like a criminal than the man who had committed the crime that killed my child. That was the night that 37 became my favourite number. Why 37, you ask? Because that night I sat down and counted out the number of pills I had in my house that I knew I could take to end this pain and confusion that I saw no end to.

"WHY 37, YOU ASK? BECAUSE THAT NIGHT I SAT DOWN AND COUNTED OUT THE NUMBER OF PILLS I HAD IN MY HOUSE THAT I KNEW I COULD TAKE TO END THIS PAIN AND CONFUSION THAT I SAW NO END TO

Luckily I had a great team of rehab therapists and lawyers who convinced me that they would get me the help I desperately needed. Even with all of their best efforts and skill, it still took 18 months (and a new adjuster who couldn't for the life of her understand why I had been denied therapy and given such a difficult time) to receive therapy from a speech pathologist with experience working with brain injuries.

Because your brain regulates everything about your body, a ABI affects every part of your life. It affects your social life, your relationships, and your physical abilities in the way that you are able to move and how any sensory feedback is understood. It can affect your level of pain and the way your body responds. I have a large extended family. I used to love to go to parties and family events. I loved the noise and chaos of those gatherings. Now it is my worst nightmare. It's like having someone put a metal garbage can on my head and having a crowd of people bang on it with wooden spoons.

Your brain sends messages to your muscles telling them to contract and relax. Imagine for a moment what it feels like to have the

message sent to contract to the point of cramping and then not getting any message to relax that muscle. Imagine having sensory inputs sent that either never reach your brain or get misfiled. I can't count the number of times that I have fallen because my left leg didn't lift like it was supposed to or how many times I have burned my left side because I didn't know that the water or pot handle was too hot.

One time I lost my keys and couldn't find them; I couldn't remember where I had put them. My friend said not to worry, 'she did it all the time.' So I asked her "What is all the time?". "Probably a couple of times a month", she laughed. I replied, "That's not all the time. Imagine losing your keys (along with a dozen other things) a hundred times a day and not remembering where you put them because you have lost the ability to backtrack."

> I HOPE THAT AS YOU READ MY STORY YOU UNDERSTAND THE BATTLES THAT SOMEONE WITH A ABI FACES; NOT JUST WITHIN THEIR OWN RECOVERY PROCESS BUT ALSO FROM EXTERNAL FORCES THAT AFFECT THEIR RECOVERY PROCESS.

I would like you to sit back and think about that for a moment. 18 months before I got the help that I needed… the help that I deserved as a human being. Eighteen months of not being able to understand what I was reading or to write a sentence that could be understood by others. Eighteen months of being afraid to speak because I didn't know how it would sound to others. Eighteen months of fear, frustration, and anxiety that could have been avoided if some insurance adjuster sitting in her office had just written 'approved' instead of 'denied'. Eighteen months before I had the opportunity to figure out who the 'new me' was. 18 months to find out that the 'new me' was going to be okay.

Eighteen months…

I will never be the person I was before the crash but because of the help that I finally received from my ABI I have learned the skills and accommodations that I need to live my life. I still don't feel my left side. I still can't regulate my temperature but I have learned the fine art of layering. When I get overwhelmed my brain still shuts down like a two year old having a tantrum but I am learning to balance my life better. My organizational skills and sequencing still suck (but I have learned to ask for help). My memory is still pretty horrific (but I have become bff's with Post-It Notes). I still struggle with words (but have learned to be incredibly good at charades and asking for help). I run like a herd of turtles through a field of peanut butter (but I run). I have made new friends that accept that I have neither a concept of time nor do I have a filter between my brain and my mouth. I am a partner again. I am now able to say that I am STILL the mother of two beautiful daughters (Just now I teach one about the world and the other I teach the world about). I am a daughter of four aging parents (by birth and by marriage) I now share a unique bond with over all of the interesting places one can leave their keys. I also now share a fear with them of becoming a burden much earlier to my injuries as I age. I am the family organizer (in that I now buy and hang the calendar with different coloured markers and have trained my family to write things on it). I have relearned how to communicate with my daughter so that she now knows that she can come to me with her problems and get advice from her Mom. I have learned how to

communicate with my husband so that we can take care of each other and know I am not a burden to him.

