

MAY 2016

# TBIHOPE

AND INSPIRATION

## What Might Have Been

## The Moment that Changed My Life

**SPECIAL SECTION**

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# TBI HOPE MAGAZINE

*Serving All Impacted by  
Traumatic Brain Injury*

## May 2016

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# Welcome

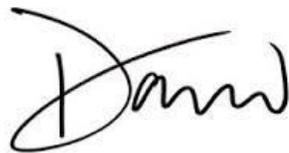
Welcome to the May 2016 issue of TBI HOPE Magazine.

Over the last several years, there has been a dramatic uptick of traumatic brain injury in the news. Ever-so-slowly, the tide is turning and the silence that surrounds TBI continues to end.

It's becoming more difficult to turn on the evening news and not hear a story about concussions in one form or another. Stories range from youth sports to the concussion challenges faced by professional athletes.

In late 2013, an editor of the Chicken Soup for the Soul series reached out to me and asked me to contribute my story to an upcoming volume about brain injury. In June of 2014, *Chicken Soup for the Soul: Recovering from Traumatic Brain Injuries* was released to very solid reviews. Little did I know at the time that other contributing writers would become part of my new circle of friends.

We are pleased to present a Special Section in this month's issue – a section dedicated to Chicken Soup contributing authors. As we strive to do every month, we hope you come away inspired and with a dash of hope!



**David A. Grant**  
*Publisher*

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# **What Might Have Been**

by Nicole Bingaman

I am the forty-five year old mother of three amazing sons ages 19, 22, and 25. Just a few years ago, my husband and I were preparing for our life in an empty nest, and all the changes that would bring. In a matter of seconds the world as we knew it blew up. And we now realize that our nest may never be empty after all.

Our oldest son, Taylor, would be the one who transported our family into the world of traumatic brain injury (TBI). Three-and-a-half years ago, on Thanksgiving Eve, Taylor fell down the stairs in our home. He suffered a severe TBI, and those moments changed us from the second they started. In time they would re-define the very fiber of our family.

Lately, I have had this recurring image in my mind of what might have been. In being honest, I have to confess that social media can be a dangerous place for someone who is grieving. The kind of grief doesn't really matter, but as many reading this know, ambiguous loss is often challenging to explain and understand. No matter how often I do it, sharing my truest emotions feels exceptionally difficult.

The night of the fall, Taylor's body and mind were immediately unresponsive and would remain so for several weeks. He finally began his long emergence from a coma while at Bryn Mawr Rehabilitation Hospital outside of Philadelphia. Taylor, with our family by his side, spent many months at Bryn Mawr, while he made both small and large strides. My youngest son referred to that time period as if he were watching his big brother being reborn. The rebirth of Taylor, his emergence, was both glorious and painful to witness,

and his recovery continues to impact us in much the same way. There are peaks and valleys, and they often shift from hour to hour. The momentum is not the same as it was in the beginning, but the pendulum between acceptance and grief is always swinging. It never seems to settle for long, forever swaying while the moments that I wish could return, feel like they slip further away.

Now that I am part of the brain injury community, I understand that Taylor, in a sense, is one of the fortunate ones. Taylor can communicate clearly. He is able to execute many parts of his self-care routine. He can eat, walk, talk and exercise. More importantly, he can express love, sadness, happiness, sorrow, joy and all that lies in between those emotions. On the downside, Taylor suffers with a major seizure disorder, numerous cognitive deficits and lacks insight into the reality of his injury. He requires 24-7 supervision, and deals daily with the emotional fallout from an event of this magnitude, as do his brothers and parents.

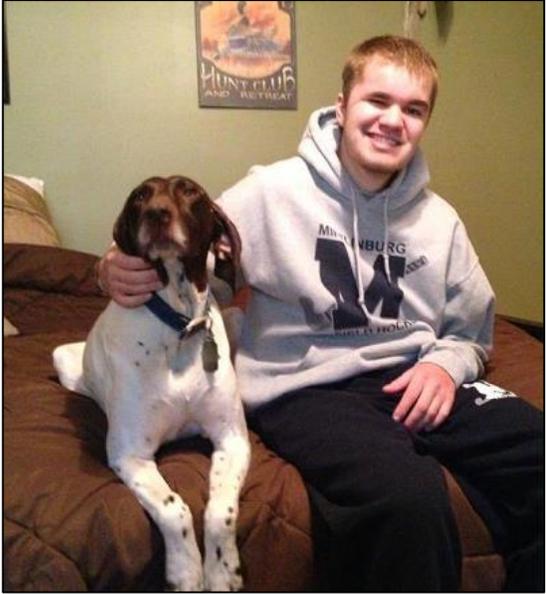
Recently in the land of sharing which exists via social media circles and on more personal levels, many of my friend's children, who are the same age as Taylor, are announcing their engagements, making huge leaps in their careers, moving out of their childhood home, while continuing to emotionally reside in the nest of safety that the love of family has afforded them. They are spreading their wings, and not only learning to fly, but actually taking off. Some of them are even having babies.



Because I have two other sons in my nest, I know that these times of change and growth are not always easy on a parent's heart, but in truth the greatest wish we have for the little people who were entrusted to us, is that their adulthood leads them to happiness and contentment.

Recently I have been listening to and truly hearing the lyrics of a song that says, "If I had to choose a day that I'd remember, my friend I'd say that would be the one." I clearly remember a day that I will always cherish with Taylor. It is a day that has haunted me since his fall. It is a day that I never want to forget, as much as sometimes the remembering hurts.

That day, I was sitting on the kitchen counter, and the sun was shining in the window behind Taylor. He was getting ready to graduate from high school, and we both had the sense that our lives were about to change. Taylor did not really want to grow up so fast, nor did I want him to. Taylor opened his heart to me that day, and we shared a moment I will forever treasure.



As time moved on, we stepped through many days of change. And Taylor faced them with a confidence and certainty that was admirable. As Taylor's mother it was always magical for me to see him evolving into more of a man than a boy. The one thing that often halted the process in my mind was that Taylor had a baby face. He had the face of a little prince from the moment he was born, and his rosy cheeks and innocence remained a delight to me. I had a small collection of dreams for him, and these were things that I never for a moment thought would not come to be. Now I find myself wondering if there is a box that I should put them in, so that I don't have to face them every day.

Taylor was a man's man. He loved the outdoors, hunting and fishing. He was excited when he bought his first truck with money he had saved for years, and when he got his first "real" job, he saved to buy an even bigger, better and louder truck. He liked to work, and appreciated his skills and energy. He was known as both a hard and dedicated worker within his HVAC company. Taylor had very few serious romances, and was still figuring out that part of life.

In the time before the fall, I wanted more for Taylor. I wanted him to explore more, to branch out a bit, and to see what life might be like discovering a sunset in a new place. Taylor grew up and lived in a small town his entire life, and before he decided to stay there forever, I wanted him to see other parts of the world. He was intelligent, bright and driven, and I pictured him spreading his wings.

Now I realize that those things that Taylor wanted for himself... stability, to own a home, a life-partner and a family were what would make Taylor happy in life. Those dreams that he had appeared to be simple, but they were treasures, and gifts that should not have been taken for granted. To be happy, to be loved, to work and provide for yourself daily, and to share with his loved ones, those things were enough.

For now I am not ready to lay the dreams I held for Taylor to rest. Doing so is just too hard for me, and I don't fully know what the future holds. I find comfort in the improvements he continues to make, and I am grateful every day for the fact that I can still be a witness to his changing, growing and adjusting to this new life. When I see the person that used to be my son, in the reserved part of my memory, I whisper to him...I miss you. All the while working in love, to accept the person he has become.

## Meet Nicole Bingaman

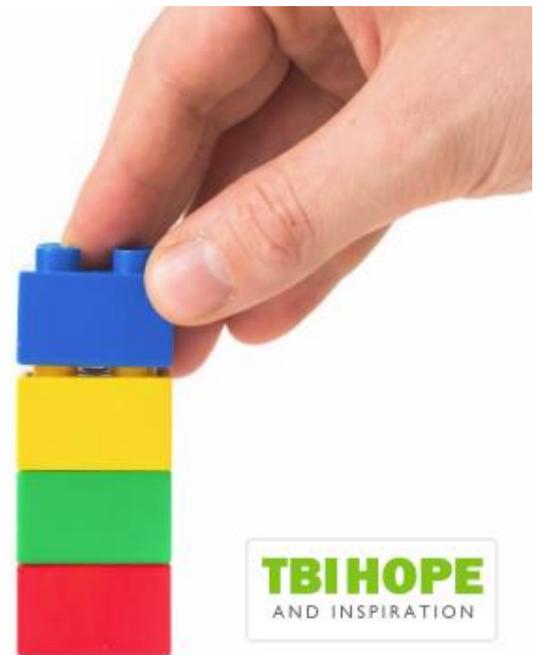
Nicole has worked in the human service field for over twenty years. Since Taylor's injury Nicole has become an advocate and spokesperson within the TBI community, speaking at conferences, trainings and events for professionals and lay people to understand the impact of TBI within a family.

