JUNE 2016

The Importance of Support Groups

MAKING THE GRADE

LEARNING TO LET GO AGAIN



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TBI HOPE MAGAZINE

Serving All Impacted by Traumatic Brain Injury

June 2016

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Welcome

Welcome to the June 2016 issue of TBI HOPE Magazine.

Over the last few years more of the national narrative has turned toward concussion and TBI, providing many new resources to survivors and their families.

This month, we are featuring an article about the importance of TBI support groups. I can speak from my own personal experience when I say that support groups can and do save lives. My local group saved my life.

Five years ago, I went in search of a concussion support group. At the time, the nearest such group was a hundred mile round trip. Fast-forward to today and the nearest TBI support group is within walking distance, with a second local group only a few miles away. Not everyone is so fortunate, but times are indeed changing.

It is our hope that those who have lives affected by TBI find hope and comfort in our publication.

David A. Grant Publisher

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The Importance of Support Groups by Ric Johnson

I became a brain injury survivor in October 2003 after I fell from a ladder and hit my head on a concrete slab on my driveway. I spent the first month after my fall in a coma and needed craniology surgery. My second and third month were occupied with cognitive, speech, occupational, and physical therapy.

During the fourth month, I was released from the hospital and sent home, but continued with speech and occupational therapy as an out-patient in a local rehabilitation center. After I "graduated" from my therapy sessions, I was told the rehab center had a support group that would be helpful for me to attend. All I could think about was, "What? A support group? I don't need a 12 Step program. I'm fully aware of my injury and accept my difficulties. I also have family and friends that support me!"

Over the years, I have met many survivors with different physical or cognitive issues that separate our injuries. As such, you will see me using words such as I, myself, ourselves or we intermixed. I do this because, even though each person is an individual, all survivors understand each other - because first, or foremost, it was our brain that was broken.

So first, let's define the "what" about support groups. A support group allows survivors and family members the opportunity to meet face-to-face with others in the same position they find themselves. There is shared advice and encouragement. Above all, a support group meeting is not a therapy session. Try to think of support groups as training sessions. Secondly, the "why" about support groups: One of the main issues for survivors is that nobody understands what we are going though. Many survivors find that their friends have moved away from them. That is tough for survivors and their families to handle. Our friends continue living their fast-paced lives, while we start living at a much slower pace. Many survivors, even if we need to use a wheelchair or another device, look no different than most everyone else. The public can't see our injuries, so they don't understand. Support groups are formed to help survivors navigate into a world that we did not expect or plan for. We do this by sharing strategies, techniques and tips.

Although every brain injury and recovery is unique, in a meeting, we meet other people who do not need an explanation. Members understand because we all have common experiences. We gain by learning from each other's experiences. We set up patterns of success instead of patterns of failure.

What do survivors talk about during meetings? Everything that comes to mind, but most importantly daily tasks or the recovery process itself. Topics usually cover memory (both short and long term memory), speech, physical issues such as walking and strength. We share about using calendars/planners, as well as using a digital recorder when at a doctor appointment, explaining tests your neurologist wants you to take as well as what kind of doctor can help with your recovery. We learn about advocacy and how to find an advocate to help you explain at work if special accommodations are needed.



By discussing a technique that we use, it gives a validation for everything we have done before, whether it was successful or unsuccessful, and can give others a new set of skills, techniques or strategies. Many times what I just heard from somebody else had never crossed my mind as something to try. It's the old "why didn't I think about that before?" as soon as we start using that strategy or technique.

We don't need to consider ourselves experts as our voices are heard and our knowledge is shared and understood. Topics are really up to the group to freely discuss issues that concern members.

Many have asked whether only "new" survivors should join a support group. It took me nearly eight years before I walked back in to that rehab center and sat in my first support group meeting. I wish I went to that group before. Not only did I gain better coping strategies, I also saw that I was not alone. I was pretty sure I was not the only person in the world who survived a traumatic brain injury, but I had never met one. There are now many survivors that I call close friends. Any survivor, regardless of the days, months, or years from their injury are welcomed at our meetings. I have sat through many group meetings at my "regular group" as well as other groups and continue to be amazed at what I learn. Many of those gems of knowledge are from people with only a few post-injury months.

Brain injury support groups benefit more than just the survivor, they benefit everyone. Nobody understands the difficult issues that a family member faces, except another family member. Asking and answering questions is just as important for family members. Sharing the tips/techniques/strategies that have been used many times and still continue to be used, is so often a godsend for others.

Support groups provide a huge benefit because of our common experience. If you don't know of a local brain injury support group, ask your doctors, church members, neighbors. Contact your state's brain injury association/alliance. If necessary, contact and invite other survivors to start a brain injury support group. You'll be glad you did!