I hope that as you read my story you understand the battles that someone with a ABI faces; not just within their own recovery process but also from external forces that affect their recovery process. I hope that you understand that a ABI is not an injury to just an individual but an injury to the whole family. I hope that you understand that the barriers that have been set up by the insurance companies and supported by the government have an enormous impact on the ability of persons living with a ABI to get the help needed in order to achieve their best outcome. I hope that you understand that a ABI is not some rare, unique occurrence that only happens to athletes and the elderly. The decisions that you are making today will continued to have a detrimental effect on survivors of ABI's in the future.

I hope you understand that I am just like each of you.

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JON'S JOURNEY

People buy insurance to provide peace of mind and to know that if anything were to happen to them that they would be covered and their loved ones would be financially stable. When I needed that piece of mind most it was taken away from me. I was involved in an accident that left me with brain injuries that have forever altered my future. This accident was of no personal fault of my own but left me in many respects disabled. The first issue I faced from my insurance company was when I was in a coma, insurance refused to pay my family any wage replacement as they deemed me ineligible from being self-employed. While still in a coma for five weeks my father was handling my affairs and he didn't believe that to be the case and stated he would bring this issue to the court system and the insurance company immediately relented.

> WHEN I NEEDED THAT PIECE OF MIND MOST IT WAS TAKEN AWAY FROM ME. I WAS INVOLVED IN AN ACCIDENT THAT LEFT ME WITH BRAIN INJURIES THAT HAVE FOREVER ALTERED MY FUTURE.

After much time I was awake from my coma and back home recovering, but still in no way able to handle my affairs with any real competency. I was contacted by insurance company accountants to determine the wage replacement I was due. They asked me a series of questions and in retrospect it appeared they were trying to catch me up on a mistake or use my information in a nefarious way against me. One such question that was taken out of context was that they asked me if I would have purchased a second van if my personal business had continued to grow and I answered that I would have under that circumstance. They used this piece of information to manipulate my wage replacement and while they determined I was eligible for $350 a week they took into account the cost of this van I said I would have bought and took the cost of this fake van into account leaving my $350 a week to $32 dollars a week. I was horrified, and the debt began to pile on. My lawyer said I should declare bankruptcy as it would be good for my case, but I had no intention of that and struggled with 17 rental properties I owned and managed, and struggled with $100,000 in left over inventory from my now closed self-employed business.

For little over five years, the Insurance Company tried endlessly to stop all services that I depended on desperately and all this was done without any warning. My therapists would call to tell me that the insurance had informed them that my sessions were now over, I would write to the appropriate government agencies and the services were always restored as they were rightfully mine.

At the start of year three, I was finally starting to regain my old cognition and abilities back. I wrote to the financial commission about the

fact that I was still paying for this imaginary van and to my surprise within five days of my letter to the financial commission I received a cheque from the Insurance Company for around $15,000. This cheque was accompanied along with a short note from my insurance company that said they had heard about my general concerns but stated nothing specific about what they had done wrong. Two days after that I received a phone call from the financial commission to say that there was nothing they could do now since the insurance had settled the matter. The Insurance in a follow up letter, said that from now on I would receive $200 a week, the lowest amount allowed by law. Now in retrospect I realize that they did not even pay me back to the original wages of $350 that was determined to be owed to me before the fake van slashed that amount. I was so in debt and struggling with bills that I just accepted anything more they would give me. I was not in a place to argue and refuse money that would continue to feed my family. It is only with hindsight and more wits about me, that I now realize that the payment was not even close to reimbursing me the $350 a week owed, but the new figure of $200.

> “WAS SO IN DEBT AND STRUGGLING WITH BILLS THAT I JUST ACCEPTED ANYTHING MORE THEY WOULD GIVE ME. I WAS NOT IN A PLACE TO ARGUE AND REFUSE MONEY THAT WOULD CONTINUE TO FEED MY FAMILY.

