

TBI HOPE & INSPIRATION

Magazine



**SEEKING MY
HUMANITY**

**CHANGE
YOUR FOCUS**

**HOLIDAY
Stressors**

**Learning to Like
The NEW Me!**



TBI Hope &
Inspiration
MAGAZINE

*Serving All Impacted by
Traumatic Brain Injury*

December 2015

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Welcome

Welcome to the December issue of TBI Hope and Inspiration Magazine. It's hard to believe that we are only two issues away from the one year anniversary of our publication.

One reader recently wrote, *"Your magazine brings joy to my heart as I have long felt the heaviness of not being able to share because no one quite gets it."*

Over this past year, our publication has been read around the world, filling a very real need for the brain injury community.

The Holiday Season can be one filled with wonder and gratitude. It can, however be a source of stress for those affected by traumatic brain injury.

It is my hope that you are able to find a bit of peace during this busy time. Time spent with family, time spent with friends, and time spent with others who share our fate - this can be the most meaningful gift of all this season.

No matter how you choose to celebrate, it is my hope that you can be in the company of those you love, and who love you unconditionally.

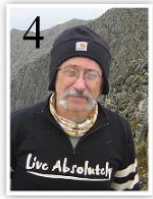
May you find peace in your journey,



David A. Grant
Publisher

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Seeking my Humanity

By Jeff Sebell

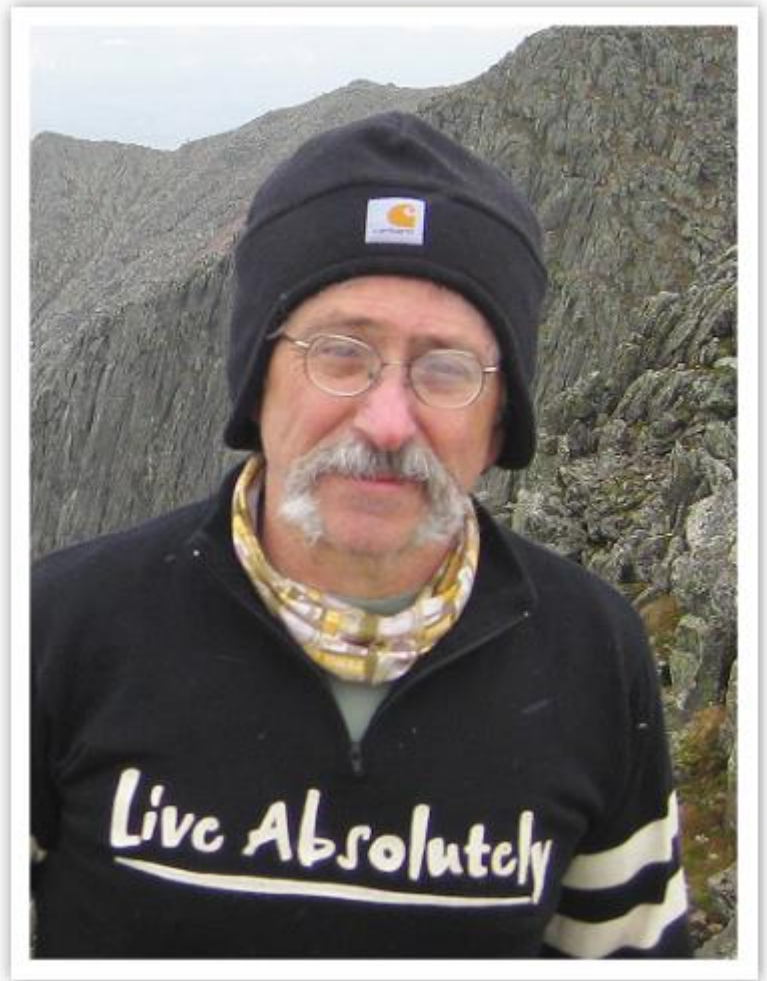
We live in a world where there is complete information overload, and I must admit I am part of that overload since I write this article. However, I do try not to focus on strategies to live your life. Rather, I talk about broader concepts.

This is quite different from what most of the writing on traumatic brain injury involves. Most blogs or articles are either personal stories or people taking an active role in your life by spelling out strategies for living your life after TBI. While the stories are human interest stories, the books or articles on strategies typically involve lists or directions to help you accomplish something which you find difficult, post-TBI.

Early on after my TBI, I made a decision that for me, has seemed to work. The decision I reached was to pursue the regaining of my humanity, and the abilities to reason and understand by focusing on the big picture, rather than living my life as a series of lists.

What this means is I wanted to concentrate on reclaiming my sense of self, thinking that by knowing myself I would gain the tools and core knowledge to make the decisions and take the actions in my life that people used strategies for. Of course there were certain strategies I had to employ in my day-to-day living, but rather than focusing exclusively on the small stuff in front of me, I carried the grander vision of wanting to find my place in the world.

I was going to be me, however that turned out, and I would learn by doing. The best way to proceed?



There are many kind, smart, well-meaning people out there who come up with ways for us to organize our lives and live them successfully, at least from their standpoint. It's so easy for us to get caught up in these ideas that sound reasonable and look like they would work, especially when we don't trust ourselves and are looking for help.

Lists, procedures and strategies are seductive; they are straightforward and simple, and can be a welcome sight in a world where we might get confused and need help with memory, organization, and follow-through.

Says Who? There is no "Right" way to live your life after experiencing a traumatic brain injury. There is only the way that works for you, that suits your personality and that allows you to accomplish your goals.

I had a list waiting for me across from my bed when I was admitted to the Rehabilitation Hospital. It was my daily schedule: all my therapies, meals and rest periods, posted in a convenient spot where I could see them, and be "gently" reminded. Now, I'm not complaining about that, because whoever put it up had the best intentions. However, I ripped it down. How was I going to exercise my brain when everything was spelled out in black-and-white in front of me?

My point is that we all approach this time period differently, and I am just suggesting another way to look at your life. There is a place for lists in our lives, especially soon after we have experienced the injury.