Meet Ric Johnson

Ric Johnson is a husband of thirty-six years and a father of two adult children. Ric sustained his traumatic brain injury over twelve years ago. He is also a member of the Speaker Bureau for the Minnesota Brain Injury Alliance, and facilitator for the Courage Kenny Brain Injury Support Group.





The brain injury that changed my life forever occurred on July 6th, 1999. One challenge in accepting my new life was coping with the anniversary date of my accident. I used to think about the car accident on the 6th of every month. That thinking faded on its own within the first year. However, for many years, every July 6th I would remember and grieve more acutely my life that was. I would more intensely miss the woman who was able to manage and excel at many activities.

During this time, my view of my former self and her past would become rosier, colored by the sense of loss I felt. My ongoing brain injury symptoms and limitations would frustrate me more. I would get angry at myself because I hadn't progressed further and in the process, I would completely discount all the gains I'd made. I needed a strategy to cope with the feelings of sadness and loss brought on by my brain injury anniversary date.

It took me eight anniversaries and the help of family and friends to come up with a strategy that worked for July 6th. It's one that I use every year now. This strategy has transformed anniversary time from a day of intense sadness to a day of reflection and even celebration. I now view my anniversary day as my second birthday and commemorate it as such.

I'm sharing my strategy in the hopes that it helps others. The anniversary strategy involves four important components.

- Do not be alone
- Remember and celebrate your progress
- Plan life-affirming activities
- Try something new

Do not be alone. It's never a good idea to be all alone on such a meaningful day. It's too easy to allow yourself to brood about what was your life. Instead, spend time with an upbeat person or persons who can show you kindness and compassion.

Remember and celebrate your progress. It's easy to forget just how much progress you've made since your brain injury, especially around anniversary time. You may think that your



accomplishments now are insignificant next to your preinjury ones. However, when compared to the early days of your recovery, I'm sure the progress is downright stunning.

And that progress, however small and however slow, will continue. As you progress, it's not fair to judge your new life by the standards of your old one. That kind of judgment will only make anniversary time more painful. If instead you compare apples to apples - start of your

new life with a brain injury to your present stage of recovery - anniversary time becomes less a time to mourn and more a time to celebrate just how far you've come.

Plan Life-Affirming Activities. It's important to think about how you'd like to spend your anniversary day. Planning and doing something fun and fulfilling serves two purposes. The planning process itself can distract you during the days or weeks before the actual anniversary and give you something to look forward to. A life-affirming activity on the day itself will prevent you from thinking too much about your pre-injury life. Whatever activity you choose, it should fill your soul and respect your current abilities.

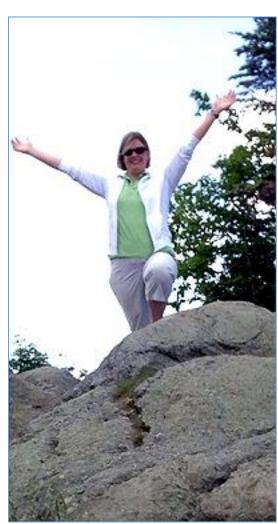
The last thing you want is to choose something too difficult that will only frustrate and depress you. Depending on your abilities, you may plan one activity or several. You may require help planning or you may be able to do it on your own. Perhaps you'd like to spend time with several people or maybe just one. You may even choose to pursue a solo activity.

Just be sure not to spend all day alone, even if all you can do is talk to someone on the phone. Regarding the type of activity, there is no right or wrong choice. It should be life-affirming to you. Some possibilities are spending time with family and friends, doing a craft/art project, volunteering, gardening, reading to a child, listening to/playing music, spending time in nature, cooking a special meal, building something, playing with a pet, exercising, or whatever else you can dream up. Listen to your inner voice for guidance and just have fun!

Try something new. This is my favorite part of the anniversary day strategy. Do something you've never done before. Since you got a new life with your brain injury, anniversary day should be commemorated by trying something new. The life affirming activity and the new activity may be one in the same, but they don't have to be. The activity doesn't need to be long or complicated, just new. For example, the first year I implemented this strategy, I simply went with friends to a restaurant and ordered a dish I'd never eaten before.

Over the years, my new activities have gotten bigger as my capabilities have expanded. It's most important to try something that's in line with whatever your current abilities are. So unless you're truly, truly up for it, I wouldn't recommend anything too exotic, like bungee jumping off the tallest building you can find! What the activity represents is far more important than the activity itself.

As with any life-affirming strategy, planning and doing something new can serve as a distraction and give you something to look forward to.



Over the years, July 6th has been a day when I've gone to the botanical gardens with my best friend, created collages with my brain injury support group, watched a rubber duck race, ridden a gondola up a mountain, hiked to a waterfall with my family, taken pictures at the beach and eaten many more new foods.