At year five and with a settlement approaching, I was sent to see several medical professionals to determine the extent of my disabilities. One psychologist in particular stood out, close to the end of our session, he asked me to hand the receptionist down the long corridor, the final test papers. The psychologist had left me with the receptionist to fill out a questionnaire and he took off to play golf. I answered the questionnaire. The receptionist upon reading my answers asked me to change a few and when I refused, she explained that I had not answered them to the doctor’s liking and she changed them herself . After this “assessment” that particular psychologist reported that there was nothing wrong with me. All along my only complaints were fatigue, memory issues and syntax issues. The report clearly stated that I was suffering from none of these complaints, and should go get a job. I was livid and took the steps to take this offending doctor to the board of Psychologists. At the first hearing the board told me I had won and they determined that the doctor was guilty of compromising my privacy in giving the receptionist the papers. This was not satisfactory. It was then my intention to take him to the appeal board. I came prepared with evidence that the receptionist was a complete stranger to the doctor, that she worked in an adjoining building, that she was not personally trained by him, as he had claimed in his defense papers. At the end of my delivered evidence, the doctor’s lawyer stood up and reminded the Board of their mandate, that this information could not be entered as the original board addressing the first hearing didn’t hear it either, and new evidence could not be presented. Fortunately, the lawyer inadvertently admitted that the receptionist was not in the doctor’s employ, and I took advantage of this and brought it to the boards attention. The board upon this new information withdrew and deliberated for 10 minutes. When they returned, they determined that a doctor has the right to instantly delegate authority, that a person once delegated will be referred to as staff, and that if a doctor had trained staff, the instantly delegated person is

also now referred to as trained, and as such, his defense that she had been personally trained by him to not do the markings I now accused him of, would stand. They also stated that the new writing on the test that was in a different colour pen and writing must have been done by me as they were not proficient in handwriting analysis to make these kinds of judgments. The only benefit I got from the year and half of taking the doctor to the Board was that during that time the Insurance once again turned my therapy and $200 a week back on. That benefit as per usual had been stopped until they received notice of my legal action. After failing with the board, I tried to take the doctor through the Ontario court system, but in the Courthouse was advised by legal authorities that it was impossible to get an unbiased judge in this particular case.

I am now past settlement, the torture is over, I am thankful that I managed to avoid bankruptcy, and I now believe the Insurance Industry is crooked.

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JULIANNA'S JOURNEY

On August 14, 2000, I was in a catastrophic motor vehicle accident. The driver of the vehicle I was in was distracted and crossed on to the other side of the road. There was a loaded dump truck coming towards us. We were on a bridge so there was nowhere for the dump truck to go. The passenger side of the vehicle got most of the impact. I was in the back seat on the passenger side. For confidentiality reasons I am only going to share how this accident impacted me, not the other individuals involved.

I was air lifted to Sick Kids Hospital in Toronto. I was in a coma for 12 days. I sustained frontal lobe brain injury and what is medically defined as a "facial smash." I lost three quarters of my vision as well as my sense of smell. I experienced a cerebrospinal fluid leak which has required at least seven surgeries and procedures to fix. Due to the persistent cerebrospinal fluid leak I have also had bacterial meningitis twice. I also shattered my right elbow. My pituitary was injured so I now have diabetes insipidus which is a fluid imbalance in my body. This is a list of my injuries, not a list of how these injuries have impacted my life. Each injury from the accident I was in has a significant and prolonged impact on my life. The accident changed the course of my life and who I would be from that point on.

> "I BECAME A SEVENTEEN-YEAR-OLD WHO WAS FIGHTING FOR MY LIFE, ENDURING COUNTLESS SURGERIES AND PROCEDURES. PHYSIOTHERAPY, SPEECH THERAPY, OCCUPATIONAL THERAPY...

Instead of being a seventeen-year-old who was enjoying a summer filled with friends, playing soccer and working at my summer job; I became a seventeen-year-old who was fighting for my life, enduring countless surgeries and procedures. Physiotherapy, speech therapy, occupational therapy... all of these became a part of my everyday life. My world was not a high school classroom like it is for most seventeen-year-olds; it was a hospital room. My life had essentially been put on hold while the world around me carried on. I wanted to go back to school and even more so I wanted to play competitive soccer. Due to being in the hospital 80 days and then going to rehab in Toronto I missed a year of school. My friends graduated high school while I was left trying to put my life back together.

Throughout my recovery there have been many stresses and barriers but I haven't let them stand in my way. It was and always will be my desire to succeed. Following the accident, I wanted to succeed at recovering. I did the best I could at whatever task was put in front of me whether it was physiotherapy or a neuropsychological assessment. I wanted my recovery to be the best it could be and I wanted any assessments I had to be as accurate as they could be. My recovery would determine how successfully I would reintegrate back in

to society and the activities I loved doing. The assessments would determine the amount of financial support I would receive for my future. In other words, my recovery and the assessments were setting the stage for the rest of my life.