“There is a place for lists in our lives, especially soon after we have experienced the injury.”

It is helpful and necessary for many people to have an assist when they are first learning how to live their lives after TBI, and this is one way to keep you organized and focused by eliminating distractions and by giving you a purpose. However, by relying on these lists, we may be doing ourselves a disservice by ignoring our core strengths as human beings.

I wanted to concentrate on becoming a human being and knowing myself. I figured that by "knowing myself", my actions would be guided by my character and by what I stood for, and what I learned was that my actions didn't always have to be "correct." I fumbled

and made mistakes. This was the “long” way to success, but for me, I believe it was the best way.

The great thing about being human, which using lists seems to ignore, is that we have the ability to reason and problem solve—to figure things out. We can use this power to understand in order to create an environment where we can succeed. Relying on lists and procedures says “we do things because they are written down,” rather than gaining an understanding of why we do things.

About Jeff Sebell

A long-time survivor, Jeff is the author of “Learning to Live with Yourself after Brain Injury.” You can read more about Jeff and his journey on his blog at www.TBISurvivor.com

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TBI Hope and Inspiration Magazine is always looking for stories to publish. Submit your story by email to mystory@tbihopeandinspiration.com.

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Surviving Holiday Stress

By Donna O'Donnell Figurski



The turkey and stuffing are gone, and the winter holidays are around the corner. For most folks, the holidays bring happiness and cheer. Extra gaiety is seen at office parties and large family-gatherings. Secret Santa's are chosen and Hanukkah candles are lit, but for many brain-injured survivors, the holidays are a stressful time, leaving them anxiety-ridden, exhausted, and distressed.

Brain-injury survivors may become melancholy as they remember their lost lives - lives in which they weren't impaired; lives in which their freedom was at their fingertips; lives in which they were independent and didn't need to rely on others for their every need. This supposedly joyous time may not be so happy for many folks. The holiday stress can be exaggerated for those living with a brain injury, compounding a survivor's unhappiness and sometimes causing severe depression. The hustle and bustle of the holidays can definitely add disorganization and chaos to anyone's life, but for those who live on a daily basis with the confusion that often accompanies brain injury, the holiday season can be an utter nightmare.

The holidays bring many additional activities, like baking dozens and dozens of holiday cookies to give as gifts to family and friends. Entertaining friends might be fun, but decorating the house and preparing food and drinks for guests can be a daunting task. Entertaining out-of-town guests complicates that undertaking even further - arranging sleeping areas with sheets and pillows and extra blankets and towels. Then shopping - ah, shopping - braving the malls with their wide-eyed, crazed shoppers and their cacophonous noise is not for the faint of heart.

The uncertainty of whether Great Aunt Sally will love the little pink unicorn that you found in the bargain basement of Marky's is tying up your brain in knots. For those who live in colder climes, weather may play a role, as blizzards and freezing rain make it difficult to leave the house and add the pressure of when to get the shopping done. The cold, gray skies can make life seem dreary, altering even the best of temperaments. But the holidays can be conquered, and a survivor can have fun if he or she tones it down a little and takes the holidays in itty-bitty steps.

To help ease the holiday doldrums, brain-injured survivors should try staying in the present or looking to the future. Survivors shouldn't compare themselves and the current holiday to holidays from the past. It's normal to feel the loss of one's "old" self. It's normal for a survivor to feel sadness at what once was and now is no longer. But if this is the "new normal," then the survivor needs to make the new normal a better place to be.

Perhaps the six-foot tree that a survivor trekked out into the woods to cut down can be replaced by a three-foot artificial tree - something that can be assembled in less than an hour, instead of enduring the stress of an all-afternoon trip. Maybe the family-gathering to eat latkes must be limited to the immediate family to minimize the chaos that a large gathering might cause.

The holiday season is a good time for a brain-injured survivor to pull back. The survivor can make the holidays simpler and avoid their commercialism. So how does a brain-injured survivor still accomplish these goals? Here are some suggestions.

Plan And Organize - Make a list of the things you want to do, and prioritize.

Choose to do only one activity or job each day. Decide when you are best able to do the job. Are you better in the early morning hours - when you have more energy? Or are you like me - alive at night? That's when I get more done. Everyone's different, and only you will know what works best for you.

Pace Yourself - Don't set your expectations too high. That is a guarantee for failure. Instead of baking ten dozen cookies in one afternoon, spread out the job by allowing several afternoons to accomplish the task. Or better still, make a smaller portion of the cookies. Set your sights lower. By planning and pacing yourself, you can avoid becoming overwhelmed, depressed, or simply exhausted.

Keep It Simple - Instead of wrapping a present the traditional way with giftwrap and ribbons, pop the gift into a pre-decorated box or a gift bag and stuff some colored tissue



paper around it. It will be lovely and it is so much easier! Do you really need to have a twenty-three-pound turkey with stuffing and all the trimmings? Probably not! A simpler meal will taste just as good and will be enjoyed by all simply because you are spending precious time together.

Accept Help - Usually family and friends like to offer help, especially during the holidays. Let them! Let them help shop for or wrap presents. Let them help cook dinner or bake cookies. It will be a lot more fun and actually make the holiday a more joyous occasion.

Make a Change - Try something different. Plan a new routine or create a new ritual.

With some small steps, life during the holidays can be tolerable – maybe even fun. You just have to open your mind, look at life differently, and begin to make “new” traditions.

Meet Donna O'Donnell Figurski

Donna O'Donnell Figurski is a wife, mother, and granny. She is a teacher, playwright, actor, director, writer, picture-book reviewer ... and, on January 13, 2005, became the caregiver for her husband and best friend, David. Donna had never heard of “TBI” before David’s cerebellar hemorrhage. Now TBI invades her life. Donna spends each day writing a blog, called [“Surviving Traumatic Brain Injury,”](#) preparing her radio show, “Another Fork in the Road,” on the Brain Injury Radio Network, and searching for a publisher for her completed memoir, “Prisoners Without Bars: A Caregiver’s Story.”