I never would have dreamed it early on, but I can honestly say I now enjoy July 6th. Yes, I will always know that it's the day brain injury changed my life forever, but with the help of my strategy, it's been transformed into a positive, celebratory, forward-looking day. I hope this anniversary strategy can help you do the same.

Meet Carole Starr

Carole is a brain injury keynote speaker, the Founder and Facilitator of Brain Injury Voices and the creator of the traveling photography exhibit Resilience: Moving Forward after Adversity. She can be contacted through the Brain Injury Voices website at <u>www.braininjuryvoices.org</u>



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Because of our unique circumstances as TBI survivors, we have a different way of looking at, and interacting with, the world.

For the general public, the world is a place where people live their lives, pursue their goals, and work to become successful. The world for us as survivors is rocky and more complicated than that of the average person. The skills and abilities that allow us to get along in the world have been damaged and we often feel lost. As a result, rather than living our lives "trying to be successful" or trying to achieve, the best we can do is to just try to get through the day in one piece.

The simplest way to express how differently we feel about our place in the world is by means of a map of the world drawn from a TBI survivor's perspective.

Our Map of the World

In our map from a TBI survivor's perspective, all the land masses are squashed together into one big hunk of rock and dirt, like they were eons ago, before the continents formed. The seven seas have been combined into a single, vast ocean surrounding this land mass. Way far away, over on the opposite side of the planet, would be a grouping of millions of tiny islands, each composed of two square feet of land. A single survivor stands on each island.

We survivors are not totally isolated. There would be bridges connecting all the tiny islands so the survivors could travel to any island for support group meetings.

That's the way the world feels to us, with humanity often feeling like it is divided into "us" and "them."

That brings up a question: why do we feel so isolated?

It's complicated. While other people might put us there by the way they treat us, we also play a role in creating this world. Let me use an example from my own life to show how I personally played a role in creating this situation.

Right after I got out of rehab, fresh out of my wheelchair, I would be walking/stumbling

down the sidewalk with my cane, getting angry and muttering under my breath at all the people who were laughing and having a good time as they quickly walked past me. I wanted to be like them. In fact, I used to be just like them. I was happy and carefree. They seemed not to see or even care about my situation. Their good natured bantering, laughter and light heartedness made me even angrier. I felt like they were expressing their happiness just to make me miserable.



The way I saw things, my situation was always being pointed out to me. What my life had become was continually being rubbed in my face. I felt as though bad things routinely happened because of something I did. All the people who passed by seemed to be looking at me like I had done something wrong.

I was helping to create this *me versus them* situation because of the way I was looking at the world. I put *myself* on that solitary island on the other side of the earth.

That Rush of Power

In a world full of social networking and collaboration, I was struggling just to keep my head above water and to find my place. The way I was dealing with my brain injury kept me from connecting with others in a meaningful way. It had conditioned me to believe that I didn't really belong.

What I couldn't realize then was that, along with the ramifications of my brain injury, the experiences in my life prevented me from being objective. As a result, I adopted a view of the world where it was me and my problems against everyone else. This was something which might have made me feel strong and self-righteous, but didn't really serve me well.

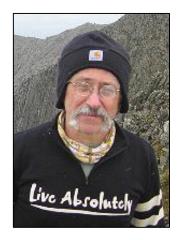
We set up situations like this partially because we don't feel powerful or in control with our lives being the way they are, and being angry gives us that rush of adrenaline which makes us feel strong, powerful and more in control. The temporary feeling of strength and power we get from setting up a situation like this is deceiving though. It doesn't last and it isn't effective. It only hurts us in the long run because it sets us even more apart than we are.

Coming to terms with the fact that we have changed and accepting our situation doesn't stop us from working to get better, but it will allow us to live our lives more fully while working to avoid the "us vs. them" mentality.

By coming to terms with the way things are in our lives we can more easily join the rest of the people on the other side of the world, the ones we thought were looking down on us. Sure, in some ways we are different, but we can find a way to fit in and live our lives as a part of the rest of the world. We don't need to always think we are separate.

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.



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Watching our children grow up with great anticipation of what's to come is a natural part of parenting. With pom-poms in hand, we celebrate every milestone. We experience butterflies when the big learner's permit day arrives. When we drop our baby off at college, we cry like babies ourselves! And low and behold the day arrives when we find ourselves attempting to embrace the long anticipated empty nest chapter. Dads tend to adjust more easily (*and eagerly*) to the empty nest chapter than Moms do. Go figure! All of these stages are normal for parents while learning to let go.

Three years ago I found out what's not a normal stage of letting go. I was faced with prematurely saying goodbye to my first born son at the fragile age of twenty-six while watching my other son fight for his life. Our sons Aaron and Steven were in a fatal car accident. Aaron didn't survive. Steven sustained a severe Traumatic Brain Injury (TBI) and was not expected to live.