I was very fortunate that my accident happened in 2000 when there was a lot more support available than there is today although, in order to receive this financial support from the insurance company, I had to go through countless tests and assessments. I was extremely lucky to have my mom handle most of the interactions with the insurance and lawyers. She wanted me to be able to focus on my recovery and rehab. At the time, I was confused about why I had to go through the same type of testing over and over again. It was exhausting. I remember thinking to myself, are they testing my brain injury or my stamina? The assessments were long and often didn't take my low vision in to consideration. I had so many assessments that my memory of them sort of blended in to one. The assessments made for an extremely long day filled with question after question pertaining to anything under the sun. Cognition, memory, problem solving, comprehension, the list of what they were testing goes on and on. I knew there wasn't much point in complaining because I had no choice in the matter and these countless assessments needed to be done in order for me to receive the long-term support I needed.

> IF ONLY THEY COULD HAVE USED THE ASSESSMENTS I HAD ALREADY GONE THROUGH I WOULD HAVE BEEN ABLE TO FOCUS MORE OF MY TIME RECOVERING FROM MY BRAIN INJURY RATHER THAN PROVING IT.

I remember on the way home from the assessments I often found myself either telling my mom about the questions I had been asked or testing her to see if she could answer them. I mostly did this to demonstrate the difficulty level of the assessments. After completing this, I sat in absolute exhaustion curious about how I had performed during the assessment.

If only they could have used the assessments I had already gone through I would have been able to focus more of my time recovering from my brain injury rather than proving it.

I remember one day: my mom took me to a neuropsychological assessment in Toronto. I sat in the passenger seat and left finding the building up to my mom. With my low vision, following driving directions was not necessarily easy and I knew I needed to conserve all my energy for the barrage of questions I was about to endure.

As we approached our destination I realized the doctor's office was in an old house. I found it very strange to be having this test in an old home. A home is a personal place and is often associated with comfort. A neuropsychological assessment was the exact opposite of that; it is impersonal and very formal. I sat in what would have been the living room as I responded to the unending questions. Why did they choose to have their office in a home? Did they think it would be comforting? Did they think the atmosphere would reduce the negative impact of the barrage of tasks and assignments I was given? If only that were the case.

It is crucial for me to have the necessary supports in order to succeed. I have had

to endure hours upon hours of tests and assessments trying to determine the extent of my brain injury. The results of the tests determined the supports I would receive for the rest of my life. I wanted to do well on these never-ending assessments but I also wanted to be able to move on and focus on my recovery. It sometimes felt like I had to go through the same assessments over and over.

If only they could have used the assessments I had already gone through I would have been able to focus more of my time recovering from my brain injury rather than proving it.

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DEANNA'S JOURNEY

The three passengers in our vehicle who survived the accident, my mother, my three year old son and myself, have no memory of the collision. My father and two month old daughter died on impact from what we've been told. I woke up a week later. While still in a coma, I underwent surgery to replace a shattered vertebra (C4), had a fractured brow bone repaired and my jaw wired to save some teeth. I had been sitting in the front seat of my parents' older model vehicle which did not have airbags. My son, sitting between me and my father, the driver, was miraculously not severely injured, being small enough to avoid contact with the dashboard. He was released from hospital after three days of observation.

> "MY FATHER AND TWO MONTH OLD DAUGHTER DIED ON IMPACT FROM WHAT WE'VE BEEN TOLD. I WOKE UP A WEEK LATER.

My mother remained in a coma for three weeks having sustained a brain injury, as well as a broken pelvis, a ruptured spleen and collapsed lungs. She had a different insurance company and has her own story to tell.

After almost a month in the Hamilton General's Burn and Trauma Unit, I was stable enough to go home with some supports put in place by the insurance company: housekeeping, physiotherapy and occupational therapy. My mother-in-law stepped in to care for our son so my husband could concentrate on getting back to work.

When the insurance company felt I was well enough to take on housekeeping on my own, I disagreed, and it was reinstated without any argument. I didn't think it was much to ask for. Injury rehabilitation came to be full-time and exhausting work.

There were reports at the time from neighbours that our house was being watched. Being in a constant state of fatigue, this was not something I noticed myself. I had nothing to hide anyway.

We hired a lawyer to help us settle the case and this took six years and many appointments and tests all over the GTA to finalize the matter. It was an immense relief to be free of the insurance company's scrutiny and control in my life.

