

my TBI story



My Traumatic Brain Injury Journey

by Cavin Balaster

AdventuresinBrainInjury.com



Dedication:

To my friends and family who were there for me and especially to my mother.

Thank you all for staying by my side through it all.

Your presence made more of a difference than you will ever know.

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Hi there!

I just wanted to take a moment and express a heartfelt thank you!

No matter who you are, how dire your situation, or how you came across this eBook, I'm honored by your taking an interest in my story and I sincerely hope that sharing my journey helps to inspire hope, and to provide valuable information to you or your loved ones about health, recovery, neurology, and brain injury.

This eBook attempts to cover--as a brief overview--the story of my severe traumatic brain injury and the many stages that followed during my ongoing recovery. I've also included information about recent aspects of my life, with a short list of frequently asked questions that I tend to receive via email and in interviews. I invite you to contact me directly over email or social media, and to take a look at my other eBooks as I continue to publish them. Thank you again!

Cavin Balaster



My TBI Story

*“That’s life, that’s what people say. You’re riding high in April,
Shot down in May.”*

- Frank Sinatra

I often think about how remarkably easy it is to take things for granted. Having been raised in the beautiful mountains of Boulder, Colorado, I had a fun and active childhood. I was involved in different sports and activities, and in my early teens, I became a passionate musician, playing and singing in different bands throughout high school and college, eventually deciding to leave my mountain state and pursue that passion in New York City.

I found myself naturally suited to Big City life. I fit right in with the atmosphere, the people, the music, and busy nights. As a 27 year old musician and bartender with an entrepreneurial disposition, I was putting together my own business providing music and sound equipment for events throughout the city. Things were pretty exciting, and I had no idea how quickly they could change.

I was riding high in April, 2011, and May was on its way.



Life changed abruptly on the night of May 7th (early morning of May 8th), 2011, when I fell 20 feet from a rooftop water tower in Brooklyn. Like a pinball, my body pounded on the steel scaffolding several feet below, breaking my hip and tailbone and thrusting me towards the next horizontal steel cantilever, which bashed my left eye as I dropped.



The collision of my face with the scaffolding redirected my fall. This put my feet under me when I landed, but I was possibly already unconscious at that point. My legs instantly collapsed, rocketing me backwards, and with a loud thud, my head slammed onto the concrete rooftop, changing my life forever.

I wish that I could tell you what thoughts went through my mind as I dove towards the hard surface below. Perhaps I was scared. Perhaps my life flashed before my eyes as I crashed from one steel beam to the next... and it must have hurt like hell.

But the truth is, I do not remember a thing. In fact, I do not remember a single moment of this entire day. What may be one of the most defining moments of my life has been wiped away, and I am only telling this specific part of my story based on information that has been relayed to me by others.