Bending over Aaron's casket to kiss his cold tender cheek goodbye was not written anywhere in our parental handbook! Especially not in the chapter dedicated to learning to let go. Neither was being thrust into the unknown world of becoming a caregiver to our twenty-two-year-old son.

In the blink of an eye, with tears streaming down my face, I sat observing my son attempt to learn the basics all over again. I anxiously waited for Steven to speak his first word. My heart wasn't prepared to hear the three words often taken for granted..."I Love You." I

cheered when he sat up in a chair without assistance. Each baby step of progress was a victory. I didn't dare allow my thoughts to linger on the predictions of deficits Steven might face. Instead, I focused on celebrating the reality that Steven was alive. His deficits were invisible to me. I had lost one son; I knew I wouldn't survive if I lost Steven.

Almost four years later, I admit that I was at a loss. I was angry. My heart felt shattered beyond repair. I had a plan for our sons. My plan was tucked away in a beautifully wrapped package safely secured with a big bright neatly tied bow on top. My plan consisted of watching our sons go to college, securing their dream careers. They would get married, have children, and live happily ever after. We would experience the joy of family dinners

and beach vacations. Our sons would watch their Mom and Dad grow old together. Isn't that the way it's supposed to be? On August 13, 2012, my beautifully wrapped package was replaced with a package that held God's plan for our lives. I had two choices; I could attempt to return to sender, or I could dig in with both feet firmly planted and fight with every fiber of my being for Steven's second chance. I chose the latter!

After experiencing a double trauma, I was faced with learning how to let go all over again. I wanted to take Steven's pain away, but couldn't. I tried to speak for him but got reprimanded. I was told Steven



needed to learn how to complete tasks with one hand. I insisted that it was too soon, it would be so much easier if I did things for him. At what felt like a snail's pace Steven relearned the basics. I thrived in taking care of Steven. Keeping busy was detrimental in those early days. It was too painful to accept the reality that Aaron was gone. Without complaint, I settled into the caregiver role beautifully. I was on a mission! It never occurred to me that everything I was doing for Steven was ultimately leading me down the path of watching Steven live an independent life!

I remember the day Steven's doctor asked what he thought about driving again. I immediately thought: *Stop that*! *What a ludicrous question*! *What kind of doctor are you*?

I have already lost one son; Steven does not want or need to drive. I am taking care of him! Steven was so gracious because he knew his mom was fragile.

Through counseling, I am learning to support Steven through each important step in his recovery, even the ones I'm not ready for. Yes, Steven got his driver's license. Each time Steven goes out the door, I wait patiently until I hear, "I made it safely, Mom." Music to my ears! To this day, Steven knows how important it is for me to hear these precious words.

Since the knock on our door, I have earned the title of being an overcomer. Against all odds I have watched my son complete college classes, endure endless hours of grueling therapy, and bravely try every technology available to aid his recovery. When we take time to reflect on where Steven was three years ago, our focus was finding a top-notch rehab facility. The miraculous milestones Steven has achieved were never expected or



voiced!

It wasn't until he was settled in at the Shepherd Center that Steven was told that Aaron didn't survive the accident. Instead of quitting, he went full speed ahead, dedicating his recovery to bring honor to Aaron's life! He has certainly gone above and beyond to do that and so much more!

There are no adequate words to describe the pain of losing one child coupled with the fear of not being able to protect your other son. I'm thankful we work

together as a family, being respectful of how we each cope and adapt differently. I'm also grateful for our team of counselors. They don't pretend to know what it's like, but they dig deep to provide invaluable resources to help us learn how to let go and watch our son spread his wings and soar like a proud eagle. Will he sustain more bumps and bruises along the way? Yes, I know he will. But, I also know he will pick himself up, dust off the debris, and keep on going.

I don't know what the future holds for us. I have hopes and dreams, but this time I refuse to bundle up what I want our futures to look like in a perfectly adorned package. Instead, I will pray for our son to hold his head high as he continues down this path chosen for him. He has a happy and healthy future in front of him, helping others as he shares his story along the way! I also want Steven to witness his mother succeed at accomplishing every unsurmountable task involved in learning to let go again! Letting go doesn't mean I won't always be there for our son, it just means staying behind the scenes watching Steven independently do life. I know he will do it to the fullest, just the way it's meant to be done! When Steven's big day of changing his address arrives and he's ready to go out our front door, for starters, I will hug him tighter and longer. With proud Momma tears, and I will say all the "*Mom*" phrases: *Be safe son, I love you, and please call when you arrive safely*.

We will get through this next chapter of life together, feeling Aaron's smile of approval every step of the way.

Meet Norma Myers

Norma and her husband Carlan spend much of their time supporting their son Steven as he continues on his road to recovery. Norma is an advocate for those recovering from traumatic brain injury.

Her written work has been featured on Brainline.org, a multi-media website that serves the brain injury community. Her family continues to heal.