One of the doctor's I saw was of the opinion that with my brain injury, at best, I might be able to find part-time employment. I have tried a couple of jobs in retail as well as some volunteer work but am presently unemployed. I'm still hopeful that I will find something that will match my skill set and interests and my particular health needs. For now, I try to stay as healthy as I can and look after myself and my family while my husband, Brian, works to take care of us all.

It's been a long way back from that winter day. This new post-accident territory is a place

where I must navigate with less physical stamina and with brain injury-related difficulties that remain with me today: short term memory problems, mental fatigue brought on quickly by over stimulation, problems processing information, balance issues and depression. These are things that aren't immediately apparent to the casual observer but they affect me in profound ways every day. The goal now is to find ways to keep moving forward.

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CHLOE'S JOURNEY

I want to tell you a story. I want to tell it, because although it will change nothing for me it is my hope that it helps to change the future care of so many others facing the same challenges.

In the beginning.

I was a single mum from the time my son Sam was two. I had always worked full time and I was working on a university degree at night. I had a high energy level that allowed me to work, take Sam to events, parties and sports, help him with homework or conjure up Halloween costumes, shop, manage my house and car and work on my education afterwards. When I was young my Dad had taught me how to draw and art became my favourite thing to do and a big part of who I was. Like most people our lives had taken their twists and turns and like most people we had addressed those challenges and moved on.

"I WAS A SINGLE MUM FROM THE TIME MY SON SAM WAS TWO. I HAD ALWAYS WORKED FULL TIME AND I WAS WORKING ON A UNIVERSITY DEGREE AT NIGHT.

My worst fear.

The school staff told me 'he's fine Mum, he's clearing his airway'. There was my little boy, on the couch soaked in sweat. His eyes were rolling up in his head and he did not know me. I asked them to call an ambulance. Instead, they suggested they could pull my car closer for me, but finally on the third time, they reluctantly agreed. Thank God…and the doctor on call who knew immediately that we needed to move quickly. Sam was rushed to Hamilton with the doctor and myself in the ambulance. My parents followed behind and my sisters were behind them. It was one of those times when the adrenalin kicks in and you just keep moving rather than fall apart. I remember saying to the doctor. 'I think he looks better now, don't you?'

When we arrived at the hospital, thankfully, we once again had a wonderful doctor. After an MRI they confirmed that Sam had a bleed in his brain from a ruptured AVM (Arterio Venous Malformation) or an abnormal cluster of veins. He needed surgery right away to save his life. My little guy was an 'old soul', who made me laugh endlessly with his amazing intuition, wisdom and an uncanny ability to read my thoughts. He was my world and now I was faced with losing him.

I had never been more terrified than I was that day. Happily my worst fear was not realized and Sam came through his surgery. He was going to be fine. He would need one more surgery and the next couple of weeks were difficult but we were finally able to go home and resume our lives.

We can start over.

In 2007 Sam was well and at high school. I

was very active playing squash and other sports and was registered for more courses at university. Sam no longer needed me to help with homework or take him to hockey and I was planning to resume school with a vengeance and finish my degree in psychology in the hopes of pursuing a career working with children. I had become a foster parent and had a young man temporarily in my care.

Then the bottom fell out of my world.

On March 2, 2007 a nearly fatal car accident, in a matter of seconds changed my life and the life of my son and family dramatically. It is a day that has become a sort of landmark in time. Sam who was now fifteen was with me and our eleven year old foster child who we were taking out on his last night with us.

Ten minutes away from our destination a truck coming the other way lost control, crossed into our lane and hit us in an offset head on. I have no memory of that day or much of the following two weeks. All I could think of was that at 15 years old, instead of me taking care of him as I normally did, he was alone watching them cut his badly injured, unconscious mum out of a badly wrecked car. Meanwhile he was trying to calm a screaming 11 year old child, and asking the police to please pick up his grandparents because they would be too upset to be driving. Subsequently, my family were the ones dealing with the stress of what had happened, while I was oblivious.

It never occurred to me that I couldn't fix it.

My primary injury was to my head. The left frontal portion of my skull and the bones around my sinus and left eye were crushed. My left eye was dislocated from the socket, I was bleeding into my brain and had a spinal fluid leak. My left leg was badly broken. I was flown to Toronto where a neurosurgeon, who has my eternal gratitude, pieced me back together and then it was a wait and see. Fortunately by the following week I was stable and they were able to repair my leg.