Living With Hope

By Patrick Brigham



What Brain Injury Survivors Want You to Know

By Barbara Webster*



I need a lot more rest than I used to. I'm not being lazy. I get physical fatigue as well as a "brain fatigue". It is very difficult and tiring for my brain to think, process and organize. Fatigue makes it even harder to think.

My stamina fluctuates, even though I may look good or "all better" on the outside. Cognition is a fragile function for a brain injury survivor. Some days are better than others. Pushing too hard usually leads to setbacks, sometimes to illness.

Brain injury rehabilitation takes a very long time; it is usually measured in years. It continues long after formal rehabilitation has ended. Please resist expecting me to be who I was, even though I look better.

I am not being difficult if I resist social situations. Crowds, confusion and loud sounds quickly overload my brain, it doesn't filter sounds as well as it used to. Limiting my exposure is a coping strategy, not a behavioral problem.

If there is more than one person talking, I may seem uninterested in the conversation - but that is because I have trouble following all the different "lines" of discussion and it is exhausting to keep trying to piece it all together. I'm not dumb or rude; my brain is getting overloaded!

If we are talking and I tell you that I need to stop, I need to stop NOW! This is not because I'm avoiding the subject, it's just that I need time to process our discussion and "take a break" from all the thinking. Later I will be able to rejoin the conversation and really be present for the subject and for you.

Try to notice the circumstances if a behavior problem arises. "Behavior problems" are often an indication of my inability to cope with a specific situation and not a mental health issue. I may be frustrated, in pain, overtired or there may be too much confusion or noise for my brain to filter.

Patience is the best gift you can give me, allowing me to work deliberately and at my own pace, allowing me to rebuild pathways in my brain. Rushing and multi-tasking inhibit cognition.



Please listen to me with patience as well, trying not to interrupt, allowing me to find my words and follow my thoughts. It will help me rebuild my language skills.

Please have patience with my memory and know that not remembering does not mean that I don't care.

Please don't be condescending or talk to me like I am a child. I'm not stupid, my brain is injured and it doesn't work as well as it used to. Try to think of me as if my brain were in a cast.

If I seem "rigid," needing to do tasks the same way all the time; it is because I am retraining my brain. It's like learning main roads before you can learn the shortcuts. Repeating tasks in the same sequence is a rehabilitation strategy.

If I seem "stuck," my brain may be stuck in the processing of information. Coaching me, suggesting other options or asking what you can do to help may help me figure it out. Taking over and doing it for me will not be constructive and it will make me feel inadequate. (It may also be an indication that I need to take a break.)

You may not be able to help me do something if helping requires me to frequently interrupt what I am doing to give you directives. I work best on my own, one step at a time and at my own pace.

If I repeat actions, like checking to see if the doors are locked or the stove is turned off, it may seem like I have OCD, obsessive-compulsive disorder but I may not. It may be that I am having trouble registering what I am doing in my brain. Repetitions enhance memory. (It can also be a cue that I need to stop and rest.)

If I seem sensitive, it could be emotional adjustment as a result of the injury or it may be a reflection of the extraordinary effort it takes to do things now. Tasks that used to feel “automatic” and take minimal effort, now take much longer, require the implementation of numerous strategies and are huge accomplishments for me.



I need cheerleaders now, as I start over, just like children do when they are growing up. Please help me and encourage all efforts. Please don't be negative or critical. I am doing the best I can.

Don't confuse Hope for Denial. I am learning more and more about the amazing brain and there are remarkable stories about healing in the news every day. No one can know for certain what my potential is. I need Hope to be able to employ the many, many coping mechanisms, accommodations and strategies needed to navigate my new life. Every single thing in my lives is extraordinarily difficult for me now. It would be easy to give up without Hope.

**Created in collaboration with the 'Amazing' Brain Injury Survivor Support Group of Framingham, MA*

About Barbara Webster

Barbara J. Webster is a brain injury survivor and the author of [Lost and Found, A Survivor's Guide for Reconstructing a Life after a Brain Injury](#), Lash & Assoc. Publishing. Her goal in writing her book was "to make the brain injury journey a little easier for others." We can heartily say that she has succeeded!

Miracles Happen

By Valerie Van Selous

Miracles happen, sometimes. One summer there was a group of people who prayed like maniacs for a young girl to recover from a life-threatening virus. They acted on their faith and their prayers were actually answered and the girl lives on. This is my story. That same summer, the same group of people prayed like maniacs for a 46 year old man and father of five, to survive a fatal diagnosis, and the man lives on only in memory. That man is part of my story too, he was my dad. While the mischievous pendulum of life weaves tales of life and death all over the world, this story begins in a quiet, northern New Jersey suburb.



To look at me lying on the hospital bed in a coma, you would see an ordinary-looking teen with brown eyes and a thick, curly mop of shoulder length brown hair that was matted down to the hospital pillow. I am certain that the sight of me; an unresponsive girl laying still on the hospital bed, pale skin, eyes slightly open, white tube protruding from mouth would make just about anyone feel the weight of an impending tragedy. Especially if you happened to pass by my room day after day and saw that nothing ever changed, except the nurses checking on me or the sight of my mother sleeping by my side.

You might wonder: How did this happen? What if I told you that there was no car; no bicycle; no soccer ball; no gang fight; no mosquito - no exciting story at all? Just a 16 year old girl looking forward to her last year of high school and to life beyond New Jersey. I was a bookworm with big dreams. My face was usually burrowed behind a paperback or glossy college brochure.

I would write furiously in a spiral bound journal about my dreams, thoughts, poems, and stories. I could, and often did, get lost in the ideas, thoughts, words and imaginings hovering on the page. One summer day, the day I fell into the coma, August 20, 1984, I got lost in a dream-world for twelve days.