Living With Hope





By Patrick Brigham





Close to a year and a half after my son's traumatic brain injury, we began working with a Neurological-psychologist. We found a terrific doctor, who seemed to grasp not only the medical side of brain injury, but also the emotional impact specifically relating to Taylor. Following a few sessions of becoming acquainted with Dr. Randy, cognitive testing was recommended. This would allow us to gain a better understanding of where Taylor's thinking processes were. A baseline could be established offering insight into a different aspect of the injury than that which was glaringly obvious.

I was still a fairly new student in the classroom of TBI, and was once again, not fully prepared for the lesson I was about to learn. Hours of testing took place and a few weeks later, we were called in to discuss the results. The fact that Taylor could undergo and complete the test process itself was an accomplishment, but sometimes even positive milestones feel painful.

Up until this time in parenting I had been fortunate to have three sons who were healthy in mind and body. They had each successfully navigated their high school education, sports and extra-curricular activities. They were part of the National Honor Society, All-Star Sports Teams and took part in community service. Taylor even graduated first in his class at the technical school where he learned the skill of being an HVAC specialist.

As I sat with Dr. Randy that day listening to the results, I felt like the world was about to suck me in to another unexplored layer of sadness and shock. I could hear my heart

beating, as my intuition warned me that something bad was about to happen. My body and mind prepared for the blow.

The doctor explained that Taylor was functioning at the level of someone who was around nine years old. He discussed the challenges in thought processing, understanding, word recognition, insight and an exhaustive list of things that represented more of what the injury had stripped away. I don't know what I came in expecting the results to convey, but it certainly was not that. I felt as if I was being punched in the gut. Ever aware that brain injury changes everything.

The strangest occurrence happened to me in those moments. I swallowed my tears, I took the deep breaths I had become accustomed to taking, I inwardly scolded myself for coming



to the appointment alone and I heard again the silent scream that had become my friend in this classroom. That scream defined the emotion I could not let out, the parts of me that no one would ever see.

More of my son was gone that I realized. Then I saw something flash in front of my memory that has bothered me since that day. I saw the bumper sticker that said, "Proud Parent of An

Honor Roll Student." The hurt and anger inside of me wondered what our bumper sticker would say, "My once strong, bright 22 year old is now functioning at the level of a nine year old." I was ashamed of my thoughts.

This was one of the first times that I realized that not only was the classroom of brain injury something that would make me incredibly sad, but it would make me angry too. Questions like "Why did this happen to Taylor?" ran through my head, and the truth is they still do. But please understand this...I wish with all of my being that brain injury never happened to anyone...ever...again.

Since that time, Taylor has been retested. For round two's results, my husband and other sons came along. We sat together for the news. The test can only take place every two years, so they were spaced out for about that length of time. I came in to that meeting with fairly high hopes.

Dr. Randy did not dive right in this time. Instead, he talked to each of us about what Taylor's injury meant in fairly concrete terms. We then discussed some ways that it affected our family and relationships. We were all uncomfortable in this room, with this psychologist, wondering how we ever got here. It has been said "the tension was so thick you could cut it with a knife", but what was thick that day, was pain.

Taylor had shown improvements in some areas, and in others he had remained the same. His emotional age had jumped closer to an eleven or twelve year old, but still that was not what we had hoped to hear. After the meeting we took the rare occasion to take Tanner and Avery out to eat. We wanted it to be a treat, but the food tasted like chalk in our mouths. We deeply missed Taylor, and life before this injury!

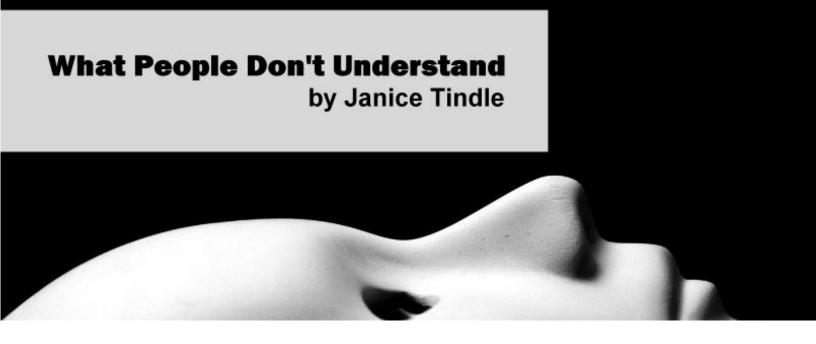
On that day I learned a tremendous lesson. I learned that people are much more than their grades, their academic accomplishments or what club they belong to. Intellectually I knew that before, but now I knew it in my heart. There are beautiful souls, who are functioning at a level far less than their peers, who are more than exceptional and deserve recognition. Before then you may have heard me talk about GPA's, and various achievements, but that has become a part of life that I have let go. Those things matter, but they do not define a person.