I was very fortunate. I was fortunate that my life was saved. I was fortunate not to lose my vision and fortunate that my leg might be broken but I still had one. I was fortunate and grateful that my son was not physically hurt and while I was sorry that our passenger had to have some surgery to his hip, we were fortunate that he made a full physical recovery too. Okay, so what needed to be done to put our lives back together? It never occurred to me that I wouldn't or couldn't do what was necessary to fully recover but I did not realize that not everything was within my control, what I had yet to face, or what an uphill climb the journey was about to be.

> **"I WAS VERY FORTUNATE. I WAS FORTUNATE THAT MY LIFE WAS SAVED. I WAS FORTUNATE NOT TO LOSE MY VISION AND FORTUNATE THAT MY LEG MIGHT BE BROKEN BUT I STILL HAD ONE.**

So much help from so many people.

I had over 20 different health care providers working to make me well again and I did whatever they told me to. But I was terrible at keeping the dates and times straight for all of those appointments. I had to write everything down so a day planner became my bible and my sister, came with me to all of my follow up appointments with the neurosurgeon, eye

doctor and orthopedic surgeon in Toronto and some of my local appointments too. She knew what to ask and remembered what we were told. I was in a wheelchair for a while, then crutches and finally a brace on my leg. It did not occur to me that I wouldn't get better or go back to work. It did not occur to me to not follow my doctors' advice, to go to the therapy deemed necessary or that I couldn't carry on with my plans if I did.

For a couple of months following the accident we stayed with my parents, so fortunately when the insurance adjuster showed up shortly after I was released from hospital, my parents and my sister where there. I know that not everyone has the benefit of the advice I did. Even prior to my accident I would not have known anything about what takes place with an accident claim. Post ABI I had difficulty even understanding what my lawyer told me so my family and my family doctor advising me to not sign anything without a lawyer was invaluable. My life was about to get crowded.

> "THE MUNICIPALITY REFUSED SAYING THAT THEY DID NOT WANT ME TO RETURN UNLESS I WAS AT 98% OF MY PREVIOUS ABILITIES. SO I LOST MY JOB.

But it never occurred to me that I couldn't fix it.

The university course I had registered for was to start the month after my accident. I decided to try and do it, which was a little crazy and truthfully really, really, hard. In the past I had been able to do two courses after work and after I put my son to bed at night. After the accident, I was doing one course full time, in between appointments. With the time I put in I should have been able to finish that degree in no time, but it was such a challenge. I could spend all day learning a section only to forget what I had learned by the next day. My therapists cautioned me that the fatigue would prevent me from retaining anything and that I needed to incorporate rests. I had extra time to write exams and a quiet room to write in and ultimately using all my spare time I was able to complete one course per semester. Fortunately, I was able to maintain good grades but at the exclusion of everything else. I was exhausted.

Upon advice I changed from a psychology program to a family services program but eventually it became apparent that at the speed I was going and at my age, this was a dream I was going to have to let go of. After completing three courses I made the decision to stop. This was such a hard piece for me and my spirits flagged. To add insult to injury the auto insurance company used it against me, saying that if I could do university then there was no problem and there was no reason why I could not return to work.

Apparently work did not feel the same way. My job was to manage two departments for a municipality, the water and tax departments. I had a very busy position that required me to wear a lot of different hats and multi-tasking was something I had become quite proficient at. That was now a real struggle for me. My occupational therapist proposed a part-time trial return to work with hopefully a gradual phasing in of more of my responsibilities. The municipality refused saying that they did not want me to return unless I was at 98% of my previous abilities. So I lost my job.

Through my work I had a good benefit package covering, prescriptions, dental, eyeglasses, physiotherapists, massage along with other perks which I lost when I lost my job. What I did not lose was my long term disability benefit. So after using up all of my accrued vacation and unused sick days I began my relationship with the LTD company. One that continues until this day.

At least my insurance would replace my income. Right?

The LTD company were relentless in pushing me to get CPP disability which meant they could pay less. CPP originally declined the claim and I had to attend an appeal to this decision with my lawyer. There was no way I could have done this on my own, yet it was not covered under her fees for handling the auto insurance claim. We won the appeal. However, now I was paid a large amount of retroactive money, which I had to give back to the LTD company. While my lawyer challenged them to pay her fee I was required to pay the income tax which amounted to $17,000. I was trying to cover my expenses on 25% less salary and had no choice but to use my line of credit and pay interest on it while they settled that dispute. I then had to pay an accountant to redo my taxes but still never recovered the full amount.