Nicole's book [Falling Away From You](#) was published and released in 2015. Her website is [www.nicolebingaman.com](http://www.nicolebingaman.com), and Nicole continues to share Taylor's journey on Facebook. Nicole firmly believes in the mantra that "Love Wins."



**Rebuilding a life  
fractured by brain injury  
takes a lot of time.**

**Brain Injury Recovery  
Lasts a Lifetime.**





# **Raw and Real**

by Amiee Duffy

**T**oday I am angry! I am really angry. I am angry about nothing and angry about everything. I know it isn't in my best interest to be angry and it adds more stress on my brain, which causes more pain, which creates anxiety, which causes stress...But I AM angry. I'm 15 months into recovery and TODAY, in THIS MOMENT, TBI is cruel.

I am angry about...

- My brain not being able to handle normal stressors.
- That my pain has not gone down from a level 8-10 migraine in almost two weeks.
- That I can't relax and enjoy my family because it takes everything in me to get through the work day.
- That I have not had energy to cook for days - and even though I feel the difference in my body and brain, I can NOT power through and cook anyway.
- The fact that I am beginning to get anxiety because one of my children has an event out of town and I am already in pain and overwhelmed - noise, sensory overload, driving in an unknown place, new schedule.
- Not healing faster than I am. C'mon, it was "only" a concussion!
- Feeling jealous that friends and colleagues have "normal" social lives and are able to do things I use to enjoy without a second thought.
- Feeling annoyed when people complain about things I judge to be trivial and then as I catch myself being judgmental, I begin feeling guilty.
- Feeling like a whiner.
- Not feeling strong...

I can feel the anger and stress in my body. I know I need to calm down and relax, but my typical strategies are not working. I am just thinking too much. My self-talk sounds a bit like this: "Stop being angry." "Calm down." "This could be worse." "You are making it worse." "You need to be grateful." And that is when I realize something. Half of my stress and anxiety is about stopping my anger. Hmm? What if I accept the anger? What if I let the anger in and really let myself feel it? Yup - scary! But, I'm alone in my home so it is safe to feel it. I let myself yell! I let myself get fully ANGRY!

And then - tears. I am not really feeling anger anymore. I am feeling fear and some sadness and I am grieving who I was. This is not fun, but the letting go of these feelings is bringing me back to a place of calmness. I think in an effort to send positive messages to anyone going through a difficult time, we often use terms like "warrior", "fight" and "strong."

As someone trying to be strong, I tend to be really hard on myself when I simply can't do what needs to be done. Does that mean I'm weak, giving in, too passive? Of course not! What would you tell our best friend or our child in these circumstances? We would say, "You are amazing! Look how far you have come! You are so brave. How can I help and support you?" Matt Kahn has written, "Whatever arises, love that." From now on, I plan on using this as one of my TBI mantras. We are not doing recovery "wrong" if we get angry. We need to accept our humanness. Anger is normal, as is fear. Let ourselves be vulnerable and feel our feelings, because with the release of the negative emotions comes calmness and space for peace. And that is what we need to continue our journey.

## **Meet Amiee Duffy**

Amiee M. Duffy is the proud mother of three children. She has been teaching for over twenty years and is looking forward to using what she has learned about Executive Function and Working Memory in order to better serve all students in her classroom.



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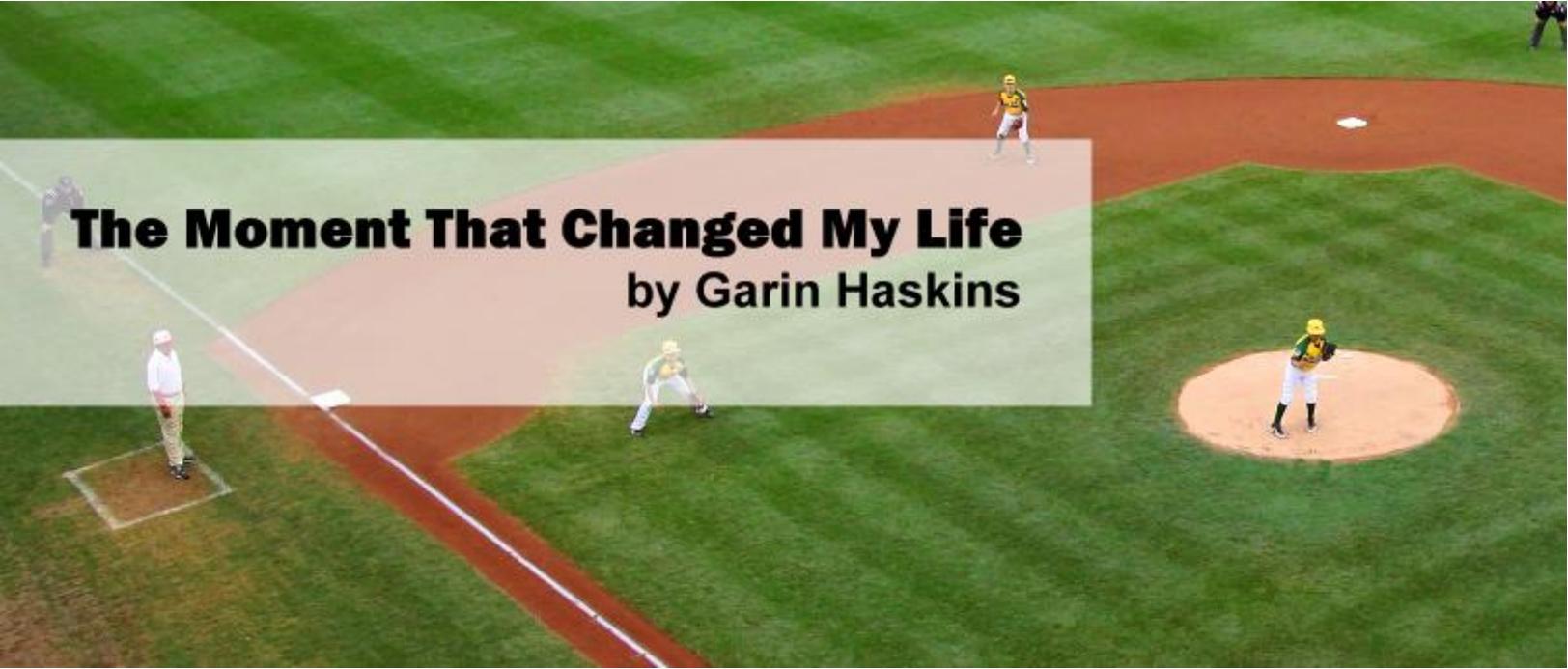
- Improved learning abilities
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## **The Moment That Changed My Life** by Garin Haskins

**T**wenty-one years ago, in the spring of 1995, I played little league baseball. I was only 11 years old. That year, my season ended very quickly. One morning during warm-ups, the left fielder threw the ball to me in right field. The ball bounced and I misjudged it.

The ball hit me just above my right eye. I didn't faint, but just stood there with blood running down my face. Once others saw this, I was immediately rushed to the emergency room. My dad met me there and I was sewed up.

I recently asked the guy that threw the ball to me from left field if he remembered that moment. He said, "Yeah I do, it split your eye open! Wow that was so long ago! What made you think of that?"

My reply may have surprised him, "I think about it almost every day. That day changed my life."

*And then told him how...*

After the incident, things seemed to be normal for a little bit, but that was short lived. My parents noticed my speech was a little slurred, and so I saw a speech therapist at school. That didn't help. They noticed me walking differently, stumbling at times, and had me get orthotics in my shoes to correct my balance. That didn't help. My eyesight got worse, so I got glasses. That helped, but I still have vision problems.