Underneath all of the ink blots, timed sequences, and recognition of simple objects such as comb or toothbrush, was my son's mind. Taylor worked with his beautiful, broken brain, which was trudging through some thick mud to come back even the tiniest bit. And although the results were less than we had hoped, they were something to be proud of. In our society we are often impressed by the letters behind someone's name, PhD, MD, MA, and so on. The letters behind Taylor's name will always be, TBI survivor, and for that I will always be grateful.

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. Nicole's book <u>Falling Away From You</u> was published and released in 2015. Nicole continues to share Taylor's journey on Facebook. Nicole firmly believes in the mantra that "Love Wins."





You take for granted that when you wake up, you will go to sleep that night as the same person you were when you began your day. You thought the same thoughts, had the same feelings, dreams, goals and abilities as you did the day before. You expect that the next day you will still look at yourself in the mirror and recognize your face, body and voice as yours.

You know yourself. Whether or not you like yourself, you have full recognition of your body, mind and spirit. You are comfortable in your own skin. You may not be content or satisfied with who you've become, but you understand how you got that way and you understand what you need to do to change, grow and progress.

Now, imagine waking up one day and within the course of your normal activities, a blow to the head removes all that. Imagine your sense of yourself disappearing like a document in your computer that you forgot to save. You remember that it's there. You search for it, you know it's there, somewhere, but no matter how hard you search, you just can't find it.

So you try to make a new one, as close to the old one as possible, but all the subtle nuances and specific details, are gone. All you can do is try to make a copy of the "you" that used to be, but you feel like an imposter. You feel like you're living someone else's life, but it's your life. You're lonely for yourself. You feel completely lost.

Things that were so important before, now have no meaning. Relationships that you once treasured, you find difficult to connect with. You understand the meaning of the lyrics in Gordon Lightfoot's song, *"If You Could Read My Mind"* because you walk around like a ghost in your own life "with chains around your feet" agonizing because "the feeling's gone and you just can't get it back."

If that is too hard to understand, try to imagine it this way: Picture yourself getting into your car that only you drive, and suddenly, the seat is in the wrong position. You try to adjust it back to where you've always had it, but your most comfortable setting is gone. The steering wheel won't tilt into place, and the climate control system no longer has your temperature of choice. The radio has been reprogrammed without any stations that you recognize. The wipers stick and squeak. The defroster only defrosts one side of the window. The gas tank is on the other side.

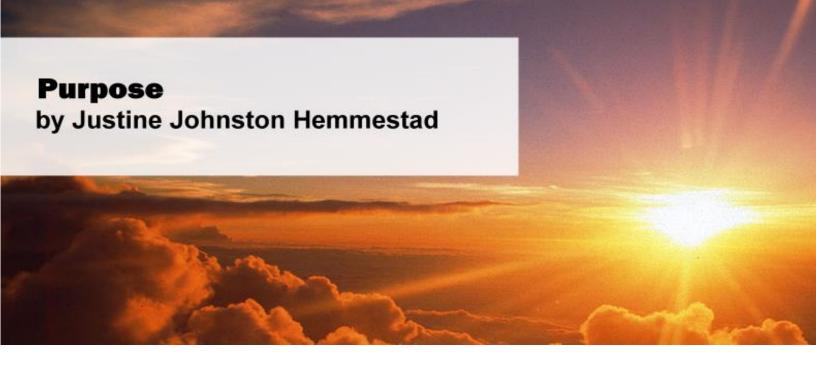
You try to drive it anyway, but no matter how hard you try, you just can't get the speed up to normal. You can't see, your back hurts, it's either too hot or too cold, the music is too loud, and the wipers are driving you crazy. You are so frustrated by everyone honking at you that you just pull over, put your head in your hands and cry.

Now imagine that car is your brain. That's TBI.

Meet Janice Tindle

Janice Tindle is a freelance writer and brain injury survivor. Janice is a frequent contributor to TBI HOPE Magazine. She suffered a traumatic brain injury and other injuries when hit by an under insured driver. It changed her life. To read more of her work, visit her blog at www.JaniceTindle.com.





In 1990 my car was broadsided by a speeding city bus as I turned out of a parking lot - I was in a coma and sustained a severe brain injury. I was paralyzed when I woke up from my coma, though I worked hard to walk and learn how to perform the basic functions of life again within a few months. I began to write when I was carrying my first child Megan, less than two years after my accident, as tool or a way to cope with feeling so alone and misunderstood in my disability.

Throughout the darkest part of my recovery, when everyone looked down on me and I had no one to talk to or relate with me, I found writing helped me to get my thoughts in focus, to learn new things, and to remember what was important to me. I felt bullied, my thoughts and perception was skewed, and I felt emotionally alone, isolated in my personal lacking (my speech was slurred; my reactions were slow, etc.).