> “HOW DO YOU SURVIVE IN A WORLD WHERE COSTS CONTINUE TO INCREASE ON 75% OF WHAT YOU WERE MAKING WITHOUT INCREASES?

The ongoing financial handicap is a great handicap. How do you survive in a world where costs continue to increase on 75% of what you were making without increases? In one year my gas bill alone increased by 25%. Yet my LTD supplier has the right to garnish any money I make over and above what they pay me, despite the fact that the money is greatly reduced from my previous income and despite the fact that it has no cost of living or merit increases. I can no longer function at the work I did previously due to the brain injury I sustained and so I cannot return to the work I used to do. I no longer qualified for a car loan to replace my car and had to have help from family to buy one. Since I no longer have anything to contribute to my pension plan, I have had to pay income tax every year since my accident and if I were to even sell a piece of art that was created pre-accident, they have the right to my money. So they have tied my hands and prevented me from improving my situation.

But I didn’t do anything wrong.

That is what it feels like. While I was trying to manage my life full of appointments, do my therapy, school and maintain my house and expenses, both the auto insurer and my LTD supplier, were using surveillance, phoning me often to find out how I was spending my day, and get up-dates on my improvements. Every time the phone rang I dreaded answering it. Every time I was required to go to a re-assessment I dreaded it and would pay for days after with extreme fatigue from the travel, the testing and the interrogations. I had appointments of my own for physiotherapy, neuropsychological testing, speech-language pathology, occupational therapy, driving rehab, doctor follow ups and counselling. At the same time I had my day to day affairs to handle too. I had a house, I needed to replace my car, I had bills to pay and my social life had been reduced drastically.

What if a stranger asked you "do you have any friends and what do you do with them?". What if a stranger followed you throughout the day and took pictures and notes of where you went and what you did. I felt violated and still do because those methods continue to this day with the LTD company and ten years after my accident I still never know who might be watching me and taking pictures.

Why were they treating me this way?

One of the big challenges for me from the ABI, even today, is fatigue. I think that even without the brain injury, the amount of appointments that were necessary just with my own doctors were exhausting. In addition I had appointment after appointment of insurance ordered reassessments. Often these were out of town and sometimes I needed to stay overnight. I was no longer comfortable driving in cities or busy areas and was taking a driving rehabilitation course to help me get back behind the wheel so I had to always arrange a driver to take me to these appointments. There was no time for prescribed rest and certainly no time for relaxation.

> "THE IRONY WAS, THAT WHAT I WAS SEEKING HELP WITH, WAS PRIMARILY HOW TO DEAL WITH THE TREATMENT I WAS RECEIVING FROM THE INSURANCE COMPANIES.

Not one of the practitioners I saw during these visits treated me with any kindness or compassion. They had never even met me before but they seemed offended by me. Some were openly rude to me and pulled doubting faces at my answers. I felt depressed and confused and sometimes just angry at the injustice of the situation. I began to dread the interrogations.

Would you share with a stranger why your marriage broke up? The poor health of my parents, my son's illness and my relationship with his father were used to point out that these things were the cause of any stress that I was experiencing.

At one appointment I overheard a secretary instruct another, to deal with the lawyers that called right away because they were the doctors 'bread and butter'. That same doctor moved my leg back and forth a couple of times and told me "I can tell you right now, you don't need a new knee." This was in direct contradiction to what I had been told by two other non-insurance surgeons and a physiatrist who had all told me based upon x-rays and ultrasounds, that it was inevitable that I would need a new knee and that also the pins were interfering with the ligament in my leg.

I could not recall ever being treated with such disdain and lack of respect by 'professionals' and was quite sure I did not deserve it. My world had just been turned upside down and honestly, I was trying to be a good sport about it. I was following all the recommendations and trying to turn it right side up again, while learning all the while about the cognitive challenges to my memory, multi-tasking, processing abilities, and fatigue that stemmed from my ABI, along with a lot of misunderstanding about it. Yet there seemed to be no compunction by my insurance company to help me in that process. There were literally boxes of test results and documentation stating my injuries, prognosis and recommendations. Why was there a question with all of this evidence? I

understood why the insurance companies behaved the way they did, I just didn't understand why they were allowed to.

The end of the game for me.