Then I started having tics (Tourette's syndrome), which some kids at school noticed and teased me for. I know today they were just being typical sixth graders. I also started having trouble swallowing, and so food often got stuck. A few years later I began not being able to stay awake for very long during the day. I remember coming home from school and taking a nap most every day.

Even today, I can't make it for more than eight hours before getting tired and taking a short nap. When I do sleep at night, it's usually for no more than 5-6 hours. I do not like to be around people for very long, and try to keep communication to a minimum.

After doing some research online with the conditions I have been having, I thought I had some type of Chiari Malformation. I saw a doctor and he said that a part of my foramen magnum didn't look as it does with someone with Chiari Malformation.

Years later I decided to look into this again, and after doing more online research, I have come to find that I have been living with an undiagnosed brain injury for most of my life. I have yet to see a specialist about it, but someday I will. I'm in a long process with SSI and SSDI, trying to convince them that I really am disabled and cannot hold down a job. It's a daily struggle living with TBI.

I know others have things a lot worse than me, though. Keeping this fact in mind makes my life today, as a brain injury survivor, a little more tolerable.

## **Meet Garin Haskins**

Garin shares that he doesn't remember much about his life before his TBI because he was only 11 years old when he was injured. Garin enjoys spending time at his church and occasionally visits with local friends. He is a first-time contributor to TBI HOPE Magazine and is grateful to share his experience as a brain injury survivor.





# **Keep Your Eye on the Prize**

by Jeff Sebell

**W**hether or not you believe what happened in the Bible is true, there are lessons to be learned in the stories.

In the story of the destruction of Sodom and Gomorrah, Lot and his wife are told by God not to look back at the city as they flee. Well, as it turned out, Lot's wife fell behind as they fled, and she did indeed look back as the cities were being destroyed. Because she looked back, the Bible says she was turned into a pillar of salt by God.

Lot's wife was too busy looking back at the past, to focus on what was ahead of her, at her future.

## **What is the Lesson for Us?**

It's clear that continually looking back at what was, is not helpful and can be harmful. We need to keep our eyes on the prize; the prize being ourselves and our future. Looking back at what our lives used to be like before our TBI won't turn us into pillars of salt, but it will distract us and cause us to lose focus as we attempt to move forward.

That said, it is a challenge to keep our eyes looking in front of us; at the prize, if you will.

Life becomes a huge challenge after brain injury. Life stares us in the face, constantly reminding us that our lives weren't always like this. As a result, many of us find ourselves looking back, often, at *what used to be*.

There are times when it is hard not to look back at the life we once knew; after all that is the life we lived, and it seems natural to want it back. That past life represents all we ever knew and all we can relate to about living, and we get so caught up in thinking about and trying to recapture the past that we are unable to look into the future and create a life.

And that... *looking into the future to create a meaningful life*...is what we need to be doing.

The truth is we can get so busy trying to recapture the past that we sometimes forget that there is more to living than always looking back. Don't get me wrong, relearning and regaining is necessary, but looking back, longingly, can become a trap if we aren't careful. All the time we are trying to relearn and recapture our skills and abilities, we should not forget to keep an eye on the future so we can create a life we are proud of, where we can be productive.



This can be tricky, because sometimes we don't feel we deserve to be happy and fulfilled because we aren't what we used to be. We're not that same person and that eats at our self-confidence. We get down on ourselves more than any human being should be allowed to, and that can't help but influence how we approach the future. However, we can't let our fears or our emotions, lack of confidence or a dependence on the past get in the way of giving our best shot to being successful.

## **Our One Shot**

Each of us deserves a shot at the life we want, and although a brain injury can have an impact on what's possible, it can't take away the fact that we can do our best with the tools we have in order to be the best we can be.

Our challenge in not looking back and looking to the future instead, is different from the other post-TBI challenges which involve recapturing parts of our lives that "used to be". It involves putting the present in perspective, how to adapt, and actually becoming *someone new*.

This is difficult. It's really hard to forget about the past.

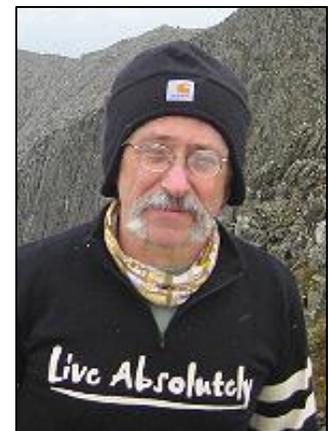
We all want to live a fulfilled life after experiencing a brain injury, and we all have different ways of going about that. Somehow we have to shift the emphasis to *moving forward*, because ultimately we need to figure out where to go with the tools we have.

For that reason, we should refocus most of our energy on "becoming" more than we ever thought we could be, using the tools we have.

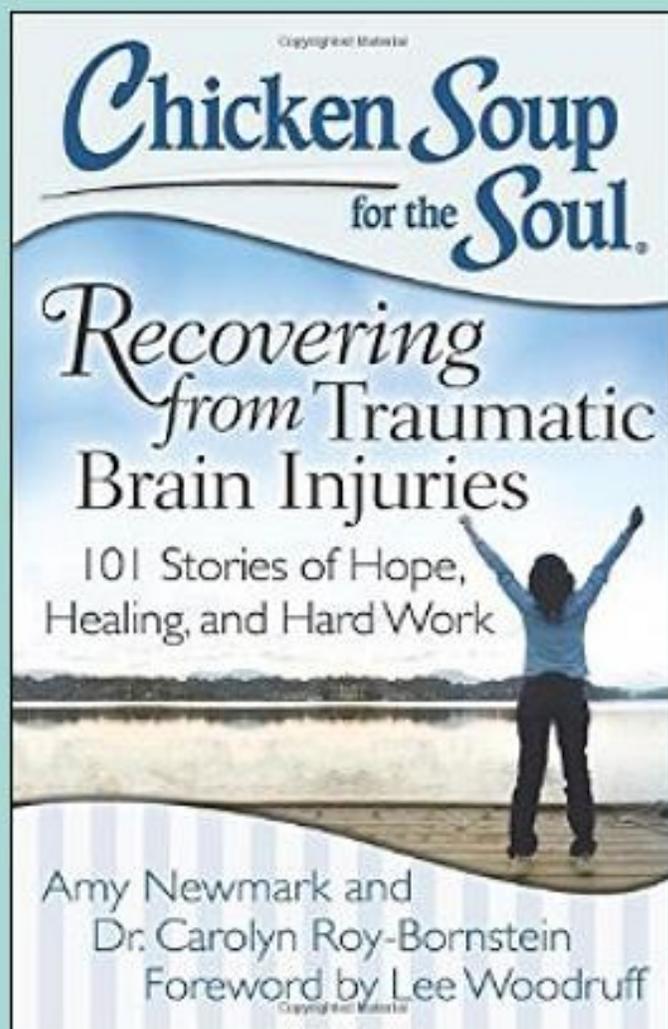
The prize we need to keep in front of us is not based on pure achievement, because that achievement is meaningless unless we can understand *who we are now*. We need to have an understanding of what we stand for and what we think is important in life. All this takes time and effort, but it is clear that looking back will detract from the mission; detract from learning about who we are now and what we need to do in order to move forward with our lives.

## Meet Jeff Sebell

Jeff is a nationally published author, speaker and blogger - writing about Traumatic Brain Injury and the impacts of his own TBI which he suffered in 1975 while attending Bowdoin College. His book "[Learning to Live with Yourself after Brain Injury](#)," was released in August of 2014 by Lash Publishing. Jeff is a regular monthly contributor to TBI HOPE Magazine.



# A TBI HOPE MAGAZINE SPECIAL SECTION



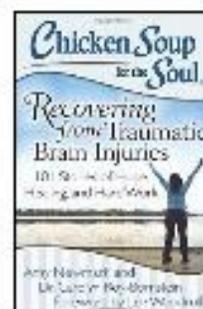
*Chicken Soup for the Soul: Recovering from Traumatic Brain Injuries* was published in 2014.

Whether you are recovering from a traumatic brain injury or supporting someone with a TBI, the book is a collection of 101 inspiring and encouraging stories by others like you and will uplift and encourage you on your healing journey.

The following section presents stories from several **Chicken Soup for the Soul** contributing writers.

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# How I Learned to Walk

by Mike Strand



I have always been lucky--very lucky. I was twenty-five, I had a great factory job and I had won back my childhood sweetheart. Linda was unbelievably attractive, but her really impressive quality was her quick and curious mind. She also had a great job working for the city. In 1988 we bought a house, got engaged, and had set our wedding date for June 24, 1989.