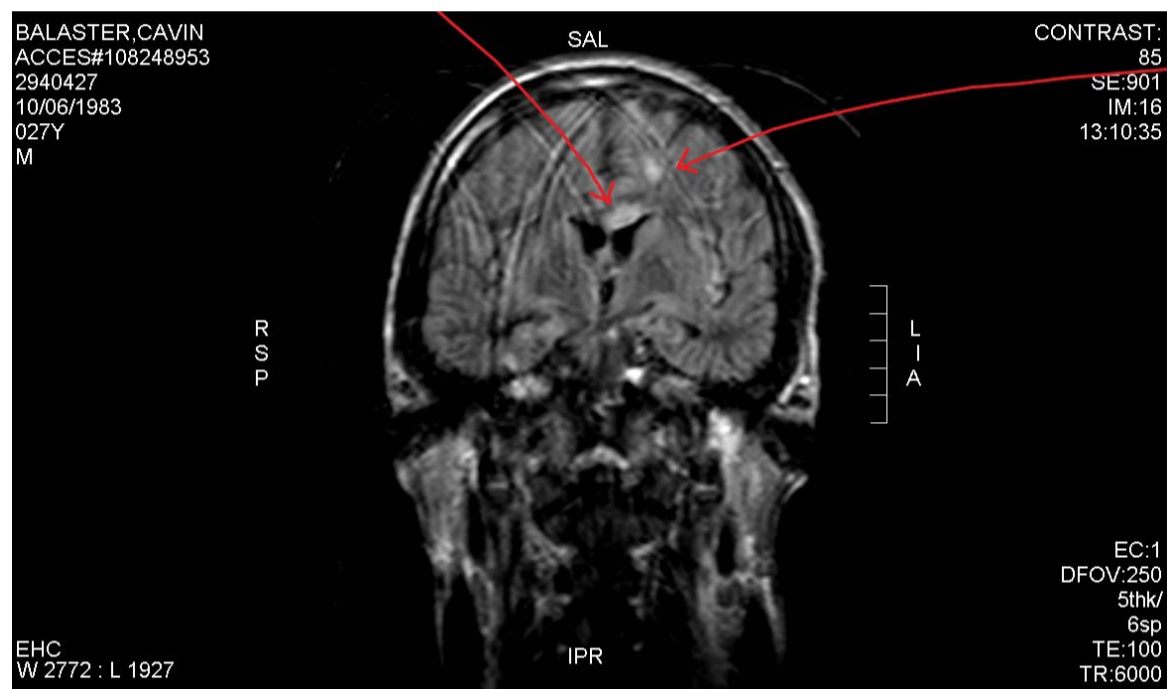
Thankfully, many friends were there to witness my slipping off the tower. As I lay unconscious, they jumped into action to get me into an ambulance and I was immediately rushed to a nearby trauma hospital in the next borough where I was put on life support, where I initially measured a level 3 on the Glasgow Coma Scale - the worst possible score! A rock has a GCS of 3. My family was notified, and they individually rushed to be at my side.

At this point, according to the CT scan, it was clear that I had endured 3 cracked ribs, 2 pelvic fractures, a lacerated (deeply cut) kidney, a bruised and swollen left eye, and both of my lungs were severely bruised. Being that it was Mother's Day, the nurse leaned over to my mother and said, "Thank God he doesn't have a brain injury. That's your Mother's Day present."

I would remain comatose for twelve days. During that time, the neurologist, confused as to why I still wasn't waking, used several techniques (including shaking me and yelling) to try and arouse me to consciousness. Days later, an MRI finally revealed why I was unable to wake...

A diffuse axonal injury (DAI - also known as "shearing") is one of the most devastating types of brain injury. The forces from the brain being slammed forward and backward against the skull cause so much trauma to the cells within the brain that they stretch and swell, triggering the beginnings of a larger chain reaction in the brain which leads to neuronal death.

My diagnosis was of a severe diffuse axonal injury throughout my Corpus Callosum (the middle region of the brain that acts as a switchboard between right and left hemispheres), as well as a subdural hematoma, and a bruised left temporal lobe. This information shocked, terrified, and confused my family, and the prognosis was devastating:



Statistically, over 90% of patients with this injury never regain consciousness, and those who do wake up will often remain in a persistent vegetative state.

Trying to make sense of all this, my mother asked the neurologist for clarity about the diagnoses to which he simply shrugged his shoulders and said, "you get what you get."

I also developed two nasty infections (pneumonia and MRSA) which, at that point, were very life threatening. Burdened with a laundry list of injuries and follow-up questions, my mother would ask, "but, he's going to live isn't he?" After hearing "we don't know" so many times, she stopped asking.

Against all odds, and after twelve long days, I somehow woke up! Heavily medicated, dazed, and confused, I was taken off of life support and transferred from intensive care to a "step down unit." Due to the severity of my injury, I was incredibly fortunate to have regained consciousness at all. At the same time, we were all quite mindful of the hard reality, that this was only the first step in a very long journey to recovery--and we hardly had any idea of what "recovery" was going to look like.



Once awake, the extent of my brain injury, physical injuries, systemic infections, and atrophy (the wasting away of muscles due to inactivity) left me in a crippling state. Eight days after waking, I developed breathing problems and was put back into an induced coma for another week, during which time I was given a treatment with sedatives, anesthesia, morphine, and steroids. Another throat scope was done, and it seemed that my breathing problems were resolved.