I was in my bedroom, stretched out on the bed reading. I had just eaten a cup of vanilla ice cream and I finally felt hopeful. I had been recovering from a case of pneumonia and had been feeling lethargic and queasy for days, but today I was able to sit outside in the sun and finally ate something more exciting than dry toast and apple juice. I read for a while longer before closing my book and turning off the light.

I slept for a few hours before I felt the need to call out to mom. It was the night the germ attacked, the night I slipped away. I called for help when I realized that I couldn't walk the short distance from my bed to the bathroom. I felt so tired, my arms and legs heavy with invisible weights pressing against every inch of my body. I felt dizzy, nauseous, and had a terrible headache. I was scared of the constant sensations of needles and pins pricking all parts of my body. "Mom, please come..."

We returned from the two minute arduous trek from the bathroom to the bedroom, I collapsed into bed. Both legs and both knees just gave out. Complete weakness. We did not say much to each other. I was too sick to communicate and she was just alarmed. What was happening to her daughter? She lay by my side and we both fell asleep hoping I'd improve by morning.

I did not. I felt dizzier and weaker in my legs and arms than the night before. My surroundings were beginning to fade. I tried to get up and to get dressed, but nothing worked. I could not get my arms to move or my legs to bend. I couldn't speak.

"I felt dizzier and weaker in my legs and arms than the night before. My surroundings were beginning to fade."

My parents sat me on the top of the stairway and pushed me down one step at a time. Then, each holding one arm, they led me into our brown station wagon, propped me up against the door (I could barely hold myself upright) and pushed me down onto the car seat.

Mom and dad left my four confused siblings at home staring out the window, scared again. They had instructions for what to have for meals (cold cereal or peanut butter and jelly) and what to do in case of an emergency (call the neighbor), but no explanations. All they knew was that another family member was being swept away unexpectedly to go into the hospital.

You see, as often happens, a double tragedy had hit my family. The pendulum had already struck once. Dad was dying from stomach cancer. Four months earlier, he was sent to the hospital to have his stomach removed. When the doctors found that the cancer had spread to other organs in his body, they sent him home, body intact. We were happy; he looked the same to us, at first.

We thought and wanted to believe that he was OK. If he would just stop eating potato chips, his stomach pains would go away and all would return to normal. Right? What did we know of death? I was soon to find out.

I remembered the drive to the pediatrician's office and the doctor's stern words, the last words I was to hear for days, "get her to the hospital, now."

Looking into the mirror that was hanging on the door while on my way out of the room, my brown hair was straggly and going in all directions. My eyes were glazed. I

barely recognized this girl in the mirror. The sight of her terrified me. What was happening to her... to me?

This thought and all my thoughts just drifted away. All my energies were used getting back into the car and then to the hospital. I was put onto a bed; the nurses put a striped hospital gown on me, stuck an I.V. into my vein and took out my gold stud earrings. I worried about those earrings and feared I would never see them again (I never did).

My bed was wheeled into the hall way where I waited. Eventually, I was brought to a room with a big metallic machine. I had no idea what it was; it looked like a rocket lying on its side. When I was wheeled into it, lights began to flash around my head and then I was gone. Think of getting anesthesia before an operation. You are awake when you see the anesthesiologist, then you are nowhere, and finally you wake up in your hospital room.



This is similar to what happened to me, I was awake when I went into the machine, fell into a deep sleep, at some point I thought I woke up, but I really didn't. I had fallen into a non-traumatic coma, and would lie there for the next 12 days.

The official diagnosis of my medical condition was encephalitis/viral meningitis, medical conditions where membranes of the brain become inflamed. According to the National Institute of Neurological Disorders and Stroke, "Encephalitis is an acute infection of the brain characterized by fever, headache, and an altered state of consciousness, with or without seizures. Most cases of encephalitis are caused by viruses."

This proved to be true in my case, though my blood was tested for mosquitos, rabies, ticks, and Reyes Syndrome no cause was found, just an unexplained virus that travelled to my brain. To everyone's frustration, no medical interventions were identified, other than the I.V. and the nurses who kept a check on my vital signs.



I could not be wakened, I did not respond to any stimuli, I had no gag reflex, and my pupils did not respond to light. I was unable to move and communicate with the outside world, but was trying desperately to. I saw the square florescent light bulb above my head. I had some awareness of my surroundings, but slipped in and out of different levels of consciousness. I saw the nurses, doctors, my parents, the hospital room and what was in it.

Sometimes, I knew when I was being pushed to one side of the bed and then the other in order to change the sheets. I could sense the different ways the nurses touched my body. Some nurses had a gentle touch; others were just fast and efficient. (Nurses, be gentle with your patients. They know.)

I had vanished into a tangled jungle of nightmares and prayers. I was entombed in a world of confusion and mixed messages: surreal images, fear and frustration verses determination, hope and sweet, joyous hymns; the demons verses the angels. A square metallic machine pops up one day. It is a ticking time bomb of my life. The machine beeps and flashes green, yellow, and red.

When I am doing well, the light flashes green, but when I have minutes to live a light flashes yellow. Red means death, my death. My closed eye fixates on this machine that actually sits beside my bed. Fear of the beeping was justified. I am told mom fiercely objected to the respirator, so I was hooked up to the monitor. I am told it tracked my breathing and that a yellow light would blink and the machine would beep if my breaths became shallow.

Whoever was nearest to me needed to tap my chest, in the hope of reminding my body to breathe. Fortunately, my body responded to the tapping and I never went on the respirator. To this day, Mom wonders why the doctors did not recommend the monitor before the respirator which was a far more severe intervention. I wonder what would have happened if she hadn't objected. I also wonder why no one told me that the machine was helping me. It would have been one less fear. (Nurses, talk to your patients. Visitors and loved ones, talk to the one lying there in silence.)

I often see my mom, Lucille, lying along beside me on the bed, often in a yellow hospital gown.



In my dream-world, she is LuAnn or Angel Lou, always my unceasing advocate. She is patient, gentle, insightful and courageous. She is always by my side, even though the doctors tell her to go home, even though she has four other children at home waiting for her while she waits for me.