On January 26, 1989 I pulled out in front of a semi-truck on my way home from work. I don't remember this; I don't really remember most of the eighties. Everything I know about that day is told to me by others. The volunteer EMTs that responded to the call were all friends of mine from work, and what I know about what happened to me that day I get from them.

Seeing the crumpled wreckage of my pick-up truck, they first thought that I must certainly be dead, then they were astonished to see me laying across the seat, apparently only unconscious, followed by dismay that they could barely find a pulse or detect any respiration. Luckily, the local volunteer rescue squad had received a pneumatic splint less than a month earlier. Without it they would not have been able to keep my blood pressure sufficiently elevated to keep me alive for the twenty-five minute ambulance ride.

My hospital medical record says that "The patient arrived in pristine condition." I was twenty-five, not quite a month shy of twenty-six, I was lean, I was tan, I was at the top of

my game. I was, in fact, in pristine condition—if pristine condition included a severe coup-contracoup closed head brain injury—the equivalent of putting a delicate stereo component in a paint shaker and turning it on for a few minutes.

My brain had been shaken so violently in the collision that I was nearly dead when they reached the nearest level one trauma center, now called Regions Hospital. I spent the next ten days in a coma. As I drifted out of my coma there was a collectively held breath. My body temperature had spiked over 108 degrees on a couple occasions and the doctors said it was likely that I had suffered further severe brain damage and that my family should start looking into long term care facilities or nursing homes. There really is no known way to tell the effects of brain injury with any certainty ahead of time, it would be easier to tell

what the weather was going to be like a few months out.



I actually made pretty good progress over the next few weeks, I was starting to remember people's names and was even getting, and then laughing at, a few jokes, and the collectively held breath was allowed to escape.

Late in February Linda asked me if I wanted to go through with the wedding. We were, after all, planning a big affair with 200 guests, and she had to know if she should

keep planning everything and reserving facilities and caterers and so forth. I couldn't believe my luck! Here I was in the hospital, I couldn't walk, I could barely talk, I couldn't really dress or bathe myself, I even had to be assisted going to the bathroom, and the most beautiful and amazing woman I had ever known still wanted to marry me! I said, "Yes, of course."

Well, this was wonderful, but what could I bring to the table? I couldn't bear the thought of her burdening herself with me. It just didn't make sense that she would stay.

You see, all my friends and family were telling her, and I agreed with this, that she shouldn't feel obligated to spend her life with a person who was, in all likelihood, going to need 24-hour care the rest of his life. She had a whole wonderful life before her and no

one would fault her for making a quiet exit. Only one person was saying that I would come through this fine, in fact, better for the experience: my mom.

Now you need to know something about my mom. She's a dreamer, always has been, always will be. She has lived her life borne aloft by dreams. Those dreams that rarely came true, but that wasn't what her dreams were for; her dreams were for dreaming.

This time her dream was spot on, and this time Linda took it as sound counsel. If the whole reason for my mom living on dreams and scant else was to be right this one time--was to be listened to seriously by Linda this one time--then her dreaming had given me a gift beyond all recompense I could imagine.

I now felt a huge obligation; what could I do to shore up my end of the bargain? I lay in this hospital day in and day out, struggling to just try and maintain some reasonable vestige of coherence, wrestling with language as I tried to assign meaning to the words people were saying to me. You know how it is when bend down to put on your shoes and then you stand up too quick? For two or three seconds your equilibrium is off and you're like, "Whoa, hang on...Geez, okay now, what was I saying?" That's what a brain injury is like, except that it lasts your whole life.



I decided that at the very least, I would walk down the aisle at my wedding. I would walk by Linda's side, as though she had an equal partner. I would learn to walk, and she would have to work full time, take care of a house, take care of me, and plan a wedding for 200 guests.

Mine was no small part. I had decided I would walk, which meant I had to convince myself that I could walk. When I made this decision, simply standing was still a challenge. I had only walked--taken a few steps, really--with a nurse holding me up. My intentions, as I had set them, were to walk as if I was guiding Linda along. I was so certain that I could do this, that if nothing else worked, I would float on sheer will with my limp feet dragging on the ground.

I wanted to tell Linda how much I loved her, but my speech was so bad I was embarrassed to say it. I would express my love for her by walking. Each step was me saying, "I love you." If I couldn't walk then it meant I didn't really love her. I knew I loved her, therefore I knew I could walk. This was my own resolve, I told no one of this.

The day came, they took me down to physical rehab and wheeled me up to the parallel bars. These were two bars side by side a couple feet apart about 3 feet off the ground so you could hold onto them as you walked. As I reached for them my trepidation turned the air into soft clay as I leaned forward and grasped the bars where they curved to the floor. I stood up as I thought, "I love you." I wobbled, but I held my grip. White knuckled and taking short rapid breaths, I felt like a ski-jumper who just left the ramp. I was only standing, but I felt like I was flying.

"That is very good Michael, if you need to sit, just let me know," encouraged the nurse.



"Nnnnyo, mm fn!" I shot back at her. I had tried to yell, but it was more an emphatic mumble. My legs felt like they were full of water, dull and heavy. My equilibrium was my main problem, magnified by legs that were numb. Center of balance was a misnomer to me, my balance was anywhere but center. I felt like there was a legion of Lilliputians pulling and tugging at their ropes

drawing me to and fro. What I really needed to do was focus, but focus and brain injury are antonyms.

This walking business was really complicated. I lifted my hands off the bars, and almost toppled over. It didn't count if I was holding on to the bars. I would keep my hands in a feather touch just above the bars. "Okay, shift your balance onto your right leg," I told myself, which somehow actually seemed easier than standing on two legs. Now I began to draw my left foot forward. As soon as I raised it just a smidge my balance swung wildly and I gripped the bars with both hands.

They're metal, but I'm sure I left a mark. I reset my feet and I tried again. Weight to the right foot, lean forward, lift up the left foot. Think, "I love you." My foot came down heavy about three inches ahead of where it had been. My Physical Therapist laughed and congratulated me. People in the rehab room started to notice something happening over at

the parallel bars. I smiled internally, but I knew this was only one step, and one step was not walking. Never one to be easy on myself, I had decided that two steps were required for it to be considered walking.

Then I panicked. My legs were burning with fatigue, heavy lead fatigue. I was really in a pickle because I couldn't plant my feet squarely on the floor. My square had become a trapezoidal parallelogram. My therapist saw my dilemma and again invited me to sit down. I swung my weight back and forth like a trapeze artist, or so it seemed, and I caught the next forward motion and brought my right foot even with my left. "I love you." I pictured myself running across a field into Linda's arms.

I had walked. Everyone was looking as I leaned on the bar with my hip and raised my arm triumphantly. There was cheering and clapping. Then I collapsed back into my chair exhausted. "You did it, Michael. You walked!" said my Physical Therapist. I smiled. It wasn't me, it was Linda. I was only returning her love.

Five months later I walked down the aisle at my wedding. In the video, Linda looks like she was walking an old man down the aisle, but I did it. We have been married 24 years now. My grandparents are 96 and have been married 74 years, I have coffee and cookies with them every week. Long lives and long marriages are traditions I intend to keep--if I'm lucky.

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# Starting Over

by Celeste Palmer



My life changed in a moment. While returning from taking my son and his friend to school, a car crashed into my SUV, causing it to roll. It took the Jaws of Life to remove me from the vehicle, and I remember nothing.

When I woke up in the hospital, I didn't know who I was. I didn't recognize my son or have any knowledge of current events. Who was the President? It was more like what is a President?

I had suffered a traumatic brain injury, which left me with retrograde and anterograde amnesia. My past was totally gone. Doctors told me that my condition was the best it would ever be. A therapist later told me to think of it as if I were a newborn, learning everything from scratch.

Life didn't get easier after being released from the hospital. Day-to-day activities were confusing. Basics like dirty dishes going in the dishwasher and clothes being inside the closet were new concepts. Meanwhile, I had my youngest child, a thirteen-year-old son, to raise. I was trying to learn the duties required of a mother in addition to the basics of functioning at home and in society, and it felt overwhelming. One day, I burned cookies when the kitchen timer in my pocket went off... while I was standing in line at the post office. But give up? Never!

My motor skills were impaired, so I was constantly running into doorways. I thought, “I must be huge!” In reality, I wasn’t going through the center of the doorway like I thought I was. I had little feeling on my left side, so there were confusing signals from my brain to my body parts. Pain was ever-present. The rest of my life will always include chiropractic, physical therapy, therapeutic massage, doctors, and believing in my instincts.