But writing was my Savior.

When I was so afraid and so filled with guilt for being disabled, writing offered me a safe and comforting place to go, where I could cry and feel loved. Writing was my confidant and gave me hope when the world was crushing me. Writing even helped me find out who I was, since everything about "me" seemed to have melted away with my TBI. Writing helped me find my words to speak again. Writing was my purpose, and writing was my healing. My novella, <u>Truth be Told</u>, is essentially the story of my recovery wrapped up in fictional characters in a different time and place. Everything is symbolic in my novella because symbolism itself taught me how to travel deep inside my thoughts and search until I found the answers, and symbolism aided my memory by the weight of its meaning. The old man in my novella is symbolic of God, prayer, and love of my children, the inner truth I found when I dug deep, the challenges that stretched my mind and that I knew I had to face when I wanted to give up on life completely.

The Lady is the aspect of my recovery in which I felt lost, even to myself – I didn't know who I was, but in prayer and meditation I learned to focus my mind, calm my thoughts (which were drowning in the guilt I felt for being disabled) and listen to God's answer...what defines me? The knight is the aspect of my recovery that was assaulted by PTSD. Not only was I recovering, but I was recovering amidst a torrent of fear, pain, and false persecution. He represents the survivor's guilt I had for living as brain-injured, and the part of myself that felt I deserved the lies that people told about me simply because it was easy to lie about me.

I illuminated my purpose - the purpose that any recovering person needs to be able to climb out of the darkness - symbolically as Jesus. When people lied about me, writing defended me and made the truth immortal. My purpose, as writing, was the well within me; writing saved me and gave me direction in life (even when I no longer had any sense of direction due to my TBI). There were people who tried to point me in the wrong direction, but my prayer, and written prayer, was always brimming with truth.

My purpose in writing raised me out of the darkness and set me on a new path. As my characters in Truth be Told founded one of the first Universities in Europe, my purpose led me to enter into college, to study tirelessly, and to set goals and reach them. For a person with a TBI, these things stretched my mind to the breaking point. And yet my savior, writing, was always there, so much that my purpose and my goals became intertwined. Every class I've had brought me new challenges; every professor's pushing has helped me more than they were ever aware.

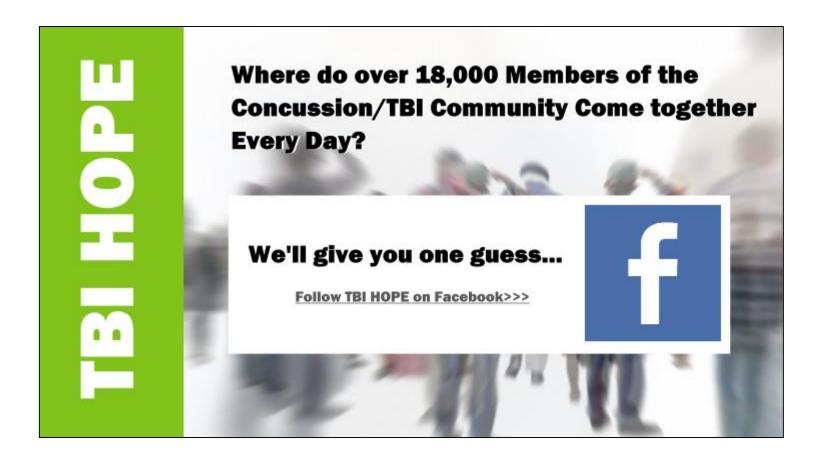
My husband and I now have seven children and I'm still writing, for both have truly been essential to my recovery. I've also earned a BLS through The University of Iowa and am now working toward a Master's Degree in Literature through Northern Arizona University. I'm grateful to have written a book that I felt so strongly, all along, could be of help to survivors, for them to recognize themselves in the characters and to know that

they're not alone. I would have recognized myself in this story and it would have given me hope. My mission now is to give other survivors hope.

Meet Justine Johnston Hemmestad

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 hopes to publish her novels and teach creative writing.







He almost killed me back in 2010. But if I saw him today, I would most likely give him a hug. And thank him.

Having a near-death experience does tend to change your outlook on the world. An endurance cyclist for many years, I was out cycling on a typical late fall day in central New England. It was one of those days that most likely drove Robert Frost to write. In fact, I was only a few miles from his birthplace when my life took a bit of an unexpected turn.

Strike that. It was more of an unexpected crash. No one gets up in the morning wondering if the day will wind down with an ambulance ride and a trip to the nearest trauma center. But on November 11, 2010, that was to be my fate.

Local authorities estimate that the teenage driver who broadsided me was moving along somewhere between 30 - 40 MPH when we met. He was in a small car – I was on my trusty bike. When car hits cyclist in a battle of metal vs. metal, the cyclist rarely wins.