I can feel the weight of her sorrow, I am near death and her husband is as well. I come to know that my kindly, lively, energetic dad will soon be dead and mom will be all alone. How can I let her lose a daughter as well? I feel strong pangs of understanding and resolve. I cannot let mom lose both a husband and daughter. Were these the feelings that enabled me to break through to the conscious world or was it something else?

At some point, I see a gold cross hanging on the wall and my closed eyes choose to focus on it, rather than the creepy bulletin board, the evil nurse, or the beeping monitor. Despite the cacophony of death and paranoia filling my head, I feel comforted. On the

twelfth day of the coma, I am told by my mother who was lying next to me waiting, that I tapped her leg. I don't remember this, but it is what happened. My mom yelled out to the nurses. "She moved! Valerie has moved."

I finally broke through the invisible glass wall. I was immobile, my muscles atrophied. I could not swallow or speak. I could not move my neck, legs, arms, or fingers, but was suddenly on a path to recovery rather than the respirator. I knew who I was; I recognized my parents and the nurses. I was thrilled to be part of the world and was motivated to recover, even though it would be one small movement at a time with no guarantee of recovery. Somehow, I knew that the hardest part was over. I would live and would not die. It was called a miracle.

Life has been good to me and blessings abound: high school and college graduations, almost 20 years of a happy marriage, and two beautiful children. I feel angels and bask in moments of clarity and peace.

More about Valerie

Many years have passed since her TBI and coma. Valerie is happily married and a mother of two teenagers. She is earning a living working for a small non-profit, but her passion continues to be reading and writing. She is proud of her volunteer position as a Reader for the journal Creative Non Fiction.

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Changing Your Focus

By Jennifer White

In the 15 years since my traumatic brain injury I have sought hobbies I could engage in such as gardening and cooking, quilting and writing. I have searched for anything that would fill the gap left from the injury I suffered in 2000. For years after my massive stroke, I played a tape in my head over and over again about the work I used to do, the friends I used to have, and the way I used to be; the operative word being USED to.

I had to be reminded that my friends had moved on in their lives and I was not necessarily a part of their lives anymore. The reality is that I do not do the things I used to do. I do not work and engage with people who I used to work with and I have had to accept this fact. Accepting this has been good for me. Recognizing the facts of my injuries and limitations has empowered me to be stronger. When I hear negativity it sets me back and propels me into the depths of despair.

Nobody is saying that brain injury is a pleasant thing to go through. It is hard, sad and limiting. But, if you are reading this you have already survived a major injury that many people succumb to or you are a relative or friend who has gone through a lot of sadness. The brain injury may have damaged my brain, but my soul is still intact and over the last 15 years I have had to change my focus to those things that are positive and hopeful. I may have lost my mind years ago, but I lived to tell people that things can be okay. I do not want to lead the rest of my life with a huge chip on my shoulder, the fear of “breaking” again, or feeling anger toward a situation that happened 15 years ago.

Instead I will appreciate the fact that I did not die when I was given a 4% chance of living, I will embrace the closeness I feel for my husband who I had little time for before, and I will enjoy the simplicity and beauty in the world. I personally feel that the measure of someone’s character is in the bad times not good. Change your focus and



make a conscious effort to be positive. You can interpret comments the way you want. You can walk away from any negative situation whenever you like! I am on long term disability and will never work again. That does not mean that I no longer have priorities in my life. I still have plenty to accomplish. And there is no room in my life for negativity...I have closed all gaps! Close your gaps. Let the good comments in and discard the bad!

Be your own person...set your own goals and pick up your life where you left it. It will make you feel better and it will empower you to regain the independence you lost!

More about Jennifer

Jennifer White is a traumatic brain injury survivor from St. Louis, Missouri. When she's not writing about her life as a survivor, she enjoys spending time with her family and of course, quilting.

Contributors Wanted!



Share your...

- ✓ Personal Story
- ✓ Photography
- ✓ Artwork
- ✓ Poetry



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Learning to Like the New Me

By Shannon Brierley



Last year I thought the worst thing that could happen to me was to not have my plan work out. I was studying to get into communications and I had to pass four subjects to qualify for a grade high enough to get assistance with my university studies. I also (finally) got engaged. I say finally because we had been together for seven years, and had a mortgage for five. Let's just say I was very ready. I am also an avid actress. I was a highly stressed person with the aim to get married, study, and have a kid all by this point in time.

I work at a hospital in South Brisbane, Australia. I was working on the 4th March 2014, when I started to get double vision. Luckily (or unluckily), I knew to go to emergency. I spent a good part of the day there awaiting the results of a CT scan that was suggesting I had a lesion on my brainstem. I was transferred to another local hospital and they were pretty sure I had a brainstem cavernoma. A what? Well after googling, I found it is a cluster of blood vessels that look like a raspberry. I was in the middle of it hemorrhaging (hence the double vision). If you know brainstem surgery, it is not an area many surgeons wish to operate. I therefore had to take the wait and see approach - very scary when you know your brain is bleeding. I ended up in emergency another time in April 2014, as I had numb fingertips (this was another hemorrhage and further growth of the lesion).

In May I called my parents (they live four hours away), to tell them I wanted this thing in my brain gone. To me I sounded normal but to them they could not understand a word I said. They told me to sit down and they were on their way (apparently they threw clothes in the car and raced to my home). I also called my fiancé and he couldn't understand me either, so he left work to come get me. I knew I would have to go to the hospital, so I packed my bag for a couple of days stay (it ended up being four months).

I went to emergency on 11th May 2014. By this time most of my body was numb, I had double vision, I was lethargic, I could not walk very well, I had hydrocephalus (water on the brain) and my left side was having tremors. I was in surgery two days later to have an EVD, which is supposed to immediately relieve pressure. I also had an angiogram to identify the location of the lesion in my brain. After this surgery I was unable to open my eyes, roll over, or talk. It was really felt that brainstem surgery can leave you with worse deficits than you started with, however, I was now almost dead. I had a craniotomy on 16th May 2014. Apparently many people came to see the surgery. As a trained actor I thought I would become a rock star from being on television! Who knew it would be from having a rare problem?