Prior to the accident, I ran my own consulting firm specializing in accounting and database management. Returning to consulting was not an option; I would have no idea how to help my clients. In fact, trying to relearn even simple math was a challenge because I couldn’t remember the number four—a common problem with my type of brain injury.

I began volunteering for my local hospital’s auxiliary, editing the newsletter and raising money. Volunteering helped me learn what functions I was good at and which activities I wasn’t able to do.

Friends encouraged me to enroll at Claremont Graduate University, where I earned a certificate in leadership. After lots of hard work, and with the help of patient professors and student-led study groups, I earned my master’s degree in management with honors. While at the university, I became a student of Peter F. Drucker, the prominent author and educator. I was fortunate to become friends with him and his wife Doris. They encouraged and inspired me.



While earning my master’s degree, I became director of the MBA program at the Peter F. Drucker School of Management. I found my rhythm as a productive, effective team member—bringing alumni, staff, students, and Professor Drucker together for the enrichment of all.

At some point during my journey, I decided to sculpt a personality for myself because I couldn’t remember my character traits from before the accident. Based on observing others, I realized that if I became known as a happy person, people would want to be around me. From then on, becoming happy in spite of my circumstances was my mission. It became what I call my “happiness project.”

As I focused on being happy, the key was to not dwell on the negative aspects of my life. For example, I made a conscious decision not to lament the absence of special memories, like giving birth to my children. Instead, I concentrated on the present.

I also became determined not to let setbacks destroy my happiness. When I was involved in a second car crash, I suffered another brain injury. It happened as I was finishing my master's degree, and schoolwork was much harder after this second injury. But I decided that happiness is a choice, and I just needed to make a conscious effort to stay positive.

In recent years, I have become focused on speaking, writing, and coaching, to empower people to break through self-imposed barriers, implement new strategies, and achieve successful outcomes, just as I have. I have founded a non-profit organization ([www.tbibridge.org](http://www.tbibridge.org)) that provides resources for survivors of traumatic brain injury and post-traumatic stress disorder. My motto is "Believe. Be patient. Never give up!"

My life now is rich with close friends, family, and activities I enjoy, in addition to my non-profit work. I don't know what my life was like before the accident, but all that matters is that I'm happy now. Attitude truly is everything!

A Facebook advertisement for TBI HOPE. On the left, a green vertical bar contains the text "TBI HOPE" in white, bold, sans-serif font. The background of the ad is a blurred image of a crowd of people. In the center, a white rectangular box contains the text: "Where do over 18,000 Members of the Concussion/TBI Community Come together Every Day?" in bold black font. Below this, it says "We'll give you one guess..." in bold black font, followed by "Follow TBI HOPE on Facebook>>>" in a smaller black font. To the right of the text is the Facebook logo, a blue square with a white lowercase 'f'.

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A photograph of a hospital room. In the center is a Stryker hospital bed with a light-colored coverlet and a green pillow. To the right is a wooden chair with a light-colored seat. In the background, there is a desk with a laptop and various medical equipment. The room has light-colored walls and a carpeted floor.

# **An In-Between Place**

by Barbara Stahura



Ken pulled open the Velcro belt holding him safely in his wheelchair and stood up, shaky yet supporting himself on the parallel bars in the busy rehab gym. I stood in front of him, between the bars. The big windows over our shoulders framed the brilliant blue sky over the Catalina Mountains outside Tucson, their brown flanks dotted with cacti and spindly desert trees. It was a beautiful January day, but I was too preoccupied to enjoy it.

“Sweetie, you know what to do,” I said, even though I wasn’t sure he did. His short-term memory was badly damaged, and he didn’t remember anything from ten minutes ago, let alone yesterday. “You’ve done this plenty of times before. Hold on to the bars and walk forward.”

My husband pointed his face at me and smiled, but his gaze was focused somewhere in the distance, as it had been since a hit-and-run driver left him with a traumatic brain injury a few weeks earlier. He was trapped inside his injured brain. The damage was invisible to imaging scans, but his behavior revealed the truth of what had happened to him. Present but not present, Ken existed in some in-between place.

“Okay,” he said and began shuffling forward. He was very wobbly on his feet. The TBI had compromised his balance and his ability to walk in a straight line.

I came to the rehab hospital every morning and stayed until after Ken ate dinner. His therapists knew me by now and allowed me to assist with his therapies. Being of use to my husband helped me, too, temporarily easing the near-constant panic that had welled up as soon as I learned about his accident.

We had been married exactly nine months before what we came to call the “brain wreck.” I tried to not let myself think of what the future might hold for us, now that my husband had been violently altered by the collision caused by the never-identified white sedan. Instead, I focused on putting one foot in front of the other, just as Ken was doing between the parallel bars, pushing myself through each grueling day.

In the first days after the accident when Ken was in ICU, he was often delirious and agitated, thrashing and calling out words no one could understand. Yet he grew calmer whenever he knew I was there. He seemed to recognize that I was important to him, even if he didn’t know why, or who I was. Each week, he improved incrementally, but he existed in some inward place, unable at least for now to overcome the damage to his frontal lobes and elsewhere in his brain. His speech was lively, even though he often made no sense due to expressive aphasia, but he could not connect in any meaningful way with anyone. Not even me.

After being admitted to the rehab hospital, he began calling me “Boo,” from out of nowhere. So one day in his room, I asked, “Ken, what’s my name?”

A haunted look came over his face as he struggled to remember. He looked as if he might cry.

“Oh, Sweetie! It’s okay,” I reassured him, taking his hand. “My name is Barbara. You just forgot for a while.”

“Barbara,” he repeated. “Good. That’s a good name.”

Curious to see what else he had forgotten, I asked, “Who am I?”

The haunted look returned. “Um, a nurse?” he asked.

I made myself smile. “No, silly. I’m your wife. My name is Barbara and I’m your wife.”

Ken grinned in my direction, looking past my shoulder. “Okay.”

Ten minutes later, he had forgotten again, so his speech therapist hung a sign near his bed that said, “My wife’s name is Barbara.” We weren’t sure he could read or comprehend it.

Not yet understanding what brain injury can do to a person, I grew impatient and sad with his lack of connection. Often I held his hand or stroked his forehead or hugged him, yet he made no move towards me. We were newlyweds, for God’s sake! Couldn’t he at least reach out to me a little bit? According to the nurses, Ken asked every evening where I was and when I would be back. My dear husband could not remember my goodbye kiss and promise to return the next morning—or that I had been there at all. It appeared he wanted me nearby, but even as we stood there in the gym, the chasm between us felt impossible to bridge.



As Ken walked toward me between the parallel bars, I encouraged him to keep going. He reached the end, so we turned around the other way. Several times, we repeated the trip. Next we faced the big, sun-filled windows and stood side by side, holding on to the bar to do leg lifts, squats, and a few other basic exercises to help Ken regain his strength.

need that chair much longer, I bet.”

“You’re getting stronger every day,” I told him. “You won’t

“Yeah. I’m going to get better,” he said. He had uttered these words many times, even though he could not possibly know the effort that would be required of him and how long it would take. Doubtful, I nevertheless prayed he was right.

During those horrible days, I existed in my own in-between place. I was Ken’s wife, but would I now mainly be his caregiver? For how long? Could someone really recover from a TBI as bad as his? What if he couldn’t go back to work? Would we have a future together? What if I eventually discovered I couldn’t live with him any longer because it

was too hard? Would I stay out of guilt? Did I need to sacrifice myself for him? Already, I was exhausted. Terror and panic felt like the only emotions I had ever experienced—secondary traumatic stress, a counselor would later call it. How long could I keep going?

Ken walked out from between the bars. I followed. He turned toward me and held out his arms—the first time since the accident—and pulled me close as he hummed a tune in my ear. We began simply rocking from foot to foot. Tears filled my eyes at this tender gesture. We had often done this at home before the wreck, spontaneously grabbing one another for a few minutes of slow dancing as one of us hummed a made-up tune.

The sounds of the noisy gym receded as Ken’s arms enveloped me. Everyone else in the room seemed to vanish. For the first time, I felt hope rising—for his recovery, for our future.

“Thank you for helping me, Boo,” Ken whispered into my hair. “I’m working hard to get better for you.”