For months, I was unable to walk, talk, eat, or control much of the left side of my body. I was also in a severe brain fog with impaired memory, dulled cognitive abilities, and vision problems that had not yet been recognized. Doctors also discovered that I was aspirating the foods I was eating and placed me on a feeding tube (NG) through my nose before I was transferred to Mount Sinai's Rehabilitation Center at the Klingenstein Clinical Center.

This is where I was to begin a full program of neuro, physical, occupational, and speech therapy, but more complications were on the way. Within two days at the new hospital I developed breathing problems again, and a tracheostomy was scheduled for the next morning...

The swelling of a stenosis in my throat had returned. Because it sat so close to my voice box, the surgeon expressed that the surgery to bring my breathing back to normal functioning, which would also give me the opportunity to retrain my voice to talk (tracheal resection surgery), might be impossible to perform. This would mean that I would have to live the rest of my life silently breathing through a tube.

To say the least, it was an incredibly difficult time. I couldn't walk, talk, or breathe normally and I lacked the strength to even sit up independently. Although I was extremely grateful to be alive and grateful to my friends and family who were there for me, I had already lost thirty pounds, and I was just cognitively intact enough to be really scared, really angry, and really hungry.



It was at this hospital that my Occupational Therapist asked about how I often closed one eye to see clearly. I was diagnosed with severe diplopia (double-vision) as a result of my brain injury and was given an eye-patch to swap between eyes. This was the extent of my vision therapy at the time, which, unfortunately, appears to be more than most hospitals provide.



The following months were all-consuming. I knew that this was my chance to get better, and in order to rehabilitate the left side of my body, I would have to put tremendous effort into different therapies. I was determined to at least regain my ability to walk again and to do simple tasks with my hand. As the months passed, I progressed from a wheelchair, to the parallel bars in the therapy room, to a walker, then to a cane, and finally to my own two feet!

Another throat scope was done to see if the surgery that would allow me to breathe normally and to begin voice training to regain my ability to talk again would be possible. Even though it was a long shot, the throat scope revealed that I was just barely within the margins in which it would be allowed. This was the best news I may have ever heard, but it would be months before the surgery could be scheduled.

Soon I was allowed to leave the hospital under the medical care of the visiting nurse service of New York. With this service, I could live in an apartment under the care of my mother, and a rotation of nurses and therapists would work with me to rehabilitate my extremities. As time passed, I saw improvements. When I regained just enough mobility in my wrist to where I could wrap my hand around a guitar, I pushed myself to try to play a little each day.

Finally, the day of my surgery came. After having my throat slit, my trachea sawed in two places, the narrowed section removed, and then the two pieces sewn back together, I went through some of the most excruciatingly painful weeks of recovery. But it was worth it. I could breathe normally... and, even though I didn't yet sound like my old self, I was now able to talk (very slowly).





In between the work, I was writing as much as my healing body and brain allowed. I was capturing everything I could with pictures of my progress, videos of my therapies, detailed experiences with medications and surgeries, and insights as to how my brain and body were healing.

The emotional swings were constant for myself and my family, as expectations were continually changing. There were many more obstacles along the way, and I was always working to push myself beyond the limit of my ability. Sure, aspects of life still present difficulty, but I feel like I have learned how to really take care of myself emotionally, nutritionally, and mentally, and I became dedicated to help others to do the same.

The truth is, I don't think we ever "fully recover" from life-changing moments or injuries like these. We learn from them, we "make room" for them, and we learn to adapt. I still have difficulty running and coordinating the left side of my body, I may dance pretty silly, swallowing can still be difficult, and I speak much slower than I used to in order to enunciate each word as clearly as possible.

But ya know what? Running is not my thing. I own my "old man" dance moves. I don't really want to chug a beer or devour my food and I never was a great rapper (although I'm told that I used to be a fast talker). It's all good!



As I continued to share my story online, I started to find opportunities to speak publicly about brain injury and neurological health.

And in March, 2013, two years after my fall, I finally got back on stage and played a live show at SXSW! These experiences solidified a passion I have felt about helping others

I continued to document my progress, and in November, 2013, my story went viral on the front page of [Reddit](#), gaining thousands of views, questions, and comments. The influx of emails that I have received from so many families searching for help and better information prompted me to begin work towards providing the information that saved my life, and to do so in an accessible, available, and understandable format, through my website, podcast, and writing.