I named my lesion Timmy. I had surgery sitting up, and was in ICU for four days, before I woke up. Over the next four months I had about six or so surgeries. I had meningitis twice in the hospital, and my final surgery was in July to insert a shunt. I had to learn to walk, eat, and talk all over again. There is nothing more attractive than a 27 year old using a wheelie walker.



Neurosurgeons are amazing at what they do, but they have no idea how to cut hair.

I ended up looking like Joe Dirt's daughter by July. Oh yeah, I had a massively attractive mullet, lucky for me everyone kept telling me it was not that bad. When I got my emotions back, I finally realized how bad it really looked. I am not one to toot my own horn, but I used to have beautiful hair, I couldn't even hide it.

My hospital stay was made longer by what I would describe as my craziness. I believe if you have never had drugs before, and you end up on a hospital ordered concoction of drugs, you end up a looney. One night I believed a man and his family were coming to pour water on me. In the middle of the night I pulled my PICC line out (the one that

goes in your blood vessel near your heart), filled up a water jug and escaped through the hospital. I could not find any damn phones to call my fiancé. I went out the front of the hospital, realized I would get in trouble, and walked back in. I ran into two security guards (they must have thought I was incredibly crazy) and I told them about my troubles. I was so angry they took me back to the ward. I ended up with security bracelets and posters of my face on the walls. Super famous again!

I also gained about 13kgs (28 lbs.) from being on steroids in hospital. Apparently the minute I ended up on full food again, I demanded takeaway every day. There was a



point the doctor thought I was pregnant. When I got to rehab I told my sister that everyone was crazy and that the nurses were trying to kill me. I am not sure why she did not believe me.... I ended up pulling another PICC line out in rehab, and locking the nurses out of my room. I had to beg for the third PICC line and I really did need it. I was discharged on 29th August 2014, a few days after getting off the wheelie walker.

We had to cancel our wedding for December 2014, as no matter how hard I try, a wig looks like a wig, though I have had some help with my image. These incredible hairdressers near home cut and coloured my hair, and made me look so much better. With the help of the gym and my fiancé, I have lost about ten kilos. Apparently, what I went through was not like having a cold and I could not just return to work; I had to make

many appointments and be cleared by many people.

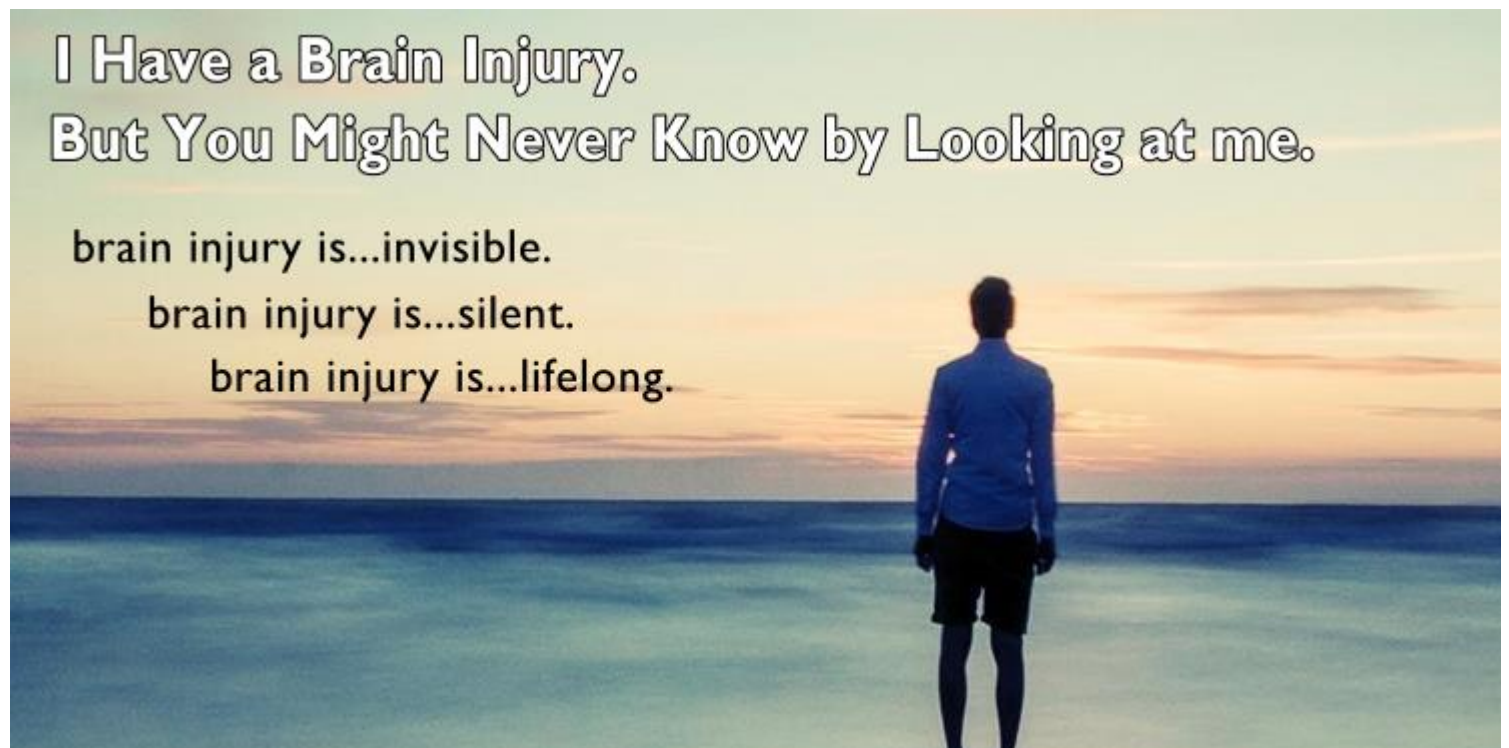
At the moment, I am volunteering at the hospital that saved my life, and finally after a year and half I am back at work for three days a week. I am completely broke and still planning my wedding for December. I had another MRI and found they could not get all of Timmy, therefore I am hoping for no more hemorrhages. Every day I wake up wondering if today is the day my double vision is gone, but alas, I still have to go out wearing my eye patch, until it leaves.