Amazed at his words, I looked into his eyes, which still gazed into the distance, then snuggled back into his shoulder, grateful for this sign of recognition.

Ken eventually remembered my name. Forty long days after the brain wreck, he came home and, slowly, we recovered together. Ten years later, he still calls me “Boo” on purpose, because he knows I love it.

## Living With Hope

By Patrick Brigham





# **I Have a Secret**

by David A. Grant

Chicken Soup  
for the Soul

I have a secret. Not all is as it appears. Most anyone living with a traumatic brain injury already knows this.

All I have to do is tell you that you look normal. At this point, you will either want to bop me on the head, or you'll simply shake yours and think, he just doesn't get it.

But I do get it. I live in the new 'Frontier Land' that is life with a brain injury.

A chance meeting with a neighbor let me know that I am not the only one with a secret. About a year after my brain injury, a new walker appeared in my neighborhood. Not a zombie walker like those in the Walking Dead. No, this was a man a bit older than me. One day he appeared with a cane and his wife, ever present by his side.

As I still cycle twenty-five miles a day, I know most all of the neighborhood regulars by sight. I have given most odd-ball nicknames like 'Dog Walking Lady,' 'The Power Walking Couple' and more. Here was a new player on the Stage of Life.

My wife Sarah and I drove past these walking souls regularly. Month-by-month, you could see his pace increasing and his stability improve. "I bet he had a brain injury," Sarah prophesied.

Quite unexpectedly, I found myself stopped at a corner on my bike as they walked by one day. The disinhibitionism that comes with brain injury can be so freeing.

My first words brought huge smiles to them both. “You are doing so well. It’s GREAT to see the progress you've made.” Introductions were shared, though his name, like so many others, is forever lost to me.

And the conversation flowed like water. He fell on ice the year after my TBI and joined our exclusive brain injury club that no one really wants to join. Brain injury is indeed the last thing you ever think about - until it's the only thing you think about.

“The doctors said I would never get any better, but I decided not to listen to them,” he chuckled. I listened intently to his tale for 5-10 minutes and smiled.

Then I dropped my own verbal bomb. “My brain injury was a year before yours and like you, my own doctor said I was permanently disabled and to not expect much. I didn't listen either!” We shared a hale and hearty laugh and went on our respective ways.

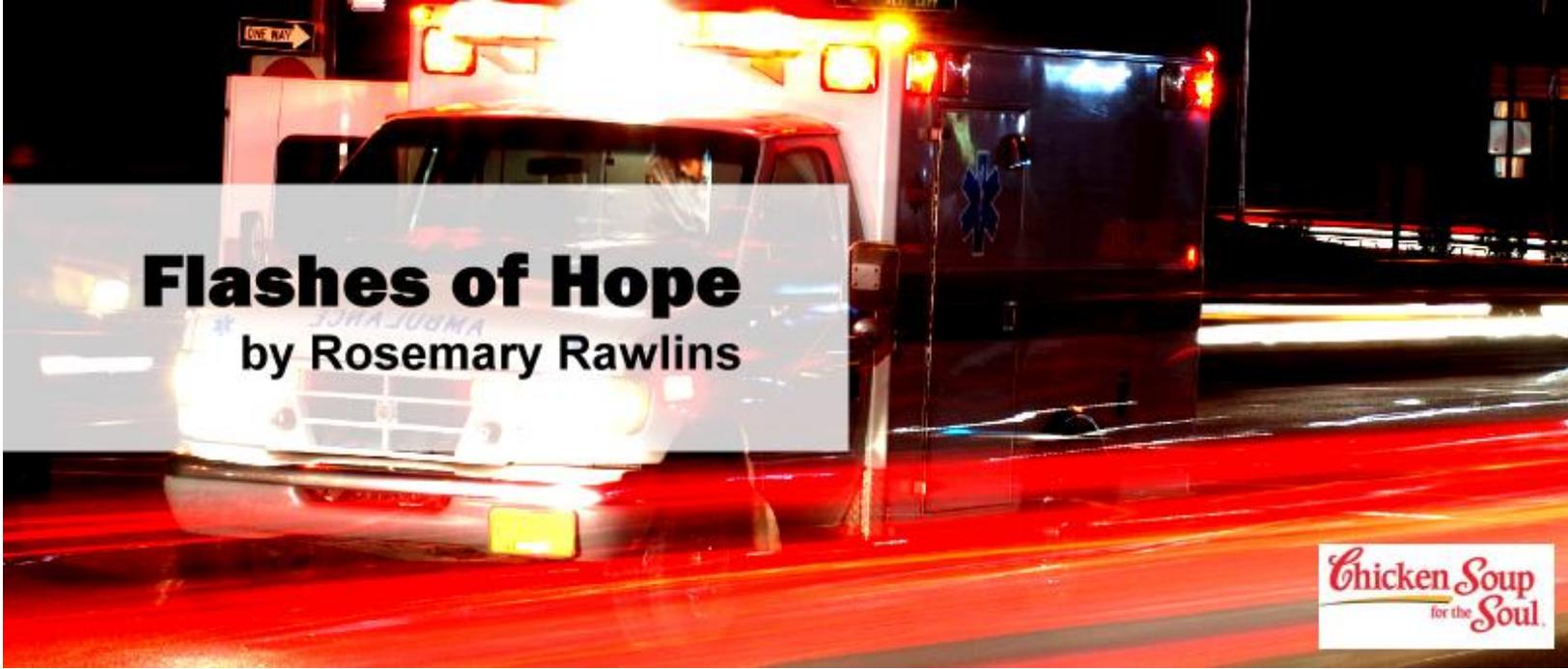


And my secret? My TBI has taught me that all is not as it appears.

That man fumbling with his wallet in front of me at the checkout counter no longer causes impatience. He might be someone affected by traumatic brain injury. That driver cruising along at 10 MPH under the posted speed limit no longer makes me tap my foot. She might be one of the 3.5 million people affected by brain injury this year. The person at the supermarket with his buggy parked dead center of the aisle as he stares at all the soups?

You know where I am going with this. We are everywhere. My TBI continues to teach me a level of patience, understanding and compassion I never had before my accident. When someone passes by you wherever life happens to take you, remember that they might just be one of us.

After all, we look normal.



## Flashes of Hope

by Rosemary Rawlins

Chicken Soup  
for the Soul

The lights were down low as Hugh and I watched the movie, *Vanilla Sky* on television while our twin daughters were out at a middle school dance. When I rented the movie, I knew nothing about it; I was in a hurry and liked the title. Near the beginning of the film, a jealous girlfriend takes her cheating lover on a wild car ride intent on crashing and killing them both.

My muscles tensed as the car veered out of control and flew over a bridge. I wanted to turn the movie off but I couldn't. I sat frozen, my heart racing. I kept watching. Hugh sat in the recliner next to the couch I was curled into. When I glanced over at him, his face looked blank, like he might doze off. He's always in a trance, I thought. The movie continued, disorienting me with its emotionally violent twists and turns.

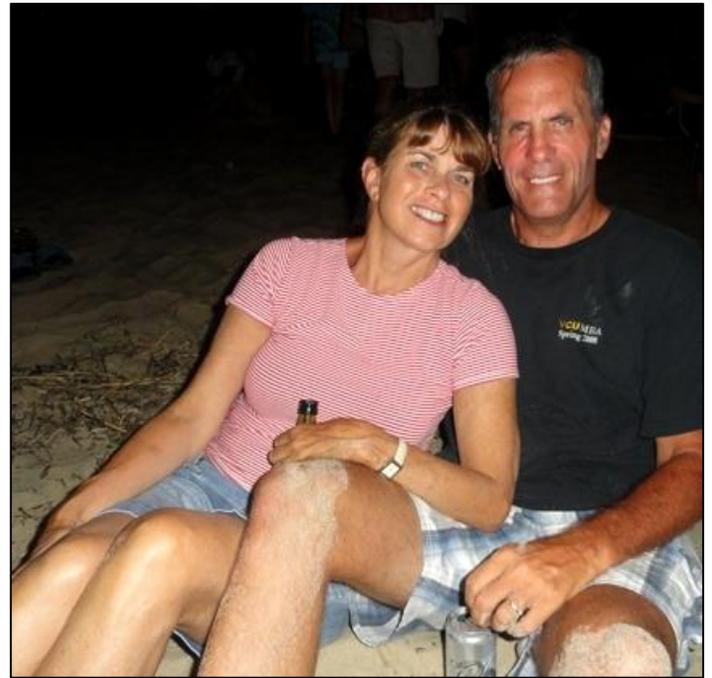
Only two months before, Hugh had left the house for an afternoon workout on his bicycle. He was a seasoned athlete who had completed many bike races and triathlons. After dropping my daughters off at a local skating rink for the afternoon, I picked up some groceries and drove home. I heard the phone ringing as I unlocked my front door, set down my paper bags, picked it up and answered.