During my deposition with the insurance companies lawyer, from the start I could feel the bad energy in the room. The lawyer sat leaning back with his arm draped over the back of his chair and looked me up and down as he asked me questions. He asked me the same questions different ways and it was a slow painful process as I tried to understand what was asked and answer it correctly. Then he asked me what I discussed with the psychologist on my 'health team'. I was stunned and I asked my lawyer if I really had to answer that. Surely that would be confidential. She said I did. At this point I don't know why but I was surprised that even the doctor patient confidentiality that we all take for granted no longer applied to me, even when it came to counselling. The irony was, that what I was seeking help with, was primarily how to deal with the treatment I was receiving from the insurance companies. How to hold steady under the challenges to my integrity and ways to preserve and recharge my energy levels afterwards.

This lawyer had access to all of my medical records dating back over 20 years and here he was, this total stranger, looking at me with this distasteful look on his face, able to pry and twist and pull at me with his questions. It was the first time I allowed one of them to make me cry.

> "TO THIS DAY I FEEL THE EFFECTS OF MARCH 2, 2007 ON EVERYONE NEAR AND DEAR TO ME, ESPECIALLY MY SON, WHO STILL HAS NOT TAKEN AN OPPORTUNITY TO UNPACK HIS FEELINGS ABOUT THAT DAY.

I wanted nothing more than to be back in that place before the accident. I had not lied about anything, why were they doing this to me? Yet even though I know that their treatment of me was not a reflection on me but rather on themselves, I have to say it didn't help. There is a breaking point when as hard as you try you keep getting pushed back down and I had reached it that day. I had been paying into insurance my whole life without a claim but the ordeal I had to go through, that was required to make this one, just didn't seem worth it. I had no choice though. I needed to stay strong for my son, myself and all of those who loved me. I needed financial support because I did not have enough money to pay my bills and I no longer had the capacity to finish my degree and improve my career.

How to value my losses.

It sure wasn't just about the value of the car I lost. I had lost my job, as time went on I had come to recognize I couldn't finish school and I began to realize that the career I had dreamed of was not going to happen. My income and opportunities were going to be severely handicapped, I could no longer play squash, volleyball or tennis or run. I was going to have to struggle with trying to remember things, and learn new things, especially amid distractions. Learning, shopping, driving or housework were all going to be things that could send me to the couch to sleep in the middle of the afternoon. My reduced energy level has prevented me from taking on things that I would have in the past such as fostering children. I still have my intelligence but

struggle with many of the brain functions that give me the ability to harness that intelligence and use it to make a better life for my son and myself. I had to just keep crossing things off the list until it seemed they were all gone.

During the 'dark years' when my whole life seemed to be revolving around my accident and the insurance claim, it was important to me to have my art. The times were fewer and further between than they should have been but when I was working on a painting with some music on, it was the only time that I could lose myself and let go of the stress for a while.

To this day I feel the effects of March 2, 2007 on everyone near and dear to me, especially my son, who still has not taken an opportunity to unpack his feelings about that day. Those emotional pains, are even less obvious than the physical ones. Just like a brain injury they are the invisible part of the damage.

Yet I know that while my situation was very difficult and my injuries serious, there are many whose journey was even harder. I believe I was a strong person going into this chapter of my life and I had amazing support in my family, yet by the time we got to settlement discussions, I had had enough. I think, had I been willing to give them any more of my life I would have taken them to court, if not just for the principle of the thing. By not going to court, along with the non-disclosure I had to sign about the settlement, I knew their actions would not be brought to light. But seven years of my life had already passed since the accident and I made the decision that they could not have any more of it and decided to settle.

Recovering my life and soul.

That was when I began to recover my life and yes it is different than it was and different than I expected it to be. My goals had to all be rewritten and I had to find a new purpose.

The good that came out of this bad piece in my life was that, out of necessity and with help, I found ways to cope through meditation and following Buddhist teachings, which keep me grounded and mindful of what I can or cannot change and always give me a way back when I feel the kind of anxiety or stress that life hands us. On an emotional level I am now well.

I have also been given the opportunity to spend more time following my lifelong love. I spend much more time drawing and painting and have set up a little studio in my house. I often get requests to do portraits for people but I won't be able to do that for another seven years when my relationship with the LTD company can be laid to rest. Instead though I will be volunteering to teach a children's art class and perhaps incorporate a tiny piece of my original dream of helping children, with my aspirations to be an artist.

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