I live every day proving to myself that I have come far. I owe many people for my life. I recently trained hard for a stair climbing event, Climb for Cancer, and made it all the way up the 810 stairs. I also gathered a bunch of people to dress as pirates for The Mater Little Miracles walk on 31st May 2015. I had chocolate coins donated to hand out to the kids. It was a great day.

My plan now is to get ready for our wedding in December, study as a Paramedic and get back into acting. I have to tell you I cried for over a year about getting back to the person I was. It has taken so long to realize I did not like that person - I like the person I am now. It may sound vain, but I am very compassionate and understanding. I am kind. I am strong. I am not confrontational. I like the new me and believe that this was the best thing to happen to me. I will one day save lives, and previously I was making no mark on the world - I am now!

Meet Shannon

Shannon was born in Perth Western Australia and now lives in Brisbane Australia. Shannon has been with her fiancé for eight years and is getting married this month. She has a real passion for acting, and loves going to the movies. She has a passion for charity work and is a volunteer at the hospital that saved her life. Next year she intends to study paramedics.



**I Have a Brain Injury.
But You Might Never Know by Looking at me.**

brain injury is...invisible.
brain injury is...silent.
brain injury is...lifelong.

Attention Problems for Students with Brain Injury

By Dr. Katherine Kimes

Many students who are children and adolescents have difficulty with attention after sustaining a traumatic brain injury (TBI). This can have serious effects on their ability to pay attention in class, study effectively, do homework and succeed in school. Teachers can help these students improve attention by modifying their instructional techniques and helping students use compensatory strategies.



Strategies to help students with attention deficits after TBI

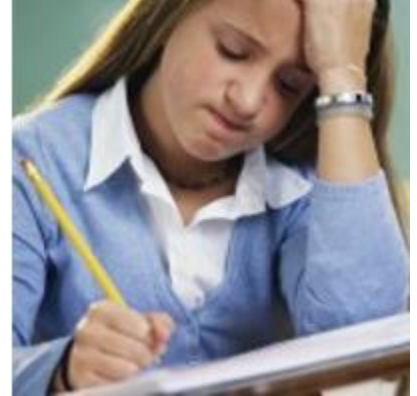
There are two components to attention, alertness and focus. Alertness can mean whether or not the brain is functioning to learn. Focus can refer to the quantity and quality of sustained mental activity.

In order to be able to focus, a child has to be aware of and understand his/her behavior and be capable of processing information. This is where the child with a brain injury or TBI can run into problems with classroom learning because attention deficit issues are a prominent challenge after brain injury.

Strategies that the teacher can utilize to help with the student with attention deficit problems can include:

1. Planning demand attention during times the child or adolescent is most receptive to the information.
2. Limiting the length of demand attention based on the student's age.
3. Keep instruction short and sweet. For example, limit instruction to 6 minutes of demand attention with a 6 year old.

4. Using an external timer to structure a child's on-task behavior.
5. Redirecting/refocusing the child to on-task behavior.
6. Keeping the child's workspace environment uncluttered and organized to prevent distractions.
7. Making the lesson plan relevant and enriching to help the child want to learn.
8. Summarizing information presented in the lesson plan.
9. Teaching the child how to self-monitor his/her behavior and stay on-task by establishing cues to help remind him/her. For example, placing a picture on the student's desk as a signal to pay attention.
10. Using preferential seating for the student away from windows and doors and seating the student near the teacher.
11. Permitting the child to take scheduled breaks during the school day.
12. Keeping a log/journal of material covered daily in the class to reinforce acquisition of information.
13. Using headphones when working on the computer or listening to books on tape.
14. Praising on-task behavior. Praising the child will reinforce positive behavior. This praise should be immediate.
15. Involving the student in lesson plan presentation.
16. Providing peer assistance in note-taking.



Conclusion

By using these strategies, teachers and other educators can help students with traumatic and other types of acquired brain injuries address challenges in attention, improve performance in the classroom, and help them success in school.

Meet Dr. Katherine Kimes

Dr. Katherine Kimes is the President of ABI Education Services, LLC, and is a Certified Brain Injury Specialist. ABI Education Services is a business focused on providing consultation, training, in-school support, and transition services to children, adolescents, and young adults with acquired brain injury. Please visit her website at <http://www.ABI-EdServices.com> for more information.

A New Perspective

By Donna Becke



I suffered a concussion in March of 2012 which caused Severe Occipital Neuralgia. Left untreated until February of 2013, I underwent a major surgery to sever nerves in my spine, in hopes of ridding my pain and now I deal with nerve regeneration.

It's been a journey of pain, agony, tears, life changes, and loss of hope. But then there are times of serendipity, and the world slows down, and you notice the smallest of things you never would have before and how amazingly beautiful they are. You find yourself taking a deep breath of the crisp air on these coming cool mornings and for the first time

you recognize how good that feels.

Those precious kisses and hugs from your grandchildren are even deeper than you thought they could get. It's these things you hold on to on the days and nights you feel you can't take it anymore. You reflect back to this and know you have to keep going and you want to. You tell yourself it's okay you forgot and it's okay you couldn't remember, you just keep finding the things that you never noticed before because you've been forced to slow down and now you can take the time.

You always miss the life you had, then you come to a point where you think you have accepted it and learn to appreciate what you can do that holds so much more value. However, for some reason, at some point, it always sneaks back into your mind: "I want my life back!", "I want to do this or that again", "I'm sick of being sick." Now it passes sooner and again you pull it together and realize that you are so blessed.