"Do you know a cyclist?" a frenzied voice asked me.

Hugh had been struck by a car and rushed to MCV Hospital in Richmond, Virginia. When I arrived at the emergency room, a police officer, trauma coordinator, and chaplain tried to guide me through the initial hour of what was to become my new life. The chaplain told me I might want to say good-bye to my husband—he had a massive head injury. When I saw him before they wheeled him up for surgery, I pressed my hand to his chest and begged him to hold on.

He was unconscious, and all I could think about was how I never kissed him good-bye before he left for his bike ride. Those first moments and the thirty-three days Hugh spent in the hospital traveling from the ICU to the step-down unit, to the acute brain injury rehabilitation center felt like a bad dream that slowly morphed me into a vague, foggy replica of my former self.

When Hugh woke up from his coma, his eyes looked dazed and empty, as if his soul had left his body. Slowly, he began to move, walk and speak, though his speech was raspy and irregular. In my bed alone at night, I wondered: *Did my husband die in that accident?*



The surgeon removed a large chunk of his skull and put it in the hospital freezer until Hugh’s brain swelling receded. He said it would take about three months before they would put him back together. In the meantime, I was told to keep a close eye on him. Hugh was sent home with a canvas gait belt around his waist that I would hold to keep him upright, and a thick white helmet to protect his skull after I signed papers as his designated “guardian.”

At home, Hugh alternated between agitation, sitting in his recliner dismantling the remote, and falling asleep from the exhaustion brought on by short bouts of rehab. He was nothing like his former self, so I don’t know why I glanced over at him as if he could shield me from the violence of the movie I was watching, but our eyes met, and for a second, I thought he actually saw me. A little while later, my cell phone rang during an intense movie sequence, and I jumped before answering it.

“Hi, hon. I’m thinking of you.” Hugh’s whispery voice said.

I glanced over at him, sitting nearby in his recliner and his eyes softened in an old familiar way, in a way that I had not seen since before the accident. He was holding his cell phone and staring straight at me. My mind, still confused from the dream sequence of the movie, felt tricked again. *Was Hugh really calling me now? Have I fallen asleep? Did his eyes really crease in that old way of his?* I played along. Slowly I rose from the couch and walked away from him into the dining room, holding my cell phone tight like a lifeline.

“I’m right here. Don’t you like the movie?” I asked.

“It’s okay,” he said.

“Why did you call me? We’re in the same room?”

“I was just thinking about you so I thought I’d call and tell you.”

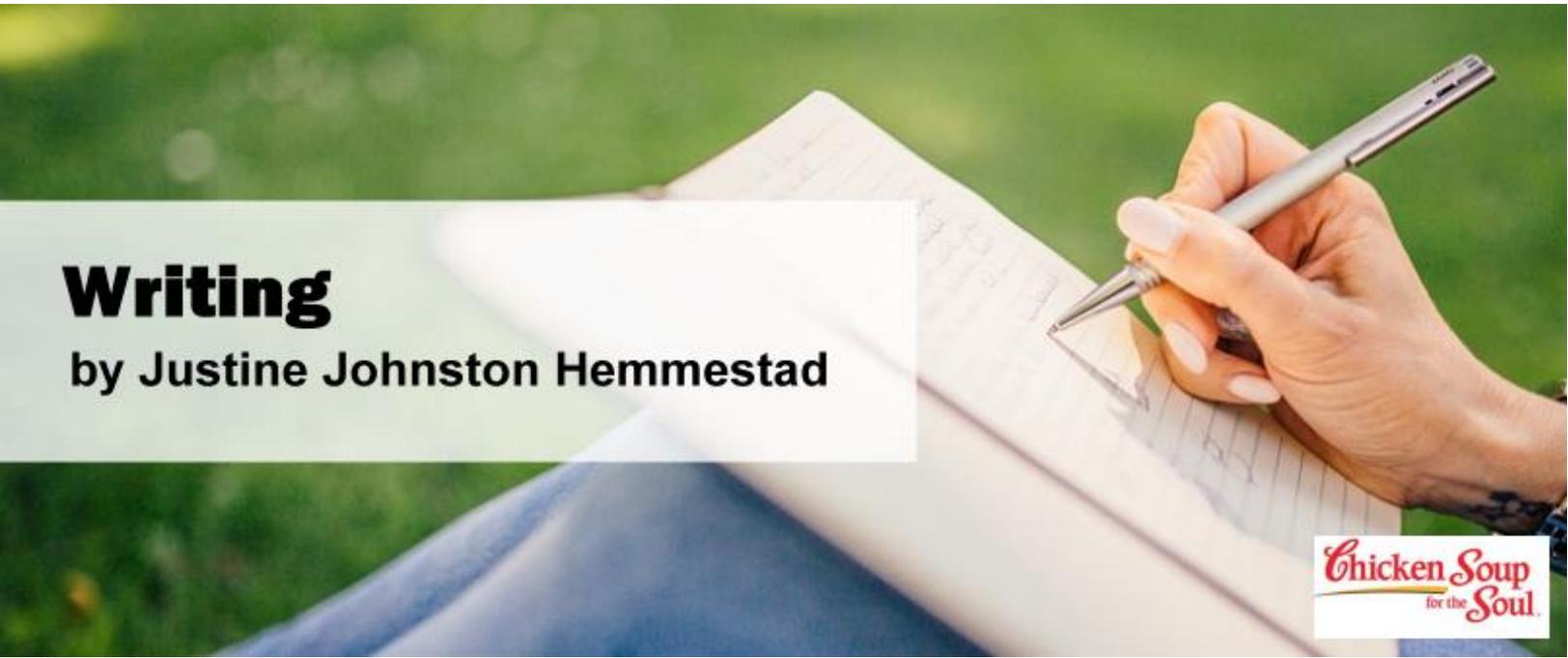
“That is very sweet. Are you courting me?”

“I guess,” he said. I held my phone through long silences as we talked for a while longer. We talked more that night than we usually did over a full day. I was transported back in time as I stood in my dining room, speaking to my husband only steps away. For the rest of the evening, we watched each other more than the movie. I kept staring at him, amazed that he was alive. He kept staring at me as if trying to get to know me all over again.

In the movie, *Vanilla Sky*, an eerie voice says, “Open your eyes.” David’s conscience plays tricks on him. He’s in a coma, and he’s battling inner demons of vanity, love, and righting past wrongs. He’s lost, confused, struggling, and hiding. That night, alone with my husband in the house, I fell in love again with the past and present version of my husband in a “Fellini moment.” The Italian film director Federico Fellini peppered his movies with flashes of intense beauty or called our attention to unexpected details that might illuminate our lives with wonder.

These momentary flashes of my pre-accident husband were flashes of hope, a fulfillment of longing. After that night, I would seek them out, and notice each familiar character trait returned to me like a gift as his brain slowly healed. The months and years passed, and somewhere along the way, the fog lifted, and there stood my husband, not my old husband, or my new husband, just my husband as he was simply meant to be.





# Writing

by Justine Johnston Hemmestad



My husband and I had been married for three months. It was 1990 and life was good. I was working at a shopping mall in Southern California. One evening after work, as I pulled out of the mall parking lot, my car stalled in the middle of the road. A city bus hit me, leaving me near death.

I was in a coma and had brain surgery. My brain was injured so badly that the doctors thought I would be paralyzed; they also said I would never be the same, never think clearly again. But I surprised them when I moved my hands and then eventually stood up and with help, began to walk. In a few months I was able to walk on my own. However, the struggle to regain my mental health as well as my balance and coordination took another ten years. Speech was also a major difficulty for me at first. My words slurred. I had trouble finding words at all.

As I recovered, I began to write. The act itself helped me to sort out the scattered words in my mind. Putting my thoughts on paper also helped me deal with the severe symptoms of post-traumatic stress disorder that seemed to get worse with the years.