Throughout my experiences since my brain injury, I have been invited to and attended several medical conferences including The International Conference on Human Nutrition and Functional Medicine, where I ended up giving an impromptu speech to a room filled with hundreds of health practitioners and medical students.



Subsequently, I have found myself on stage as the keynote speaker for several nationally organized conferences, and I have presented to hundreds of survivors and health practitioners as a guest health and medical expert.

It brings me great joy to be able to aid in increasing awareness for brain injury, health, and healing by sharing my story and perspectives.

In addition to speaking, I've also recently started the [Adventures in Brain Injury Podcast](#), hosted with former bandmate, good friend, and fellow medical survivor in his own right, Alek Hess. Together, we feature interviews with fellow survivors, scientists, and practitioners, in an effort to shed light on important health issues.

Today, I live in Austin TX, and I continue to work with fellow survivors, doctors, psychologists, therapists, naturopaths, cell biologists, functional nutritionists, neuroscientists, optometrists, professors, and other specialists.



Hindsight

I still have no memory of what happened the night of my fall. In fact, there's a good portion of about a month of missing memories from that time. The fact is that I was inches away from death a few years ago and that I have endured severe damage to my brain and body. This is not a bad thing. It is not a good thing. It is just a thing. It happened and I recognize that I am extremely fortunate to have survived.

Charles Darwin is often credited for saying, "It is not the strongest of the species that survives, nor the most intelligent that survives. It is the one that is the most adaptable to change." To bring Darwin's idea to a more personal, individual level, I would be forced to include the necessary elements of luck and community.

Our chance of surviving any severe injury is largely out of our control, but afterward, survival becomes an ongoing, day-to-day endeavor. Adaptation is one thing that every single survivor I've had the pleasure of meeting is skilled at. We survivors are simply forced to adapt.

I have been fortunate to meet and befriend many families and fellow survivors in the brain injury community since sharing my story and working within the field of neurorehabilitation... and so many of these folks share unshakeable determination. Some have come back from unbelievable circumstances, and many are as tough as nails.

I've learned first-hand that it is the trials that improve a person. It is the difficulties that one truly learns from. That is why good schools are difficult schools. That which threatens our lives, tries us. It tries our will and ability to survive; and if we live through it, we learn and grow... we are forced to. We become stronger.

As I reflect on the years that have passed since my traumatic brain injury, I am eternally grateful for the incredible support of all of the doctors, nurses, nutritionists, naturopaths, counselors, friends, family and to everyone of my readers. Here's to many more years to come! May we climb new heights together!

Of all the therapies and treatments you did for your brain and body after your injury, what was the most beneficial?

There were many therapies I found to be beneficial for reasons I wouldn't have expected, and overlapping different therapies also made an impact. Vision Therapy, for example, seemed to not only help my double-vision greatly but also aided in bringing clarity to my mind.

The most important thing had to be addressing my [leaky gut](#) and really making sure I was getting the right nutrition. Otherwise I simply wouldn't have been able to supply my brain and body with the supplies it needed to benefit from the work I was doing--and the tragedy is that most hospitals are not oriented to recognize or to address the role of digestion in rehabilitation, and the sugar-loaded "nutrition" I was given through my gastric tube reflects this.

After your accident, do you feel that people perceived or handled you differently as a person?

I was originally babied by people and would get mad and tell them that I want to be treated "normally." Truthfully, every brain injury is unique, and it's hard to have an idea about what to expect, but it helps just to give patience to people who are faced with adversity. It is also important to understand that what separates a brain injury from a broken bone or other injury is that people's cognitive, emotional, and mental abilities often change.

The real harm done, and the reason we need better awareness, is that most people hear "concussion" and think you're fine, while they hear "brain injury" and think you're in severely bad shape. The truth is that a concussion is a type of traumatic brain injury, and the effects of different scenarios are different for each individual.

You suffered your injury in 2011, what are you still struggling with today? What are your current diagnoses and do they limit you?