It can be a lonely world living with a brain injury. You can become lost in yourself because so many don't understand or it's hard for them to believe because you look so fine on the days they see you. So how could you be sick?

I have to take charge when it comes to this. I have to slow down, say no, make adjustments, and the big one: ASK FOR HELP. I just have to know I'm not the same

person. A lot of me was lost in this three year journey, but I have also gained deeper inner peace. My eyes are opened to see the beauty in the smallest things, and I forgive and love even more deeply. I'm also blessed with family and friends that do understand my struggle and I don't know what I would have done without them by my side.

This is just another blessing in the midst of struggle, pain, and agony. I hope those of you suffering daily just to get by can learn to experience some of this, so you can keep it close and use it on those dark days and nights when nothing seems to help.

More about Donna

Donna is a first-time contributor to TBI Hope and Inspiration Magazine. Donna currently resides in Kentucky and loves spending time with her family.



Compensatory Corner What Works for you?

We continue to offer strategies that help those impacted by Traumatic Brain Injury. Compensatory Corner is your place – by survivors, for survivors.

“I’m slowly learning that I’ll never be the same person that I once was. One thing that helps me is to not spend too much time looking backwards. If I stay focused on where I am TODAY, life is much easier. I hope this helps someone!” ~R.G.

“Before my brain injury, I was always on the go. I need to take breaks a few times a day to rest my brain. When I take regular breaks, my day goes much better. If I don’t – watch out!” ~T.M.

“I have to remind my family that I can no longer do some of the things I used to do. It’s hard because I miss some of those things. Reminding them helps them and me to remember to pace myself.” ~K.G.

Learning to Live Again

By Michael Coss

On May 18th, 2006 Michael was driving to Kelowna with his former spouse and seven-month-old twins to attend a work function and stay with friends. Catastrophe struck while on the Coquihalla highway Michael lost control of his van and it rolled at least one and a half times. Miraculously, his former wife Ann and daughter Danielle escaped only with minor injuries, but Nathan and Michael were not as fortunate.



Nathan spent several weeks at BC Children's Hospital with head injuries. When the medical services arrived at the scene of the accident, Michael was unresponsive, with evidence that the airbags had deployed and he was restrained by his seatbelt. His Glasgow coma scale rating at the scene was 8 out of a possible 15, which indicated a comatose state. He was transported by air to Royal Inlands Hospital in Kamloops where he was assessed by Neurosurgery. He had bilateral ventricular shunts inserted. Later, he was transferred to Royal Columbian Hospital to be closer to his family where he remained comatose.

Michael's injuries were nearly fatal and despite comprehensive treatment at two hospitals, he remained in a coma for six and a half months. Doctors told his family that his chances of recovery were remote. His wife Ann was devastated, facing the challenge of raising their two babies without a father. Recommendations were made to his family to look for a long-term care facility to look after him for the rest of his life.

But they did not know Michael Coss and his family. Michael's family had researched hyperbaric oxygen therapy (HBOT), the medical use of oxygen at a level higher than atmospheric pressure. The treatments are commonly used in Asia and Europe and are available in Canada, where they are not approved by Health Canada and therefore not

covered by medical insurance. The more the family learned, the more they came to believe that these treatments might work for Michael, though they were prohibitively expensive and came with no guarantee. His friends and co-workers saw a chance to mobilize and make a difference in Michael's life. Within a few weeks, funds were raised from donations from friends, family, and his former work colleagues at Molson Coors Canada.

Five days a week via ambulance, his mother accompanied him from Royal Columbian Hospital to the Richmond Hyperbaric Health Centre. Staying by his side, she would dampen a sponge with water to make him swallow and equalize the pressure within his ears. It worked, and on Christmas Eve of 2006, after three treatments and half a year in a coma, Michael awoke and uttered his first words.

Only three months out of his coma, he learned about Rick Hansen's Wheels in Motion events to raise funds for research and to improve the quality of life for people with spinal cord injuries. Michael was inspired by Rick Hansen and wanted to be a part of the event. In the midst of his rehabilitation he canvassed his network and once again they rallied in support. Friends, family members, Molson Coors co-workers, and other corporations raised over \$22,000. His team (Team Cosco) not only won the award for the top fundraiser in Canada for Wheels in Motion 2007, they also set a fundraising record for the entire six year history of the program. Through a long, intensive, and grueling rehabilitation he re-learned how to talk, eat, and is now re-learning how to walk.

Today Michael serves as an inspiration, motivational speaker, and catalyst for traumatic brain injury survivors everywhere. He currently resides in a group home not too far from his family and visits with them several times a week. His long term goal is to be an able and active participant in his family's life. He is not yet ready to walk hand in hand to the park with his children but at least he is in training for it.

More about Michael

Michael Coss is the author of “The Courage to Come Back: Triumph over TBI - A Story of Hope” (2011) and the inspiration behind the creation of the Michael Coss Brain Injury Foundation. The foundation was created to raise money for children in need of financial support to access brain injury treatment and the proceeds from the sale of Michael’s book go directly to help the kids. The book is a moving account of Michael’s journey facing the challenges of traumatic brain injury.

The Back Page



To Our Family of Readers,

Looking back over this past year, it's hard not to be filled with a spirit of wonderment. When we first gave thought to a monthly publication that served you, the TBI community, never did we envision the worldwide family that our magazine would touch.

To our readers and contributors, we thank you. Without you, there would be no publication.

As we look forward to 2016, we've set more goals for our publication – goals that will make TBI Hope and Inspiration Magazine even better.

How about you? Have you set goals for your own life's journey? We've found that having something to aspire to, something to work toward, adds a new meaning and sense of purpose to life.

It is our hope that you have a meaningful holiday season, that you can spend time with those you love, and that you continue to walk with us as we move forward in the new year.

Best Wishes,

David & Sarah Grant



**Get Your FREE MAGAZINE SUBSCRIPTION at:
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