Recovery from traumatic brain injury has been unbelievably intense, but also incredibly deepening and spiritual. At the beginning, recovery focused on my physical limitations. I still have extensive trouble with memory, speech and PTSD. The emotional toll my limitations took on me was a major obstacle. But even at my worst, I kept writing. It

helped me to face my trauma and work through it. Nurturing these positives, which I needed more than life itself, healed my mind and eased my PTSD.

My husband and I eventually had seven children. Their love gave me courage and perseverance to live and recover. And writing—regardless of the story—was therapeutic for my heart and mind. Journaling finally grew into novels, leading to my return to college thirteen years after my accident.

The more I studied, the clearer and more organized my thoughts became. The research I did for my novels helped me in my coursework, but my recovery while in college has become more defined. My thinking has grown sharper than it would have ever been before I had the brain injury and recovery.

I am grateful to have gained the strength and courage to recover from such an insurmountable injury. Now I have the courage to share what I've written with others, and though my memory still suffers, it's a small price to pay for the bounty I have received.

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# **Adjusting Your Goals after TBI**

by Kelly Buttiglieri



My life changed completely as a result of my traumatic brain injury (TBI). I was in my third year of law school at Suffolk University in Boston. I had dreamed of becoming an attorney since I was in high school. I was a few months away from graduating and beginning my career as a trial attorney. At the time, I also worked part-time in an insurance defense law firm. I was in the top two percent of my class and made it to the quarterfinals in many trial competitions at school. My husband and I had married the summer before and were just starting our lives together.

My TBI happened as a result of a car collision. I had just left my job and was driving to Suffolk for my afternoon class. I was on a winding road heading towards the highway. I came around one bend and another driver came in the opposite direction, passed out at the wheel, crossed the median into my lane and hit me head on. I don't remember the accident, or even anything that first week, but I had the best witness in the car behind me: an FBI agent!

After the accident, I was in a coma for five days at Massachusetts General Hospital. A cranial bolt was placed in my skull to monitor the pressure in my brain. My family and friends stayed by my side waiting for me to wake up but the only person I remember visiting me at MGH was the dean of Suffolk University Law School. I had just taken his trial practice class.

I spent the next five weeks at Spaulding Rehabilitation Hospital where I received speech, occupational and physical therapies. My biggest problems were short-term memory, word

retrieval, remembering names and loss of abstract thinking. In the beginning, I could not count from twenty to one backwards and could barely read.

One of the most vivid memories I have at Spaulding was when the speech therapist showed me flash cards with pictures on them. I simply had to name what was on the card. The pictures always started with basic objects like a ball and then would become more complex. I remember always getting stuck on one card, a picture of a frog; I could not name a frog.

I improved rapidly with all the therapy at Spaulding. Before I was discharged, the lead neurologist held a team meeting so we could learn their outpatient recommendations. While I sat there, I waited for one to comment about me going back to school. I did not understand the seriousness of my injury. When friends came to visit, I told them that I was not going to graduate with my class but I would go back to school in the fall, finish up and take the bar exam in February.



I waited and waited for someone to discuss my academics but no one did. Finally, I asked them about it. After a very long pause, the lead doctor stated that she did not think I would be ready for school in the fall and maybe I would never be ready. I finally understood the reality and seriousness of my injury.

After I left this meeting, I told my family that I just could not believe this prognosis. The doctor came back to talk to me that day and recommended that if I was that resolute that perhaps after undergoing more speech therapy I might be ready in the fall to go back to school but should only take one class at a time. Despite all the sadness and shock in trying to understand my fate, I now had a long-term goal.

For the next year and a half, I participated in outpatient speech therapy at a local hospital. I did go back to school, and with the help of my speech therapist, took my classes one at a time. I would often bring my law school books to therapy and read her the cases that I needed to comprehend.

I would then explain to her what I had just read. She would also review writing assignments to make sure that my ideas flowed. I didn't do as well with my classes as

before my TBI but I did complete them. Two years later, I finally graduated cum laude and took the bar exam. With extra time accommodations, I was able to pass the bar on my first try.

I also have epilepsy because of my TBI. I began having partial complex seizures right after the accident. Periodically, I would have a grand mal seizure and I had one status epileptic seizure, continuous unremitting seizure lasting longer than five minutes. I have been on many anti-seizure drugs and have had to live with many side effects but still did not have complete seizure control.

Almost eight years after my accident, I chose to have an operation to help, a left temporal lobe resection. My operation is considered a success because I now have just one or two partial complex seizures per month instead of a dozen, although I still have to take multiple anti-seizure medications and probably will for the rest of my life.

I had to go through a lot to come to terms with the reality that I am not able to practice law but can use some of the skills to move on to another career. I found a way to use my talents working at the Brain Injury Association of Massachusetts (BIA-MA). At the BIA-MA, I helped to implement the Ambassador Program.

I recruit Ambassadors, either survivors or family members, to share their knowledge and personal insight into brain injury and to make a seamless link between prevention and real life examples. I assist Ambassadors to write their aw-inspiring stories. The Ambassadors then present their stories to a variety of audiences, including at local civic groups, businesses, and medical facilities. Finally I am using my legal skill to implement a better Advocacy Program for our organization for TBI survivors. I am trying to make things better in a small way for the brain injury community.



# Meet The Writers



**Kelly Buttiglieri** received her B.A. degree with honors from Boston College in 1989 and J.D. degree with honors from Suffolk University Law School in 1994. She is married, has a sixteen year old son and eleven year old daughter. Kelly has worked for the Brain Injury Association of Massachusetts (BIA-MA) for eight years. She now is exclusively working as an Advocacy Associate for BIA-MA.



**David A. Grant** is a freelance writer and the author of *[Metamorphosis, Surviving Brain Injury](#)*. In early 2013, he founded the Facebook page, “TBI Hope & Inspiration.” In its first year alone, the page has emerged as a vibrant and important online support platform for both people living with brain injury and their caregivers. David is also the publisher of TBI HOPE Magazine.



**Justine Johnston Hemmestad** is a wife and mother of 7 children, ages ranging from seven to twenty-three. She’s just earned her BLS degree from The University of Iowa, and she will pursue a graduate degree in literature through Northern Arizona University. She is the author of *[Truth be Told](#)*, a story that mirrors the author's recovery from brain injury.



**Celeste Palmer** is the founder of Bridging the Gap ([www.tbibridge.org](http://www.tbibridge.org)), a non-profit providing resources to help TBI survivors, their caregivers, and families. She speaks, writes, and coaches to help others learn mindfulness and find their happiness. She has three children and two grandchildren, and enjoys lots of walking, swimming, golf, knitting, and volunteering.



**Rosemary Rawlins** is the author of *[Learning by Accident: A Caregiver’s True Story of Fear, Family, and Hope](#)*, an inspirational memoir about learning and growing through adversity. Rosemary’s writing has been featured in the TBI Today VCU Model Systems newsletter and Brain Injury Journey magazine published by Lash and Associates.



**Barbara Stahura**, Certified Journal Facilitator, has guided people in harnessing the power of therapeutic journaling for healing and well-being since 2007. A faculty member of the Therapeutic Writing Institute, she is co-author of the acclaimed *[After Brain Injury: Telling Your Story](#)*. She lives in Indiana with her husband, Ken Willingham, a survivor of brain injury.



**Mike Strand** and his wife Linda have been married over 25 years and have known each other since they were kids. In January of 1989, six months before their wedding, Mike was hit by a semi-truck as he drove home from work. Mike has written [three books of essays](#) on brain injury that are available from Lash Publishing.

# TBI HOPE Back Page



*From the Desk of the Publisher...*

It's been our pleasure to present this expanded issue of TBI HOPE Magazine. As the years continue to pass since my own traumatic brain injury, I marvel at how alive, vibrant, compassionate and giving the entire TBI community is.

We share a common fate and there are so many who give of their time and their experience to serve others. And it is in serving others that their respective humanity is revealed. It was a special pleasure to put together this month's *Chicken Soup for the Soul* section. At the time the book was initially published, many of this month's contributing writers were unfamiliar to me. I am blessed beyond measure that I now count many of these amazing souls as friends.



We have a very exciting 2016 ahead of us. Brain Injury Awareness Month is now a thing of the past, but that does not mean that you can't advocate for those affected by TBI. No matter what your current circumstance, you have a voice. Together we can do what none of us could accomplish alone.

Filming started this month for our upcoming TBI documentary, [Fourth Strike](#). If all goes well, the trailer will be released later this month with the documentary scheduled for a late fall 2016 release. Be sure to stay tuned for more information.

Peace to all affected by TBI,

*David*