Rushed by ambulance across state lines to the nearest trauma center, my wife Sarah following the ambulance, not knowing the condition of her husband, our two vehicle convoy came roaring into the ER. The impact was violent, it was horrific and it was painful. The windshield of the car that hit me was pushed right into the passenger's seat. A first responder later shared that anyone in that seat would have been gravely injured.

Thank God for not-so-small miracles.

My injuries were extensive. Broken bones, torn tendons, and head-to-toe bruises. For the next several days, my wife pulled shards of glass from my head. And the icing on this accident cake? A traumatic brain injury.

A medical professional, a full year after that November day, let me know in no uncertain terms that my life would never be the same. In fact, he labeled me "permanently disabled." It's been several years since that fated day – the most difficult years, the most glorious years, and the most unexpected years of my life. As predicted, my bruises faded from black to yellow to gone. My bones mended, and the visible signs of my accident faded from the public eye.

But living with a traumatic brain injury, well... to say that life has become a challenge would be an understatement of truly epic proportion. A hale and hearty case of PTSD only added to the mix. Many things that I used to take for granted, things like knowing the day of the week, what season we are in, or even how to read, have become challenges.

I hold no bitterness toward the young man who careened into me. To hold any bitterness, animosity or resentment bars me from moving forward in my own life. Everyone has "stuff." If you have a heartbeat, life has thrown you a curveball or two. It's part of our shared human

experience. I've seen close friends lose parents. And children. Many I know battle lifethreatening or life-changing chronic illnesses. And some of us get hit by cars at the prime of our lives.

The biggest question is this: Will I let my life experience, no matter how painful, pull me down or lift me up? I've seen many who choose to be beaten by life's hardships. They wander around, melancholy at what they've lost, willing to tell their own tale of woe to anyone who will listen. Thanks, but no thanks. I choose to be grateful.

Life is indeed for the living. It has taken me many years to come to grips with the fact that life as I knew it is gone. This was not an overnight process. There were peaks and valleys,



wonderful days and months defined by ever-present thoughts of suicide. But out of every season of living when fate seemed harsh, new lessons were learned and new strength was found.

Life today is vastly different than I ever envisioned. Most of my time these days is spent advocating for those impacted by traumatic brain injury. From one-on-one working with others who share my fate to multiple keynote presentations at medical conferences, the life that I live today simply astounds me.

I have emerged as a new person with a new mission. My experience as a brain injury survivor has made me uniquely qualified to serve others. My written work about life as a true survivor has been read around the world. I have been blessed with many opportunities to share my story of hope and inspiration with groups large and small. How can I not be



grateful?

On occasion, I think about the young man who forever changed my life. Initially he impacted just one life. But the events that unfolded that day have now touched the lives of tens of thousands.

Sometimes I wonder how my life might have unfolded had I chosen to hold on to anger, to not forgive the young man who has

unknowingly affected the lives of so many. Had I chosen that path, misery and discontentment would now define my life. This I know as surely as I breathe as I have seen others who have not been able to let to, to forgive, to move on. They live in constant misery.

And the young man who started me on this new, wondrous path of discovery, what ever happened to him? Humbly I must admit that I tracked him down on Facebook a while ago. If his page is any reflection of his life, he is a student at a local college and moving forward in his life. I remained transparent in my quest to search him out. It is my hope that he rarely thinks about that fall day so many years ago. And the one time that I did meet him face-to-face in the weeks following my accident... What did I do? If you guessed that I gave him a hug, you are correct.

Meet David A. Grant

David is the publisher of TBI HOPE Magazine as well as a regular contributing writer to Brainline.org, a PBS sponsored website. He is also the founder of <u>TBI Hope</u> and <u>Inspiration</u>, a Facebook community with almost 20,000 members.

Getting back on a bike after his accident, David can still be found cycling the highways and byways of southern New Hampshire.







TBI HOPE Back Page

From the Desk of the Publisher...

It seems like there is news of brain injury and concussion at every turn. From the evening news to new books, movies and documentaries, the new national narrative no longer excludes traumatic brain injury.

Late last month, we released the trailer to our TBI documentary, *Fourth Strike*. This will be the first-ever survivor produced documentary – illuminating life after brain injury from an insider's perspective.

We invite you to <u>View the Trailer on YouTube</u>. (A word of caution to those living with PTSD, as some may find the trailer to be a trigger.)

Always on the lookout for new ways to advocate, we are looking at a possible podcast series by year end and will continue to produce our short videos in the <u>TBI HOPE &</u> <u>INSPIRATION YouTube Channel</u>.

TBI HOPE is a community in its truest form. We would love to hear from you. We are always looking for people to <u>contribute stories</u> so that others can best understand life after TBI.

Summer is fleeting here in the Northern Hemisphere. Go out and have some fun.

Peace to all affected by TBI,

David