After initially regaining consciousness from my second coma, I was in a severe brain fog, had cognitive and memory impairments, had several broken bones, a lacerated kidney, breathing problems, was unable to eat, walk, or talk, and the left side of my body wasn't working very well (my left hand was 'stuck' pointing inward and I had drop foot).

Although Vision Therapy helped tremendously in several ways that I was not expecting, I still have double-vision (diplopia) due to damage to the 4th cranial nerve of my brainstem. I can walk again, but I can't run or dance very well. I also have slightly less mental resilience now, and can 'hit a wall,' but I have learned to supply my brain with the right nutrients to avoid these energy dips so that they only happen when I slip up with my self care.

I've done quite a bit of work with a speech therapist because I have been diagnosed with dyspraxia and dysarthria (slurred speech), and if you listen on my podcast, or during my speeches, I speak slightly slower to make sure I'm processing and enunciating each word correctly. Most people do not recognize that I have any problem at all...though often times, people mistake me for being intoxicated.

What kinds of exercises or unconventional things did you do after your injury?

I was actually recently interviewed [here](#) on local news talking about the beneficial effects of yoga after brain injury! As I've said on my blog and in the interview, "Yoga was the least expensive, most effective therapy I did for my brain and body after my injury." The environment of a yoga studio facilitates a kind of mindful attention to one's self that seemed to strengthen the communications within my brain and body. [Love Your Brain Yoga](#) (born from the story of Olympic hopeful and fellow TBI survivor, Kevin Pearce) is working to make yoga available to survivors with free brain injury classes in at least one studio in every state!

I can't stress enough how important nutrition was as a foundation for recovery, but nutrition should not be approached as a "one size fits all." I think it's important for us all to pay heed to bio individuality, and my philosophy surrounding any treatment is to take into account the risks and costs against the potential benefits. There are plenty of medicines and treatments out there, whether they be conventional or "alternative"--just, first do no harm!

How was your attitude through recovery? How did you and your family navigate all the ups and downs?

It was honestly pretty difficult at times. There were many obstacles and changed expectations... But people don't just "get over" or "recover" from a major life-changing event like this: we adapt! We have to learn to balance accepting what's happened with the drive to make our situation better. Survivors, spouses, families...all have to "make room" for the reality of what's happened, and keep a positive attitude.

Attitude is a big deal. Every brain injury is unique, and it's hard to know what to expect. I've met fellow survivors who've really come back in huge and unexpected ways.

We also have to realize that we haven't necessarily "lost" the ability to do things. Our brain does re-wire and, in many cases, we are able to re-learn to regain our lost abilities. I was determined to sing and play guitar again. As soon as I could talk, I tried to sing. As soon as I could wrap my left hand around the guitar, I tried to play. One task at a time, we are literally re-learning how to live.

Links

View our continually growing list of [resources](#) on [Adventuresin-BrainInjury.com](#), including information, useful links, recommended reading, and products.

- See where it all began with my first blog post: “[It’s About Time.](#)”
- Listen to the [Adventures in Brain Injury Podcast](#).
- Check out our [YouTube](#) channel for video series, including podcast episodes, speeches, and stages of my recovery.
- See my viral story in picture format, on [Imgur](#).
- Join our [Facebook](#) Community!
- Join our [newsletter](#) and receive free eBooks as I produce them!
- To inquire about **speaking** services, please visit my [speaking page](#) for additional info and testimonials.



Adventures in
BRAIN
INJURY

Thank You!

I'd like to thank you again for taking the time to check out my recovery journey! Ever since sharing my first blog entry, it has been a personal mission to inform and support other survivors and their families--no matter what their situation. I sincerely hope that my story brings hope and value to you and those you love.

If for whatever reason you found my TBI story without ever subscribing to my email list (which is totally wonderful because I appreciate people sharing this information), then I invite you to head on over to AdventuresinBrainInjury.com and subscribe for more content like this!

Might I also suggest you check out [this page](#), which is an ever-growing collection of both free and affordable eBooks I've created for the purpose of helping those looking to improve their health and better understand the brain, digestion, and surviving traumatic brain injury.

Cheers, and I sincerely wish you the best!

Cavin Balaster

<http://AdventuresinBrainInjury.com>

